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Authoring Health Literacy in the Everyday

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AUTHORING HEALTH LITERACY
IN THE EVERYDAY

By

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B.S. Indiana University East, 2014

A thesis submitted in partial fulfillment of the requirements
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ABSTRACT

My experiences with healthcare providers, which pervade my earliest childhood memories, motivated me to become autonomous in managing my health and wellness. This autoethnographic research explores the literacy activities embedded in everyday lived experiences that informed the process of lamination in composing health literacy which influenced health practices and outcomes. By tracing textual trajectories and examining the process of chronotopic lamination to compose my health literacy across everyday literacy activities this autoethnographic thesis project highlights how nonmedically trained persons can use official and nonofficial sources to create a social and culturally contextualized health literacy. This research calls for recognition of the agency that instills confidence in the patient-author regarding their own health and wellness and positions them in authority as the expert of their own embodied experiences. The implications of this research point towards suggestions for the systems that influence health literacy in order to recognize the autonomous agency of patients.
Dedicated to my beloved husband and friend, John W. Rumsey, who has helped me to grow stronger each day in body, mind, and spirit. I love you ten-finity.
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“Health is a state of complete mental, social, and physical well-being, not merely the absence of disease or infirmity.” – The World Health Organization 1948

CHAPTER 1: INTRODUCTION AND SCHOLARLY CONVERSATIONS

Medical Disclaimer

This study is intended only for the analysis in writing and literacy studies. I am neither formally educated nor trained in the fields of health, nutrition, or medicine. Thus, all information within this study is based on a layman’s understandings of the documents discussed. None of the information in this document or any of the sample texts are intended for medical or nutritional advice. None of the information here is a suitable replacement of professional medical advice on health, nutrition, or medical treatment.

Introduction

My earliest childhood memory is a flash of blinding light interrupted by masked faces hovering over me while I struggle fruitlessly against tight restraints on my arms, legs, and torso. Thrashing my head back and forth, I screamed; I was eighteen months old. The details of my sundry childhood illnesses are largely irrelevant, but the psychological scarring it created was fairly substantial. Until I was nearly six years old, the sight of anyone in a white jacket or button up shirt sent me into hysterics.

Though my aversion to health care providers continued into my adolescence and through adulthood, my mother, by contrast, held a very traditional high regard for doctors. At the slightest sign of a fever, all four of us children were rushed to the office. Our physician was a small-town family practitioner who had cared for my grandparents, my parents, and their children, so he was dearly loved as well as respected. My mother took his words with deference and gratitude. This
position she assumed caused her to follow, to the letter, every piece of advice and treatment instructions given to her without question.

Just after my college graduation in 2014, my mother had some minor health complaints, just some aches in her side. She was given several different medications without much explanation and sent home. Her condition worsened. She was referred to a number of specialists who gave her additional medicines and a different explanation for the cause of her complaints. In a matter of a week, my youthful, energetic mother was reduced to a wheelchair and barely able to articulate full sentences lacking control of most of the muscles in her body. She was then placed on a full regimen of medications which required around-the-clock administration. She set alarms throughout the night and carefully followed every step for the twelve different prescriptions. She remained wheelchair-bound for two years. Finally, my mother chose to see a different specialist who took her off all medications entirely. She recovered, slowly, over the course of a year. She would continue to do physical therapy for two years to recover from the two years of partial paralysis.

Despite her traumatic experience with medical malpractice, my mother’s faith in medical experts did not initially waver much, but it had a noted influence on me. I decided to make a concerted effort to learn as much about my health as possible. I intended to know and do everything within my power to optimize my health and stay out of the doctor’s office. While I had no serious medical conditions after childhood, I was never very healthy either. I continually struggled with a minor but chronic digestive condition, and I was about 10-15 pounds overweight on average. I often fell ill with colds, the flu, and an annual bout of pneumonia. My sleeping patterns were completely erratic, struggling with insomnia throughout my undergraduate years. Overall, I just didn’t feel “well”. Though I was a vegetarian for ten years and ran regularly, these practices seemed to have little effect on my overall health. Starting in 2016, I decided to put a great deal of effort into learning
my body intimately enough to improve my overall health. I wanted to understand how my body’s physiology would react to nutritional changes and exercise. Some of my goals were related to losing body fat, gaining muscle, regulating my sleep patterns, and finding a diet that would allow me to stop taking daily medication for my digestive condition.

In this thesis, I will discuss the texts and literacy activities which informed the composition of my health literacy. The composing process which I exercised was motivated by a desire to empower myself with medical agency by taking an active role in my health. This agency bridges a gap between patients and medical experts that I felt acutely. The medical field has sought a variety of ways to heighten health literacy among patients by providing accessible medical texts, but the divide refers more prominently in the patient-provider communication exchanges and relationships (Rudd 69). The gap is one of institutionally and culturally established power structures between patients and providers in which patients are expected to take passive roles in their health care (Nimmons and Stenfors-Hayes). It is also one of expectation on the physician’s capability to take biometric data and interpret, not only the problem, but the solution accurately. Medical institutions depend on these expectations of physicians to be able to diagnose based on biometric data, rather than on a full understanding of a patient’s larger health narrative. Rita Charon describes this gap: “This encounter between health professional and patient lies at the heart of medicine. So many pitfalls are possible--the professional might not be smart enough, patient enough, imaginative enough; the patient might not be trusting enough, brave enough, receptive enough. Yet from this inauspicious meeting between two unlike people proceeds whatever healing medicine might provide,” (Charon 33). As I set out to increase my personal health literacy through everyday literacy activities, I increased my medical agency. Throughout the course of several years experimenting with my health and wellness and keeping careful track of my health outcomes, I found myself better able to overcome the gap between myself and my health care providers. I felt confident enough to come to the table with an
intimate understanding of my body and health narrative. While there is undoubtedly a valid hierarchy of expertise in my interactions with healthcare providers, I felt confident enough to be an active participant in what should be a partnership between patients and providers, rather than a power dynamic.

Hannah Bellwoar, in her case study of everyday literacies informing health literacy, addresses these issues by employing cultural-historical activity theory (CHAT) theoretical frameworks; “By blending cultural studies and ethnographic methodologies, my research project both critiques the structures of power that silence user-patients as knowledge-making technical communicators and considers local practices of technical communication in everyday spaces,” (329). Expanding on the work of Bellwoar and others, I also intend on bridging the gap between medical experts and patient-users in efforts to promote the authoritative expertise of patients by showing the process of lamination patients take to author their own health literacy through everyday literacy activities. I suggest that the recognition of a patient’s agency will level the power distant present in most patient-provider interactions and promote a partnership of “power sharing” (Nimmons and Stenfors-Hayes).

The texts I analyze here in this autoethnographic study are artifacts that show my personal growth in health literacy and how that literacy influenced my health practices and outcomes. Through the acquisitions of these literacies, I made the transition from a vegetarian and casual distance runner to weight training, acrobatic performances and a ketogenic diet. I developed an intimate understanding of my body’s metabolic processes, blood levels, weight fluctuations. I learned how to use my understanding to produce specific results like muscle gain, fat loss, and regulated sleep patterns. Along the way, I learned to develop and keep nonofficial personal medical records which would continue to inform my daily decisions and lifestyle.
Defining Key Terms

I discuss the notion of health literacy in this thesis research as both a text as well as the composing process through which it comes into being. Drawing upon the definition upheld by many scholars (*Health Literacy*; Lee and Hickman; Rudd), I define health literacy as follows: the socially and culturally informed process by which individuals obtain, interpret, and laminate information from official and nonofficial multimodal sources to inform their health decisions. This adaptation originated from a commonly used definition of health literacy: “The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions,” (*Health Literacy* 32).

The first key change I made to this definition is to highlight that the composition of health literacy is not a measurable skill for which individuals have “capacity.” Health and wellness are ubiquitous aspects of humanity, and thus every individual composes their own health literacy through their lived experiences (Lee and Hickman 5). The commonly accepted definition of health literacy stated above insinuates that health literacy is an aptitude that some people may potentially lack. I assert through my definition that every individual engages in a health literacy composition process to construct a highly individualized “text” that they act out in the world through their health habits. Admittedly, some patients have health literacies that yield better health outcomes, but this is so complexly linked to sociocultural influences and privileges (and the lack thereof) that it cannot be attributed merely to an individual’s “capacity” for gathering and processing information (6).

The second key change I made to this definition is to recognize that health literacies are composed through the gathering and processing of both official and nonofficial multimodal sources (as opposed to the typical kinds of sources people may readily associate with “basic health information”). This revision yields a better picture of how individuals compose their health literacy by engaging in “everyday literacy activities.” These activities are common and seemingly ordinary
interactions with multimodal texts such as social media posts, books, television shows/movies, podcasts, conversations and so forth. Nonofficial information gathered from these sources are just as influential (consciously or subconsciously) as “basic health information” distributed from official sources like doctor consultations, medical records, or pamphlets. To ignore the impact of these sources is a serious oversight as these everyday texts and our interactions with them are perpetually present. This study specifically investigates the role of everyday literacy activities in the composition of my health literacy.

Third, I have traded the term “process and understand” in the original definition for the new term “interpret and laminate.” The former is a measure of an individual’s ability to cycle data through a set of cognitive processes to yield a “right” response to the information’s originally intended meaning. For example, the original definition suggests that a patient who reads a pamphlet on post-procedural care after surgery should be able to process the intended information and act it out according to the instructions. However, such one-to-one results aren’t always possible, practical, or desirable. Paul Prior and Jody Shipka use the term “lamination,” drawn from Bakhtin’s work, to describe the process by which individuals collect bits of text combined with lived experiences and layer them together to gradually build a comprehensive whole. In Bellwoar’s case study, she describes how Maghan collects bits of information from medical publications, TV shows, internet sites, conversations with family and friends, as well as her own lived experiences to compose her understanding of her pregnancy. The term “lamination” recognizes that no piece of text or information is “processed” or “understood” in isolation. Rather, it is interpreted in conjunction to all prior pieces of information that are all translated through sociocultural perceptions and highly individualized lived experiences.

