Religion, Chronic Pain, and Reconstructing Norms

A Collection of *Hopeful* Illness Narratives

By

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“God, grant me the serenity to accept the things I cannot change,
The courage to change the things I can,
And the wisdom to know the difference.”—Reinhold Niebuhr (1892)
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“Hopeful Narratives”

Chapter 1: An Overview of Chronic Pain

Millions of Americans rely on federal disability benefits, and the number one reported cause of disability in America is chronic pain (Steglitz et al. 2012). Chronic pain is estimated to cost the United States between 560 and 635 billion dollars each year in medical expenses alone (Gaskin and Richard 2012:715). Although this affects around 100 million people in the United States (Steglitz et al. 2012) it is not a universally experienced or identified illness (Good et al. 1992:3). While etiological explanations for illness can be political and social in nature, biomedicine seeks to explain chronic pain in terms of its underlying concrete pathology. Yet, medical anthropologists have suggested that pain is all encompassing or biopsychosocial: affecting the social, emotional, and biological self (Schepfer-Hughes and Lock 1987:8).

This thesis explores the subjective experiences of adult members of Catholic and Protestant churches located in North Carolina who experience chronic pain. The purpose of this study is to better understand how an individual’s lived experience, self-understanding, and language are ultimately shaped by the biopsychosociality of pain. Because pain can be all-encompassing, social institutions like churches, schools, and hospital play an significant role in shaping how an individual and society perceive/understand pain. Using ethnographic methods to

1 According to the Institute of Medicine’s 2011 report titled Relieving Pain in America- A Blueprint for Transforming Prevention, Care, Education, and Research:

- 116 million Americans experience chronic pain
- Chronic pain in America results in around 40 million medical visits each year
- Pain is the #1 complaint brought to clinicians
- Chronic pain affects Americans more than heart disease, cancer, and diabetes combined
understand pain as more than merely biological is important because “in our current era of
global capitalism, there is a need for research that links human biology and health to social,
cultural and political-economic dynamics” (Leatherman and Goodman 2011:29). Certain
social/emotional experiences such as trauma, bullying, isolation, and stress can affect a person’s experience with pain. The social world’s significant role in health and illness has influenced my interest in examining how religious institutions (Catholic and Protestant) broadly shape one’s experience with chronic pain.

My thesis examines religious institutions in relation to chronic pain because religion “has
dealt with pain not by trying to stop it but rather by trying to transform it into an experience that leads to meaning, insight, and even salvation” (Incayawar and Knox 2013:x). Although biomedicine is premised on the separation between science and religion, many people still draw on religion for understanding and meaning in experiences of illness. This may be particularly true in the case of chronic pain, where treating “pain” that lacks clear biological etiology is different than treating a wound or a disease. X-rays and diagnostic tests may not provide doctors or patients with a visible biological cause or understanding of pain, causing people to look elsewhere for meaning and understanding of how to live with their pain. As “a clinical, public health, and fundamental rights issue” the ubiquitous nature of chronic pain offers an interesting and important area for medical anthropologists to study (Incayawar and Knox 2013:xiii).

Despite chronic pain affecting so many Americans, medical schools still lack adequate pain education courses. A study at the John Hopkins School of Medicine found that only “80% of U.S. medical schools requires 1 or more pain session [courses]” and “many topics included in the International Association for the Study of Pain core curriculum received little or no coverage.” This highlights the need for “knowledgeable and compassionate care regarding pain” that is not
only “associated with better medical outcomes and quality of life”, but also “lower health care costs” (Mezei and Murinson 2011:1199).

Using a phenomenological approach that focuses on the political and social economy of the body, medical anthropologists are critical to studying and better understanding individuals with chronic pain. Through ethnographic methods – particularly through the act of listening – they analyze the complex and tightly interwoven factors that shape experiences of chronic pain. In the field of medical anthropology listening is highly valued, and it is through patients’ stories or illness narratives that listening becomes a mechanism in better understanding “the different models of illness meanings- symptom symbols, culturally salient illnesses, personal and social contexts” (Briggs 2011:464). In particular, medical anthropologists Arthur Kleinman and Nancy Scheper-Hughes “have brought the analysis of narratives to the center of medical anthropology” and it is through their research (and many others) that illuminates the need to approach chronic pain differently (Briggs 2011:463).

Popularized in the 1960’s, chronic pain clinics were opened in the United States in an effort to help treat patients using a holistic approach coined biopsychosocial (Buchbinder 2011:461). Pain clinics offer mechanisms to cope and manage pain rather than to cure pain, and value listening to the patient. In her ethnography of a pediatric pain clinic, medical anthropologist Mara Buchbinder has shown that more than simply managing pain, pain clinics can offer patients legitimacy and hope. In her research among young adolescents suffering from chronic pain, Buchbinder finds that physicians in pain clinics typically explain the patient’s illness as something neurological, dealing with the brain or nerve signals (Buchbinder 2012:16). The physician gives the patient’s pain a name by labeling it as Irritable Bowel Syndrome (IBS) or a migraine in an effort to legitimize the patient’s suffering and to help explain perceived symptoms, treatment, and an expected illness career (Buchbinder 2011:461-4). These chronic
pain diagnoses lack a concrete etiology or diagnostic tool to identify the source of pain, but naming the pain offers a source of symbolic healing (Buchbinder 2011:461). Despite this, the majority of chronic pain patients still struggle to legitimize and articulate their pain to be viewed as “real” in western biomedical societies (Scheper-Hughes and Lock 1987:21). Cartesian dualism, the separation of mind and body that has shown to be deeply cultural, informs the divide between psychosomatic illnesses and biological illnesses (Scheper-Hughes and Lock 1987:6-7). Typically, psychosomatic illnesses involve stigma and are deemed to be “all in a patient’s head,” while bodily bound illnesses that are identifiable using specific diagnostic tools and have a biological etiology are acknowledged as real and legitimized by society. This helps to explain why psychosomatic diseases can create issues with legitimacy because they imply that the individual is at fault or responsible for their illness (BuchBinder 2011:459).

**Pain, Language, and Social Worlds**

In her seminal work on language and pain, Elaine Scarry moves pain from the bodily to the linguistic level by arguing “physical pain does not simply resist language but actively destroys it” (1985:4). Because pain is all consuming, it ultimately corrupts consciousness and complex thought, first monopolizing language then destroying it (Scarry 1985:54). She supports this argument by explaining that physical pain destroys language through reverting a person to cries and groans. Since it has “no referential object” one can only describe it as a state of being or as an “it” (Scarry 1985:4). An individual’s certainty of his or her own pain can lead to another’s doubt. Because pain is difficult to explain it is linked to doubt, and for this reason Scarry describes pain as an individualized experience (1985:3).

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2 Scarry quotes Virginia Wolf: “For all the poems about love, no poet can describe a migraine effectively” (1985:4).
Yet in order to understand and treat something that can only be described, communication through language is necessary. Scarry discusses medical establishments’ attempt to understand pain through a categorical approach: the thermal dimension of pain (burning), the temporal dimension of pain (throbbing), and the constrictive dimension of pain (crushing) (1985:7-8). But, this approach describes pain by means of a weapon, objectifying and externalizing pain in order to describe it to an audience. “As an actual physical fact, a weapon is an object that goes into the body and produces pain; as a perceptual fact, it can lift pain and its attributes out of the body and make them visible” (Scarry 1985:17). Unfortunately, describing and categorizing pain as such makes the person in pain become invisible (Scarry 1985:22). She also discusses the role of the social world in how we experience, understand, and perceive pain. In particular, Scarry focuses on religion as a social world, discussing how the Hebrew Bible gives meaning and understanding to experiences with pain by understanding healing as confirming belief in God and wounding as disbelief (1985:213).

Buchbinder offers an alternative claim to Scarry’s destruction of language theory. Instead, she argues that chronic pain patients reconstruct or create a new language and cultural/social world (Buchbinder 2015:31). Chronic pain patients must seek to construct language and their illness narrative to legitimize their suffering and pain as real in order to maintain morality and value through language. Through illness narratives among her pediatric pain patient informants, Buchbinder examines the role institutional dynamics and language play in illness narratives. Illness narratives provide people the ability to shift the agency of blame by transitioning from the active to the passive voice and by placing pain at the center of their

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3 The Medical Language of Pain is based on the description of pain through the McGill Questionnaire: based on gathering patient descriptors of pain into various categories (thermal, temporal, constrictive). Other Languages of Pain: Amnesty International (organization works to end torture by naming it), Courtroom (plaintiff’s lawyer speaks for the injured party), and Art (more psychological pain representations) (Scarry 1985:7-11).
narrative (Buchbinder 2009:116). This transition also implies a certainty of a person’s pain instead of conversational ambiguity. The construction of the illness narrative can legitimize a person’s suffering. Buchbinder depicts in an interview with Faith, a mother who places her son Allan’s migraines at the center of her illness narrative to not only legitimize her son’s suffering and pain by means of language, but also to provide a different perspective of God as one who participates in human suffering (2009:117-20). Buchbinder explains that in contrast to Scarry’s interpretation of pain as something that is destructive, pain is in fact constructive. Patients learn how to describe, explain, and interpret their pain within specific social contexts to gain support and legitimacy from social structures like biomedical and religious institutions (Buchbinder 2015:22).

