Pain without Pathology:
A Discourse Analysis of Medical Websites on Chronic Pain

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Abstract

The prevalence of the internet has supported a vast expanse of online medical information covering a variety of ailments, treatments, and prognosis. The extent of this knowledge seems to promise a shared increase in medical information for all, shifting existing powers in the medical field. However, the medical information circulated may not reflect a change in this power. This thesis works to analyze the circulation of information about chronic pain and how it is conceptualized in popular medical websites and the American Chronic Pain Association (ACPA) website. Chronic pain was chosen as a topic of focus due to its prevalence in western society, the lack of a consensus on its causes and meaning, and the stigma associated with it. Drawing on insights from neurological, biopsychosocial, and Foucauldian approaches, my analysis revealed the hegemonic appeal of neurological view in how these medical websites represent chronic and a lack of attention to the social and economic factors that might shape the experience of patients. Furthermore, existing power relations in medicine were on the whole reinforced by these conceptions, yet there seems to be a possibility for a change in the encounter between the doctor and the patient. As medical information becomes more accessible and voluminous online, anthropologists must account for how the circulation and representation of knowledge about pain and its management are shaping the medical gaze and the practice of medicine.
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Introduction: Studying Pain

A few years ago, a family member was suffering from constant backaches. The pain was so intense that he struggled to get through work and exercise, and had to constantly use heating or cooling pads. At some point, the pain became too much and he googled his symptoms online. The internet informed him that he might have chronic pain, and listed his symptoms. Eventually, he went to the doctor’s with the knowledge that he might have chronic pain, and was able to use what he learned in discussing his condition with his doctor. Although he still treats the pain in similar ways as before, he now has a diagnosis for his symptoms and finds it important to check the internet on a regular basis for new tips. This situation could be repeated across countless families in America as more and more people turn to the internet for medical knowledge and guidance.

As information becomes more easily disseminated in all spheres of life on the internet, medical information in particular has become easily accessible online. It quickly and conveniently provides descriptions of symptoms, treatments, and causes of a variety of different ailments. While the legitimacy of these sites and their medical authority is not universally clear, there is no doubt that they are popular; they are able to boast millions of users. In general, this information seems to promise a new type of medicine, in which a person can look up their symptoms from home and have an idea of their issue before even going to see a physician. In large-scale medical events, such as in the US experience in 2020 of COVID-19, people were able to gain access to medical information within minutes of publication from their homes, a radically different experience from populations in other pandemics in previous centuries. This medical information may keep readers better informed about their health without needing to talk to a
physician. This circulation of knowledge poses important questions such as: How is medical information circulated in new ways using the internet? How could this change traditional aspects of medicinal practice?

In order to understand more about how information on chronic pain is available to a western population and what it might mean for patient care, this study performs a discourse analysis on popular medical websites. These websites, *WebMD, Healthline.com, Medlineplus.gov*, and google sidebar, are at the top of a google search for chronic pain. Additionally, the American Chronic Pain Association website is also analyzed. The information presented on the medical websites themselves are reviewed for what they reveal about conceptions of chronic pain, pain as a whole, and the relationships between physicians and patients in this new age of medicine.

Chronic pain is chosen as the area of focus in these medical websites due to its far-reaching demographic and ambiguity in the medical field. There is a wide-variety of different conditions classified under the umbrella of “chronic pain,” and many have unknown causes and no known cures. For a discipline that has advanced itself in modern society as champions of empirical, objective evidence, this lack of information about chronic pain in medicine is unique. I suspected that this non-universal definition of chronic pain and the individualistic nature of pain in general may lead to a variety of different information on the sites. These differences may further demonstrate the benefits of medical websites in providing information to people outside of the doctor’s clinic, and a potential disadvantage if the information is different from what an in-person physician would recommend.

I argue that the use of medical websites in sharing information about chronic pain represents a novel way to share medical knowledge, both illustrating and challenging previous
assumptions about the impact of medical knowledge and its circulation on a physician-patient relationship. In many ways, the information presented on the medical websites reinforces traditional conceptions of the doctor and patient as found in the work of Michel Foucault on the medical gaze. Most sites reinforced the authority of the doctor, placed emphasis on objective definitions of pain, and encouraged established medical procedures such as pain medications. Additionally, the sites displayed capitalistic influences on medical treatment by focusing on a return of the body to work as the main goal of treatment and placing emphasis of recovery on the patient instead of addressing the structural forces that are known to shape health and medical experiences. Furthermore, the sites themselves portrayed an ideal patient suffering from chronic pain, regularly displaying white bodies as the archetype of pain. However, the websites did provide additional information that could empower the patient during their doctor visits. They also encouraged alternative treatments and patient advocacy, and gave their readers more information about chronic pain that they could then take to their physician.

The websites analyzed were chosen based off of their accessibility to a casual reader. A google search of the term “chronic pain” was done in the Fall of 2019, and I selected the top 3 sites to pop-up, as well as the google sidebar, which is usually automatically visible to the reader. These sites may not be the most accurate, but they are the most visible to the reader when wanting to learn more about chronic pain on the internet. The sites boasted thousands of visitors, but it is possible that sites further down on the list were more popular. Each part of the site’s page on chronic pain was imaged and analyzed for the information it conveyed on chronic pain through language, fonts, set-up, pictures, and advertisements. My analysis of these sites draws on studies from medical anthropology and aims to look at the commonalities and differences in how these websites depict chronic pain and its management.
The thesis consists of five chapters. Chapter 2 presents a literature review of major anthropological theories regarding pain, chronic pain, and medical knowledge. Chapter 1 introduces my methodology and looks closely at the websites and highlights the common patterns found between them. The influential works of authors such as Michel Foucault, Arthur Kleinman, and Jean Jackson are particularly highlighted. The information found from the medical websites are then analyzed in chapter 3. In addition to exploring how these sites depict chronic pain and its management, I discuss how they help us rethink existing theories. In chapter 4, the additional website, the American Chronic Pain Association, is presented and analyzed. This website was chosen for review due to its status as an association dealing specifically with chronic pain. The site was analyzed for the information presented on select pages of the site on categories including treatments, pain logs, and “patient rights,” and compared to existing theories of pain and medical knowledge as well as observations from the other medical websites. Taken together, the discourse analysis of these sites presents an examination of the importance of medical websites as a new and influential source of medical knowledge that could profoundly shape the complex doctor-patient relationship that forms the basis of medical treatment.
Chapter 1: Literature Review

Existing literature has demonstrated different conceptualizations of the way pain, including chronic pain, may be experienced and displayed in the social presentation of the body. As pain is something that impacts both the body (in the form of physical sensation) and the mind (typical neurological processes describe pain as a result of neuron activity), many previous studies depict pain as associated with the Cartesian mind-body dualism. These works fall into different approaches, which can be classified as neurological, biopsychosocial, and Foucauldian. As the discussion will show, each of these approaches have limitations similar to the limitations present when pain is conceptualized in the biomedical setting. Pain typically does not adhere to only anatomical definitions but rather is embodied throughout the entire body, perhaps giving an explanation for the stigma and difficulties we encounter in how chronic pain is represented and treated in our society.

Neurological Approach

Biomedical definitions of pain typically view it as an unpleasant sensory experience with associated tissue damage (Jackson 2011). Despite this, definitions of pain can differ widely due to the struggle of classifying different types of experiences. Some types, such as emotional pain, do not include physical/tissue damage. However, many neurologists argue that emotional and physical pain cannot be separated as both are embodied by the sufferer in the form of neural activity that connects the body and the brain (Jackson 2011). Rather, the attempts to separately approach different kinds of pain privilege focusing on the cause of pain over the experience itself (Jackson 2011). As biomedicine became more advanced, new ways of thinking about pain also
developed. Gate control theory came into favor in the 1970s and suggested that multiple pathways involving emotional, behavioral, and cognitive inputs shape a nociceptive signal that creates the sensation of pain (Jackson 2011). Such changes in the thinking of the causes of pain are reflected in treatment, as many who would have had their pain experiences classified as psychological are now considered to have similar pathology as other types of pain (Jackson 2011). Neuroimaging has also had an impact on the view of pain, as it provides biomedicine an “objective” basis on which to diagnose pain, relegating it as a symptom of a greater pathology (Jackson 2011). While the overall definitions surrounding the neurological approach to pain have changed with new scientific findings and technology, its focus on an objective, biological explanation for pain remains constant.

“Personhood Diagnostics: Personal Attributes and Physical Explanations of Pain” by Mara Buchbinder (2011) further explores the idea of making pain “real” in the context of illness narratives in interactions between patients and physicians, reflecting the use of the neurological approach to chronic pain by physicians. In the observed clinic, patients were told by their physicians that they fit into the mold of typical patients with pain in that they are smart, productive, and talented. These positive attributes are said to contribute to the pain that the person is experiencing. The physician even tells the patient that they do not need to run scans or diagnostics. While this is not true in the neurological sense of the chronic pain, this way of describing pain was actually a strategy by the physician to attempt to validate and understand the patient’s experience. This would hopefully make them more likely to continue treatments that may be deemed as more unorthodox, such as hypnosis. Additionally, the explanation of the pain by the physician was in terms of anatomical terms, such as nerves firing (Buchbinder 2011). This explanation in the neurobiological sense helps to validate the pain that the person is experiencing.
as something that does fall within biomedical definitions. This may help the patients feel more validated by defining their pain as “real” and making them more likely to continue treatments. However, it also runs the risk of classifying a “type” of person who will get chronic pain, which may come across as blaming the patient for the pain that is inherently part of them (Buchbinder 2011). Defining the pain as inherent to the person and their personal attributes is also interesting because it does not localize pain in the body or mind as other treatments were seen to do, but rather demonstrates the view that the person themselves create physical changes in their body that make them more at risk for chronic pain. For example, the physician told one of their patients that the fact that they are so intelligent made the neural networks in their brain work faster and tighter to get information, and these same quick connections are what cause the continuation of pain to occur to the point where it became debilitating (Buchbinder 2011). While the actual evidence behind this statement by the doctor is unconfirmed, it suggests a strong link between personhood, body, and mind. This suggests that chronic pain is something that cannot be confined to only the body or mind, but rather takes a role in the person’s self as a whole. Additionally, the use of the neurological explanation of pain by the physician to reassure the family of its validity demonstrates the importance of such an approach in the biomedical field.