Finally, at the heart of my definition is the recognition of the individual as the primary agent of health literacy composition. People’s ability to construct their personal health literacy opens a
wide door of opportunity for them to take up ownership in their health and wellness practices as well as advocate for themselves within health systems that are often overburdened and impersonal. Individuals attempting to manage their health and wellness may take the position of “patient” if they seek the professional opinion of healthcare providers, but these individuals are also inextricably informed by the context of their cultures, communities, values, beliefs, and experiences. It is through this contextual lens that patients interpret the interactions and advice of healthcare providers and choose to either accept or reject it. They may also draw from nonofficial, nonmedical sources like Google search results, conversations with family, or social media posts. The “patient” then takes up the active role of authoring by navigating sources and assembling information to make informed health decisions.

In recognition of this agency, I use the term “patient-author” to refer to individuals composing health literacy through the context of everyday lived experiences. As one such individual, I have often identified as a “patient” under the care of medical professionals, but my lived experiences have taught me that it is neither possible nor desirable to act only in the passive role of compliant patient. Every interaction with and advice from healthcare providers is interpreted through a lifetime of memories, decisions, experiences, and beliefs.

**Conceptual Framework: Threshold Concepts of Writing Studies and Lamination**

In this section, I will describe the theoretical framework, the lens through which I view this project. While my intention is to make a contribution to the conversation within the health and medical community, my primary perspective stems from the field of writing and literacy studies.

*Lamination & Everyday Literacy*

This project draws heavily from the work of Paul Prior and Jodi Shipka (“Chronotopic Lamination”) and Hannah Bellwoar (“Everyday Matters”). Prior and Shipka, drawing from the work
of Bakhtin, define chronotopic lamination 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 of multiple activity footings that are held and managed,” (181). This nonconsecutive, embodied act of writing and meaning-making is congruous with the threshold concepts of writing studies and describes how an author can draw from multiple, socio-culturally situated texts and/or experiences to create something new. Bellwoar’s work builds on Prior and Shipka by describing a case study in which a woman, called Maghan, experiences various medical circumstances and uses sources from medical institutions, the internet, and even television shows to create her understanding of her own body and its conditions. Both research articles utilize cultural historical activity theory (CHAT) along with the concept of lamination. I intend to build on their work to describe the phenomena of authoring health literacy. The goal of this research is to promote individual patient empowerment by representing health literacy development as accessible and by promoting patient voices and lived health experiences as authoritative.

Threshold Concepts of Writing Studies

This projected is grounded in writing studies. Naming What We Know is a collection of short scholarly articles that each describe a threshold concept of writing studies. For this thesis research, I draw from the following concepts:

1. “Writing Is a Knowledge-Making Activity”
2. “Writing Is an Expression of Embodied Cognition”
3. “Writing Mediates Activity”
4. “Texts Get Their Meaning from Other Texts”

In describing the concept that “Writing is a Knowledge-making Activity,” Heidi Estrem asserts how writing is not merely a process of communicating already discovered knowledge but is itself a knowledge-discovering process. In light of my project, this threshold concept describes how
collecting and laminating sources together to create a variety of new texts weaves together knowledge that is new even to the author. The writing process is not so sequential as to follow the path we often learn in school: plan, research, report. Writing and literacy activities which form health literacy continue to evolve as embodied experiences inform the patient-author.

For the concept that “Writing is an Expression of Embodied Cognition,” Charles Bazerman and Howard Tinberg describe how writing is not only socially situated among other people and cultural constructs but is also a product of lived experience. Meaning can be made through writing and writing can be created from embodied experiences. The authors state, “If cognition assumes complex mental processes at work, then embodied cognition draws in addition upon the physical and affective aspects of the composing process,” (Loc. 2095). This threshold concept is relevant because as the patient-author constructs health literacy, the literacy activities mediate life activities that cycle back to inform the initial composition. As the patient-author lives out their health literacies, their embodied experiences produce new knowledge with which they can continue to adjust and rewrite their health literacies.

Not only is writing an expression of embodied cognition, but it also drives activity. David Russell describes the concept “Writing Mediates Activity” by elaborating on how writing instigates action from the knowledge writing creates through the embodied experiences that one lives. This threshold concept shows how the process of laminating health literacy is an embodied experience that not only creates new knowledge for the patient, but also incites action, namely, the decisions and activities required to adhere to the newly formed health literacy. This is not merely the end of a simple, sequential process. As new sources and experiences are acquired, health literacy evolves. Then actions, attitudes, and habits continually shape and reshape the patient-author’s behavior.

Finally, Kevin Roozen describes how “Texts Get Their Meaning from Other Texts,” which highlights the deeply intertextual nature of writing, reading, and the knowledge-making. Both writers
and readers bring with them all the texts they have encountered to compose, understand, and create meaning. This concept is relevant at multiple levels. First, it demonstrates the importance that all texts have on a person’s health literacy, not only those from official sources. Even if not consciously, a patient’s encounters with all the texts in their environments influences how they understand and act. Roozen states, “The meaning writers and readers work to make of a given text at hand, then, is a function of the interplay of texts from their near and distant pasts as well as their anticipated futures” (“Texts Get Their Meaning from Other Texts” loc. 1446). Second, Roozen’s article describes the nature of a socially and culturally situated health literacy as a text itself made up of multiple texts that the patient-author has encountered in their lived experiences. By the process of lamination, patient-authors weave together multiple texts to create their health literacy which exists as its own “text” whether or not it is written down as such.

The Problem, Central Argument, and Research Questions

My experiences with healthcare providers, which pervade my earliest childhood memories, motivated me to become autonomous in managing my health and wellness. Interested in understanding my body, its conditions, and its capabilities, I gathered information from conversations, texts, and activities, all of which informed the creation of new habits. By enacting everyday literacies, I authored a health literacy that enabled me to maintain wellness and to assert authority over my own body. This thesis explores the literacy activities embedded in everyday lived experiences that inform my health literacy and health practices. By examining my own efforts to build my health literacy across my everyday activities, this autoethnographic thesis project highlights how nonmedically trained persons such as myself can use official and nonofficial sources to create a social and culturally contextualized health literacy. This agency instills confidence in the patient-
Health literacy stands as an imperative area to understand and optimize for the public health because of its close connection to health outcomes (Health Literacy 4). Health literacy has traditionally been viewed merely as one’s ability to read, understand, and use medical and health-related text materials (Cummings et. al.; Health Literacy; Rudd). This limited perspective guided the development of assessment tools to measure health literacy and formulate means of making health information more accessible (Health Literacy; Lee and Hickman; Rudd). The assessments revealed a dire deficiency in the public’s aptitude for reading and applying complex health texts, so the seemingly obvious solution was to make health texts “easier” to read and obligate education institutions to focus more heavily on reading levels (Health Literacy; Rudd). This move towards simplifying texts that offer health-related information poses two major concerns. First, this approach turns the burden of reform onto the already burdened education and health care systems while blaming the patient for continued deficiencies (Health Literacy; Rudd). Second, this view of health literacy neglects the cultural values and belief systems that permeate every individual and their relationship with health, wellness, and relationships with healthcare systems and professionals (Charon; Cummings et. al.; Prior and Shipka).

One proposed solution is to adopt an understanding of health literacy as a socially and culturally situated concept that is embedded in everyday literacy activities and embodied practices (Cummings et. al.; Lee and Hickman; Rudd). Like writing, health literacy is situated socio-culturally and is both a knowledge as well as a practiced activity that produces knowledge (Estrem; Russell). The primary importance of an effective definition of health literacy is that it recognizes this position. In the words of Prior and Shipka, “...gender, race, sexual orientation, nationality, religion, and so forth are not irrelevant to, say, scientific practice. They’re always already there,” (207, emphasis added).
While many scholars are starting to recognize the socio-cultural situation of health literacy, it has been framed in such a way as to put agency and responsibility on the institutions that inform an individual's health literacy. Figure 1 is from Health Literacy: A Prescription to End Confusion. While it accurately shows how the various social and cultural institutions inform a health literacy, the flaw of this model is that it portrays the institutions as the primary active agents in health literacy composition. If culture/society, the education system, and the healthcare system are effectively pumping information to the individual, then that individual should be able to produce effective health outcomes. However, this is not the case as institutions have not been effective in notably increasing health literacy enough to impact health outcomes.

Alternatively, my thesis seeks to advocate for the widespread recognition of how nonmedically trained persons such as myself weave together bits of information from visual, audio, social, and textual sources to create a comprehensive whole that then influences their health practices. This view places the patient-author at the center of health literacy creation and recognizes the individual as having authoritative agency. The patient-author actively interacts with the informing institutions, but then processes the received information through a series of lenses that
are shaped socially, culturally, and experientially. Patient-authors interpret information uniquely through these lenses and embodied experiences and it is through this system of interpretation that a health literacy is composed which is then applied to health outcomes. I show this process in Figure 2. I revised Figure 1 to place the patient-author at the center (rather than a disembodied “Health Literacy”). I also illustrate how the patient-author interacts with the institutions in a two-way relationship. The patient-author can choose to accept or reject information from these institutions based on their experiences and interactions. Lastly, the patient-author uniquely combines all this information into a unique composition of their own personalized health literacy which they then use to enact health habits that influence health outcomes. Through the lamination of health literacy, patients become active participants in their wellness. If the educational, social, and medical institutions grant recognition of this agency, I believe the result will be an increase of positive health outcomes.