In this thesis, I draw on analysis from both authors to support the central claim that I develop in the coming chapters: that those who suffer from chronic pain can reconstruct language in order to gain legitimacy and to make meaning. I will also analyze the influence that an individual’s social world (like a school or church) has on the construction of language and ultimately a person’s illness narrative. To do so I will utilize research from other anthropologists in my analyses. In particular, I plan to use theoretical approaches on pain put forth by Mary Jo Del-Vecchio Good, Paul Brodwin, Byron Good, and Arthur Kleinman in their book, *Pain as Human Experience: An Anthropological Perspective*, to analyze how social affiliations and the culture surrounding social institutions (like churches or schools) shape individuals’ illness narratives and understandings of their pain. Their attention to language is of particular importance to my research because new meanings of certain words are used in the context of pain. These anthropologists show how chronic pain sufferers use language and descriptive vocabulary to construct their world in a way to gain support from their social institutions, gain legitimacy, and avoid certain expectations.
Pain and Morality

Biomedicine provides a very specific framework rooted in science to understand illness. But biomedicine is only one framework for understanding illness and disease. The earliest form of healing—religion—offers another. For this reason, this research also draws on chronic pain illness narratives to analyze the relationship that religion creates between pain and morality. Ultimately, I hope to see how this relationship affects an individual’s coping mechanism and ability to cope with pain.

Returning to Scarry’s discussion of language, Scarry states that pain destroys language and that it also implies a lack of morality: the body experiences punishment or pain as a result of disobedience to God. Language and the ability to articulate are associated directly with one’s morality. Lack of articulation ultimately does not allow a person God’s sympathy or others and implies that the person’s own lack of morality is the cause of their pain (Scarry 1985:201-4).

Buchbinder offers a different perspective on pain in her illness narratives of chronic pain patients, where a person’s construction of their illness narrative can actually gain legitimacy and depict the individual as moral and ultimately deserving of care. Morality here is not as finite as Scarry’s understanding, but its understanding and implication are based on contextual factors like the type of God one believes in (rigid or merciful) (Buchbinder 2009:120). In an attempt to appear as a “Good Christian Woman”, one of Buchbinder’s informants Faith constructs her God as a participatory God in her and her child’s suffering (2009:118-20). Faith is not just making an assertion about her child’s innocence in the matter; she is constructing herself as a certain kid of mother and as a Christian (Buchbinder 2009). She talks about her son’s suffering in a framework of her own to make herself appear as “the kind of mother she desires to be: a mother who responds in an ethical way to the injustices of her son’s long lasting pain” (Buchbinder 2009:117). She frames her son’s narrative around his migraines and her own suffering, instead
of social factors that may imply that Faith is an inappropriate advocate for her son (Buchbinder 2009:118). In order to portray the role of a good and moral mother Faith “draws on tropes of maternal sacrifice to portray prioritizing [her son’s] care over her own” (Buchbinder 2009:119).

Faith’s illness narrative contrasts with Scarry’s interpretation of suffering and pain as an experience isolated from God, demonstrating how morality is constructed differently by different individuals even within the same religious and social institutions. In other words, morality is shaped by multiple factors and illness narratives provide a mechanism to frame one’s role in suffering as a way to attain or restore one’s morality.

My understanding of morality is informed by Nancy Scheper-Hughes and Margaret Lock’s discussion of the role of the mind and body in relation to morality (1987). Cartesian duality ignores the role sociality plays in illness and health; however, Descartes was a devout Catholic. Through the mind-body divide, he meant to portray the soul as the center of the human with the ability to direct the body like a puppeteer (Scheper-Hughes and Lock 1987:9). But Western society has curtailed Cartesian dualism to benefit science and biomedicine, placing the body as the priority and as the “real,” and the soul/mind as ambiguous, as the “unreal,” and not as important (Good et al. 1992:139-143). The discord between mind and body relates suffering and pain to a moral issue that is largely spiritual and this goes back to the deep roots pain has in religion. As discussed earlier, pain from a religious perspective can be a result of penance or punishment. Thus, judgment on one’s morality (conscious or unconscious) is a result of not only a person’s religious and/or spiritual beliefs, but an attitude in American health care that seeks to blame someone or something for illness and pain (Khatri et al. 2009).

4 The conceptual article From a Blame Culture to a Just Culture in Healthcare the issue of blame in relation to health as a result of biomedical system is discussed. In short, “a prevailing blame culture in health care has been suggested as a major source of a high number of medical errors” (Khatri et al. 2009).
Jason Throop in his book *Suffering and Sentiment: Exploring the Vicissitudes of Experience and Pain in Yap*, depicts how pain and sensations of the body are related to morality and can be a determination of whether an individual is living a virtuous life or not. In particular, Throop discusses the roles of pain and fatigue as felt experiences of the body that others can use to judge a person’s morality or character. A key to determining morality and it’s relation to suffering surrounds the question of whether the individual in pain is suffering for a purpose or is just simply suffering (Throop 2010). Thus, it is ultimately an individual’s illness narrative, and how a person frames themselves in relation to suffering, that provide meaning and implications of their morality.

**Site of Study: The Religious Social World**

Using these two broad/overarching themes of: **Morality and Pain** and **Pain, Language, and Social Worlds**, this thesis explores how some pain sufferers turn to their faith, to other members within their church, and to religion to construct their illness narratives and ultimately to make sense of their experiences. I have chosen religious sites and churches as a fruitful place of research for three reasons. First, the historical relationship between pain, God, religion, morality, and language is deeply intertwined. “Pain goes back to religious symbols when severe chronic pain is described as hell even in it’s medical setting, so religion interweaves its way into basic pain language and biomedicine” (Good et al. 1992:140). Second, a person’s religion can influence the way he or she understands and copes with pain. Third, this site of study provides evidence of the role that belief plays in hurting, healing, and dealing with chronic pain.

Narratives of chronic pain in religious institutions, such as the Catholic and Protestant churches where I conducted research, are all the more significant given that chronic pain clinics are proven to help their patients, but the majority of individuals suffering from chronic pain are
unable to afford the out-of-pocket expense of pain clinics. Thus, pain sufferers often turn to
social institutions to cope, making they’re suffering a communal experience rather than
individual one. In contrast to Scarry, I believe that pain is social. Anthropologists such as Byron
Good, Arthur Kleinman, Nancy Scheper-Hughes, Margaret Lock, and Jean Jackson describe pain
as something that is social, communal, and a “we” experience. In the chapters that follow, I
analyze the role religion plays in this experience and how it affects a person’s ability to cope and
the methods used to cope. Anthropologists have studied coping mechanisms and the power of
belief previously. However, little research has been conducted on the complexity of factors
surrounding religion and belief that affect a person’s method and ability in coping with pain.

Religious institutions are important sites for understanding pain experience for another
reason. Through in-depth interviews and literature review, this study analyzes how
religious institutions (specifically Protestant and Catholic places of worship) affect the
phenomenology, symbolization, and narratives of chronic pain. In a society where health is
understood as an achieved, not an ascribed status, chronic pain patients are stigmatized as
responsible for their pain. This research will better provide an inlet into the world of chronic
pain sufferers, which could lead to better treatment for chronic pain patients in the future if
multiple frameworks are used to understand pain like religion and biomedicine. These
frameworks must be given equal credibility.

Chapter 2: Study Methods and Inspiration

The following chapters are a collection of individual chronic pain narratives followed by
concise anthropologically based analyses. These narratives were collected through ethnographic
research, which includes behavioral observation, participant observation, interview questions,
and audio recordings. All subjects were informed of the purpose of this study and have been
given pseudonyms in order to protect their identities. As a general disclaimer, the following chronic pain narratives and analysis are not reflective of my personal beliefs or opinions.

Although I have included in this thesis only four ethnographic accounts of subjects interviewed, the overall findings are a result of a 9-month study that involved interviews conducted across North Carolina. In order to conduct this study I obtained approval from the Institutional Review Board in Chapel Hill, North Carolina. My analyses, findings, and conclusion are not confined to the four illness narratives discussed in the following chapters but are a result of interviews with 29 individuals and participant observation that took place over the 9-month period. The subjects of my study are adults (ages 18-75), who experience chronic pain and are members of either a North Carolina Catholic or Presbyterian church. The subjects are current residents of North Carolina, and most of the individuals live in the Triangle area - Raleigh, Durham, Chapel Hill.