In *The Mindful Body: A Prolegomenon to Future Work in Medical Anthropology*, authors Nancy Shepard-Hughes and Margaret Lock explore the challenges of practicing medicine in a strict biological sense. In such an approach, the “illness” portion of human ailment, meaning the societal relations to sickness, is medicalized in purely the biological sense (Shepard-Hughes and Lock 1987). When medicalization occurs, the social aspect of an ailment is lost in the conversion to the individual, biological sense. Medicalization also explains the creation of new classifications of disease in a biomedical society (Shepard-Hughes and Lock 1987). As certain
bodily conditions correlated with negative social effects, such as women’s rage, new medical classifications were created, such as PMS, to explain such social disruptions under the authority of the medical profession. The gathering of these real complaints under the umbrella term of “sickness” is what is known as medicalization (Shepard-Hughes and Lock 1987). In such a way, the medicalization of industrialized society can be seen as the conversion of social signs into medically controlled sickness (Shepard-Hughes and Lock 1987). In the case of PMS, the medical term is not universal to all societies and developed as women began to take a more active (and often unappreciated) role in social life, and thus their symptoms became an obvious disruption to westernized society, influenced by pre-existing social conditions of mostly men at work in industrialized society. Medicalization in western societies makes a fine distinction between pain and medical pain. As pain without cause is a distinctly individual experience, it would not be considered a medical condition without its incursion into the social sphere. In an industrialized society, pain that disrupts the working body becomes a hindrance to the production of wealth, and a disruption of society. Therefore, medical approaches must be taken to return the body to its working state, but not necessarily completely to no pain. The existence of bodily pain is detrimental to a functioning society, and therefore it is not surprising both that it is increasingly medicalized with new medical classifications despite a lack of biological understanding, and that it still does not have a cure beyond a return to work.

Overall, the neurological approach emphasizes the anatomical aspects of pain typically associated with nerve firings. This way of thinking aligns well with western biomedicine as it gives an objective cause of chronic pain that can allow the physician to find a cause without patient input. This can allow the patient to be validated that their pain is “real.” However, the problem with such an approach is that the true cause of chronic pain may not be known or able to
be described, as evidenced by varying anatomical definitions over time. The concept of medicalization demonstrates that these definitions are really an attempt at anatomical labelling of a phenomenon that is rooted in both the body and social space. Other approaches to chronic pain, such as the biopsychosocial approach, attempt to take the social sphere into account in defining chronic pain.

**Biopsychosocial Approach**

A further approach used to conceptualize pain while acknowledging societal impact on chronic pain is the biopsychosocial approach. This approach combines biological, psychological, and social factors in the construction of illness and its treatment. Most indicative of this approach is the work of Arthur Kleinman, whose *Illness Narratives* demonstrates the complex factors that turn a person’s diagnosed disease into a lived illness that has implications beyond the clinic.

The *Illness Narratives* book introduces the concept of illness narratives as the way in which problems with normal bodily functioning are rationalized. An illness narrative does not only include what is wrong with the body, but also accounts for the patient's distress and includes the forces that shape their position in the social space as well as the multidimensional impact of pain on one’s daily life. This also includes the frustration that sufferers may feel if they are not taken seriously, or that there are no objective signs of their ailment (Kleinman 1988). These illness narratives are culturally shaped, as each culture will have “appropriate” ways to demonstrate their distress, which can change depending on social networks and associations of the individual (Kleinman 1988). The practitioner, however, focuses on treating the pathological disease that is diagnosed, and does not necessarily factor in the full narrative. In the biomedical model, this would be the biological cause of the pain. This creates conflict for those suffering
from chronic illness, as they cannot be cured but must instead live with their ailment (Kleinmann 1988). The term “sickness” is used by Kleinman to describe the larger concepts behind the illness, including the economic, political, and institutionalized forces (1988). In contrast, the biomedical model focuses on the technical aspect of controlling symptoms rather than alleviating the additional difficulties present in this narrative (Kleinman 1988). In the case of chronic pain, this can be a problem as controlling the cause of the pain may not be possible. Patients must also explain their symptoms, which in the case of pain must be done by adhering to culturally relevant ways of speaking, and those that are better understood will have their ailment understood better by physicians and can be correlated with signs of disease to make a diagnosis (Kleinman 1988). Along with this way of describing pain is also the way in which it is described in the context of the body, with western culture focusing on the machine-like qualities of the body as an “it.” Chronic pain is said to be particularly difficult for physicians because they are trained to be suspicious of illness narratives and instead rely on objective data, which may not be present in all cases of pain (Kleinman 1988). The significance of these illnesses is that once a person is labeled as ill, they may suffer from social consequences such as stigma (Kleinman 1988). The concept of illness narratives in the context of chronic pain helps to better understand the importance of language surrounding pain and the social effects that chronic pain may have on the patient, which in turn may influence its diagnosis and treatment.

A work by Jean E. Jackson, *Camp Pain*, is an ethnography of a chronic pain treatment center that explores chronic pain as a disruption of the body-mind dualism typically present in biomedical treatments. The study demonstrates the need to account for further factors beyond the biological. Patients in a pain inpatient treatment center struggled with their sense of self throughout their treatment (Jackson 2000). The pain was a part of the patient in that it impacts
their daily life, but also separate in that they thought of it as coming from their back, leg, etc., and not their true self. Jackson found that “the usual response to pain involves attempts to objectify it, to separate it from the self” (Jackson 2000: 147). While patients would try to objectify their pain as separate from themselves to attempt to control it, they were often unable to, as “an individual with a pain-full body finds that, to a great extent, this body has determined the self he or she has acquired” (Jackson 2000: 149). While patients may have preferred an objective, neurological approach to thinking about their pain, they were often forced to acknowledge the pain in the context of their whole self, which is more aligned with the biopsychosocial approach.

This struggle with conceptualizing pain further demonstrates the importance of discourse in speaking of and conceptualizing chronic pain. Patients also suffered because their ailment “lacked the legitimacy of well-established pain-causing disorders such as arthritis or sickle-cell anemia” (Jackson 2000:3). They did not want to hear that their pain was not valid and struggled to demonstrate that it was “real” (Jackson 2000:3). As pain is something that is not objectively physically detected, patients must somehow reveal their pain to receive the treatment that they need. This is difficult to do, however, due to the lack of a firm definition of pain and the absence of the language that could narrate it. For example, people know that a heart attack and heartbreak are manifestations of different kinds of pain, but it is hard to express the difference in words (Jackson 2000). Using language devices, such as metaphors, to describe pain cannot truly capture the experience of pain, and thus may limit the ability to communicate one’s experience. Pain therefore cannot be truly understood by a physician without a way of socially conveying it. Additionally, speaking of the pain in the social sense objectifies the pain for the patients, as they speak in terms of things afflicting their body, and not the self as a whole (Jackson 2000).
result of this, many patients found that only other sufferers could truly understand the pain that they were feeling (Jackson 2000). For the physicians, however, the pain must exist in a social space in order to receive effective treatment. This struggle demonstrates the challenge in treating chronic pain in the biomedical setting, as patients attempted to adhere to body-mind dualism in their presentation and treatment of pain, but also faced many difficulties in doing so. Many of the patients spoke of attempting to gain control over their pain, viewing it as an enemy (Jackson 2000). They viewed the pain as rooted in their body and separate from themselves, something to get rid of. This way of thought reinforces the split between the mind and the body. Some patients did find results in this method of thinking, but others did not. Most patients found that while they attempted to place the pain solely in the sphere of the body, they became associated with the pain as part of the self as well (Jackson 2000). Chronic pain, lasting so long and becoming extremely debilitating, also became associated in the patients mind with their concepts of self as they adjusted to their new realities. In doing so, they subverted the mind-body dualism commonly part of the biomedical approach by having to view their pain as part of the self and not an ailment of the body.

“Stigma, Liminality, and Chronic Pain: Mind-Body Borderlands” by Jean E. Jackson focused on chronic pain specifically and presented the idea of chronic pain as a liminal period. Liminality is characterized as a transitional period between a start and an end stage. Chronic pain, Jackson argues, falls between being healthy and being ill in a biomedical sense (Jackson 2005). A person with chronic pain does not have the physical markers that define a person with a biomedical ailment, however, they are most certainly not well, as they are afflicted by severe pain and have trouble functioning as a healthy person would. Therefore, in a western society that relies primarily on biomedicine, sufferers of chronic pain fall between these two states. Liminal
periods, or “transitional states and ambiguous beings and objects, being neither one thing nor another, are disturbing and threatening,” leading to stigma (Jackson 2005:332). This is certainly present in people with chronic pain, who typically find it difficult to convey how they are feeling to non-sufferers, and may find it difficult to have their pain validated as “real.” The liminality of chronic pain is the result of conflicting definitions of this condition (Jackson 2005). As pain is only able to be demonstrated through the sufferer, it is hard to define it in a particular set of guidelines, and when it is defined, it is commonly done so under various metaphors that can further obscure a workable definition (Jackson 2005). The fact that pain is so difficult to define is precisely what makes it so hard to fit into the existing framework of illness. In addition, this biomedical model typically views pain as a symptom that is indicative of a larger problem, and not the problem itself. For example, intense abdominal pain could be an indicator for the illness of appendicitis, which can be confirmed with various scans and tests. When the pain itself is the problem, this typical approach to the presentation of pain in a patient does not work, as it is both the symptom and the perpetrator. As a result, chronic pain has sometimes fallen into the role of a default condition, when there is no biomedical explanation for the pain (Jackson 2005).

Additionally, chronic pain also runs the risk of being associated with hysteria, somatizing disorders, or a “pain-prone personality,” all of which are extremely stigmatized in westernized societies (Jackson 2005:336). Interestingly, each of these associations place blame on the person themselves and contribute to the stigma endured by chronic pain sufferers.

The biopsychosocial approach to conceptualizing chronic pain acknowledges aspects of pain beyond the biological. The way in which chronic pain can disrupt a person’s livelihood and ability to do things like hold a job is included in this conceptualization. Additionally, this approach attempts to appreciate how a person suffering from chronic pain might see their pain as
more than a collection of nerve firings, but rather something deeply felt and intertwined with themselves as it impacts all facets of their life. The struggle with such an approach is that patients need to work hard to make sure their pain is still “real” to their physician in the biological sense in order to avoid stigma and receive appropriate treatment. The Foucauldian approach views pain through the interplay between the physician and the patient and emphasizes the role of the power relationships in shaping this encounter and the type of treatment received.

**Foucauldian Approach: Knowledge, Power, and Medicine**

While the neurological approach to pain focuses on strict biological definitions of pain and the biopsychosocial approach expands to other aspects of the pain experience in a person’s life, the Foucauldian approach recognizes the importance of neurological definitions and the role it plays in diagnosis. It also incorporates the power physicians enjoy in contemporary society and how this power shapes their interaction with their patients. Different from the Biopsychosocial approach, the Foucauldian approach acknowledges the total chronic pain experience beyond the anatomical and pays particular attention to the role of the physician in making a diagnosis. The information that the physician draws on to make a diagnosis may not align directly with a patient’s experience of pain but is still vital in understanding chronic pain.