![Figure 2: Health Literacy Model Revision with the Patient-Author as the Authoritative Agent](image-url)
When health literacy is conceptualized as a set of purely academic skills, namely reading comprehension and numeracy, then the institutional and cultural structures that place people at a disadvantage remain in place (Lee and Hickman; Rudd). Additionally, by viewing patients as passive receivers of health information as a prescribed health literacy composed by institutions, we neglect the inescapable influence of the patient-author’s autonomy.

By recognizing that health literacy is “embedded in everyday life” (Lee and Hickman, 3), it becomes easier to recognize the systems and power structures that prevent some groups of people from achieving adequate, autonomous health literacy levels that empower patients to propagate wellness practices that prevent disease or self-management strategies for chronic conditions. The public’s lack of health literacy is not only the fault of the medical system or the educational system; rather, it is the result of all the benefits and/or detriments of the patient’s social and cultural contexts and their interactions therein (Charon; Cummings et. al.; Health Literacy; Rudd). The first step forward is to recognize the patient-author as the primary authoritative composer of health literacy as they process and translate information from socio-cultural institutions and embodied experiences through everyday literacy activities.

Healthcare providers should recognize the path and active role that patients take in the process of lamination as they author their own health literacies as well as the authoritative perspectives they bring to patient-provider interactions. I hypothesize that by understanding the lamination process and placing the patient-author at the center of the health literacy paradigm, health literacy and health outcomes can be improved.

Employing an autoethnographic approach, I explore the long-term process by which I have created my own health literacy and applied it to health outcomes by laminating official and nonofficial multimodal sources in socially and culturally situated activities. The goal of this research is to promote individual patient empowerment by representing health literacy development as
accessible and by promoting patient voices and lived health experiences as authoritative. I will be addressing the following research questions:

1. In what ways do my everyday literacies contribute to efforts to manage my health?
2. In what ways do I consider my everyday literacies as a reliable source of information for managing my health?
3. In what ways do the textual processes and practices of my health literacy influence my health?

**Literature Review**

Much research has been done to trace the discussion of health literacy across disciplines to define and understand the scope of the term (Lee and Hickman). Like writing, health literacy is situated socio-culturally and is both a knowledge as well as a practiced activity that produces knowledge. My research is informed by scholarship that supports a socio-culturally contextualized view of health literacy and the influence that everyday activities and experiences have on the development of one’s comprehensive health literacy.

The Institute of Medicine of the National Academies’ book, titled *Health Literacy: A Prescription to End Confusion*, uses the popular definition of health literacy also described by Lee and Hickman; “the degree to which individuals have the capacity to obtain, process, and undertake basic health information and services needed to make appropriate health decisions,” (*Health Literacy*, 2). Drawing upon this definition, I define health literacy as follows: the socially and culturally informed process by which individuals obtain, interpret, and laminate information from official and nonofficial multimodal sources to inform their health decisions.
The book then creates a framework that describes the situated nature of health literacy within the beliefs and values of culture and society’s institutions. The framework places health literacy at the center influenced by 1) the education system, 2) medical institutions, 3) culture, and 4) society as shown in Figure 1 discussed previously.

As discussed previously (Fig. 2), I revised this structure by placing the patient-author at the center as the active composing agent of health literacy. This recognition gives a way forward for my project to more clearly establish the two-way relationship between these influential factors and the patient-author as I seek to describe how the author-patient draws from and interprets the official and nonofficial sources and embodied experiences to create their health literacies. Health literacy is first and foremost situated in the patient-author and informed by their social and cultural environment. This position includes the history, culture, beliefs, and values that are carried, embodied and enacted in everyday activities. Health literacy is then influenced by medical and educational institutions. Interactions with these institutions is heavily interpreted through the social and cultural lenses each person naturally carries. This project aims to explore that socio-cultural lens by investigating my everyday literacy activities, how they interacted with the medical and educational institutional components, and how the composition of a personalized health literacy supplies the patient-author with the authority and autonomy over health outcomes.

Other sources offer a closer examination of the interactions that patients experience in these individual facets of the health literacy framework described in Health Literacy: A Prescription to End Confusion. Rita Charon’s chapter, “Bridging Health Care’s Divides,” explores the medical institution facet and investigates the deep chasm that is created by the power distance between patients and medical providers. This distance is made up of social and cultural beliefs, values, and (mis)trust that both parties carry into every interaction. While traditional views of health literacy would explain
away patient-provider miscommunication by accusing the patient of having poor oral communication skills (and low health literacy), the more contextualized definition of health literacy recognizes the burden of socio-cultural context that deeply influences what is said and understood, but also what remains unsaid and misunderstood. John Ike, Ruth Parker, and Robert Logan’s article, “Health Literacy and the Arts: Exploring the Intersection,” elaborates on this cultural context and gives credit to nonofficial (nonmedical) sources, specifically visual sources from the arts, by recognizing them as reliable means by which to build and improve health literacy and health outcomes. The researchers suggest that the education system needs to promote more intentional instruction on “reading” images which serve therapeutic or informational purposes (Ike et. al., 83). Their argument is that we live in an increasingly visual world and images are both full of information as well as socially and culturally situated. The ability to “read” these images is crucial for the development of health literacy.

Four of my sources, from a collection titled Health Literacy: Breakthroughs in Research and Practice, clearly highlight the irrevocable intersection of health literacy with digital literacy. They describe the development, implementation, and complications of using mobile personal health records, health tracking applications, and online patient-provider portals. They show an understanding of the socio-cultural situation of health literacy and the necessity for patients to be empowered and actively involved with their personal wellness and/or self-management of chronic diseases. They also describe tools that would allow more seamless patient-provider interactions as well as those that would enable patients to take preventative health measures.

By describing the use of digital platforms and tools that empower patients to gather information from (non)official sources and to track and record their own health data, my project will also highlight the significant intersection of digital literacy with health literacy. Digital tools enable
and empower patients to develop their own health literacy more easily and accurately than ever before; however, scholars also discuss the constraints of digital and web-based information and advocate that the education system and/or health care system provide and promote reputable sources to mitigate misinformation.

Building upon and extending these scholarly conversations, my thesis describes the composing practice of health literacy as a text, laminated from multiple, seemingly disparate sources, contexts, and experiences. By analyzing this process and its outcomes, I further a contextualized conception of health literacy, but also promote lamination as a legitimate composition process of health literacy and the health literacy “text” that arises from it as an authoritative source which patient-authors use to make health decisions and achieve health outcomes. Validating laminated health literacy gives patients autonomy and a better understanding of their health lives while taking guidance from the health care system.

In this chapter, I have refined the definition of health literacy and situated it within the context of writing and literacy studies. I have outlined the importance of health literacy as it relates to health outcomes and have described the problem with the traditional and current views of health literacy. Additionally, I have proposed an alternate view of health literacy by advocating for a recognition of the agency and authority of patient-authors who engage in the composition of their own health literacy through the process of lamination as they engage in everyday literacy activities. In the following chapter, I will describe the methodology of my thesis research, review the data collected for this study and briefly describe how I analyzed those data by following the trajectories of the texts described. Collectively, these artifacts describe the narrative of how I have composed my own health literacy by laminating various sources through everyday literacy activities and interpreted them through the socio-cultural lens of my personal lived experiences.
CHAPTER 2: RESEARCH METHODOLOGY & DATA COLLECTION

Research Methodology

For my thesis research I have chosen to adopt an autoethnographic approach because it is an ideal methodology for several reasons. First, as the researcher, I am able to explore the development of my own personal health literacy grounded in the social and cultural understanding of each text and lived experience. Carl Herndll’s article “Writing Ethnography: Representation, Rhetoric, and Institutional Practices” warns against the dangers of misrepresenting cultural acts and artifacts as they are observed by an outsider. By conducting autoethnographic research, I can fully contextualize the texts and lamination practices observed. Prior and Shipka describe the lamination process as “the dispersed and fluid changes of places, times, people, and artifacts that come to be tied together in trajectories of literate action, the ways multiple activity footings are simultaneously held and managed,” (181). As the creator and curator of various textual artifacts for the assembly of my health literacy, I can most accurately describe these trajectories of literate activities as described by Prior and Shipka. I can authoritatively illustrate the motivations and intentions that informed each consecutive step. Autoethnographic methodology allows me to build on previous research on textual lamination and health literacy by detailing the relationships between various textual artifacts, their collation, and application in the practice of my health literacy towards improved health outcomes.

Second, ethnographic research processes closely mirror the process of health literacy lamination itself. Tony Adams et. al., in their book titled Autoethnography, describe the research method that observes and reflects on experiences, collects a variety of textual artifacts, creates textual artifacts in the process of analyzing them, then composes a report that produces new knowledge. This process is similar to the process of lamination one undergoes to build a health
literacy. There is a process of reflecting on lived experiences with medical institutions, a gathering of sources (consciously or subconsciously), and a creation of texts, posts, and other artifacts that come together (on paper or embodied by the patient-author) to create one’s health literacy. Thus, the work of the autoethnographic researcher is closely mirrored by the health literacy composition process of the patient-author. This close relationship in process makes autoethnography the most fitting method for this thesis project.

The product of this research process aims to be a representation of the relationships between everyday literacies and the social, cultural, and institutional factors that influence my health literacy to demonstrate the autonomous authority that I, as a patient-author, have over my own wellness. I do this by exploring artifacts that I accumulated or created in relationship to my health and wellness and by recounting narratives of how they were assembled, as well as narratives of my interactions with health care institutions and how all these elements laminate together to create an evolving “text” by which I make health and wellness decisions. Following the example of Bellwoar, I will “follow the trajectories” of the texts as they were assembled/created (330-331). As my health journey began, I started by collecting information about nutrition, health, and exercise. The collection of official and nonofficial texts is a recursive process. As one text or experience informed my actions, it simultaneously led me to the creation or acquisition of other textual artifacts. Bellwoar refers to these artifacts linked by connections as “chains of reception,” (328). In this autoethnographic study, I trace the narrative of literacy practices by describing the trajectories of literacy activities which create the chains of reception that ultimately culminate in the lamination of my health literacy.