I chose to focus on chronic pain patients within Catholic and Presbyterian North Carolina churches because the South (in general) is saturated with churches as a product of history. After the Second Great Awakening, slavery and segregation were justified and largely defended by Southern churches. Unlike the North, the South lacked great diversity, and most of the inhabitants were Anglos, Scottish-Irish, and blacks. In general, the South is filled with a culture full of religious revivals. Whites and blacks in the South turned to religion to support their beliefs and to provide support during times of economic struggle. After the Southern Baptists split in the mid-1800’s over the issue of slavery, religious fervor increased. The South remains saturated with churches and is comprised of many people with beliefs and principles rooted in their religious upbringing. For this reason, the South is a great location to study the impact of religion as a social structure. North Carolina, in particular, is an excellent site for this project because of its dense population and a large number of churches.
This study involved first attaining IRB approval, which involved outlining my methods of recruitment. I initially thought that flyers left in churches asking if individuals wanted to participate in my study would solicit enough interested responses. I asked local churches to place my flyers in their welcome center or a place that had heavy foot traffic. The flyers received basically zero responses so I switched to a more time-consuming and uncomfortable method—attending 18 different Catholic and Presbyterian churches every week for 5 months. Going to a church where I did not know anyone was a bit daunting. Initially, I was insecure that people may ask me to leave (because I was there ultimately for research and not worship), or that people might judge my own morality. Despite my insecurities, this was the best recruitment method by far. I learned more about the religion itself during service, and ultimately developed relationships with members, who after getting to know me as someone more than a researcher were enthusiastic to participate in the study or to help me recruit more subjects. The 29 individuals interviewed are regular members of their churches, as well as individuals who have positions like fathers, deacons, etc.

I “cold-called” a few churches to ask if they would answer questions about their religion, and if they could guide me to potential individuals within the church experiencing chronic pain to contact. The churches were easy to find because North Carolina is saturated with Catholic and Presbyterian churches. A simple Google search produced a list of hundreds of results. My largest resource in this study, however, was networking. In addition, to my connections made by attending different churches, I announced my study to my classes and left my email address on a board so people interested in the study could contact me. Other students at UNC-Chapel Hill were incredibly helpful and willing to not only participate in the study but to recommend others who may want to participate. In addition to attending church services, I attended local chronic pain support groups. Essentially, I wanted to immerse myself in not only religion but in how
people within particular religions (Catholic and Protestant) understand and experience chronic pain.

Out of the 29 individuals I spoke with, 21 were women, and only 8 were men. I found it very difficult to solicit men, who were more inclined to tell me that they did not experience chronic pain. They spoke of pain instead in terms of “injury”. At the chronic pain support groups, all were women, despite the fact that chronic pain affects all genders. This suggested to me that chronic pain is gender stigmatized and needs further studies analyzing the role gender plays in constructing a person’s experience and understanding of pain.

All narratives were collected in person and/or over Skype video chat. In general, the interviews lasted 2 to 5 hours and typically consisted of multiple meetings. For the majority of my in-person interviews, I used an audio recording device, and interviews were later transcribed to retrieve direct quotes. These devices allowed me to analyze tone and pauses in conversations. A few of the participants opted out of being recorded. I also brought a laptop or notebook to all interviews to record informants and to note anything else interesting said in our conversations. Directly after each interview I wrote down my observations and overall thoughts. My analysis comes from anthropological literature and briefly mentions medical/psychological studies to support my findings.

This study was exciting for me because I was able to be a part of each individual’s experience. I will admit there were some incredibly uncomfortable and awkward moments. In particular, I remember meeting a man who suffers from chronic back pain and his pastor at a local church after their service. Our interview started as expected with basic questions. Then things shifted as the pastor told me he could heal with his hands. The pastor explained to me that he could make blue hands appear in a smoke-like fashion to fix broken bones and cure illnesses. As he told me this, the man with chronic back pain started to fall over and slur his words as if he
were having a seizure. I was placed in an uncomfortable position in deciding whether or not to call for an ambulance or to hope that this was some type of religious performance. Luckily, the man got up after a few minutes and seemed normal, but I realized from this experience and many others that our understanding of God and healing (even within the same religion) can vary drastically. I had a few other uncomfortable experiences, like when a woman heading up a chronic pain support group announced that I was a medical doctor specialized in treating chronic pain. I corrected the mistake as soon as I could, but that did not stop me from receiving a flood of emails asking if I could treat people. I felt uncomfortable knowing that individuals thought I was a medical doctor, and may have had false hope that I could treat them. I feared they would get angry or call me a fraud after correcting them.

The experience, although challenging, was also rewarding. I forced myself out of my comfort zone every week, attending new churches alone, going to lunch with people I had never met, and being asked personal questions I was unprepared to answer. But through this process I met so many friends and people that inspire me. I laughed, cried, and shared frustrations with people I interviewed because ultimately I became immersed myself in what they were experiencing. I found that even in a world of chronic pain there is so much good, laughter, and happiness.

This study is inspired by current and past chronic pain research, my environment (living in the southern bible belt), and linguistics. But most importantly, this study is based on a word I have heard and continue to hear in my pain studies from doctors, patients, and anthropologists: hope. Each chronic pain patient hopes for something, and it is that hope that comforts those who suffer and attempt to cope daily. It is also hope that motivates me to research individuals who suffer because I hope to bring somehow them a source of legitimacy through my writings.
I aim to emulate medical anthropologists like Jason Throop, Douglas Hollan, and Mara Buchbinder, who seamlessly balance empathy, objectivity, and professionalism in their fieldwork and analysis. The format of this study and layout of the narratives/analysis is inspired by Arthur Kleinman’s book *The Illness Narratives: Suffering, Healing and The Human Condition*.

This research and these narratives are for the individuals who have fearlessly shared their personal stories with me. Although the individuals themselves are anonymous their stories will not be. I want to thank all my participants in this study for giving me their time, stories, and trust to portray them as accurately as possible and analyze their experiences with anthropological literature.

This study is still in the process of being conducted, and ethnographic research will continue until June 2016.
Chapter 3: Illness Narrative #1
Sophia’s Miracle

I picked up Sophia on a drizzling afternoon from her apartment in Carrboro, NC. Sophia is a well-poised devout Christian woman who has dealt with bouts of chronic pain for many years. Now in her 70’s, after a triple bypass surgery, hip pain from an earlier break, and paralysis in her left hand, she relies on heavy pain medication to allow her the ability to function. She hoisted herself in my passenger seat exclaiming with laughter “ride on cowgirl” then jokingly remarked, “I can do things myself; sometimes it’s just easier when people offer to accept.” When I asked how she deals with her pain, she responded that “laughter is the best way to deal with it because if I didn’t laugh from the pain I would cry.”

Sophia moved to an apartment complex for the elderly about 6 months ago. She told me that initially, the “old sick people” wandering the halls in their walkers frightened her. After a while that fear went away as she focused on making friends and finding things to do, like playing pinochle with a group of ladies at the complex. Throughout our lunch, I took notes as Sophia described her health issues. She flew through them as if to get on with her afternoon so we could discuss lighter things. In between her pain narrative she would stop to make a crude joke or comment that would leave us both out of breath from laughing. She told me about how she was glad she had a walker because hot younger men sometimes opened doors for her, and she took full advantage in these situations to “check out them out.”

Sophia’s health history was drastically more serious than her jokes. At 25 she developed rheumatic fever, which she credits as placing great strain on her heart. At 43 she had her first, what she considers “major,” heart attack. And at 52, she had triple bypass surgery because of congestive heart failure. After she had a heart transplant she developed cytomegalovirus a common infection in transplant patients resulting from a suppressed immune system. It was not
until two and a half years after contracting CMV and dropping to about 95 lbs. that she was properly diagnosed. Right before her diagnosis she told the doctor that she was sure she would die soon, so he better figure out what was wrong. All these issues were told to me within a quick 20-minute time span.

However, Sophia did not consider any of these serious events as a part of her chronic pain narrative. Instead, these are merely health issues she previously battled. She now seeks medication and relief from her primary issues: chronic hip and neck pain. The hip pain stems from a previous break, and the neck pain is something she has dealt with for years and does not really know how or why it began. She brushed off the previous illnesses and surgeries as simply things she went through, focusing on her current situation. She notified me that if her hip started “acting up” [she] would need to go back to her apartment to rest. I asked how she would describe her pain, and she explained that it was worse than childbirth, which she experienced twice. The only word that embodies her daily pain is “horrible,” she told me.