*The Birth of the Clinic* by Michel Foucault establishes the concept of the “medical gaze” as the basis of western biomedical thought. The “medical gaze” refers to the practice of the separation of the body from the person, which allows the medical professional to diagnose the body through physical manipulation and tests, and treat these ailments accordingly (Foucault 1963). This is necessary because “following the same continuities or the same breaks, experience reads at a glance the visible lesions of the organism and the coherence of pathological forms; the
illness is articulated exactly on the body, and its logical distribution is carried out at once in terms of anatomical masses” (Foucault 1963: 2). Foucault acknowledges that despite differences in perceptions, a doctor trained to use the medical gaze can use anatomical problems found on the body to come to an objective conclusion as to a person’s ailment. This has the result of focusing on the body (or more accurately bodily parts) and not the whole person. The Birth of the Clinic documents the change of medicine from a cultural practice to the measurable science that reflects modern biomedicine (Foucault 1963). The ability of doctors to treat and diagnose patients with new, exciting technologies sparked a shift in the way in which the body was viewed and treated. Problems were not mysterious or unknown, but rather the direct result of something malfunctioning in bodily processes that can be discovered and treated by the doctor. The medical gaze can be applied to chronic pain, which is typically characterized by the absence of physical irregularities generally associated with biomedical pathologies. As a result, doctors must rely on the person themselves for their account of the pain as they cannot rely on tests and bodily observations for confirmation. In this way, it can be argued that chronic pain subverts the medical gaze by making the separation of the body and the mind impossible for physicians and patients. When applied critically to chronic pain, this concept can help to better understand some of the difficulties in treating and understanding it, as it does not fit into the typical framework of medical conditions due to its lack of physical markers. In treating chronic pain, “the objective” signs that Foucault states the physician is so dependent on are not always present. The objective science that the physician uses is not there, and the physician is now dependent on the patient, a reversal of roles. Because the physicians are trained to favor objective evidence, the information provided by the patient may be looked on with suspicion or disbelief, leading to stigma. In such a
way, chronic pain cases may actually serve to increase the power of the patient more than in
typical medical interactions.

“Medical Discourse” by James M. Wilce, analyzes the power of language in medicine as
having an influence on the way in which biomedicine recognizes and treats disease. The way in
which doctors and patients present themselves to each other, particularly in how they express
pain, is important in determining which patients are diagnosed and receive treatment (Wilce
2009). An example of this is a doctor who presses patients to be open with everything they may
or may not have done in relation to their disorder, a way of “confessing” and reinforcing the
power for the physician (Wilce 2009). Creating an appropriate narrative in the treatment process,
which is also stressed in the biopsychosocial approach, is a way to acknowledge that pain
impacts all parts of one’s self. However, the main goal of discourse in this medical setting is to
create an understanding between the physician and patient and to enable sufferers to illustrate
that their pain is “real” despite a lack of objective evidence. In chronic pain, this may present
difficulties as patients may struggle to define and present their symptoms and doctors may also
have difficulties in diagnosing and treating.

The Foucauldian approach differs from previously described conceptualizations of pain
in that it focuses on the power relationships that shape the encounter between the physician and
patient. The previous approaches struggled to provide validation for the patient when their pain
could not be described neurologically as “real.” The Foucauldian approach, however, enables us
to conceptualize pain as something that defies the typical “medical gaze,” which aims to
examine, diagnose, and heal.

Conceptual Framework
Previous literature demonstrates how distress in the body may be conceptualized in different ways. The neurological approach demonstrates the conceptualization of pain in an anatomical sense, but also has flaws. Pain frequently defies such anatomical standards and can occur without known cause or physical damage, creating problems in developing an overarching anatomical model. An alternate approach, the biopsychosocial approach, attempts to take into account the complex factors surrounding health, illness, and treatment. The Foucauldian approach, on the other hand, focuses on the relationship between power and knowledge that is operationalized in the clinic as the patient seeks care. In such a setting, language is vital to creating a diagnosis and receiving proper treatment. However, this treatment may not take into account additional problems reflected in the biopsychosocial approach, such as socioeconomic burdens, and thus may cause tension between the patient and physician.

Drawing insights from all three of these approaches, this thesis aims to analyze how medical websites represent chronic pain. Specifically, the Cartesian mind-body separation, which is frequently utilized in the neurological approach to describe the typical view used in biomedicine, in which the mind is viewed as separate from the body and pathologies are typically depicted as rooted in the body, is often not applicable to chronic pain. As shown in the studies by Jean Jackson (2000, 2005, 2011), chronic pain challenges this conceptualization and forces us to consider the strong link between the mind and the body and how this link shapes the holistic embodied experience. The acknowledgment of this total experience is present in the biopsychosocial framework of chronic pain. This framework shows that the experience of pain is heavily influenced by psychological, economic, and social factors, but as it is not the framework of choice for physicians, patients may have trouble making their pain “real” to healthcare providers. The Foucauldian approach focuses on the physician’s perspective of treatment and
describes the use of the “medical gaze,” which adheres to anatomical conceptions of pain to provide a diagnosis. Patients must then adjust their language and display of pain to communicate their problems, even if it is not the best way to demonstrate what they are experiencing. It will be interesting to see how medical websites depict chronic pain and how this depiction reinforces or subverts the idea of body-mind separation in the context of chronic pain. The next chapter looks at how three medical websites depict chronic pain, its causes, symptoms, and treatments.
Chapter 2: A Focus on Anatomy: Reading Chronic Pain Website

In order to better understand how chronic pain is conveyed to the public, especially to people who may not receive the diagnosis they are looking for from their physicians and look to the internet for guidance, several different public websites were explored. In google, the phrase “chronic pain” was searched in September of 2019 and the first few sites were selected for analysis, as these would be the first sites for anyone searching for information to check. While the order of websites listed on a google search may vary due to user location, previous searches, etc., these websites were determined to be the most relevant based on their current hierarchical order on the google search. Websites were a mix of government or private sites, which used advertisements as a means of finance. In addition, all sites similarly cited a medical professional as the author or reviewer of their information, most likely to add credibility. The website entry on “chronic pain” was screenshotted and analyzed.

Website Structure

The websites consulted had varying organizational structure. Healthline.com is a site that provides medical information and, as stated on the page, has been designed to be less confusing and to enhance the well-being of the readers. They stated on their site that they have over 200 million visitors on their site every month, citing Google Analytics. The Healthline.com page on chronic pain was organized in several different sections. Each section had a few paragraphs, and some were also accompanied by bullet points. The font was larger than a typical scientific size found on medical journal sites such as PubMed, and the style was more casual than in a scientific paper. The color scheme was a teal and pink color, which were used on the accents of the
website and the bullet points. In addition, the top of the page on the side lists a PhD, RN as having reviewed the content of the site. In addition, there was a tab on the side with the option to easily share on Facebook, Twitter, Flipboard, Pinterest, or email. There were also many links on the page, either to subscribe to the site (a popup on clicking on the page also gave an option to subscribe), or click on additional articles on the same website, all of which were related to pain in some way, whether it was picking a good mattress, getting pain medication, or exercising for relief.

Interestingly, there were no pictures on the site, but several of the suggested articles had photographs associated with them, and all of them were of women of various ages. Additionally, all of them were Caucasian except for one. Advertisements were also on the sides and in the middle of the articles, typically as videos. Some of these advertisements were for medications, and some were for other products such as concerts, cars, video games, etc. The site also had many features concerning user feedback, including a spot on a sidebar to click if the article was helpful, and a ranking of the page at the bottom.

The other popular medical site, *WebMD* is listed as having 75 million users. The website describes its pages as composed by many doctors and editors. The site is made of blue and black accents, with a casual font. The top of the page gives tabs for a subscription, as well as tabs for more information on other conditions or healthcare news. The top also offers a search to find a healthcare provider and reduced drug prices. On the page for chronic pain, there is an option to share the page to Facebook, Twitter, Pinterest, email, etc. In the advertisement space at the top of the page, the site promotes its app.
Figure 1. *WebMD* Chronic Pain title page

The overall structure of the page consists of many headers of several different categories describing different aspects of Chronic Pain, including prognosis, potential causes, and treatments, with accompanying information underneath each header. A video under the header plays an advertisement, and then plays an informational video on esophagitis, which is not linked to chronic pain. Suggested articles are on the side of the page. These are not related to chronic pain, but are associated with other pain ailments, including MS, RA, and migraines. The pictures featured in these articles are of both men and women. Further down, under the title “recommended for you,” more articles from the same site are displayed that are associated with chronic pain. All of the pictures for these articles feature white women, except for one man. Links to skip to certain parts of the article are also available, as well as hyperlinked words that can lead the reader to another page. The site is continually interrupted with advertisements in the form of article links, pictures, and videos. These advertisements are so present that it becomes difficult for the reader to navigate the article. Many of the advertisements listed are for medications, although not all are for chronic pain. The bottom of the page also lists doctors that are “in my area” for potential treatment.
The site Medlineplus.gov is different from the other web pages in that it is government-funded and is run by the US National Library of Medicine. The website’s stated goal is to provide free information to people in a language that they can understand. The National Library of Medicine reported that the site sees about 150 million visitors over the course of a year, making it less popular than the previous sites. The color scheme of the site is green and blue. Interestingly, the site logo is a cross, suggesting a potential religious influence on a government website. The site has an option to be shared on facebook, instagram, email, pinterest, etc. There is a section to subscribe to a regular newsletter from the site, but there are no advertisements on the page. There is one accompanying picture on the page, which is of an older, white man who looks to be in pain.

Figure 2. Medlineplus.gov title page

The site is organized into different sections with accompanying links to other pages. There are a few paragraphs on the site about chronic pain (with linked words) but it is mostly headers and links to other pages, but not advertisements. There is also an option for the page to be read in Spanish. In addition, reader feedback seems to be valued as there is a section at the
bottom to rate the page. Other topics available besides disease information include drugs and supplement pages.

In a google search for “chronic pain,” the sidebar information pops up on the right side down the first page. The color scheme of this information is teal, which is different from the typical google colors. There is also a link on the side of the page with an option to email or post on facebook, and a link that can be copied. The page only shows a basic definition for chronic pain which includes a picture of a man who seems to be in agony and an anatomical graph illustrating the nervous system. There are further tabs on symptoms and treatments in that order. Each of these tabs include further information and some include links to additional pages.

![Google Sidebar Chronic Pain page](image)

Figure 3. Google Sidebar Chronic Pain page

The last site to be analyzed is different from the other four because it is entirely devoted to Chronic Pain. The American Chronic Pain Association (ACPA) website, has a color scheme of black, blue, and dark green. The stated goal of this site is “help you better understand your pain and work more effectively with your health care team towards a higher quality of life” (theACPA.org). The site has a language option at the top of the page and offers over 50 languages. The site also has a membership structure, and a button on the top urges users to sign
in or create an ACPA account. Links at the top of the page give pathways to more information on chronic pain, new treatments, and clinical trials, as well as pain management tools and tips. Underneath this bar, there is also a link to learn more about the ACPA itself and a “contact us” link. The bottom of the page gives more links to news about chronic pain and links to other pages within the site. The title page has images and links, with the most prominent picture of patient artwork depicting pain and another of doctors. The very bottom gives options to follow them on various social media accounts, including facebook, twitter, pinterest, youtube, and instagram. The bottom also displays various awards, including America’s Best Charity Seal, HONcode standard, and Goldstar seal of transparency. There is also a statement saying that the site does not advertise but does have a link to donate.