In using autoethnography as a method, my thesis project seeks to further the current scholarly conversation surrounding health literacy in three ways. First, I intend to further the work
of Hannah Bellwoar and Prior and Shipka by using CHAT to describe the phenomenon of chronotopic lamination (Prior and Shipka), particularly as it pertains to health and wellness choices (Bellwoar). Second, I intend to continue the scholarly conversation on the perception of health literacy by advocating for a contextualized definition of health literacy that encompasses the values, beliefs, experiences, and socio-cultural position of the patient (Charon; Cummings et. al.; Health Literacy; Lee and Hickman; Rudd). Last, I intend to promote the agency of the patient-author and the legitimacy of a laminated health literacy as an authoritative source from which to make health choices (Bellwoar, Hallenbeck).

Data Collection

For this study, I use as data the textual artifacts that I have collected or created over a period of four years. These artifacts feature “official” sources, which I define as sources that are created and published directly from medical experts or stem directly from institutions which are considered to be expertly informed in areas of health and medicine. Examples of such official sources include medical health records and peer-reviewed research papers. My artifacts also include “nonofficial” sources. These are artifacts that are more culturally and socially situated and created, and while they are not considered to be canonical health resources, they are products of my everyday literacy activities which have had a noted influence in the development of my health literacy and practices. Examples of nonofficial sources that I discuss in this thesis include Instagram and Pinterest posts, recipes, photos, and my own personal compositions of essays and record keeping of my health and wellness. Finally, there are some sources that might fall somewhere between “official” and “nonofficial.” These sources include documents of my health records that were not directly prescribed or sanctioned by my personal care physician or healthcare institution but come from sources that are backed by educated professionals in the scientific and/or medical field. An example of a hybrid
sources is a document detailing my genetic make-up and proclivities towards various health risks, a document I received from an algorithm created by Dr. Rhonda Patrick. I use these artifacts to trace the narrative of my own personal health literacy and to examine how the lamination process of my health literacy directly influenced my health literacy and my wellness choices. Table 1 below shows an index and description of the sources I discuss in this research.

Table 1 Summary and Description of Artifacts

<table>
<thead>
<tr>
<th>Date Created</th>
<th>End Date</th>
<th>Type</th>
<th>Source</th>
<th>Health Impact</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aug-2015</td>
<td>Continuous</td>
<td>official</td>
<td>Medical Records</td>
<td>At 24, I started being more attentive to the information provided to me by medical institutions by accessing my medical records via patient portals.</td>
</tr>
<tr>
<td>Mar-2016</td>
<td>Continuous</td>
<td>nonofficial</td>
<td>Relationships &amp; Gym membership</td>
<td>John started training me how to work out properly and I came into contact with his friends at as well as making my own friends in the gym/body building community</td>
</tr>
<tr>
<td>Mar-2016</td>
<td>Continuous</td>
<td>nonofficial</td>
<td>Podcasts</td>
<td>Podcasts were our first introduction to the keto diet, so it struck our curiosity and our investigation.</td>
</tr>
<tr>
<td>Jul-2016</td>
<td>Jan-19</td>
<td>nonofficial</td>
<td>Body Measurements</td>
<td>As I worked out in the gym, I started becoming aware of how my workouts influence my body &amp; wanted to track that change.</td>
</tr>
<tr>
<td>Jan-2017</td>
<td>Mar-17</td>
<td>hybrid</td>
<td>Books/PubMed Articles</td>
<td>I started gathering information and assessing if keto diet is healthy/effective.</td>
</tr>
<tr>
<td>Mar-2017</td>
<td>Jul-17</td>
<td>nonofficial</td>
<td>Pinterest Board &quot;NomNomNom&quot;</td>
<td>Once we decided to try keto, I used Pinterest to gather recipes for planning meals, and learning how to empty our pantry of carbs, shifting nutritional focus.</td>
</tr>
<tr>
<td>May-2017</td>
<td>Jun-17</td>
<td>nonofficial</td>
<td>Ketogenic Diet Spreadsheet</td>
<td>Once we officially started keto, I wanted to learn what my body did throughout the process and keep careful track of changes.</td>
</tr>
<tr>
<td>Date Created</td>
<td>End Date</td>
<td>Type</td>
<td>Source</td>
<td>Health Impact</td>
</tr>
<tr>
<td>-------------</td>
<td>----------</td>
<td>------------</td>
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<td>---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Jun-2017</td>
<td>Jul-17</td>
<td>nonofficial</td>
<td>Instagram Post</td>
<td>I started making posts about going keto for accountability and to starting conversations about it friends. I followed several keto accounts as well for support and meal ideas.</td>
</tr>
<tr>
<td>Jun-2017</td>
<td>N/A</td>
<td>hybrid</td>
<td>LabCorp 2017</td>
<td>A few months into going keto, we ordered our own blood test panels to have information about my baseline health on different markers that could be affected by the diet.</td>
</tr>
<tr>
<td>Jul-2017</td>
<td>N/A</td>
<td>nonofficial</td>
<td>Persuasive Essay Summer 2017</td>
<td>Going keto fueled my interest in, not only the health aspects of the diet, but also the rhetorical and political aspects of diet generally. Writing this paper for my graduate class helped me understand the rhetorical context of nutritional standards and that even scientific &quot;data&quot; is presented rhetorically with bias.</td>
</tr>
<tr>
<td>Oct-2017</td>
<td>N/A</td>
<td>hybrid</td>
<td>Genetic Report</td>
<td>Using raw data from a 23 and Me ancestry kit, we used Dr. Rhonda Patrick's algorithm to create a report that showed me my genetic predispositions. This helped me understand what supplements to take and to be cautious about regarding our diet choices.</td>
</tr>
<tr>
<td>Jan-2018</td>
<td>N/A</td>
<td>nonofficial</td>
<td>The WHOLE Story Essay</td>
<td>Having published social media posts about our diet change, I had many friends asking for details on what our lifestyle change was like and how it helped us. I wrote this essay for those friends, but it helped me to summarize everything I'd learned about diet, nutrition, and exercise in the last year.</td>
</tr>
<tr>
<td>Jul-2018</td>
<td>N/A</td>
<td>hybrid</td>
<td>LabCorp 2018</td>
<td>One year into going keto, I repeated the blood panel test which showed me the impact of the keto diet and exercise on important blood markers.</td>
</tr>
</tbody>
</table>

The creation or acquisition of these artifacts occurred organically through experiential learning. In my health journey, I followed my curiosity and listened to my body as I grew to
understand my health more fully. Bellwoar refers to this accumulation and creation of sources as “chains of reception.” She states, “I use the notion of ‘chains of reception’ to indicate that patients actively chain together receptive practices to make knowledge in their everyday lives. Chains of reception indicate agency: the complex interactive uptake (According to Freadman [2002], uptake is about what people do with texts.) and production of technical texts outside as well as inside institutional boundaries,” (328). The artifacts in Table 1 represent the full collection of texts, gathered and composed, that played a role in the chains of reception as I composed my health literary. As these chains of reception are composed, to some degree, subconsciously, I recognize that there are possibly more texts that could have been included (specific conversations, text messages with friends, articles read in passing, social media posts, etc.). I did specifically choose to omit the discussion of transcribed conversations between myself and health care providers. Though initially, it seemed that it would be beneficial to reconstruct those conversations and relate those experiences, I found that my memory of those instances proved to be biased with negative emotion. Because memories are fallible, I wasn’t sure I could accurately recall the details of those interactions. Leaving out those interactions would preserve the integrity of the data set. I have done my best to be as comprehensive and objective as I could in the data collection to give a full and accurate representation of the chains of reception that led to the lamination of my health literacy.

To analyze these data artifacts, I follow the trajectories of these chains of reception and trace the narrative of their movements and influence on my health outcomes. Bellwoar notes that by following the trajectories of text lamination, research can highlight the “connectedness of institutional and noninstitutional spaces and the diversity of activity systems and events involved,” (330-331). As I trace the trajectories of my various texts and textual activities, official (“institutional”) and nonofficial (“noninstitutional”) artifacts become laminated.
CHAPTER 3: NARRATIVE OF HEALTH LITERACY LAMINATION

Introduction

Every human’s relationship with health and wellness is uniquely handcrafted by that individual. While those relationships are influenced by the three systems discussed previously in Figure 2 (healthcare systems, culture and society, and educational systems), the agency rests with the patient-author to collate and interpret that information through lived experiences which all come together to laminate a cohesive health literacy. In this chapter, I will describe the narrative of my health literacy lamination within these systems and the texts I encountered and created in the process. This narrative describes my learning how to exercise and learning how my body reacts to different nutritional programs.

I recognize that this narrative is highly specified to my experience and is laden with a specific set of constraints and privileges unique to my life. I am constrained by my lack of formal education in health, medicine, and exercise, since I did not formally pursue training these fields of study. On the other hand, I recognize my privileged experience as a white, able-bodied, citizen of the US. The authoring of my health literacy clearly shows the privilege of access to healthcare systems and information. As a white U.S. citizen, I benefit from a national and cultural recognition of my right to proper healthcare without discrimination. As an able-bodied person, I benefit from my capacity to adapt and experiment with my diet and physical activity with very few limitations. Though I had tumultuous health experiences as a child, and I currently live with some minor chronic conditions, I maintain the access and abilities of able-bodied persons.

While these constraints and privileges might limit the direct applicability of this narrative, my intention here is to detail and analyze one specific example of health literacy lamination and to posit that health literacy is a text itself that is unique to the patient-author. It is not merely a set of skills or knowledge accumulation. It is created from texts and is a text itself whether or not it has been
written down as such. I also assert through this narrative that the agency of creating a cohesive health literacy rests in the agency of the patient-author, and the lamination of health literacy is a process that directly impacts health outcomes.