After showing me pictures of her children and grandkids, she said matter-of-factly, “They think I’m an addict,” I asked what she meant exactly, to elaborate. Prescribed hydrocodone after her hip surgery, she lamented that after 3 months her orthopedic surgeon referred her to a pain clinic because he couldn’t continue to legally prescribe her more pain medication. Because Sophia had built up a tolerance to hydrocodone, the pain clinic prescribed her fentanyl patches. She wears the patch 24 hours a day on her chest, and it releases pain medication every hour or so. “I don’t get a high from the pain meds. I need them. My doctor says I’m not addicted because I’m in pain, and they help me function. Well, I am 75 years old! I guess if people want to think I’m an addict….sure I’m an addict! Who cares, I’ve dealt with this pain every day.”
After this statement, I immediately asked questions surrounding her faith and coping. One of the first things she said to me upon our introduction was that she is a Christian and attends Sunday church. I wondered how (and if) her use of painkillers and faith worked together.

She told me that she goes to church sometimes and when someone drives her, but at this point she does whatever it takes to function. The focus is more so on functioning. For now the painkillers help her best with this because the church is difficult to get physically to every Sunday. At the moment Sophia’s faith does not give her immediate relief from the pain, it just gives her hope. However, she told me that she does pray every day and believes that prayer eventually works in most situations. Sophia does not just pray to cope better she said, “I pray to be healed, my family comes first, then faith, then medicine.” When I ask what helped with the pain most she said the medicine. Prayer is something she has always believed in but knows that her medication has proven to help alleviate the pain. Sophia has attended the same church for many years and feels like the Lord understands why she stays home when she does. For her, the church is the institution and prayer, which can be done anywhere, is what heals/cures.

As we got ready to head back to the car, after ending on a rather heavy note, I noticed a bookstore I had passed before. Sophia saw me eyeing it and suggested we walk in after she assured me that her pain was low, and she would enjoy looking at some of the books as well. I picked up a book with medical images on the cover and commented to the cashier that it looked like a good read. Oddly enough, a book signing for that book was going to take place in a few minutes. Sophia seemed excited by the news and insisted we stay; she had never been to a book-signing event, and honestly I had not either. We waited for the author and Sophia moved in her seat uncomfortably. I asked if we need to leave, and she said that we could stay maybe part of the time. The chairs were hard and she did not think sitting for a long period would be comfortable or good for her pain. I agreed and told her just to elbow me whenever she was ready...
to leave. Neither of us had read the author’s book, and we seemed to be the only people in the room who were neither his personal friends nor family. The author is a respected doctor who contracted Lyme disease at the peak of his career. He suffered from unexplained symptoms for years because doctors claimed his Lyme disease test was inconclusive. Without a definitive answer to the Lyme test the doctors would not treat his Lyme symptoms. Her eyes got bigger as he continued to speak and read chapters from his book. He got to one point about having a heart transplant, and she nudged me. I asked if we needed to head out, and she said, “No, I want to stay, I know him.”

Sophia asked me to grab a few copies of his book and refused to leave early. With her walker, she moved faster than I had seen her move all day, winding up first in line to get her books signed. She asked him if he remembered her. He did. They met many years ago in a waiting room when both were undergoing heart transplants. She told me later that this man was not just a doctor or a patient she knew, but someone who helped her get through her transplant and pain from his kind words spoken in that waiting room. She carried her books back to the car and raved about how coincidental the book signing was. As she situated herself in my car, she said, “Now that is how I know that the Lord is here, and that miracles can happen. That is the Lord working.”

Her excitement was impossible to ignore, and she began to talk about her doctors. She told me that her orthopedic surgeon and occupational therapist were great. When I asked what qualifies as a good doctor, she told me that they care. “Some doctors I had were good, they were just good people. They want you to get better they care for you. My certified nursing assistants [CNA’s], they were awful… so bad. Rehab was terrible. I had to get out of there; they just didn’t want to deal with all my problems. I couldn’t walk, and they would hand me my own
bedpan. I never want to go back. They ignored me. Some of my doctors acted almost just as bad.”

As we walked up to her complex, she told me about a woman she wanted to befriend. She said she wished she could be like her; she has lived there for 19 years and always is so well put-together. Sophia told me, “her makeup, hair, and outfit are always perfect. I wish I felt good enough to get dressed up each day like that.” I asked if she has introduced herself and she said “Oh, multiple times. She doesn’t have friends, doesn’t talk to anyone. I’ve tried, but I want to be friends with her, so I’ll keep trying. I’ve made some friends here and it’s just not normal to not talk to people.” I sat in my car and before riding away I thought back to the book signing. She introduced me to the author as her friend…not as someone interviewing her, or a friend of a friend, but her friend. Even though she was doing me a favor by answering my personal questions, she behaved as if we were old friends, caring more about making me laugh and smile throughout the day. Sophia did more than answer questions as honestly as possible about her life and pain; she allowed me to gain a new friend.

**Laughter, Jokes, and Pain Tolerance**

Sophia laughed while she poked fun at her heavy medication use, pain, and surgeries throughout our entire visit together. Anthropologists have documented in various cultural contexts that humor is often used in situations that are uncomfortable, sad, or negative. To understand why joking about serious matters seems common, it is important to examine cultural perceptions in America surrounding social patterns and responses to pain.

Anthropologist Radcliffe-Brown first analyzed joking within African tribal societies in the 1940’s. He found that one could detect what is important about a society’s rights, obligations, roles, and statuses by analyzing who jokes with who, when someone jokes, and so
forth (Radcliffe-Brown 2008:197). What one jokes about ultimately tell us about a society and their expected norms. These norms are clarified by philosopher Immanuel Kant, who notes that in Western societies there is a perceived appropriate response to situations that make one feel sad, angry, or pained (2012:122). Kant observes that the act of laughter, joking, and having a pleasant expression when something is disturbing is better and more acceptable than to show repulsion, tears, or anger (2012:122). Others understand a controlled laughter within a particular group or society that the individual does not in fact find the situation funny but is giving a “socially acceptable” response. This can be attached to understanding the transparent correlation between joking and pain in America (Kant 2012:122). When Sophia joked about her pain and laughed off her near-death experiences, her reaction exemplifies that joking in regards to pain and fear is a patterned activity, which reflect a positive outlook. This highlights characteristics that are valued among her social peers: positivity, jocularity, and optimism.

But, laughter and joking serve a larger purpose than simply adhering to norms, a physiological purpose especially beneficial for those in pain. There are two types of laughter: a controlled and intentional laughter (Duchenne), and a spontaneous, uncontrollable, and contagious laughter (non-Duchenne) (Dunbar 2012). Sophia laughed throughout the day in a genuine and spontaneous way that left her short of breath at times- experiencing non-Duchenne laughter. A study analyzing social laughter and pain thresholds found that non-Duchenne laughter elicits a positive biological response (Dunbar 2012). A physiological response to release endorphins triggered by the “long series of exhalations” during laughter, help to reduce stress and increase an individual’s pain threshold (Dunbar 2012:4). Laughter plays a large role in helping Sophia to cope and tolerate her pain. She benefits from a natural laughter that stems from her “joking nature” demonstrated by when she exclaims while cackling, “ride on cowgirl.”
Because of her age, joint issues, and hip injury she is unable to participate in moderate exercise, making her ability to laugh freely with others an important component in tolerating her pain. Exercising in a social setting has similar effects to genuine laughter— it is a social bonding and endorphin-releasing experience. Studies show that sports or physical activity in a social setting can increase pain tolerance. The University of Oxford, in a study analyzing a team of rowers, found that when the rowers worked out together their pain threshold doubled in comparison to when they worked out alone (*Pulling Together Increase Your Pain Threshold* 2009). Laughter, like working out in a group, is social because it can be contagious in experience⁵. I found myself cracking up with Sophia throughout the day proving that some norms, while bringing understanding to a society’s social structure, can also be physically beneficially, especially for individuals living in chronic pain.

**What Would Jesus Do**

When Sophia said, “It’s better I laugh than cry” her perception in how to best respond to pain parallels a contemporary Christian description of “Christ-like” suffering. After speaking with Christian leaders in the surrounding North Carolina area and reading current Christian literature, I found that a perceived “positive” or “Christ-like” response to pain and suffering is a dominant ideal. This response includes laughter, smiling, joking, and not discussing the pain too much. In other words, the goal is to suffer quietly and happily— to focus outward not inward.

But, is this the way Christ would suffer? Perceptions of pain response, even in regards to biblical context, are culturally constructed (Free 2002:143). The *New International Version of*...