Figure 4. ACPA main page

The structures of the sites (except for the ACPA) are similar in that they all typically have header sections and are followed by different descriptions. As the ACPA is completely devoted to Chronic Pain, it has various links on its main page that are all related to chronic pain. All have some variation of blue in their color scheme, but some, such as Healthlineplus.com and Medlineplus.gov are much brighter in their color schemes than the ACPA, which is mostly filled with dark colors. The two most popular sites Healthline.com and WebMD.com both had different
advertisements in a pop-up form along the course of their articles, while Medlineplus.gov and the ACPA have no advertisements at all. All had the option to share their site on social media or email or follow the site itself. In addition, while most of the pictures with the related articles or advertisements seemed to depict white women, this was not universal and there were some depictions of men on Medlineplus.gov and google sidebar and some women of color on advertisements popping up on Healthlineplus.com and WebMD. Overall, there were not many pictures related to the actual article, none seemed to have more than one main visual unless there were advertising pop ups or other article links, which had an accompanying picture. The ACPA website actually has its largest link on the title page and artist’s work on bodies with chronic pain, so the main pictures of patients on that page was a blue woman with puppet strings and a woman with a cactus for skin.

Describing Chronic Pain

Each site was reviewed to see how it described chronic pain. The sites were organized into categories on different aspects of chronic pain, and typically at the top, under the title, there was a description of chronic pain. I traced how each site navigated the technical definitions, such as with more anatomical terms or with more descriptive words similar to patient symptoms. Additionally, I observed how other ways of considering pain and patients’ experiences were portrayed. I paid particular attention to the words used and overall tone of the messages.

The website Healthline.com was the first site to be observed, and was the first hit on google search. The general information about chronic pain, which is on a page title “What Causes Chronic Pain?” is listed under the header “Overview.” Before getting into a description of chronic pain, which is the main focus of the site, there is a short paragraph on pain in general.
This pain is described in simple, yet anatomical terms. For example, pain is first clarified to be something that is normal, good for a person, and vital to alert for possible injury. In addition, pain is described simply as signals that “travel from the injured area up to your spinal cord and to your brain.” The use of “your” is present throughout, as if the person reading the article is experiencing pain and is the main target of the site. It is not until the second paragraph that the phrase “chronic pain” is mentioned. The site states that “chronic pain is “defined as pain that lasts at least 12 weeks.” Chronic pain is said to be different from other types of pain because it does not go away soon after an injury is healed. Again, a simple anatomical explanation follows by saying that the signal mentioned above does not go away but instead continues, which may limit “your flexibility, strength, and endurance.” “Your” is also used throughout this paragraph.

The second hit on the google search is the website WebMD. This website has a page dedicated to chronic pain that is named “Do I Have Chronic Pain?” The first paragraph of the page starts with a paragraph about the broad meaning of pain. This paragraph does not provide an anatomical explanation of pain, such as the description of nerves found in Healthline.com, but does describe pain as something that is beneficial for people, as it is “your body’s way of telling you something is wrong.” “Your” is also used throughout the opening paragraphs, in addition to the use of “I” in the title of the page. Chronic pain is then defined in the next paragraph as something that does not go away, but “keeps hurting weeks, months, or even years after injury.” In addition, the definition of “chronic pain” is included and is defined as pain that lasts for at least 3-6 months. A further paragraph clarifies that chronic pain affects everyday life, and also includes an uplifting message that “you and your doctor can work together to treat it.” In addition to the information provided in the paragraphs, there are also links provided to further pages on some of the terms used in the opening section. “Pain” and “mental health” are linked in
this way to further pages. The anatomical aspects of pain are covered in a later section, “What Makes You Feel Chronic Pain?” This section further describes pain in terms of message signals sent by nerves through the nervous system to the brain and that in chronic pain, this signal continues even after the cause of the pain is resolved. In this section, “brain” is also hyperlinked.

The website Medlineplus.gov was the third site to appear in the search and had a page on chronic pain. The first section on the page is labeled “summary.” It also starts by describing pain in general. This begins in anatomical terms, by describing pain as “a signal in your nervous system that something may be wrong.” The site then goes in depth by describing different ways that pain may feel, such as burning, aching, etc. It also describes the difference between acute and chronic pain. In the case of chronic pain, some potential causes are also listed, such as infection or cancer, but it is also noted that in some cases there is no clear cause. The next paragraph in this section lists risk groups, which are first said to be “older adults”. It also stated that women “report having more chronic pain than men, and are at greater risk for many pain conditions.” It also emphasized that people can have more than one pain condition. In the final paragraph of the section, it concluded that “chronic pain is not always curable.” However, some potential treatments are listed, which include biomedical treatments like drugs and “non-drug treatments” such as surgery and PT. The alternative medical treatment of acupuncture is also listed. Certain words on the page are also hyperlinked to further pages. These words are “pain,” “pain relievers,” “non-drug treatments,” and “acupuncture”.

A google search also lists quick facts on the sidebar of the search. The “about” tab of this section provides a drawn picture of a Caucasian, older, white-haired man holding a shoulder in pain. A diagram of the skeletal nervous system is also included and is labeled as “nervous system”. The total picture is labeled in the middle as “persistent pain signals in the nervous
system.” Underneath this, the chronic pain is described as “persistent pain that lasts weeks to years.” It is listed as “very common” with more than 3 million cases a year (location unspecified), and it is noted that “treatment can help, but this condition can’t be cured.” The condition is also listed as “self” diagnosable,” typically not requiring labs or imaging. It is also listed as “resolving within months.” Causes are listed as inflammation or dysfunctional nerves, with the main symptoms of persistent pain. In addition, potential treatments are medications, surgery, acupuncture, electrical stimulation, and cognitive behavioral therapy (which is psychiatric). At the very bottom, the reader is encouraged to consult a doctor for advice. Sources are listed as Mayo Clinic “and others.”

The ACPA website does not list their definition of chronic pain on their title page, but, under a tab for “conditions A-Z,’ there is a link for chronic pain, which defines it as “ongoing or recurrent pain… more than 3-6 months, and which adversely affects the individual’s well-being.” It is more simply defined as “pain that continues when it should not.” Links on the same page also give “related resources,” which includes links to treatment options such as acupuncture, yoga, massage, and other sites and articles with information on chronic pain. There is also a small note at the bottom advising the reader to consult with a medically trained professional for medical information.

The overview of each of the popular sites for “chronic pain” would most likely be the first thing that someone looking at the page would see. The pages that were run by independent sites (not the google sidebar) began their page with a description not of chronic pain, but rather of pain in general, especially making it clear that pain is something that is completely normal and generally beneficial for the body. In addition, all of these sites use language that focuses on the reader by the use of the words “your” and “Do I” that direct their information to someone who
thinks or knows that they may be suffering from chronic pain. In this sense, the pages do not appear for use by someone searching for a diagnosis, but rather a direct patient source for those suffering already. Although each differed in the exact technical language, sites except for the ACPA gave anatomical information on how chronic pain occurs. The definition of chronic pain as pain for around 3-6 months was also agreed on for the ACPA and WebMD, however, Healthline.com only listed the shorter end of 12 weeks as the minimum time to be considered chronic pain. Medlineplus.gov and google sidebar did not even list a minimum lower time frame, but acknowledged that the pain could be for weeks, months, or years. The ACPA did not list their definition on the top of their page, but rather in a separate link under a list of other conditions. Perhaps since the site is devoted to chronic pain, the user is expected to have a basic idea about what it is before they find the website. While not all of the sites gave risks or treatment information at this early section in the site, all did attempt to make clear that chronic pain is something that can disrupt the everyday life of the sufferer. While there are more specified different types of chronic pain, none of these names were mentioned, used, or linked in the overview of the sites, except for the ACPA, where chronic pain was found listed among these other names. Instead “chronic pain” was the only term that was used to describe the persistent pain explained by Healthline.com, WebMD, Medlineplus.gov, and google sidebar.

**Recommended Treatments**

The treatment description of each of the sites were also observed. Some of the sites had mentioned the names of treatments in their overview, but others did not describe potential treatments until future pages. Typically, the section for treatment was after a general overview of chronic pain and got its own section or paragraph.
*Heathline.com* has multiple subsections on treatment for chronic pain. The first section is titled “How is Chronic Pain Treated?” This section provides an overview of the overall goals of treatment, which is to “reduce pain and boost mobility,” with the ultimate goal of resuming daily activities. The website states that doctors will create a personalized plan determined from the patient’s specific pain symptoms and underlying health conditions. This regimen is stated to be composed of lifestyle changes and/or medical treatment. Potential medications for chronic pain were listed. For each medication listed, the category of medication is listed, followed by examples of its generic name and a commercial name. For example, over-the-counter pain relievers are listed, which is later followed by ibuprofen (Advil). The medications listed, in order, are over-the-counter pain relievers, opioid pain relievers, and adjuvant anagelsics, which includes antidepressants. Medical procedures are also listed in bullet form as potential treatments to “provide relief.” Some of these treatments are surgery and a nerve block, but also electric stimulation and acupuncture. Each is explained with a definition, and surgery is the last option listed. Examples of lifestyle remedies for chronic pain are also listed to “ease chronic pain.” This list includes various types of therapy, including physical, massage, art, music, pet, and psychotherapy. In addition, various forms of exercise are also listed, including tai chi and yoga.

The treatment suggestions on *WebMD* are one paragraph. The first recommendation is to see a primary care doctor or pain specialist if the reader is experiencing long term pain. It is said that these doctors will “help you find relief so pain won’t keep you from living your life.” Examples of treatment that are given are both medical and lifestyle. The medical options are stated to be medicine and various types of therapy including relaxation therapy, physical therapy, and acupuncture. The lifestyle changes listed are to sleep more and to stop smoking. As in the
rest of the article, there are many different hyperlinked words. In the paragraph on treatment, these words are “physical therapy,” “acupuncture,” and “smoking.”

The Medlineplus.gov website lists potential treatments in its overview, and also through different attachments linked to the article. The goal of treatment is not to necessarily cure chronic pain, as it is noted that the condition might be incurable, but rather to “help” to relieve the symptoms. Potential treatments listed are drugs, surgery, and therapies such as acupuncture. Multiple other sites are also linked under the heading of “Treatments and Therapies.” These potential treatments are all options beyond pain medication, which is usually the first treatment option listed (it was the first listed in the main chronic pain Medlineplus article above). Many of these attached treatment articles were more alternative health practices, including two articles for “complementary health” options to treat chronic pain and one on managing pain without opioids. The other two articles listed were on biofeedback treatment and one on antidepressants and a treatment.

The chronic pain sidebar on the google search has a tab specifically for chronic pain treatments. This divides the treatment for chronic pain into several different categories. In bold at the top of the page, it is first made clear that the treatment will differ depending on the severity of the pain. The tables listed are, in order, “self-care”, “therapies”, “medical procedures”, “medications”, and “specialists”. Each tab then pulls down to reveal several more examples. The examples of “self-care” include exercise, stress management, and relaxation therapies. Therapies include biofeedback, acupuncture, and physical therapy. The medical procedure listed is a nerve block. Medications are only listed by type and not specific examples. The types listed are nerve-pain medication, analgesics, and narcotics, each with a short description of each with a link for
examples. The providers listed are not specific practices, but rather types of medical specialists. None of the providers listed are alternative medicine providers.