Texts and Chains of Reception

Friends at the Gym & Weightlifting: Embodied Experiences

After my mother’s physical decline and during her process of recovery, I started my focus on health and wellness first by shifting my workout practices from distance running to weight training; I joined a gym for the first time. Initially, this switch was made for a reason unrelated to my goals, namely, there were very few safe running environments in my area, and there was an inexpensive gym right next door to my apartment. Exposure to the gym community was my first informal “text” in physical fitness. I made friends with several bodybuilders, men and women, two of whom were longtime professional competitors. I listened to the stories of their carefully calculated meal plans, workout regimens, and habits of taking all sorts of body measurements. Working out in this environment taught me correct form and, with the help of this encouraging community, I began to create a literacy for weight training. Yet, it was more than an understanding of workout technique. This process taught me to tap into specific muscles I had never even known were there, to isolate the contractions of muscle groups I had never thought about before, and to control every movement of my body with intention.

This sort of embodied experience is described in Hallenbeck’s article in which women’s experiences in the nineteenth century with exercise, bicycling specifically, and their subsequent writings about them, overthrew commonplaces held the medical community regarding female frailty and sensitivity to exhaustive activities. Women, against the institutional advice of the medical community, chose to engage in bicycling and wrote about their experiences in popular magazines. This connection between embodied experiences and everyday literacy activities highlights the power
of health literacy lamination and its potential influence on society. Hallenbeck states, “Certainly in the case of the bicycle craze, evidence of nonmedically trained women’s rhetorical efforts abounds...In each of these articles, nonmedically trained women authors subverted women’s medical objectification and the practices that it authorized. They called into question some long-held medical assumptions, or commonplaces, that persisted in the arguments of both bicycle opponents and more cautious supporters,” (329). Although my embodied experiences have not moved the medical community at large, my interactions in this sub-culture of body building helped me rewrite commonplaces I held in and about myself, and thus played a large role in my health literacy lamination.

I originally thought my body was capable of a very limited subset of activities, which had been informed by the culture in which I was raised. I was never especially athletic, and where I grew up very few people lifted weights, especially not women. Though I’d very seldom been outright told I “couldn’t” do things because I was a woman, there were certainly subtexts within the small, rural town in which I was raised that read “women are weaker.” Additionally, I never knew any women in my life who lifted weights. Children could play team sports, which I always hated (I wasn’t competitive enough to care who had the ball, let alone chase them for it). “Women’s exercises,” on the other hand, were walking, jogging, or some sort of video exercise routine. I never imagined that I’d ever be able to bench press my body weight or squat two hundred pounds! My own experiences rewrote what I believed about my body and its capabilities. My activities and gym social network informed my health literacy and were powerful enough to even rewrite years of cultural influence. For this reason, embodied experiences should not be overlooked when considering “everyday literacy activities.”

Discussions with my friends at the gym also taught me new nutritional vocabulary. Although I conceptually knew what “fat” and “protein” were from freshman year biology, I didn’t really
understand how they were practically relevant my nutrition or health. Most of the bodybuilders stayed regulated to a “low-fat-high-carb” diet and were constantly counting “macros.” I had been vegetarian since I was sixteen, but mostly out of a desire to be “different.” I had never considered macros as a means of monitoring my nutritional intake. Around this time (2015-2016), I met and married my husband, John. We met at a park gathering where a group met every Sunday to practice acrobatic yoga (i.e., acro), which I had just begun to learn. Throughout our relationship and into our marriage, exercising and sports like acro and marital arts would become central to the quality time we spent together. John was also in the bodybuilding community and followed the standard diet. Additionally, John was a trained biomedical research scientist with experience studying metabolic diseases and skeletal muscle physiology. Considering his advice and experience, coupled with his scientific research in metabolic pathways, I acquiesced to his dietary habits and began to reintegrate meat.

Podcasts: Introduction to the Ketogenic Diet

While running or exercising, I’ve always found music to be somewhat tedious and repetitive, so I generally chose to listen to audiobooks or podcasts. The first time I ever heard of the ketogenic diet was while John and I were listening to his favorite podcast, Jocko. It wasn’t my preference, since it was mostly targeted toward a male audience, especially former military, most of the discussions being war-related. Yet, the host often discussed his training and dietary habits. He described the ketogenic diet as mostly high fat, zero carbs (not even allowing for fruits), and moderate protein and dietary fiber. This diet seemed counterintuitive since most of the standard knowledge about health and nutrition preached “low fat” for “heart health,” and carbs were necessary for energy; this I knew from my running days. A high fat diet sounded like a recipe for a heart attack, and I was only just getting used to eating meat again. The nutrition plan stirred our curiosity, especially John’s who took a professional interest in the idea and designed a biomedical research project around it.
Books, Documentaries, and More Podcasts

The brief diet discussion on the podcast lead to our investigative study and subsequent texts. The podcast host recommended the book *Keto Clarity* by Jimmy Moore, which we both read. It gives a good overview of the diet but is written by a layman-gone-celebrity as an advocate for and practitioner of the low-carb diet. The author at times exaggerates the diet beyond reason and bordering on the absurd; “Bring me more butter than you’ve ever brought any one human being in your life!...You should see the reaction I get when people watch me eat a bite of butter with nearly every bite of food,” (Westman and Moore 81). We also watched several documentaries for a casual overview including *Hungry for Change, Paleo Love,* and *The Magic Pill,* which were not as scientific as they were persuasive. These texts were somewhat informative, but my husband and I both recognized the persuasive strategies used in these pieces only presented part of the picture of nutrition which varies as widely as each individual body. These texts made claims to the diet’s benefits but presented the diet as an all-encompassing cure for everything ranging from ADHD to cancer. I made note of the hyperbolic “cure-all” diet attitude and made a concerted effort to not simply buy into the craze, but to conduct an experiment on my own body to determine its health needs and tendencies.

Though I maintained a carefully curbed enthusiasm for the keto bandwagon, I recognized that these popular media outlets (books, documentaries, podcasts) were examples of other people upending commonplaces as described in Hallenbeck’s article; “[M]embers of the public have their own persuasive resources, because they can connect abstractions of scientific knowledge to lived experiences, and the public debates provide their own sorts of challenges to arguments,” (330). These authors were describing their lived experiences with nutrition which broadly go against most medical commonplaces. They helped me reconsider my previous understandings of nutrition and resolve to experiment outside the boundaries of my previous knowledge. In this way, they helped me to construct my health literacy, imbuing me with a confidence in my ability to alter my
nutritional habits and listen to the text written by my body’s reactions. To further our research, when we didn’t necessarily trust the bias of popular media, we sought out more scientifically centered texts.

The inflammatory and flamboyant narration of Moore’s book and biased agendas of the documentaries made the diet a hard sell for John and me initially, and we were concerned about the legitimacy of the diet as it related to athletes of intense training, since we were both weight training daily and involved in other athletic hobbies as well. John trained Brazilian Jiu Jitsu almost daily and I began my aerial silks practice. Occasionally we would revisit our partner acrobatic practice together as well. With all of these physically demanding hobbies, we needed to know that our diet would continue to meet our physiological needs.

Probably the only real beneficial result of reading Moore’s book was the connections we made to resources he references. Throughout his book, Moore references *The Art and Science of Ketogenic Performance* by Dr. Jeff Volek, whose professional career centered around clinical application of the ketogenic diet. This book made a more scientific case for the use of the ketogenic metabolic pathway as a more efficient means of energy in high-performance training.

Other texts which we used to learn about the ketogenic and similar diets included the podcast called *Found My Fitness*, a casually named podcast which actually provides deeply scientific explanations of health and wellness as it relates to diet and lifestyle. Dr. Rhonda Patrick hosts global experts in the field of diet and nutrition and discusses these topics at the molecular level. The podcast is dense with field-specific terms, but it made me realize that “science”, a field I had always felt was beyond me, was just as accessible to me as anyone. Several of Dr. Patrick’s podcast episodes focused on intermittent fasting in conjunction with low carb diets. This was about the time that John and I decided to make the personal change to the ketogenic diet. Having spent a great deal of
effort gathering information from various sources, we felt assured that it was a safe and interesting path to pursue. This move was not out of a desire to lose weight necessarily, especially not for John. We were both curious about the relationship between the diet and several markers relating to energy levels, muscle building, and management of the chronic digestive condition I’d had since childhood.

As the next few sections describe my transition to the ketogenic diet, it’s worth noting that this transition was made as a collaborative effort by John and me to learn more about our bodies and their performance levels under various dietary conditions. I also enjoyed the experience of logging personal biological data about how my body changed through this experience. These logs, included in the data set for this project, tracked my body measurements, weight, blood levels, along with the macros of my nutritional intake for each day. What we learned from this experience proved extremely valuable, even though we don’t still adhere to the dietary plan strictly. This paper is not a recommendation for the ketogenic diet or for any particular lifestyle relating to health or nutrition. Individual bodies react uniquely to different nutritional plans, and there are no nutritional plans that can act as a guaranteed prescription to a healthier, better life. Personal health is a spider’s web of complex threads like genetics, lifestyle choices, age, and other factors. Each of these threads are tied to many other threads that each move uniquely through one’s personal experiences. This paper only sets out to describe how my experiences with everyday literacy activities informed the lamination of my health literacy.

_Collaborative Lamination: A Team Effort_

Throughout this process, I had the privilege of having a scientific professional on my team. My husband is a biomedical research scientist, and much of his personal interests in research, especially in his doctoral and postdoctoral studies, dealt with metabolic pathways. Specifically, his master’s degree research focused on Crohn’s disease, an inflammatory bowel disease (IBD) where he showed a role for a bacterium in the disease’s etiology. His Ph.D. research focused on
neuromuscular tissue engineering where he helped to establish several cell-based models of neuromuscular physiology. Finally, his post-doctoral work explored the intracellular signaling pathways that regulate skeletal muscle metabolism and their roles in exercise, obesity, and type II diabetes. We were both interested in experimenting with the ketogenic diet and decided that if we were to start it, we would go all in as a team effort. Our casual investigation of the ketogenic diet and its relationship with metabolic diseases (heart disease, type 2 diabetes, obesity, NAFLD, etc.) actually informed several of his work projects later on.