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⁵ *In The Anthropology of Empathy: Experiencing the Lives of Others in Pacific Societies*, anthropologists Douglas Hollan and Jason Throop discuss that smiling is sometimes described in association with laughter and happiness. This “[includes] the beliefs that laughter is contagious and that one cannot laugh without becoming happy” (2011:164).
the Bible [NIV] does not describe Christ as stoic, unemotional, or jocular. One of the most memorable and emotional biblical quotes in the New Testament is when Jesus cries out before he experiences suffering and pain on the cross, “My God, My God, why have you forsaken me?” (Matthew 27:46). The depiction of what most modern Christians perceive as Christ-like suffering ignores the impassioned quality that the bible depicts of Jesus wailing, crying out to his father, and reacting with passion not poise while in pain. This may be partly because we have moved from a medieval imagery of Christ that depicts him bleeding, suffering, and in agony to images of a clean and reserved Christ (silently suffering on the cross). The images below reflect the drastic change in Christian imagery from the early medieval era to current and common Christian depictions of Christ. These images and a current regard for Christ-like suffering as reserved and optimistic prove that our understandings and perception of Christ change as a reflection of cultural norms, especially in regards to suffering and responding to pain.

Broadly speaking, Christ-like suffering demonstrates how religion can “sets guidelines for acceptable behavior” (Haviland 2011:332). Sometimes cultural constructions of appropriate behavior can benefit the individual, but this depends on other factors like how rigid these
guidelines are adhered to. In Sophia’s case, it seems that the contemporary Christian interpretation of Christ-like suffering helps her to cope, and in turn makes her a joy to be around. I left our meeting in a great mood, smiling and thinking about how inspiring her attitude is in regards to her pain. Anthropologists have found healing to be more successful in individuals whose “therapeutic process was characterized by an initially positive disposition” (Good et al. 2010:103). This disposition is reflected in what contemporary Christian literature claims as Christ-like suffering. This proves that behavioral guidelines can at times reap therapeutic benefits, such as in Sophia’s case, who focuses on the small joys in life that help her to create meaning despite her pain.

Morality, Power, and Care

Sophia talks about the medical providers who were caring, professional, compassionate, and treated her with respect. She also discusses those who treated her poorly and avoided helping her, like handing her a bedpan. I aim to discuss the poor treatment and care Sophia received as a component of issues concerning power. This analysis does not attempt to provide reasoning, understanding, or compassion for the biomedical providers who did not treat Sophia as a deserving human being. Rather, I will highlight how decisions within healthcare, like who deserves treatment, are a part of a power relationship that emphasize social inequalities.

Bioethics, which emerged as a field 1970’s, focuses on biomedical morality and acting in the patient’s best interest (Muller 1994:449). The premise of bioethics has good intentions, aiming for humane care. However, the actual decisions surrounding morality and whether or not the decisions benefit the patient are deeply subjective. In particular, moral dilemmas surrounding care and quality of care can develop into a power struggle, exemplifying the role that social factors play in the decisions made surrounding the worth of a person’s life. These
factors include things like age, race, socioeconomic status, wealth, gender, and religion (Muller 1994:451-2). Ultimately all lives are not equal in biomedicine. The harsh reality of this statement is demonstrated in how a medical provider allocates their time amongst patients, the care a patient receives, and ultimately the degree of choice that a patient is given in regards to their treatment. The doctor aims to remain unbiased, but the decision-making process is unavoidably subjective and reflects judgments made surrounding morality, like who deserves care and to what degree (Muller 1994)?

In her article on embodiment and transcendence, medical anthropologist Carolyn Rouse explores moral decisions surrounding life, death, and medical care (2004). A family fights to maintain their power and parenting duties over their sick infant Jasperlynn. The parents are former drug addicts, poor, and lack formal education, but have a strong sense of responsibility to family and love for their children. The doctors tell the parents that Jasperlynn is a vegetable and is dying, in an attempt to get the family to sign a do not resuscitate order. Who control’s Jasperlynn’s life is ultimately called into question: the parents or the doctor? Had the parents been wealthier, had formal education, and not relied on government assistance for their daughter’s medical care, the doctors may have been more inclined to follow the family’s wishes. Ultimately the doctor’s decision, in this case, and so many others are influenced by judgments made surrounding a patient’s (or, in this case the family of the patient’s) morality. Jasperlynn’s story, although one surrounding life and death, ultimately demonstrate how social factors can and do influence the care and degree of care a person receives within a health care setting.

Sophia at times clearly did not receive the care and attention she needed from her medical providers. At one point when Sophia was very ill and weighed only 95 lbs., she told her doctor that if he did not figure out what was wrong with her she would die. She felt like her provider was not taking her critical medical state seriously. Perhaps her doctor and nurses made
judgments on the amount of care and quality of care she received from them based on her age, status of wealth, behavior, and/or judgments surrounding her prescription drug use. For whatever reason, her medical providers made a decision to avoid her at times and/or not to take her seriously when she asked for medical help. Some may argue that this could be a result of time constraints, not enough doctors, and too many patients. While this could be true, it is the social factors and judgments concerning morality that greatly affects who receives more attention and ultimately who is worthy of that attention (Muller 1994).

Sophia’s prescription drug use could serve as a reason that her doctor did not take her case as seriously and the nurses ignored her. They may have made judgments concerning her morality and the type of care she deserved based on her drug use, even though her drugs were prescribed and legal. In the article “Is there any way that I can get something for my pain?” Patient strategies for requesting analgesics, Buchbinder examines how back pain patients ask for pain medication over an 8-month study (2015). She finds that a majority of pain patients are not drug seekers asking their doctors for scripts to achieve a “high,” contrary to what the public may assume (Buchbinder et al. 2015). Sophia’s family thought that she was addicted to drugs, leading me to speculate that her medical providers might have thought something similar. This could cause her providers to question her pain’s legitimacy and her own morality, which ultimately could have resulted in or perpetuated the poor medical care and attention she received.
Chapter 4: Illness Narrative #2
Abigail- An Altruistic Spirit

Abigail did not show up to class much and when she did she would pull our professor to the side after the lecture to sheepishly apologize for her many absences. I overheard a few excuses and noticed that she seemed to be sick more often than not, but never brought in a doctor’s note. We barely exchanged a hello in class, so I was surprised when after the semester ended, she contacted me interested in discussing her chronic pain for my research.

We met at a mutually favorite dinner spot between our homes. Walking in she smiled and said, “Today is a good day. I feel good.” Abigail is a 26-year-old African American female and recent UNC graduate. People know Abigail as a disciplined student, hard worker, and Christian women’s group leader (Life Group). But, what many do not know about Abigail is that she has suffered from chronic pain since elementary school.

Abigail’s pain began with a sharp knee pain in fifth grade while running on the playground. Her doctors thought that she was behaving dramatically, and the pain would subside with time. But the knee pain continued for about two years in conjunction with increasing chronic fatigue, muscle aches, and depression. The knee pain turned out to be a torn meniscus; but even after it healed Abigail continued to experience body-encompassing pain. Over a course of two years, doctors tested her for numerous diseases like lupus and cancer before diagnosing her with fibromyalgia after a simple trigger point test. By the diagnosis, she had lost faith in finding something that the doctors could “fix” because each test was just another letdown. Her cheeks became flushed as she described her doctor’s elation after determining that she had fibromyalgia. Abigail was frustrated because the doctor seemed excited that he had given her pain a name, but no way to manage or alleviate it. He recommended a high dosage of daily ibuprofen and for her to see a psychiatrist. The therapist gave her tools to deal with her emotions.
but did not alleviate the pain. The ibuprofen created a larger problem, painful stomach ulcers, that now amount to the worst of her current symptoms.

With no relief, Abigal began to lose hope in the doctor’s ability to cure her. She decided that the pain was not going anywhere so she would have to learn to deal with it herself. At first she tried to ignore the pain, but that only seemed to make it worse. She would lie to her doctors about its severity when asked to rate her pain on a 1-10 scale. Abigal said, “I was careful answering questions like when I had to rate my pain. If I went to the doctor with something like a cold and then told them other symptoms, we would go down the rabbit hole.”

The consistent knee pain, muscle aches, and fatigue kept her homebound for most of middle school. This caused stress on her parents, who had to alter their schedules to make sure she could be watched and tended to during their work hours. They said that during this time (middle school) her demeanor changed and that she acted “evil” and angry. Abigal argued that she was not evil, but simply frustrated and trying to deal with feeling horrible.

What did help Abigal quite a bit was a nearby biofeedback center. She learned “medical mindfulness,” a technique used to quiet her mind and relax. Being aware and centered helped Abigal to deal with the anxiety, pain, and flood of emotions better. It taught her to stop the constant flow of information and thinking so she could relax more, especially at nighttime, to get sleep. Despite a decline in faith in her doctors, she still tried whatever they suggested. Abigal went to physical therapy, sports therapy, and water aerobics. Even though she didn’t trust her doctors, she was still willing to try anything to feel better.