Each of the sites are different in the way in which they give information on pain treatment. While healthline.com and the sidebar on google had a large amount of information, with many different subcategories, WebMD and Medlineplus.gov had only a short paragraph with a condensed list of options, however both provided links to further information. The sites also had some similarities. Each of the sites separated types of treatment into sections and listed medical and lifestyle treatments as different topics. While medications, including opioids, were listed first, alternative medicine options were also listed prominently in all sites. Healthline.com and WebMD listed these treatments separately, but were still given the same amount of space on the page. WebMD actually exclusively listed these options on their linked section on treatments. Acupuncture was also listed as a treatment common to all of the sites. While each of the sites did provide a significant amount of information on alternative medicine, none of the sites gave information on a specific type of alternative medicine provider. On the contrary, other sites listed examples of biomedical specialists suggested for treatments. The ACPA provided a tab for “A-Z treatments” that listed a variety of choices, mainly the same ones found on the other sites. In addition, while each of the sites suggested that the reader consult a doctor for any medical treatment at the top of the page, the sidebar google search results listed its recommendation to consult a physician only in small print after its medical advice was listed similar to the ACPA.

While the websites chosen for analysis are not the only ones providing information on chronic pain, they are at the top of a simple google search for “common pain” and would therefore be most accessible to people doing a search on the condition. The goal of this study is to analyze sites of information where people who have trouble understanding or receiving a
diagnosis may go to, an assumption supported by the growing popularity of these medical sites. However, despite the growing accessibility of computer skills and access across Westernized societies, not all have the means or skills to read these medical websites. Furthermore, these same people may also have increased difficulty in both gaining medical treatment and accurate diagnosis. While these people cannot be spoken for in the analysis of this study, their needs and experience with chronic pain must be recognized. Further chapters will analyze the descriptions and information given on chronic pain in these medical websites with the goal of discovering patterns in pain conceptions and management. These patterns show the medical and social conceptions that are being circulated on online resources and give insight in how they are circulated.
Chapter 3: The Pain of Understanding Pain: Close reading of Medical Websites

Each of the websites typically gave some sort of reference to the neurological approach to their description of chronic pain. On the site Healthline.com, an overview of chronic pain describes pain as a “reaction of the nervous system” that sends pain through signals through the spinal cord to the brain and that chronic pain results when these signals continue after the physical problems have been solved. Similarly, the WebMD site and Medlineplus.gov describes chronic pain as an electrical signal that travels through the nervous system to transmit the feeling of pain. Finally, the google sidebar on chronic pain describes chronic pain as the result of dysfunctional nerves. This description of pain is solely in terms of the biomedical, as the pain is never described as an experience consisting of emotional and psychological cues as well that creates the experience of pain in a person.

As discussed in chapter one, the neurological approach is restricted only to definitions in terms of neural activity, and does not engage other pathways such as social experience. The focus on the anatomical aspect without acknowledging the other factors that shape the human experience may restrict the classification of chronic pain to only those with a neuron dysfunction, when in actuality many types of chronic pain do not have a known cause. Due to the general hegemony of biomedicine among healing methods in western society, it is not particularly surprising that chronic pain is firstly described in terms of anatomy. However, chronic pain is unique from typical biomedical ailments in that it is more difficult to assess by physical examination or may have no known trigger at all. Furthermore, there is no known cure for chronic pain, and recommended treatments are intended to mitigate the pain enough to return to activity.
The diagnosis and treatments of chronic pain suggest that it does not fall under the umbrella of a typical biomedical disorder, but rather something more difficult to define. So while it may not be surprising that the websites adhere to biomedical definitions of chronic pain first, they also give very little solid evidence for a definite diagnosis and treatment. The sites fail to acknowledge the ever-changing definitions of pain, which does not allow readers to fully understand the condition that they are seeking to find answers for.

**Biopsychosocial Reading of the Websites**

When looking at the chronic pain websites through the lens of the biopsychosocial approach, it is clear that they did give some acknowledgement of the experience of chronic pain beyond the anatomical. However, none specifically focused on the psychosocial aspects of chronic pain or acknowledged it with the same emphasis as in the biological definition, suggesting that the strictly biological definition of pain is most valued by the writers who are a part of the medical community. *Healthline.com* encourages sufferers to seek support from friends, but does not acknowledge any social aspect in the experience of pain, even as it acknowledges difficulties in treatments under a purely anatomical definition (which includes alternative medicine treatments such as acupuncture). *WebMD* acknowledges the impact of chronic pain on mental health, but not how it may impact a person's existence as they must deal with increased stigma and stress in a social context. Similarly, *Medlineplus.gov* mentions that environmental or psychological problems can make chronic pain worse, which is a novel concept in chronic pain disorders, yet does not include how these factors contribute to pain with the same importance and detail as is described in the biological sense. Additionally, google sidebar gives no mention of how chronic pain may be conceptualized in ways beyond the nervous system, such
as by exploring the fact that it can have no known cause and change in character due to other factors. Instead, pain is only attributed to dysfunctional nerves.

This focus on the biological explanation of chronic pain without the more nuanced view of the biopsychosocial leaves out a significant aspect of pain that has been shown by scholars such as Kleinman (1999) and Jackson (2000) to have a role in the way people experience their diagnosis and receive treatment. As Kleinman’s *Illness Narratives* shows, it is vital for medical professionals to understand the additional impacts a diagnosis can have on the patient beyond the strictly biomedical. For example, race, gender, and socioeconomic status play a role in how chronic pain will be experienced by different people as well as their ability to take time out of their daily activities to recuperate. The websites can be very telling about how the narrative of chronic pain is established by the general population. While some of the websites acknowledge the significance impact of chronic pain on a person’s life, they still focus on a general return to activity as a goal for treatment, and not how the experience of chronic pain is heavily influenced by particular factors beyond the biomedical lens.

As the main description of chronic pain is focused on the biomedical and not the socially-influenced factors contributing to the differing experiences of chronic pain, it follows that those suffering outside of this narrow definition of nerve disorder may feel stigmatized by their community and the medical community they need for help, leaving the patient in a form of a liminal period (Jackson 2005). *Healthline.com* describes chronic pain as a condition without a cure, but something that can be managed in order to return to everyday activities. The person with chronic pain here is someone who is not completely healthy, but who is not completely sick either, placing them in a liminal state of existence. WebMD encourages readers with chronic pain to find a physician to help them return to their daily activities. In this sense, the patient is
not only between a state of good health and incurable disorder, but they also have the responsibility to find the help needed to pull them out of their in-between state, which may not be possible. On the other hand, Medlineplus.gov admits that chronic pain is not always curable but emphasizes that some treatments can help patients return to their daily activities. Google sidebar does not give any references to the lives of those affected, however, similar to Medlineplus.gov, states that the condition cannot be cured but treatment can help.

Each of the sites conveys the idea that chronic pain can be debilitating and disruptive to daily life. At the same time, they emphasize that the patient should be able to return to these activities with treatment, which may or may not be effective in curing the pain. This type of language surrounding the treatment of chronic pain supports that sufferers are in a liminal period because they are expected to get better but treatments may not be adequate to their needs. Additionally, the focus on a person returning to “activity” as the stated goal of treatment signifies that the way to leave this liminal period and its stigma is to return to work, not to be free of pain. The liminal period becomes not a state between healthy and sick, but rather between working and not working, reflecting the capitalistic emphasis on functional bodies capable of performing work. The result of this is an association of chronic pain with displacement from work, and a “cure” as a return to work, even though there is no true cure.

Chronic Pain Websites through a Foucauldian Perspective

A Foucauldian reading of these websites shows how the role of the doctor is key to the treatment of chronic pain and the normalization of the patient’s life. However, we see the possibility for a different relationship between the patient and the doctor that reaffirms but also challenges the authority of the medical gaze. Each site emphasizes the authority of the physician
in providing treatment and suggests that the reader see a physician. The ability of the physician to decide on the treatment and determine when the patients can return to work reflects the role of medicine in the normalizing process of chronic pain. However, the ultimate decision of the physician to decide that the focus of treatment is a return to “daily activities,” which can be taken to also include work, and the responsibility of the physician to decide when a patient is ready to return to work reflects the power of the physician and the institution of medicine as a whole in exerting discipline over bodies. If the patient then does not return to these activities after their physician deems them treated, whether it be work, exercise, or meeting friends, they may suffer from social consequences such as stigma. Under a Foucauldian lens, this acknowledgement and the portrayal of the physician as the necessary decision maker in determining the ability to do these activities holds up the medical institution as the ultimate authority in the life of a person with chronic pain’s life. They are dependent on their physician for the care they need and their approval to return to activities, which is supported by institutions, such as worker’s compensation, that require physician’s input in receiving work benefits from injury. The acknowledgement of the physician’s role in determining a patient's activities on the websites reflects this authority and the importance of the medical gaze.

This focus on the return to “daily activities” by the websites is also reflective of Nancy Shepard-Hughes and Margaret Locke’s work regarding medicalization. The absence of the painful body in work is reflective of an industrialized society that does not allow for people to take excessive time off if they are in pain and does not provide adequate measures for people who do not participate in labor. Therefore, the lens of medicalization can explain how chronic pain has become noted as a widespread condition in western society.
The focus on the bodily aspect of pain over the mind and social experience of the pain is suggestive of the Foucauldian approach to medicine in which the objective fact of the body is prioritized by the doctor to create a diagnosis for the patient. According to Foucault, the “medical gaze” is utilized by doctors to help pick out the information that can be used to find what is really wrong with the patient. Typically, this means that the physician will focus on biomedical signs as they can be objectively obtained without necessary input from the patient themselves. In the description of chronic pain in the websites, the biological aspects (nerves, etc.) are prioritized and placed first as the definition, and other aspects such as characterizations of the type of pain experienced or feelings associated with chronic pain are placed later down in the article, if at all. In the case of chronic pain, under this framework of the “medical gaze” patients may have particular trouble in receiving diagnosis as they must display their bodily ailment, as pain is not something that can be as easily measured with objective methods as, for example, in an infection. This places the burden on the patients and it becomes their duty and responsibility to convince the doctor of their ailment. Restricting the definition of chronic pain to be valid only when there is a nerve defect in the body is not only too restrictive a definition of chronic pain conditions (such as in vulvodynia), but also gives power to the physician as they rely on bodily information to give diagnosis and treatment to chronic pain. The “medical gaze” gives power to the doctor in the sense that the identity of the patient is not as vital as the body in receiving treatment, and when the diagnosis is not able to be objectively verified, such as in chronic pain, the burden falls on the patient to describe their symptoms in a way in which the physician can understand in order to give a diagnosis and legitimize the condition of the patient.