John started pulling all relevant research articles on the ketogenic diet from PubMed, the National Library of Medicine’s biomedical literature database. Having never read a scientific research article, the jargon was overwhelming. John taught me how to read the medical research journals, focusing mostly on the introduction, conclusion, and summary portions of the text which set the stage for the study and summarized the findings. The methods section, literary discussion, and findings analysis were usually too outside my wheelhouse to be much help. Yet, even through this narrow view, I started to feel empowered by the ability to search out the work of science itself rather than getting the information through a second-hand informer who begins statements with “Studies show” or “Scientists have proven.” John taught me to look for papers from reputable journals with experiments that were planned with controls and were replicable. Not every scientific study is created equal.

With the ability to discern the meaning of medical research, I felt armed with much of the same information as the medical experts. Though I understood my limitations as a layperson, I felt qualified at least to discern the best course of action concerning my personal diet and lifestyle habits. The research papers we gathered from PubMed made a convincing case for the ketogenic diet. It seemed to provide efficient energy while regulating blood sugar levels, satiation, as well as mitigating
metabolic diseases such as type-2 diabetes and heart disease, primarily by regulating the insulin signaling pathway. Below is the citation for one of the research papers by which John helped me to develop the literacy of reading academic research articles in the field of medicine:


*Chains of Reception and Strengthening Agency*

All the texts discussed thus far played the role of creating my chains of reception through which I had come to understand my physical health. As I linked together advice from friends, my partner, books, podcasts, documentaries, and published research, I grew more and more self-assured that I was capable of understanding the biological processes of my body, and I was authorized to make decisions for its well-being. This confidence distanced me from the dependence on a medical physician as the sole source of information regarding my health habits. The secrets of the professionals were demystified and accessible; this motivated me further to begin an experiment surrounding our decision to change diets. In the next section, I will be discussing the texts which I was able to create from my chains of reception to create new information and meaning from my newly acquired literacies in conjunction with everyday literacy activities.

*Social Media: Instagram Posts and Pinterest Boards*

Transitioning a bodybuilder and a vegetarian to the ketogenic diet was no small feat. I started by ridding our kitchen/pantry of all grains, flours, rice, sugars, and processed foods of any kind. Once our pantry was “clean” of all carbs, it was also fairly empty. Having been cooking vegetarian for the larger part of ten years, I struggled to know what to do. I turned to social media
communities, Pinterest and Instagram specifically, to find/share meal ideas, explain our process, and connect with others trying the ketogenic diet.

I created a Pinterest board to start a collection of recipes to try. Then I announced our new diet approach on Instagram using hashtags related to the food pictured and then several that were variations of “ketogenic diet” (#keto, #ketorecipe, #ketogenicdiet, etc.). The first keto post and the Pinterest board for recipes (titled “NomNomNom”) are pictured below (Fig. 3 and Fig. 4).

Figure 3: First Instagram Post about Ketogenic Diet
By posting about the ketogenic diet on Instagram and using hashtags related to the keywords “ketogenic diet” I was then connected to other accounts who focus on the ketogenic diet. Those accounts would like and comment on the photos with those hashtags, allowing me to enter a discourse community that I didn’t know existed before. There were multiple accounts centered around the keto diet, posting their ketone bodies and blood glucose numbers on a regular basis, keto recipes, and exercise inspirations. I browsed through those accounts on occasions for ideas and inspiration and followed several. I got a lot of positive feedback and even more questions from friends and followers, so I was encouraged to keep posting meal and progress updates on Instagram. Pinterest continued to serve as a place to acquire and file meal ideas and recipes. Pictured below is an Instagram food post (Fig. 5) and a Pinterest recipe pin (Fig. 6).
Figure 5: Instagram Food Post

Figure 6: Pinterest Recipe Pin
Records and Logs: Creating My Own Medical Records

The gathering of information about the keto diet and recipes on social media continued over the course of one year. With the knowledge I gained by laminating various texts to develop new literacy skills, John and I started the ketogenic diet, and I began creating my own medical records by documenting various body measures, purchasing blood panel tests to keep in my personal files, as well as acquiring genetic data to run through an algorithm that would render a genetic report of potential risks or propensities. Again, as the main motivation for this self-experiment was to learn about our bodies, we tried to gather as much data as we could throughout the process, starting with the acquisition of a baseline in the form of blood panels.

At the very start of the diet, I ordered a pre/post blood test to see the diet’s effect on my hormones, cholesterol levels, and other important biomarkers. Instead of going to the doctor, I ordered a direct-to-consumer test (a women’s health panel which covered data on major hormones, cholesterol levels, and several other biomarkers). These tests are ordered online and electronically sent to a local lab (like Quest Diagnostics or LabCorp). I had my blood drawn at one of these labs and in a few weeks, my results were sent directly to me via email. It was an extensive test and I had to do some internet searching to identify all the biomarkers and their significance, but it didn’t take a great deal of effort to decipher; I also employed John’s help in reading these results. I printed the results and keep them on file.

After being on the ketogenic diet for one full year, I ordered the same test panels and was able to see the influence the diet had on my blood markers. There was a marked improvement in multiple areas, and I was pleased to have the ability to track my own blood levels. At one time during the year, I did go to the doctor’s office for a routine physical. I referenced the records and showed him a screenshot on my phone. He looked at the image puzzled and said, “Hmm. Interesting. You really need to send us those records so we can keep them on file.” I said I would,
but I never did. My growing confidence in understanding and keeping my own medical records made me even less willing to trust medical institutions, especially regarding individual biometric data management. For the first time, I felt some authority over my personal health data and agency regarding what I could and should do with it. I chose not to submit my bloodwork to the PCP because it was not relevant to his purposes, and I owned the information. As my health literacy grew through everyday activities and embodied experiences, I became more informed, more in-touch with listening to my body, and thus more empowered to make the very best decisions for me and my own health.

A major aspect of the ketogenic diet experiment I conducted was the careful process of documenting my body’s progress through the diet change. The key purpose of the ketogenic diet is to cause blood glucose levels to drop very low by depriving the body of carbohydrates and cause ketone bodies (created from fat) to form and be used as the major source of energy. The ketogenic diet is ineffective unless one is actually in nutritional ketosis (blood glucose levels of <100 and ketone levels of at least 0.5 mmol/L). To determine whether or not one is in ketosis, it is necessary to blood test at least once per day. We purchased a blood monitor, one which could test blood glucose levels as well as ketone body levels. At the start of the diet, I tested once per day on average and logged these numbers in a spreadsheet.

In addition to the ketone and blood glucose numbers, I downloaded a calorie counting app which allowed me to log everything I ate and gave me readouts on the macros I was consuming. I also logged morning and evening weight, noted what meals I skipped (“Fasted”), and how many total calories I ate. Twice I checked my body fat percentage using a caliper (relatively accurate, low cost, and most commonly used by bodybuilders). Below is a screenshot of the table I created starting May 31, 2017 (Table 2).
I started a separate log to track body measurements. While my weight initially dropped a great deal, it fluctuated as I began to train more heavily with weights. I lost a lot of fat but gained muscle. Below is the table I created to track body measurements, tracked every few months with no specific regularity (Table 3).

**Table 3: Body Measurements**

<table>
<thead>
<tr>
<th>Date</th>
<th>7/25/16</th>
<th>2/26/17</th>
<th>6/21/17</th>
<th>4/22/18</th>
<th>7/6/18</th>
<th>1/3/19</th>
</tr>
</thead>
<tbody>
<tr>
<td>Above chest</td>
<td>33&quot;</td>
<td>34&quot;</td>
<td>35.5&quot;</td>
<td>35.5&quot;</td>
<td>35.5&quot;</td>
<td>35.5&quot;</td>
</tr>
<tr>
<td>Chest</td>
<td>36&quot;</td>
<td>37&quot;</td>
<td>35&quot;</td>
<td>37.5&quot;</td>
<td>37.5&quot;</td>
<td>37.5&quot;</td>
</tr>
<tr>
<td>Rib Cage</td>
<td>30&quot;</td>
<td>30&quot;</td>
<td>30&quot;</td>
<td>33&quot;</td>
<td>32&quot;</td>
<td>31&quot;</td>
</tr>
<tr>
<td>Waist</td>
<td>29&quot;</td>
<td>27.5&quot;</td>
<td>27.5&quot;</td>
<td>31&quot;</td>
<td>27.5&quot;</td>
<td>29&quot;</td>
</tr>
<tr>
<td>Hips</td>
<td>35&quot;</td>
<td>36&quot;</td>
<td>35.5&quot;</td>
<td>38.5&quot;</td>
<td>37&quot;</td>
<td>38&quot;</td>
</tr>
<tr>
<td>Thighs</td>
<td>21&quot;</td>
<td>20.5&quot;</td>
<td>22&quot;</td>
<td>22&quot;</td>
<td>22&quot;</td>
<td>22&quot;</td>
</tr>
</tbody>
</table>

**Nonvariables**

- Inseam: 26"
- Girth: 60"
- Height: 5’ 1/2"
I initially started these logs because once we started the diet, I began losing a lot of weight quickly. At the start of the diet (not logged here) I was 135 pounds. I thought that if I started tracking these numbers, I would see the progression. What I actually saw was, after the initial weight loss, a stabilization of my weight. What I gained by keeping the charts was the knowledge of how food and exercises influenced my body and how to adapt my life habits to achieve my athletic goals. I found control in knowing how my food influences my blood and metabolism. I also felt empowered by documenting the numbers and tracking them. I felt that I was in more control of my body and health. The control helped me not obsess over the “perfect numbers” but to enjoy the ability I had to take care of myself without having to rely on an expert’s opinion formulated after a five-minute observation and interpreting my calculated body-mass index (BMI) (body weight (lbs)/height (inches)).