During this period, Abigal and her family attended a non-denominational Christian church. She said the congregation prayed for her and her pain, but they did not really understand what she was going through. It made her feel like an outcast and the church members treated her different, causing her to behave somewhat defiantly. She said, “They didn’t understand what I
was going through with my pain. Also- I’m a black female, and I started developing curves at the same time as my pain developed. I was compared to other girls my age who were white. I was scrutinized because of my body shape and my attitude stemming from the pain. The church was very strict in how I was supposed to behave, look, and dress….it made me anxious.” Abigail was asked to leave her church’s congregation in 8th grade, due to her defiant and moody behavior. She said there was nothing in particular that she did wrong, but that her attitude was not upbeat or positive that they (members of the church) expected from her. She was allowed back into the church about a month after being asked to leave. But what followed were “years of judgment” until she and her family left the church permanently about 3 years ago.

When Abigail left the church, she was able to experience freedom for the first time. She was free from the constant criticism and could express her own thoughts and opinions. This freedom included “partying” with new friends, drinking to get drunk, and using cocaine regularly. She said, “I was free from the church, and I had tried everything legal to get rid of the pain. When I was partying and high, I didn’t hurt….I wasn’t tired; I felt good.” Abigail explained that the drugs gave her an escape from the pain, but in the midst of her partying and self-medicating her freshman year she was raped on campus. She locked eyes with me and said quietly, “After the rape I looked back at my life and was like, wow, why me? I was smart; I had everything going for this and now me? But, I can’t focus on why I have the pain or these things have happened. To get through my pain now it’s different. I tell myself I survived this, I’m alive, I can get through anything.” Part of her survival she credits to her renewed faith in God and the support of a new church. Abigail said that the rape brought her back to God, and now she is in a much better place spiritually.

Her new church friends are supportive of her but do not know about the chronic pain. She told me, “my church friends don’t know about my chronic pain. I think that goes back to my
parents being frustrated whenever I would say something hurt. They would say something like—Oh what doesn’t hurt? I felt like a problem child, and I still have so many issues that I try to think of my pain as the least of them. I don’t want people’s fake sympathy; I know they get sick of hearing that I don’t feel well.” Instead, Abigail focuses on discussing maintaining her sexual purity and helping others with their problems within her life group. She now tries to accept her pain and cope with it rather than to fight it.

I asked what role prayer has in Abigail’s life and with her chronic pain. Apprehensively she said, “Prayer is huge, but I have yet to recognize its potential. I rely on myself more.” Instead, she moved the discussion to talk about her future plans to become a patient advocate for those who experience illness. She hopes to give others faith and hope in something or someone, something she lacked in her own life. Abigail does not want others to feel alone or unheard when they speak to their doctors. I asked her what exactly keeps her going. She smiled and said, “Hope. Hope that I can make a difference and help someone not have to experience what I did.” I am not quite sure if she was referring to her experience with the doctors, church, drugs, the rape, or everything, but Abigail looks outward now. She no longer focuses on battling her inner demons or talking about them but focuses on helping others with their journey with pain. I hurt for Abigail when I left our dinner. I knew I could not offer her any words that would change all the pain and suffering she had already experienced in only 26 years, but I could listen to her. And maybe through listening I could help Abigail to feel heard and less alone.

**Linear Narratives and Hazy Details**

Like the pain narratives analyzed by other anthropologists, Abigail’s chronic pain narrative began with an account of pain that is acute (her torn meniscus) (Good et al. 1992:32). She could remember when the pain began, but how it progressed exactly, and the details
following her acute pain seemed hazy. In place of a defined chronology, she focused on details and specific moments within her pain experience that do not necessarily follow a clear timeline. “Time is an issue with those who suffer from chronic pain, because although they may be able to describe painful episodes in clear detail, the chronology and order becomes blurred” (Good et al. 1992:41). In The Concept of Emplotment, anthropologist Cheryl Mattingly explains that chronic suffering and illness generate a narrative loss; and the drama of the narrative is based on suffering (1994). Abigal did not focus on the succession of painful events, or attempt to formulate her illness narrative as linear. Instead, she focused on the drama surrounding her suffering and specific life events that she felt were important to her suffering and pain-like being kicked out of church and her drug abuse. In the United States, things are discussed in a linear fashion: time, events, history, evolution- moving in an efficient unilinear trajectory. Although Abigail’s narrative provides clear details of her painful episodes, a timeline like Abigail’s, that is non-linear in nature, can cause problems in understanding for biomedical providers and others listening, who may expect a timeline that follows a chronological sequence.

Censoring Language

Abigail is apprehensive to discuss her pain with her family, friends, and church members. She is careful to censor her words because “doubt is associated with the pain and the wounded” (Scarry 1985:201). When Abigail’s parents say comments like “what doesn’t hurt?” they imply skepticism of her suffering and infer that her pain is an attention-seeking tool. Comments implying doubt of pain can “amplify suffering” according to Scarry (1985:7).

Doubt plays a role in amplifying Abigail’s suffering because “pain can’t be measured technically, so it has a lot to do with perception and someone’s individual reality” (Good et al. 1992:2). But Abigail’s narrative contests Scarry’s assertion that chronic pain destroys language
Instead, chronic pain causes Abigail and other chronic pain patients I spoke with to censor their language, due to implications of doubt and stigma, and this is further compounded for patients with chronic pain lacking a definitive etiology. Although, destroying and censoring language are both methods of language suppression, their implications are very different. Destroying language means that a person is unable to explain their feelings, thoughts, and experiences. Ultimately, the destruction of language leaves a person unable to communicate in a cogent manner. Censoring language means that a person does not lack the ability to communicate certain thoughts but makes a conscious decision to withhold particular details and information. Censoring language is different from the destruction of language because it is still cultural, social in nature. It involves reading social relationships, expectations, and ideas of morality and adjusting language in relationship to these things. Chronic pain patients do not lack the words to explain how they feel or to describe their pain, in fact, many develop an extensive vocabulary used to describe pain for others to understand with sensory words like pounding, throbbing, and burning. Patients censor their language in relation to context and social cues. Having the ability to read facial expressions and to hear undertones of skepticism allow a person to decide what to say, when to say it, and who to say it to to maintain legitimacy, morality, and to avoid stigma.

Anthropologist Jean Jackson in her late-career work on chronic pain briefly points out that chronic pain lacking definitive etiology can be extremely stigmatizing because it appears as a period of ambiguity, “lying between mind and body threatening Cartesian Dualism in a period of liminality” (2005:333). Anthropologist Victor Turner describes the liminal period as a period of anti-structure, where normal rules are temporarily thrown aside, and the status of an individual is ambiguous (1967:94). During this phase, those undergoing the transition find themselves between statuses; in essence, the subject is transitioning from an old role/status to a new one, so
he/she lacks identity during this period of liminality (Turner 1967:98). Abigal’s chronic pain and depression lie in between the mind and body in ambiguity according to her doctors and even her church members. This ambiguity causes people to question her pain’s legitimacy because it is not something that “can be seen or touched so we either observe it or are told about” (Good et al. 1992:139). Depression is thought to be a product of the mind/spirit, but Abigal also suffers from physical pain (fibromyalgia), which lacks a “certain ontological status [provoking a stigmatizing reaction] from others” (Jackson 2005:333). Fibromyalgia lacks this status because it can not be proven in theory to exist. It lacks matter and, therefore, is not a state of being. Unfortunately, there is still a prevailing assumption that if a person’s pain does not have an understood biological condition then it must be psychological, which places the responsibility and blame on the individual for their pain and suffering (Good et al. 1992:143-59).

**Local World and Experience of Pain**

Central to Abigail’s experience of chronic pain is the church (her local world) (Good et al. 1992:173). Abigal mentioned the rules and expectations that her former church had in regards to her attitude, what she wore, and even how her body looked. The rigidness and expectations, especially surrounding her body, enhanced (if not created) her stress. The acute pain first started when her body began to mature and when she first noticed her curves, distinguishing herself apart from the predominately white pre-teen church girls. Abigal felt controlled by her church and unable to think on her own in terms of how she should behave, dress, act, look or feel.

These are components of social control, which is based on the ability to socially control and manage large groups of people under an umbrella of power and knowledge channeled through an institution like “academia, medical, juridical discipline” or church
The concept of managing large groups parallels to the biblical metaphor of a shepherd managing his flock of sheep. The church (or the “shepherd”) can behave as a structure of bio-power “that aims to control the actions and reactions of individuals” as a form of behavioral control (Foucault 1998:137). Abigail was kicked out of the congregation because the church could not control her. Her deviation from the expected norms posed a threat to lead other members “astray” and to harm the power structure in place that aims to maintain discipline.