As pain does not neatly fall into the domain of the “medical gaze,” it is important for people to have a common understanding of pain and a way to conceptualize it in the social sense
so that patients can understand what they have and doctors can properly diagnose and treat those suffering from chronic pain (Wilce 2009). Physicians look for pain to be described in a specific way and patients must follow this standard in order to present their symptoms in a way understood by the physician, who has the power to provide treatment. With pain, it is especially important that the patient and doctor utilize a common language, as pain exists in a social context and may not give objective evidence for the physician to observe. Therefore, medical websites may be especially important in enabling potential patients to acquire knowledge and learn the right medical terms to use when discussing their condition with the doctor. For example, a patient who suspects they have chronic pain may search with their symptoms online, and use the information they find online to talk to their doctor. This might help facilitate the interaction between the two parties and might secure a diagnosis and better treatment plans. The chronic pain sites observed have varying ways of describing what chronic pain should feel like.

*Healthline.com* depicts the chronic pain as “sharp or dull, causing a burning or aching sensation.” It can also be “steady or intermittent” and can feel different in different affected areas. Clearly, chronic pain can manifest in a wide variety of symptoms, potentially making a consensus on diagnosis difficult.

**Website Structure: A Foucauldian Reading**

The structure of the medical websites is also important to the use and credibility of the sites. In a study of college students' use of medical websites, many preferred WebMD because they thought it was commonly used, and its user-friendly nature made it seem more trustworthy (Bulled 2011). The sites all proclaim to have their information either vetted or created by medical professionals, either doctors or nurses. This medical authority added to the sites may
give these websites similar credibility to a physician, and explain why the websites are seen as trustworthy. Both WebMD and healthline.com appear to have the most professional looking websites, with links to medical term definitions, bright colors, and clear fonts. However, these two sites also have the most advertisements, which are present on every page and sometimes are overwhelmingly larger than the words. These advertisements come across as more professional than medlineplus.gov, which has a less user friendly structure but no advertisements. Therefore, it is interesting that users would find WebMD as more trustworthy than the government designed and run site. Google sidebar is different in that it does not have a full website structure, but rather pops up under a search for “chronic pain” on google and is thus the first thing that people will see when searching for information on chronic pain. Healthline.com, WebMD, and medlineplus.gov do not have pictures describing chronic pain. The general lack of pictures on the websites is surprising given that the proposed goals of these sites is to inform the average patient, and diagrams or pictures are typically the best way to demonstrate a medical concept to someone unfamiliar with anatomy. This may reflect the inability and difficulty that medical professionals face when dealing with pain as they are unable to gain an objective view of the body and instead are forced to rely on language and other patient-mediated methods of displaying pain.

There are also no pictures on Healthline.com to supplement what the chronic pain would potentially look like. However, the sidebar advertisements on the site that lists other ailments/articles related to pain each have a picture of a white woman of various ages displaying pain with a concerned expression or holding her wrist. WebMD, on the other hand, describes chronic pain as a dull ache, throbbing, burning, shooting, squeezing, stinging, soreness, or stiffness lasting longer than 3-6 months after injury. WebMD similarly did not have pictures of chronic pain in the main article, but did have links to other pain-related pages on the sides with
pictures of white women. *Medlineplus.gov* describes chronic pain as a prick, tingle, sting, burn, or ache that lasts for weeks, months, or years. There is a stock photo of a man with graying hair with his face hidden, who is hunched over and holding his back on a couch. The symptoms section on the google sidebar, however, describes chronic pain as “pins and needles or sensitivity to pain” that can last from weeks to years. The picture displayed on google sidebar is not a photograph, but a drawing of a white man with gray hair holding his shoulder with an expression of pain. This display of only white bodies and the appearances of pain that they make, is an incisive view of what chronic pain should look like, namely, that it should be enough to force a concerned look or a grasping of a joint in a patient. Furthermore, the display of a white woman as the sole sufferer of chronic pain on *Healthline.com* and *WebMD* of the sites shows who is thought of as a victim of this condition. Perhaps these sites are more targeted towards women than google sidebar or *Medlineplus.gov*, which has a singular picture of a man suffering from pain. Additionally, advertisements lining the sides of the sites all have pictures of women, and no site has more than one picture of a man if at all. This disparity in the portrayal of women vs. men on the site is not an accurate representation because while women are more likely to experience high levels of chronic pain, they are also more likely to be more active while experiencing it, and men are more likely to move less (Rovner 2017). The debilitating effects, then, would certainly apply to the men experiencing chronic pain, as they would be more likely to restrict movement and halt daily activities. It seems then, that pictures should include depictions of both genders equally. The pictures on *Healthline.com* and WebMD sites are only of different women. Looking at the totality of photographs offered by the sites, it is also interesting how age is depicted. Both of the men featured on the sites have graying or gray hair, while the women vary in ages from youthful to elderly. This may signify the view that women may experience chronic pain at all
ages, but not young men, playing into stereotypes depicting young men as strong. A study of Maine residents found that young men do experience chronic pain, increasing with age and reaching significant levels of 20% of the population in the 35-49 cohort (Malon 2018). Additionally, such depictions of chronic pain as consistently female and/or older could skew such epidemiological findings, as pain must be self-reported and men who see chronic pain under this narrowed lens may be more hesitant to classify themselves as such, reinforcing the stereotype and potentially reducing the care given to those with chronic pain.

The lack of diversity in the pictures suggests that the ideal type of sufferer with chronic pain would be white. This focus on the pain of white bodies further exemplifies findings that “a substantial number of white laypeople and medical students hold false beliefs about biological differences between blacks and whites and demonstrates that these beliefs predict racial bias in pain perception and treatment recommendation accuracy,” with black patients being undertreated for their pain (Hoffman 2016). Only viewing the potential body in pain as white demonstrates some of the bias associated with this under treatment, as physicians were found to “underestimate the pain of black patients (47%) relative to non-black patients (33.5%)”
(Hoffman 2016). As the studies of Foucault and Wilce have illustrated, the relationship between the doctor and the patient is vital in receiving correct diagnosis and treatment for ailments. In chronic pain, the doctor must hear the symptoms from the patient, understand what they are saying, and believe them in order to diagnose. False biases and views on the archetype sufferer of chronic pain is dangerous in that it may limit the effectiveness of these vital steps. The display of white, and mostly female bodies on the pages of these medical websites, reveal that this archetype is very present in the thinking surrounding chronic pain, and may have consequences for those visiting the site as they see which bodies may suffer from chronic pain.

**Advocacy as a Different Approach to Medical Websites: TheACPA.org**

The ACPA website is different from the rest of the sites in that their largest picture on their title page is not a depiction of a man or a woman, but rather a link to an art project depicting people with chronic pain, with a sample picture of the art. The bodies of pain described in this picture, are both women, which may be due to the fact that the artist is a woman, but the skin of the bodies are made up of a green cactus or a blue china pattern. Choosing to use a picture of an artist’s work on chronic pain instead of a rendering of a “typical” chronic pain sufferer as the other websites did may be due to the differing purpose of the ACPA site. The other websites list their primary purpose as to inform readers about various medical conditions. The ACPA also works to provide advocacy. Therefore, they display a work of art done by a chronic pain sufferer to help to show what pain is really like through the eyes of the sufferer, as people coming to the site for advocacy would most likely already know what chronic pain is. The impact of this is that instead of displaying a “typical” image of a person in pain that may convey exclusionary expectations, the images centered are those created by the sufferers themselves, which works to
center patient experiences in a more inclusionary way. The ACPA functions differently from the other websites in its stated goals and functions, which will be explored more fully in chapter 4.

The use of metaphors is an additional powerful tool that could potentially be used in the websites to help convey the experience of chronic pain. The metaphors that are used to describe complex biological terms can be very revealing of the society that utilizes them, as they show which structural forces, such as gender, class, and race, are most thought of when thinking through the scientific terms (Martin 1991). While most of the websites refer to pain simply as a “signal” firing from nerves, WebMD refers to pain as the result of a series of “messages” that move through the brain and that are “processed” by the brain to the feeling of being hurt. The metaphor of a collection of nerve firings of neurotransmitters as a message anthropomorphizes specific parts of bodily anatomy to take on roles that have a human meaning and implied action—as in sending a specific message. This anthropomorphism of the body process of pain is significant because it may reflect the societal need to give a human intention to the suffering of pain. In a condition like chronic pain, where the meaning of the pain is not clear and is not easily explained by bodily processes, linking the pain with a human meaning through the use of metaphor may help to better conceptualize the pain in a westernized society that is dependent on biomedicine and anatomical explanation. In this case, it reinforces the westernized idea that the self is defined into the two parts: the physical body and the cognizant mind. If the pain cannot be classified in terms of the body, then it is in terms of the mind. The description of chronic pain as an anthropomorphized metaphor is then unsurprising in this context. It becomes a way for a biomedically dependent society to understand what is happening in a simplified version. This anthropomorphized metaphor reflects current societal norms. An anthropomorphisation metaphor focuses on the cause of pain (which is unknown) as something human related, and
therefore something that the person is expected to be able to fight. This shows an expectation that a person will be able to fight the cause of their problem and return to activity, reflecting the ethos of a capitalist society that stresses productive bodies (for more on this, see Emily Martin’s analysis of medical metaphors and how they relate to broader capitalist values). This metaphor becomes problematic as pain is not caused by a specific person or thing, and there is nothing to fight against. The assumption that for a person should fight and defeat chronic pain can instead lead to stigma when it is not accomplished.

While each of the websites typically list a broad range of symptoms classifying chronic pain, the wording is slightly different from each other. The sites are said to have been written or edited by a medical professional, but these differences in symptoms suggest that there are varying thoughts on what constitutes chronic pain even among medical professionals. This may suggest that a unifying definition, such as found conditions with objective, anatomical changes, is not possible. For example, if a patient with persistent pain for a few weeks checks WebMD, they will not think they have chronic pain because they have not suffered for the requisite 3 months, and may not seek help. However, if they look at google sidebar, chronic pain is described as something that can last “weeks to years,” a broad range that may confuse when to seek help. These small differences used to describe chronic pain, especially descriptions of the way the pain might be experienced, are important because they may impact the way in which people present themselves to their physicians, which has been shown to have an impact on the way in which they are treated. A study of college students found that women were more likely to look up their symptoms online (Bulled 2011). Additionally, the varying definitions and treatments found on the websites led students to mistrust the treatment options presented on the site, and instead 55% only use the sites as a guide for if they should see a medical professional,
not as a source of information (Bulled 2011). Therefore, the way in which the sites are used is dictated by the varying information presented and an overall distrust of what is said. The sites are used to provide background for the decision to see a physician, impacting that relationship.

However, the study did not analyze if the websites made changes to the actual conversation the students would have with their physicians, but 82% of the students reported looking up medical information online so that they can ask their doctor relevant questions, and 71% said they did so to help feel “in control” at their appointment (Bulled 2011). Clearly, these websites have some sort of impact on the doctor-patient relationship by providing information to readers.