The ketogenic diet helped me maintain consistent energy throughout the day, even through periods of fasting. I integrated intermittent fasting after listening to the Found My Fitness podcast by Dr. Rhonda Patrick. I experimented with learning my body’s boundaries for hunger by conducting several short term and long term fasts. In my macro and blood glucose log above, I note which meal I skipped each day. This habit of meal skipping was a result of adapting to new energy and hunger levels on the keto diet. I just wasn’t hungry very often, so I ate less often (though my caloric intake was about the same as before because high fat foods are also calorie dense). I then graduated to periodic 24-hour fasts and then to multi-day fasts. My body reacted well to these fasts, especially when my digestive disorder flared up; I found fasting to be an effective treatment and I stopped taking medication. My longest fast was 75 hours; I wanted to see how far I could push my body’s limits. I did extensive reading and carefully planned my activities and fluid intake for those three days. I kept a log throughout the three days to track my physical and mental reactions.
These practices helped me learn how to listen and understand my body’s needs in relationship to the quantity and timing of my food intake. Though I don’t regularly practice extended fasting, I have a new understanding of my body and its relationships to hunger; this gives me the freedom to meet those needs regardless of social expectations mealtimes and portion control. I learned that some days, I could eat 1 or 2 meals and feel perfectly happy. Other days, I might need 4 or 5 meals. Some days I eat nothing at all. On those days, I focus on water intake and on listening to my body’s other needs (activity, rest, stress management, etc.). All of these new practices helped me to finally manage, without medication, the digestive disorder I’d lived with my whole life. They empowered me with intuitive listening skills for my own health and wellness.

The final text in my personal medical records actually came by accident. My husband purchased us ancestry kits from 23andMe just for fun. We enjoyed the results and information it gave us but were not much more interested until we were listening again to the Found My Fitness podcast by Dr. Rhonda Patrick. On one of her podcasts, she discussed her website (https://www.foundmyfitness.com/genetics). On this website she had developed an algorithm that could take the raw data from an ancestry kit and produce a comprehensive genetic information report. The report is generated by aligning an individual’s gene sequence data with curated databases of population genetic information to give insights into genetic disease risk factors based on single nucleotide polymorphisms (SNPs). You can purchase kits that will give you similar information, but they are more expensive and, from what I could tell, not as complete as the ones produced by her website. The report was pay-by-donation and we each spent $10 for the comprehensive report. Similar to the blood panels, I had to do some research and get some help from John before I could fully understand the results of the report, but I found the information extremely valuable and kept the eighteen-page report in my file. A small sample is found below in Table 3.
Reconnecting to Literature: Bellwoar

Bellwoar, in her case study, views Meagan’s literacy activities through CHAT. She states, “To consider health literate activity as dynamic, engaged, and interactive, I draw on cultural– historic activity theory (CHAT). According to Russell (1997), CHAT in writing studies ‘takes as its object the roles writing plays in various activities, particularly those activities in which writing most powerfully mediates work: academic disciplines, professions, and other large and powerful organizations of modern life’,” (328). Bellwoar’s study, like my own, both evaluate the role of writing as it challenges
the “large and powerful organizations of modern life,” specifically, the power dynamic between patient and medical expert.

In Meagan’s case, she created chains of reception from nonofficial sources to create her own framework of understanding for her pregnancy and her medical condition. She used these laminated frameworks to conceptualize her experiences as well as make decisions concerning her health. My own study brings Bellwoar’s work a step further by more clearly demonstrating the agency that was gained through these chains of reception that caused a disruption in the traditional view that gives complete authority to medical experts for maintaining medical files and making decisions based upon that information. My study dispelled dependence of the patient upon the expert by laminating multiple sources (official and nonofficial) through everyday literacy activities to create health literacy and agency in tandem.

**Limitations and Collaboration**

One key factor in the success of this lamination process was its deeply collaborative quality, especially regarding the teamwork between my husband and myself. However, this specific collaboration works against my aim to assert that medical agency can be obtained with greater distances between the patient and the professional. I recognize that my dependence on the collaboration with my husband as a biomedical expert might somewhat contradict my claim, and it certainly points to a specific privilege which is not afforded to most people.

To address the first limitation, I assert that the professional-patient relationship potentially present between me and my husband in this study is different than the professional-patient relationship I challenge above. The partner collaboration reflects mutual motivation and interest. John’s influence contributed to my autonomous agency when he taught me to read and understand the PubMed primary research articles. His instruction and collaboration increased my independence
and furthered our mutual goals. He supported my record keeping by contributing to my blood test information, teaching me to read the results. The medical professional, by contrast, was not interested in creating an autonomous patient, as was made evident during my encounter with the doctor who requested copies of my blood work for his own files. The collaboration with my husband also lacks the power imbalance which is usually present between doctors and patients.

As for the second limitation, I recognize the access to an altruistic professional is uncommon. The legitimacy of my laminated knowledge was vetted through John’s professional expertise, which is a privileged access point most people do not have. I recognize this as a limitation of this study, but I think the collaboration still highlights two important factors. The first factor is the important contrast between a self-limiting dependence on medical professionals and a mutually-motivated collaboration with a partner. This relationship must lack a power imbalance.

The second factor is the certain level of privilege required to start developing medical agency. My privilege was not only access to a scientific professional, but also access to informational resources like the research studies on PubMed and the access to the education necessary to be able to build a new literacy. Many patient-users do not have these privileges of access and are left to sift through infinite sources, many of which are unreliable. This causes a lamination of false information. It would be beneficial to conduct further study in the nature of access to medical resources and information at various levels of privilege and how those access points serve as the gatekeepers to medical agency and autonomy.
CHAPTER 4: DISCUSSION & CONCLUSIONS

Influencing Systems and the Patient-Author

With the increasing ubiquity of personal technology, the practice of lamination is becoming increasingly routine to most people. Though not always accurately constructed, many people consult multiple internet and multimedia sources to understand their health or specific conditions by chaining together bits of information and anecdotal stories found on the web. The idea that all the medical information influencing people’s decisions will come from the single expert or medical organization is probably outdated as more people take ownership of their own bodies and information. Bellwoar states, “Users contribute to infrastructure and network through their knowledge work or, in my research, patients take up and remake medical discourse in their everyday lives for their own purposes. But just because these practices occur outside of institutional boundaries does not mean that the discourse is no longer legitimate knowledge work,” (329-330).

The deconstruction of health organizations’ authority gives way to a more informed population capable of managing their own health and possibly creating lifestyles more conducive to longer health span and proactive in preventing disease. This rise of agency does not negate the need or validity of health care professionals, but it does critique the imbalance of knowledge and responsibility regarding personalized health care.

In this chapter, I draw from my data and autoethnographic narrative to suggest some possible implications and suggestions for better understanding and improving health literacy with an eye towards the practice of lamination through everyday literacy activities. I do this by revisiting the primary components shown in figure 2 that influence health literacy composition. Healthcare systems, culture and society, and education systems are all in a two-way relationship with patient authors. The interactions between the individual and these systems are mutually influential, and from these interactions the patient-author gathers and interprets information. This information becomes
the unwritten composition of health literacy that mediates the patient-author’s health practices, influencing health outcomes. If individual patient-authors had a conscious awareness of the lamination process and if the influencing systems understood and welcomed this process, it would be possible to create a more collaborative effort in improving patient-provider relationships, increasing access to reliable medical information, and creating communities that promote and propagate health literacy.

Healthcare Systems

Healthcare providers face a seemingly Herculean task. They have acted as the gatekeepers to information in an ever-changing field of medical science and technology, and they are overburdened by extraneous obligations and paperwork. The weight of these obligations, along with a host of social and cultural barriers, creates a communication gap between patients and providers. Literature in the medical field as well as humanities studies have commented on the need to close this gap, to treat the “whole patient” as opposed to the symptoms (Charon and Ike et. al.).

One approach to solving this issue places the burden of responsibility on the shoulders of medical professionals. Rita Charon proposes that medical professionals take an approach that she calls “narrative medicine.” This strategy suggests that healthcare professional can close the gap by intentionally building relationships and trust with patients. She states, “Narrative medicine is a very practical undertaking. It arises from the day-in, day-out events of the doctor’s or nurses’ office,” (17). The foundation of this approach is empathy on the part of the provider, requiring them to understand the socio-cultural and emotional factors that influence their health and wellbeing. Charon continues, “In addition to needing expert diagnosis and treatment, seriously ill people simultaneously need those caring for them to recognize that something of value has abandoned them,” (17). This notion of relationship building and narrative medicine, founded on empathy, is
also shown in Kevin Roozen and Joe Erickson’s case study of a nurse, Terri, who employed this empathetic approach by writing poetry to connect with her patients and their conditions. The authors describe her literacy activity as a crucial component of her caregiving; “As Terri enrolled in courses to pursue a Licensed Practical Nurse (LPN) degree in the early 1980s and started working as a health care professional, many of her poems focused on her work as a nurse. Terri frequently referred to these poems collectively as “see me” poems because they all tend to center on looking beyond patients’ diagnoses, symptoms, and treatments in order to acknowledge their humanity” (6.03). The notions of relationship-building and empathetic connections are a valuable suggestion, especially for chronically or seriously ill patients, but they may be impractical undertakings in the short, periodic interactions that constitute most office visits for general health maintenance.