**Mind, Body, and Emotion**

Abigail’s religion shaped how she, the church members, and her family experience and respond to pain (Good et al. 1992:30). To better understand how Christianity shapes these responses I spoke with different religious leaders and attended local churches to see if there was any literature in the lobbies on chronic pain. I purchased a small book (or more so a pamphlet) sold at the front of quite a few N.C. Christian churches, advertised as a Christ-like coping manual for Christians who experience and suffer from chronic pain. Written by a medical physician and Christian counselor, the author explains that there is a godly and sinful way to respond to pain, and this is why “suffering is largely spiritual” (Emlet 2010:7-8). Scarry states that pain is historically rooted in the biblical context of punishment (1985:16). This hints at the idea that pain is the result of spiritual perversion, and that the individual in chronic pain is at fault or is to blame. Foucault in his book *Discipline and Punishment* discusses how pain can be perceived as reflective of an individual’s morality and spirituality (1985). This insinuates that illness can be seen as a form of punishment. He discusses that in earlier times hangings and executions were public so that spectators could come and watch, as well as to detour people from having a similar offense (Foucault 1985:57-8). Foucault describes the body historically as the foci of punishment, and this idea carries over into an individual’s health as a result of a person’s
morality or immorality (1985). However, “chronic pain has shifted from a religious understanding of suffering to a more biomedical and technical understanding” (Good et al. 1992:13).

In contemporary times, medical institutions can serve as a system of justice to legitimize an individual’s suffering by naming the illness and explaining the cause as biological. But in Abigal’s case, the church seemed to serve as the primary system of justice when her pain lacked definitive etiology and targeted in question her own morality and pain’s legitimacy (Buchbinder 2009:117). Anthropologist Joralemon states that we have “culturally derived prejudices” in our notions of disease and illness (2006:4). I argue that there are also strong culturally derived prejudices against the chronically ill, and even more so against those who cannot pinpoint an etiology. These culturally derived prejudices affect the illness experience and treatment, causing chronic illnesses to be attributed to a spiritual issue and one of self-blame when biomedicine fails to establish a cause or a cure. Chronic pain patients feeling these prejudices, learn to “tell stories that their therapists want to hear” and to censor their list of symptoms (Buchbinder 2009:110). Abigal attempted to behave in a way consistent of her expected performance role (of someone in good health) at her church. She felt prejudices against her body shape and race, so she altered the way she dressed to avoid judgment, but struggled to hide her emotions and was persecuted for this, (kicked out from the church for behaving rebelliously). Clifford Geertz says that emotions bridge the mind and body, however, this pamphlet and Abigal’s church expected her to behave using a Cartesian dualistic blueprint- to do the impossible and separate her mind and body in suffering, even at such a young age (Schepfer-Hughes and Lock 1987:12). Abigal could not separate the two because she suffers from physical and mental pain (depression).

Medical Anthropologist Jason Throop eloquently describes “physical and psychic pain as poles along a continuum of possibilities” that is influenced by things like culture, religion,
family, or an individual’s local world (2010:7). Pain is “a form of communication” regardless of how it presents itself and it is nearly impossible to understand Abigail’s depression as separate of her body aches, fatigue, and muscle pain. Just as the mind and body work in conjunction, chronic pain and depression “are a cyclical issue- chronic pain can cause depression, which can make the pain worst, so you must treat both” (Rudy 1998:129-40). But, to try and separate the two can lead to what Freud calls “a war with one’s self” and in Abigail’s case drug and alcohol abuse (Schep-er-Hughes and Lock 1987:11).

**Coping: Drugs and Hope**

Coping with chronic pain is difficult because it doesn’t always encompass one particular area; it typically radiates or affects multiple areas or is body encompassing (Good et al. 1992:39-42). To deal with multiple sites of pain Abigail underwent therapy, sports physical therapy, water therapy, and later mindfulness exercises. Abigail mentioned that despite her loss of trust and frustration towards biomedicine’s inability to provide her with something to alleviate her chronic pain she still followed all her doctor’s recommendations. Abigail continued to seek treatment because she has hope to get better. Hope occurs when chronic pain patients feel that their pain is not something they have made up, but something that can be cured (Schep-er- Hughes and Lock 1987:44). This frame of mind is essential to healing and proves that: the mind and body are not exclusive of each other or militantly mechanistic, but are organically intertwined and reflective of one another (Schep-er-Hughes and Lock 1987:29).

After separating from her church, Abigail turned to cocaine and alcohol as a form of coping. Historically, cocaine is rooted in medical use, and its medical form (cocaine hydrochloride) derives from the organic product coca (Quintero and Nichter 2011: 348). However, culturally it is constructed to imply immorality and Abigail’s shift to heavy drug use
and alcohol after years of dealing with chronic pain provide evidence of Wachholz and Lynn’s assertion that “pain can challenge your belief system” (2010:7). Abigail was ready to try anything to get relief from her chronic pain even if it was considered illegal, immoral, and dangerous. Chronic pain sufferers like Abigail are more inclined to turn to substances like cocaine to deal with fatigue and pain as a coping mechanism (Wachholz and Lynn 2010:6). When the doctor’s suggestions and prayer didn’t provide relief from pain Abigail self-medicated. As a new college student and having fibromyalgia she was constantly exhausted and the cocaine not only helped to wake her up but while she was high she didn’t feel depressed and behaved more social (Quintero and Nichter 2011:341). Anthropologists Quintero and Nichter found “boredom as a primary drug use for an over-stimulated society,” but Abigail used drugs and alcohol in an effort to keep up with society because she lacked the energy that most of her peers had without substances (2011:342). Not only did the cocaine and alcohol provide Abigail with a temporary coping mechanism for her depression and physical pain but, allowed her to keep with the college “cultural norms, value and expectations” in a generation where drugs are apart of building social bonds (Quintero and Nichter 2011:343-50).

After Abigail was raped, she experienced a low that biomedicine and drug/substance use could not alleviate. She turned back to her faith and religion, but this time focused on turning outward for healing. Healing is a sign of God, and although Abigail has yet to experience relief of pain from prayer, religion allows her to maintain hope for healing (Scarry 1985:213). What differs from Abigail’s first experience with church, religion, and God is essentially the type of God she now believes in and worships. A vengeful and iron-fisted God can intensify pain while a loving, forgiving, and merciful god, can mollify the experience of pain or increase tolerance (Wachholz and Lynn 2011:11). Although, it is the underlying theme of hope, which helps Abigail to cope it is her role leading Life Group, practicing mindfulness, and pursuit to become a
patient advocate that help her to best cope with physical pain and depression. Her new life group and future goals encompass “compassion, [demonstrates] altruism, and is task focused” which enhances her ability to better cope with her pain, alleviates anxiety, and to have happier/positive emotions (Wachholz and Lynn 2014:130). These are all biblical principles, but they are also principles of humanity, Buddhism, and other belief systems that foster humility. Thus, it is not necessarily religion, prayer, or therapy that help Abigail deal with her chronic pain and depression, but the results of a positive psychology approach that look outward instead of inward through communal like support (Wachholz and Lynn 2014:129).
Chapter 5: Illness Narrative #3  
Maria- Looking Forward

Maria, a college student, struggles with chronic pain and the symptoms, which range from severe vomiting to her fingers turning blue can become frightening. We have been friends for about two years so when I contacted her about this study she was happy to share her chronic pain narrative with me.

Maria remembered being a healthy child until about the fourth grade when she started experiencing stomach cramps, headaches, and nausea almost daily. Two years prior to these symptoms, her father committed suicide; she described this time (second and third grade) as somewhat of a blur. I asked if she spoke with a therapist and how she coped with the tragedy as a young child. Maria told me, “Mom attributed my stomach issues and the headaches to a poor diet and stress as a result of my father’s death. I didn’t have a therapist, and I don’t think my mom could totally deal with it, so I was left to pick up the pieces. I didn’t understand the gravity of the situation and the full details of what happened up until a few short years ago.”

In middle school, Maria’s elementary friends turned into her bullies. She said, “I think the girls were somewhat jealous because of the attention I received from my teachers… because of what happened with my dad, and because I did really well in school. They also picked on me because of my height and called me a lesbian because I wasn’t a girly girl.” During middle school Maria gained weight, became aware of her mother’s financial struggles, and started to fully grasp exactly how her father had committed suicide. She tried seeing a therapist with her mother, because they fought a lot, and it was around this time period that her mother was diagnosed with bipolar disorder. Maria described her mother as someone lacking mental stability, combative, and on an emotional rollercoaster. But, at the same time as someone who
did the best she could to make sure that Maria knew she was loved, received an excellent education, and had her immediate needs provided for.