Table 2. The Internet as a Health Information Source

<table>
<thead>
<tr>
<th>Factor</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you look up health-related topics for yourself, friends or family on the Internet?</td>
<td>628</td>
<td>89.1</td>
</tr>
<tr>
<td>What purpose does the Internet as a source of health information serve for you?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>General health information</td>
<td>398</td>
<td>63</td>
</tr>
<tr>
<td>Information on treatments/medication options</td>
<td>156</td>
<td>25</td>
</tr>
<tr>
<td>Information on where to get care</td>
<td>212</td>
<td>34</td>
</tr>
<tr>
<td>Help me determine if I should go to a doctor</td>
<td>342</td>
<td>56</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Factor</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>before seeing a medical provider? (Agree/Strongly Agree)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Information</td>
<td>445</td>
<td>71</td>
</tr>
<tr>
<td>Uses</td>
<td>562</td>
<td>90</td>
</tr>
<tr>
<td>likeness</td>
<td>290</td>
<td>46</td>
</tr>
</tbody>
</table>

*calculated based on total number of individuals reporting use of the Internet for recovering health*

Figure 6: Bulled 2011

Conclusions

Medical websites are an increasingly utilized tool in the American medical system/scene. For the simple price of internet access, a person who is feeling unwell can google their symptoms or suspected ailment and receive copious information from medical experts on medical sites. This ease of information challenges the typical Foucauldian view of the clinic, as the patient does not need to rely on their doctor to explain what is wrong and could develop an understanding facilitated by web searches, which could aid in achieving the legitimacy to their physician necessary for diagnosis. This could be supported by the fact that many people, 55%, in
Bulled’s research, search their problems online to determine if they should see the doctor (2011). As the internet has become even more accessible since 2011, these numbers should have only increased in the present day. If the information given on the sites is accurate and impacts the patients' encounter with the doctor, it would allow them to narrate their pain in a way that would appeal to the doctor and facilitate acquiring the best diagnosis and treatment. They would not be as dependent on their doctor to find out exactly what is wrong with them, and would increase the power that they, as patients, have in playing a more active role in the diagnosis of their condition.

On the other hand, the information used by the websites and its conveyance of chronic pain is vital to the success of the patient. This analysis has demonstrated that the depictions of chronic pain on these websites are shaped by western, biomedical discourses, the capitalist systems of production and consumption, and racial and gender biases. These societal influences on the depiction of pain reflect problems that could add more confusion and hinder the patient’s ability to get treatment. The various definitions and models of pain such as biological, social, neural, or biopsychosocial demonstrate how difficult it is to conceptualize and unify pain under one definition even without the further influencing forces.

Each of the websites analyzed functioned with the goal of circulating knowledge about chronic pain to the reader. The conceptualizations formed about chronic pain were not all uniform across the sites. These differences in definitions, language used, and treatments described in providing information about chronic pain reflects the difficulty in creating a common conception about pain. By looking at these websites through the lenses of previous literature, the sites can be seen to reflect some of these theories, particularly in how they relate to the patient-doctor relationship and overarching conceptions on how pain is typically viewed by western society.
While medical websites are a growing and important source for gaining medical information, they are not the only sources available on the internet. The American Chronic Pain Association is different from the other medical websites because it is a site completely devoted to chronic pain. The purpose of this site is not only to circulate knowledge about chronic pain, but also to provide a place of advocacy and fundraising for patients. This difference may shape the way in which information is presented in comparison to the other websites and portray different notions about chronic pain.
Chapter 4: The ACPA Website: From Conceptions to Advocacy

Unlike the other medical websites listed below, the American Chronic Pain Association (ACPA) website does not have a variety of information on different disorders, but focuses solely on chronic pain. A tab of information about the history of the organization states that it has been in existence for 30 years. The accomplishments listed over these years range from awards for spreading information about chronic pain through publications to actually implementing treatment methods, such as relaxation tapes. Unlike the other medical websites, which have advertisements for drugs and other items, there is a statement on this page that the ACPA does not partake in advertising of any sort. However, they post a list of corporate sponsors that include Google, and various healthcare and pharmaceutical companies. This lack of advertising shows a voluntary attempt to reject the capitalist nature of medicine that is reflected in the other websites, in which the advertisements constantly remind the reader that the buying and selling of things is a part of medicine, even when simply trying to gain information. By rejecting this, the ACPA may appear to look more legitimate in their information because they are not trying to sell anything to the reader and are only trying to inform. On the other hand, a highlighted red tab at the top of the site asking for donations makes it clear that although the site is not advertising from outside sources, it still wants money from the reader to support its cause, reflecting the need in western medicine to privately raise money and awareness to gain medical advancement.

An interesting section of the ACPA website is the information on the treatment of chronic pain, which is simply defined as “persistent pain”. There are 10 steps listed detailing what to do when suffering from chronic pain that will let someone move from “patient to person”. The steps are acceptance, getting involved, learning to set priorities, setting realistic goals, knowing “your
basic rights,” recognizing emotions, learning to relax, exercise, seeing the “total picture,” and reaching out. The first step, acceptance, encourages the reader to realize that there may be no cure for their pain and it may be something “you have to deal with.” Like the other website, this use of “you” includes the reader in their own diagnosis and treatment, but also has the effect of placing the burden of treatment and pain management primarily on the patient. The patient is told not to expect to be cured and brace themselves to adjust their life accordingly. For an organization that prides itself on its ability to spread information about chronic pain and support clinical trials and even in its page title seems to focus on the sufferer as a person more than a patient, this kind of outlook seems very different. Instead of pressuring the physicians to develop new treatments, the patients are told to learn how to deal with the pain in order to become a “person”. While some of the steps acknowledge the rights of the patient as a person such as the steps of setting priorities and goals, some of the other steps, such as exercise and relaxation, also seem to place personal burdens on the patient if they are to be a “person.” In doing so, structural forces including race, gender, and class that impact the treatment of chronic pain are not acknowledged, instead giving individual responsibility to the patient to manage their condition. While it is important and necessary for patients to be able to better live with their pain and take responsibility for their care, it is also important to work just as equally towards overarching change that can make these lifestyle changes more possible, such as increasing abilities to attain accommodating housing, jobs, and equal healthcare access, which is not mentioned on the site.

Additionally, the overall idea that a patient must follow certain steps and lifestyle changes to become a “person” may help patients to avoid stigma, but it is not true that people with chronic pain are somehow less than a real person. Creating this type of mindset is indicative of Jackson’s “Stigma, Liminality, and Chronic Pain: Mind-Body Borderlands,” (2005), which
discusses the potential for stigma of chronic pain sufferers as members. Jackson describes the chronic pain sufferers as being in a liminal state, between the states of healthy and sick, and therefore at risk for stigma. This ACPA list of steps seems to place sufferers as between a patient and a person, as if those identifications were mutually exclusive. The in-between state created and the steps needed to move from one state to the other could lead to stigma when the patient is not able to overcome their chronic pain and move to a healthy state.

A treatment tab on the ACPA website lists a variety of recommended treatments listed from “A-Z.” Surprisingly, there are few treatments listed, perhaps a testament to the difficulty in treating chronic pain. Some of the treatments listed are common biomedical responses: NSAIDS, Nerve and Facet blocks, and TENS, which includes an electrical current sent through the skin. Other alternative treatments are also suggested, including acupuncture, ergonomics, which is to make sure people function best in their working environment, and yoga. Interestingly, opioids are not listed in this treatment of A-Z, which is a common form of treatment for people with chronic pain, and was listed as a potential treatment for the other sites. Could this be the result of increasing awareness of the dangers of opioids and the ACPA's wish to prevent patient expectations of receiving the drugs? In any case, the high prevalence of alternative medical treatments listed reflect an emphasis outside the biomedical field to find relief. However, like the other websites, the reader is encouraged to see their healthcare provider to consult on treatment, giving them the ultimate power to prescribe certain medications, even if alternative medicinal practices from another practitioner are ultimately recommended. In this way, the focus on the physician as the ultimate authority in deciding on treatment types reflects Foucault’s discussion of the doctor-patient relationships and the ultimate adherence to objective symptoms, which is indicative of biomedicine in treatment.
Unlike the other sites, the ACPA website provides a page on the “rights of patients.” These rights follow the general theme of the patient having the right to be respected and believed by others, as well as to be able to disagree with others or “say no without feeling guilty.” It is also said to be a right to ask for help or for more explanation about something. These “rights” appear to promote the expansion of the knowledge of patients of their condition and advocate for more control over their treatment. It seems to support that they explore new methods and to be open about what is most comfortable for them, even if it does not agree with the physician. This kind of mindset seems to align with the literature on illness narratives, as the patients are encouraged to determine what is most comfortable for them in their treatment and personal lives as they manage the condition. In this case, the exertion of more control over a person’s self-worth and treatment plan, regardless of the chronic pain, reminds the patient that it is ok to demand respect from their physician and be well informed. This reflects the ACPA acknowledgement of the challenges faced by people with chronic pain as they “find it hard to express [their] needs and require that others respect them.” They also show a need for greater power by the patient in their experiences with pain, as they do not have to be “people-pleasers” but “do have the same basic rights [they] grant to others”. This type of acknowledgement is different from other conceptualizations of chronic pain found on the other websites and the treatment tab on the ACPA website, which emphasize the authority of the doctor in receiving medical care. It is also very different from Wilce’s (2009) work on the importance of patient skills in communication with physicians. Instead of having the patient modulate their language as “people-pleasers,” they are reminded that they have the same rights as others and can stand up for what they need from their physician. The different role of the ACPA site as a source of advocacy as well as information may play a role in this difference in tone. The site seems to be
working to make things better by increasing the power of patients in their relationships with their physicians. However, the referral to the authority of the physician in the treatment tab of the site contradicts this idea and suggests the site’s advocacy for the patient over the doctor is only upheld to a certain point.

While the “rights of patient” does acknowledge the need for respect and information as well as input by the patient in the treatment of chronic pain, these “rights” also place pressure on the patient to conform to a certain model of chronic pain to retain these “rights.” For example, right number 1 is that the patient has a right to “act in a way that promotes dignity and respect.” This does not seem to be a right that is afforded to the patient by others, but rather a command that before any of the following “rights” can be gained, the patient must act in a certain way, no matter what their personal pain is. The pressure to act a certain way when potentially under extreme pain in order to be treated with respect is surprising considering the other rights listed that focus on the respectful treatment of patients. Additionally, the last right is to memorize the list of rights and make them “part of your daily life.” This also places the responsibility of knowing these rights on the patient, and not the physician, who is actually expected to follow them. This focus on the role of the patient demonstrates a subversion of the type of Foucauldian doctor-patient relationship in which the doctor has more power to control treatment and make diagnosis as the patient is encouraged to speak up for themselves and set boundaries in their healthcare experience. However, according to the ACPA, if the patient wants to increase their power and have more input in diagnosis and treatment, they must be the ones to advocate for themselves, not their physicians. This means that the responsibility to practice these rights falls on the marginalized patient and not their physician. Asking a patient who is already under the pressure to convey their pain in an appropriate way to their physician to also stand up to their
physician is a huge undertaking. They must not only change their language and appearance to allow better communication with the physician as Wilce (2009) describes, but, according to the ACPA, they also must advocate for themselves to their physician at the same time and risk a disruption of this communication.