Another avenue for improvement is to place the burden of agency on the patient. Balouchi et. al. support this perspective in their research stating, “If medicine is to achieve economies of scale and capabilities, it is important that patients assume and active role in the management of their health because patients are more in tune with their own symptoms and healthcare providers are increasingly overworked,” (199). Traditional health care depends heavily on the patient-provider relationship. However, long periods between doctor visits leave patients with a level of autonomous freedom that could benefit or jeopardize a patient’s progress depending on their lamination of health literacy and the recognition of their level of agency. If deep, meaningful interpersonal relationships between patients and providers is unrealistic, I suggest that both parties take a partnership approach to the treatment and wellness plan of individuals. This would require patients to intentionally understand the process of their own health literacy lamination and their position as autonomous, authoritative patient-authors. It would also require that doctors tap into the resource that is the patient’s knowledge of their own wellness and all the socio-cultural factors that contribute to it. In short, medical professionals should take steps to practice narrative medicine as proposed by Charon,
but patients should also take up the mantel of agency in understanding and engaging in their wellness plans. Balouchi et. al. state “Self-management is critical in the case of chronic disease because lifestyle factors and medication adherence between healthcare provider visits are vital for the long-term health of patients,” (200). I suggest that the same is true for those who are not chronically ill but are seeking to elongate their health span (the length of time which a patient enjoys good health).

This interactive partnership between the patient-author and the healthcare provider must be individually personalized for each interaction. As the lamination of health literacy is influenced by socio-cultural and educational factors as well, the confidence and willingness of patients to participate in this partnership may vary. Balouchi et. al. state, “Simply providing health information is not enough to engage patients to change their health behaviors. Some patients may feel overwhelmed and unprepared to manage their own health while others simply require more in-depth information to adequately care for themselves. A customized approach to healthcare that incorporates different health beliefs, goals, and motivations would improve clinical outcomes, lower costs, and heighten patient satisfaction,” (201). With a mutual awareness of how patient-authors laminate their health literacy, custom healthcare can be provided in a way to maximally impact health outcomes.

**Educational Systems**

Formal education systems, like healthcare systems, are also overburdened. K-12 schools are tasked with providing for the physical, mental, and emotional care of a student population with diverse needs, cultures, languages, and backgrounds. Additionally, schools aim to guide the educational development of students across all subject areas to standardized levels of mastery. The obligations that are saddled upon school systems and their professionals leave little room for
specified instruction and practice of varying literacies that fall outside the more traditional alphanumeric skills. This causes a deficit in crucial multimodal literacies such as visual literacy, digital literacy, and, ultimately, health literacy.

Varied literacies are interdependent. To laminate a working health literacy that results in positive health outcomes, the patient-author must be able to process, understand, interpret, and evaluate visual, audio, digital, and written texts and to assimilate them into their health practices, so the exclusive focus on alphanumeric skills is not adequate to ensure that students will accurately be able to navigate the world of digital, visual, and health information in order to effectively laminate a working health literacy. While state education standards encourage multimodal learning in the form of using digital activities and texts, the standards do not explicitly cover the development of digital literacy as a whole which is tightly connected with health literacy (Lagumdzija et. al., Monkman et. al., Usher). Education systems should promote a more critical focus on digital literacy and visual literacy with a recognition that the application of these literacy skills through the process of lamination will directly impact the health literacy composition and health outcomes of students as patient-authors.

In schools, the teaching of visual literacy skills is often relegated to extracurricular or elective courses, such as art classes and clubs. This subtle segregation reflects the prioritizing of alphanumeric literacy at the expense of visual literacy. Medical experts John Ike, Ruth Parker, and Robert Logan explore the detrimental impact of this hierarchy by arguing that a targeted education in the arts and visual literacy actually enhances health literacy in a way that is contextually situated in sociocultural patterns. The authors state, “Viewing the arts as communicators, especially seeing their messages related to context, can enhance our health literacy approaches that seek to address both content and context. The underexplored intersection of health literacy and the arts holds promise for advancing how we enhance our skills and abilities to help individuals and populations navigate,
understand, and use all that is available to improve health,” (93). Now more than ever, information is presented in visual formats (e.g. social media posts, graphics, videos, photos, etc.). The ubiquity of visual information is especially present in everyday literacy activities such as accessing news information on TV or internet and browsing websites and social media posts. Ignoring visual literacy as a critical skill in favor of antiquated educational preferences will continue to have a negative impact on health literacy levels. Similarly, digital literacy is another crucial avenue to pursue in the education system as it rests in the overlap of visual literacy, alphanumeric literacy, and generally reflects sociocultural trends and research concerning issues of health.

Digital tools and resources provide a seemingly infinite number of avenues by which to gather health information and practice health outcomes in the form of news, sanctioned medical and health information sites such as the CDC, as well as health tracking and monitoring tools for independent use or as a collaborative resource between patients and providers. Recent research in the medical community consistently points to the power of patient empowerment through the collaborative use of e-tools in the form of mobile personal health records (Balouchi et. al., Lagumdzija et. al., and Monkman et. al.) and two-way communication portals between patients and providers (Usher). However, the obligation lies with the education system, not only to provide students with accurate health information, but also to effectively teach students how to access, interpret, and use multiple digital platforms for the composition of health literacy. Education systems must prioritize a wider range of literacy skills, including visual literacy and digital literacy, in order to teach students how to accurately gather information for the composition of a working health literacy which will positively impact health outcomes.
Culture and Society

Culture and society are our earliest teachers concerning what we believe about our health and our bodies. This influencing system persists throughout our lifetimes as an instructor influencing our thoughts as we engage in everyday literacy activities and social interactions with people in person, through texts and images, and on digital platforms. Cultures prescribe what various people groups (of varying ages, nationalities, races, genders, religions etc.) believe about the nature of health/wellness, healing, and medicine. The complexity of this web touches every other influencing system. It defines how specific people interact with and are treated by healthcare systems and professionals. It permeates the education system by influencing how individuals interpret, evaluate, and laminate pieces of information. In light of the pervasive influence of culture and society on health literacy, researchers in the medical field and in humanities urge the importance of recognizing health literacy as socially and culturally situated (Charon, Cummings et. al., and Ike et. al.). This requires education systems to acknowledge the position of students in relationship to their personal and cultural beliefs while providing accessible education in critical literacy skills that will contribute to the effective lamination of health literacy. This also requires healthcare systems to provide equitable access to information and services while promoting empathetic patient-provider interactions that are sensitive to individual’s culture and belief system.

Though the influence of culture and society is complex, researchers suggest that empowering patients to engage in self-management of health conditions while promoting social interactions on social media platforms among patients increases health outcomes (Cummings, Ellis, and Turner). The authors describe the building blocks that form the nature of social media: identity, conversation, sharing, presence, relationship, reputation, and groups (295-296). They state, “For health professionals the first step in responding to the ‘social’ is to acknowledge that it is happening! Thereafter, exploring ways that social media can be leveraged to enhance health communications
with patients and improve quality and reliability of information and advice access will be important,”
(297). The more centralized influencing systems (education and healthcare) can make use of this
more decentralized influencing system of culture to promote a properly situated and contextualized
health literacy by providing avenues for people groups to discuss, share experiences, and collaborate
on matters of health and wellness.

The Patient-Author

The individual patient-author exists at the center of the health literacy model presented in
this thesis. The reason behind this centrality rests in the threshold concepts of writing studies. First,
Bazerman and Tinberg suggest that “Writing Is an Expression of Embodied Cognition,” which
supports the unique influence of a patient’s lived experiences upon the lamination of their health
literacy and, subsequently, the exercise of practices that influence health outcomes. While patient-
authors are learning from and interpreting texts through their lived experiences, they are
simultaneously creating new knowledge as Estrem posits in “Writing is a Knowledge-Making
Activity.” While one’s health literacy may not be an explicitly “written” text, it is a comprehensive
“document” that informs the actions and attitudes of the patient-author towards issues of health,
medical treatment, wellness, healing, and routine health practices. As the patient-author constantly
adapts to new information and experiences, the health literacy “document” is edited and revised in a
recursive process. Part of this editing process is influenced by the threshold concept that “Texts Get
Their Meaning from Other Texts,” as proposed by Kevin Roozen. He describes the nature of this
process saying, “The meaning writers and readers work to make of a given text at hand, then, is a
function of the interplay of texts from their near and distant pasts as well as their anticipated
futures.” As patient-authors compose their health literacy over time through everyday literacy
activities, gathering, evaluating, and laminating written and unwritten texts, they also apply their
health literacy to their daily lived experiences, thus reenforcing the threshold concept posited by Russell—“Writing Mediates Activity.”

These connections between the patient-author and the threshold concepts of writing studies suggest a powerful level of agency over one’s own health literacy and subsequent health outcomes. While the influencing systems have some power of influence over the individual, it is ultimately the patient-author’s actions and reactions to various texts that create meaning through the lamination process. Patient-authors are constantly evaluating texts through sociocultural lenses as well as comparing them to other texts and to their lived experiences.

**Conclusion**

Consciously or subconsciously, patient-authors maintain the authority over their health literacy composition which impacts their health practices, habits, and outcomes. This proposition highlights the autonomous agency of individuals which carries weighty implications for the various influencing systems. More importantly it should empower individuals to more consciously and intentionally seek out avenues by which to compose the most effective health literacy possible. With a conscious level of intentionality, patient-authors can laminate a health literacy to produce the most positive health outcomes possible. As I guided myself through the process of learning my body’s reaction to different dietary strategies and exercise programs, I gained confidence in my ability to make the best decisions for my health and wellness. I also gained confidence in my ability to voice my health concerns, desires, and plans with healthcare providers. This collaborative relationship between patients and providers is desperately needed as medical systems continue to be overburdened. Instead of a being a passive patient, struggling through power dynamics of the patient-provider relationship, I became a patient-author with agency concerning my body, empowered to collaborate with professionals to make the best decisions for my health.
REFERENCES


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