An interesting aspect of the website is a tab called “how to communicate symptoms to HCP [health care provider].” The tab gives access to a “pain log.” This “log” is an online tool that patients can use every day to keep track of their pain. They are asked about different aspects of their life and told to rank their pain accordingly. Questions asked include pain level of the day, days per week exercised, amount of stress, level of activity, sleep, fear of pain, bowel movement, sexual activity, appetite, mood, social life, alcohol consumption, finance worries, fidelity to medication prescriptions, side effects of medications, and smoking. Patients are told to record daily in order to track patterns in their life and try to identify “triggers” for their pain. The log is especially recommended to patients with Fibromyalgia, and patients are recommended to print out the results of their log and show it to their physician.

The concept of the “pain log” is anthropologically interesting in many ways. By creating this log and instructing readers to use it as their main form of communication with their physician by suggesting they bring the log to their appointment, the ACPA constructs itself as a main authority on communication between the chronic pain patient and physician. In doing so, the ACPA attempts to insert itself into the relationship between the doctor and their patient in the hopes that it will improve the ability of the patient to make their pain clear, presumably by giving more authority to the way they are describing their pain. The log itself displays some aspects of Kleinman’s *Illness Narratives* in thinking about the impact of chronic pain on the body. Unlike depictions of chronic pain simply in terms of anatomical dysfunction, the pain log attempts to
include the influence outside life may have on management of chronic pain by taking into account outside factors such as exercise, stress, and alcohol. However, the site is not reflective of *Illness Narratives* because the structural forces that shape the treatment a patient receives when suffering from chronic pain is not sufficiently documented as part of the pain log. While financial worries are listed as a potential trigger, other structural forces such as race, gender, and sexuality are not listed as potential “triggers” for pain. These forces may not be as easily addressed as drinking less alcohol, but they do play a major role in how difficult it is for a patient to heal from injury. Furthermore, as Kleinman makes clear, these structural forces that are so often ignored in patient care play a role in other aspects of an illness narrative. For example, the ability of a person to find time or means to exercise, reduce stress in their community, or fill and take their prescriptions, is very influenced by forces of class, race, and gender. A person of color may not be able to feel low stress when in a heavily policed community, a person with low financial means may be unable to afford to fill all of their prescriptions or attend a session at the gym. The absence of these factors in the pain log by the ACPA suggests that the focus of this log is on the individual patient and their ability to make changes in what may be worsening their pain. However, by ignoring the full illness narratives that create the experience of chronic pain in a person, they place a responsibility on the patient to make changes in their care that may be impossible. More problematic is the suggestion that this log is the best way to communicate the pain experience from the patient to the physician, which risks omitting the structural forces from the discussion between the two sides severe challenges, such as resources for aid in meeting needs for healthy foods, housing assistance, or job placements for people with chronic pain.

Unlike other sites, the information on the ACPA website is shown to be verified by its stamp of HONcode standard. The HONcode standard is an outside foundation that approves
medical websites for the content that they post. The sites are said to be ranked on who gives the information and why, its privacy and advertising policy, and the justifiability of the content provided. The ACPA is said to have met the requirements of each of these sections, and gained the HONcode approval. The site claims that other sites with their seal of approval have passed their standards of “code of conduct” but makes it clear that they are not liable for any breaches in these sites that they have not been made aware of. The role of the HONcode site as a way to certify medical websites is interesting because it seems to be trying to bring some standardization of medical websites that often varies in the medical information they circulate. While the standards promoted by the site may not actually be the most accurate way to judge other sites as it bases its certification off of its own standards and not a universal list of rules, it still gives some form of standardization by comparing various websites. All three of the websites previously examined, WebMD, Healthline.com, and Medlineplus.gov, are listed as certified by HONcode, but did not display their certification on their site like the ACPA site. Perhaps they do not wish to bring attention to a link to another site for medical information, while the ACPA does not have this concern. Or perhaps they do not have to assert their medical legitimacy in the same way ACPA does. By gaining this HONcode certification, the sites now have more authority. Regardless of the content and views that these sites are promoting, they are spreading more knowledge about chronic pain and how it should be conceptualized in western society, and the HONcode certification is used to add authenticity to the ACPA as an authority on this information.

In the setup of the ACPA website, the information given on treatment, communication with physicians, and a focus on certification, signifies the role of the site as a (semi) medical authority. Having the authority to give applicable advice on patient life and treatment without a
white coat demands calculated work. The emphasis on the HONcode certification and lists of potential treatments, clinical trials, and focus on patient feelings and point of view in its “patient rights” demonstrates that the site is trying to provide information on all the different aspects of chronic pain a patient may find useful.

The site does a good job in providing this information, especially the focus on different types of treatment beyond opioid medications. While the ACPA site does a good job of providing a large breadth of information on chronic pain and giving advice for patients in their relationship to their physician, the failure to acknowledge the full illness narrative that is common to many with chronic pain still leaves many at risk of stigmatization, misdiagnosis, or mistreatment.

This lack of a full illness narrative is not exclusive to the ACPA site, as the other websites analyzed also did not display the entirety of the experience of chronic pain. *Healthline.com* acknowledges that chronic pain can make it “challenging to get through daily tasks and activities” but does not expand on what these may be or how it can inform a patient’s experience of chronic pain. *WebMD* says that chronic pain can have effects on “day-to-day life” and “mental health” but does not go into how this may be detrimental to care or living. *Medlineplus.gov* says that “environmental factors” can play a role but does not mention how chronic pain can impact living, nor does google sidebar. In comparison, the ACPA provides much more information on how chronic pain can impact life. While the structural forces that make living with chronic pain so difficult are not acknowledged, the pain log acknowledges the difficulties that people with chronic pain have in working, exercising, and other activities.
Conclusion

The use of websites for all sorts of information will only increase in coming years. These sites promise to bring new resources and information to more people than ever before. However, as these sites provide more knowledge, particularly medical knowledge, it becomes even more vital to observe how information is circulated online. The traditional frameworks of medicine had not accounted for the internet and how it circulates medical knowledge to a broader audience, which is now sure to play a role in medical practice more than ever. Researchers must examine the effects of the internet on social relations and patient-doctor interaction.

This thesis aimed to better understand how chronic pain is represented on medical websites.

Overall, the websites promote ideas of chronic pain that could impact the doctor-patient relationship. The definitions of pain itself varied and an exact definition of chronic pain was not uniformly described. The commonalities that were displayed generally focused on a neurological explanation for chronic pain, with little to no explanations of social or psychological aspects. Additionally, the information presented, when observed through the lens of literature on doctor-patient relationships such as Foucault’s *Birth of the Clinic* (1973), Kleinman’s *The Illness Narratives* (1999), and James Wilce’s “Medical Discourse” (2009), show the possibility for both reinforcing and subverting the traditional patient and doctor relationship. My analysis also gives support to Jackson’s argument in “Stigma, Liminality, and Chronic Pain: Mind-Body Borderlands” (2005). We see how the websites depicted those who suffer from chronic pain as in a state of in-betweenness, neither fully healthy nor fully sick. Furthermore, Jackson’s ethnography, *Camp Pain* (2000), finds that the traditional body-mind ideas about pain which see
pain as separate from the self were attempted to be upheld by chronic pain patients. However, the patients often could not separate their pain from their sense of self, suggesting the inability to chronic pain to fit into this conception of self. The overall premise of medical information online seems to lend itself to the idea that patients may be better informed in their meetings with their physicians, increasing their power during their doctor’s visits, and giving them a more active role in selecting the desirable treatment. This is supported by the proponents of the “Patient’s Bill of Rights” on the ACPA website. However, the lack of description of some of the social factors involved with the experience of chronic pain in favor of the objective, neurological definitions necessary to clinical work still focuses treatment plans and diagnosis on the physician, with all the power associated with it.

Each of the websites is slightly different in its conceptualization of chronic pain. As stated above, the previous studies have demonstrated the multitudes of ways chronic pain can be conceptualized by a society. Therefore, the fact that all of these websites were able to similarly describe an experience that is unknown in the biological sense is remarkable. It must be concluded then, that these similarities must have a societal connection in the place that the sites were made, that is, some sort of similar thinking that leads people to describe pain in the same way, perhaps due to an ingrained sense to participate in shared medical discourse. The description of pain with the prioritized description of nerves firing demonstrates a clear priority of biomedical explanation, meaning the neurological approach, in a westernized society. The fact that none of the sites represent a person of color with chronic pain paints a clear picture of what kind of bodies are able to display chronic pain (white, mostly female), and the way in which they are displayed shows to what extent even these bodies can display their pain to society (slight discomfort). The stated goal of treatment for these sites is not to make the pain go away
completely, but rather to return the sufferer to their daily life. The prioritization of the functionality of the body over the experience of the sufferer may be the best that can be done with no cure yet available. For medicine to improve, however, researchers and doctors must continually strive to make their goals of treatment better than before and aspire to help the sufferers fully rejoin society instead of focusing mainly on a body that must return to functionality.

An interesting future study could see how reading medical websites might impact a patient’s narrative when describing symptoms to their physicians, and if this narrative matches the language expected by physicians diagnosing chronic pain. Furthermore, studies could be done to determine if doctors may be more likely to believe patient’s reported symptoms when presented with medical terminology. The fact that chronic pain is chronic means that it will impact the sufferer’s life in some way, and it is important for people reading and writing the sites to fully acknowledge this to give complete understanding. While the overall impact of these limited definitions on the sites is unknown without data on the subtle influence they could have on readers, it is known that many users will read these sites prior to seeing a physician. This change can be helpful in disrupting the traditional medical gaze and giving knowledge power to the sufferer. However, false or conflicting information could cause confusion between the patient and the doctor, who ultimately has the power to provide care. Future work should therefore analyze the impact of these sites on patients and, in the meantime, these websites must adopt a full, comprehensive view of all aspects of chronic pain in order to give people seeking information a full understanding.

The use of the internet as a source of medical information has great potential to change the way in which people understand health conditions and receive treatments. The huge amount
of information available to any user could allow people to understand what may be wrong with them, and advocate for themselves at their visit with their physician, drastically changing the way medicine is practiced. The importance of the internet in gaining medical information is no better exemplified than in the current COVID-19 pandemic, during which people sheltering in their homes use the internet for their main source of information about disease symptoms, treatments, and news. Some of the information presented on these websites correlate with the information presented by authoritative bodies such as the WHO and CDC, and some spread incorrect or faulty information. In the face of this, the success of this form of communication in better treating patients remains to be seen, but it will undoubtedly change the way medicine is practiced as people learn to use their computers and phones for medicine. In fact, this dependence on the internet for medical information serves to show the lack of regulation of online medical knowledge accreditation, and the benefits and risks such a phenomena carries. Whenever medical information is circulated online, it may have an impact on the conceptions people form regarding health, bodies, and medicine, which can then impact care. During and after this pandemic, it is even more important to understand the ways in which medical information is circulated online. We see here a clear paradox: On the one hand, the way the information online is used can present new ways of practicing medicine. On the other hand, the perceptions provided and user availability of these increasingly necessary sources may not reduce inequality in healthcare, but actually maintain it. It is this potentiality that should encourage us to consider carefully how medical knowledge is constituted, circulated, and appropriated by different actors and through different venues.
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Websites Reviewed


Google Search: “Chronic Pain”


Literature Cited


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