Maria was the first student to receive a full financial scholarship at her private high school. The classes were small, and most of the students had attended school together since their early elementary years. Despite being the new student, Maria was not bullied, excelled academically, and became the student body president. Maria told me that she truly enjoys school and academia in general. She did recall being jokingly called “white trash” behind her back from the wealthier students but brushed it off since these were the same students who felt she was capable of excelling as student body president and voted for her. Freshman year in high school Maria first experienced her current chronic pain issues. “It started with backaches, bizarre symptoms, and daily stomach pains. My teachers asked me if I was depressed. I would tell them that I loved being at school and had friends. Everyone thought I was depressed because I missed a lot of school, but I didn’t want to miss class. I constantly had colds, pounding headaches, and stomach pain so bad some days I couldn’t get to class. My body felt tired….constantly exhausted.”

Sophomore year things became worse for Maria. She developed a scaly, itchy, and painful elbow patch breakout that the doctors diagnosed as eczema. Maria wore a sling for several months because of the painful outbreaks that caused her skin to break, used steroids, and tried different eczema creams. After nothing worked a dermatologist haphazardly remarked that it could be a result of Celiac disease. “I didn’t have enough money to get the testing at the time for Celiac. I stopped eating gluten and within a short time it went away, and I felt better on a gluten free diet. I didn’t have stomach pains again until about senior year, but I think that was the stress of college applications and me becoming laxer with my diet.”
Maria’s freshman year of college she experienced reoccurring throat infections and had to get her tonsils removed. The antibiotics from the tonsillectomy wiped out her “good” bacteria resulting in *C. difficile* (a bacterial infection), which created symptoms of cramps and diarrhea to the point she was passing tissue. After two rounds of antibiotics for *C. difficile* Maria experienced relief from severe diarrhea, but was about 25 lbs. lighter. After the drastic weight loss, she battled an eating disorder and at about the same time she was diagnosed with Raynaud’s disease. Raynaud’s disease causes numbness in the extremities and is affected by cold temperatures as well as stress. I asked her what was going on personally at this time. “This all really took off in January- all my severe issues I am having with chronic pain, especially with Raynaud’s. I learned around December a lot about my dad and family that was pretty shocking. My dad apparently cheated on my mom before his death and did other stuff that made me really hate him. I wasn’t sleeping, my Raynaud’s became progressively worse, and my stress increased thinking about all of this. I didn’t have a car to get off campus or enough money to go to find real help, so I went to campus health. They literally threw a few anti-depressants and sleep medication at me and kind of said good luck.” The anti-depressants made Maria groggy, and she would only really take them before family functions.

I asked Maria to explain her chronic pain with Raynaud’s in further detail, and she told me that basically ever since she was diagnosed she has experienced ongoing finger pain, joint pain, and knee pain. When she realized that her pain increased and continued after maintaining a gluten-free diet, she started to think that gluten may not be the culprit. She said, “I realized that not eating gluten didn’t help because I didn’t get the itchy eczema-like elbow reaction again or any skin reactions when I ate it. Looking back it makes perfect sense; it all correlates with my dad or school. I was making rash decisions. These were not terrible life decisions, but things I normally wouldn’t do, like dating a guy I barely knew. I think the guy I briefly dated impacted
my eating disorder because he constantly commented on me needing to be in the gym. It made me more insecure with my weight and body image.”

I asked Maria again if she sought out any new therapists and if she took any prescribed drugs. She explained to me that she did try to get in touch with therapists off campus and her mother actually helped her get to one and to pay for it. However, she felt the visits were not helpful because they focused on her attitude and relationship with her mother, so she stopped attending sessions after about the fourth visit. During these visits, Maria told her therapist that she cut her wrists regularly, and the therapist only seemed to sympathize with her problems, but did not give her solutions to handle or fix the issues. Maria told me that she made a conscious decision to stop cutting and moved to the Outer-Banks for a semester study program after she stopped. She attributes the new environment to bolstering her current emotional and physical health.

Christian born and raised she attends church on and off, citing resentment as a large issue with her struggle with faith and low church attendance. “My mom is constantly praying, she prays about everything. She is very religious, much more than me. Instead of praying for God to fix this I pray and ask God to make this less painful. I started reading the Bible more in the Outer-Banks to get back to my values. Religion was honestly the last decision for me. Pain made me question my religion. I started to think the same thing about religion, God, and doctors. If it could heal me or help me great, if not whatever.” Maria told me about one of her best friends, who is a pre-med student, and that even prior to being accepted to medical school, she has started to look at health in a methodical and cold manner. She apprehensively told me that it is difficult to find a great doctor because of the way they are taught to be. “They are taught to look at medical records, they never ask hey what’s going on in your life. I’ve had a few
bad experiences with doctors, and I think it’s a product of the systematic medical school they are molded in, they are taught to simply follow protocol.”

Maria is now a senior in college. She still experiences painful bouts with Raynaud’s, stomach cramps/pains, joint issues, and chronic fatigue. She is getting married this weekend to a man she met while in the Outer Banks who works in the Coast Guard. Since meeting Peter, Maria says that her trips to the doctor and hospital have reduced from about 10-20 trips a semester to 2 or 3. She feels more confident financially because they work together to pay bills and manage their finances collectively. She also feels better about her bouts with chronic pain and sickness, because Peter makes a point to let her know that through sickness or health he will be there. Initially, Maria worried that her fiancé and his family would not accept her because of her health issues and view her as a burden, but no longer is she worried about this.

Visibly in good spirits I asked her how she is currently coping with her pain- exactly what keeps her moving forward and able to handle it. She replied, “I’ve always pretended that when I get out of school it will end- whether or not that’s true I don’t know. It’s easier to push through when I tell myself only one more year. I also think I’m much happier with Peter in my life.” Maria also credits her re-newed faith as a way to cope, attributing her good days or days when she feels less pain to God and hard work in remaining optimistic. Maria told me, “I don’t think God wants us to hurt per se. I don’t think he gives you more than you can bear, so if he puts it on you (or me), it is because you can handle it and someone else couldn’t. I think my chronic pain and experiences, in general, have made me a stronger person although some days I would like God to ease up on me a bit.” Maria ended the conversation in good spirits. I could tell she was excited about her upcoming wedding and seemed optimistic about her future, health, and marriage.
A Social Approach to Healing

When Maria started dating Peter her health drastically improved. Her doctor visits decreased exponentially, and although she still experienced/experiences chronic pain she finds it easier to manage and her level of pain seems to be reducing. In *The Mindful Body* “social relativism” is how Japanese people understand and discuss the individual (Scheper-Hughes and Lock 1987:14). This is a holistic approach that views the body as interconnected and understands that social situations have a large impact on a person’s health and wellbeing (Scheper-Hughes and Lock 1987:21). At the beginning of her relationship with Peter, Maria worried that her health would be a burden. But, once she realized that her relationship with Peter was different than the tension that she felt with her doctors she was able to trust and to rely on him. Maria’s health improved as her social relations improved. Her reliance and trust in Peter exemplify that health is somewhat socially relevant and that when an individual is sick being dependent on others may provide health benefits (Scheper-Hughes and Lock 1987:15). Michael Jackson in his book *Myths, Histories, and Lives* discusses the importance in understanding suffering in terms of “we” instead of “I” (2010). He says that within Aborigine families, residing in Cape Town South Africa, when someone dies because of sorcery a life has to be given from the tribe. This translates into a “we” experience, because it allows people not to feel isolated, self-blame, or repressed when suffering, but is approached as a group (Jackson 2010:137-42).

Biomedicine focuses on suffering and health as an individualized experience that is medicalized- anxiety, stress, depression, aches and pains (Scheper-Hughes and Lock 1987:27). But, it ignores the social factors, such as Maria’s father’s suicide and her difficult relationship with her mother. Social factors can affect health because the body is “venerable to feelings and the world (or our local world) can be embodied” (Scheper-Hughes and Lock 1987:21-2). Maria’s pain began when she lost her father, and this cannot be brushed off as something
confined to a psychological state because she has visible physical symptoms. However, many of her symptoms are exacerbated and impacted by times of stress, such as her diagnosis of Raynaud’s and the intensity of pain experienced when she found out about her father’s infidelity. This exemplifies that pain is not confined to biology but extends to the social realm. Therefore, pain should be thought of as more than simply an individualized experience, but as something that is a communal experience (Good et al. 1992:9). When Maria went to speak to campus health, she was handed pills for her symptoms, without the psychiatrist asking details about her family history or feelings. This demonstrates how medicine fails to understand the social factors that are so important to understand the source of suffering and to mediate or alleviate it. The narrative surrounding Maria’s health is just as important as the actual health issues themselves. Her narrative provides insight into potential trigger sources and markers of life events where the pain or symptoms heightened. When Maria began experiencing her suffering as a “we” experience by relying on her significant other Peter, she found it easier to cope with her pain.

Control: From Self-Harm to Self-Control

Like Abigal and many other chronic pain sufferers, Maria was ready to try most anything to alleviate her pain, but instead of turning to drugs Maria explored self-harm. Elaine Scarry discusses in *The Body In Pain* that physical pain can serve to mollify or rid one of emotional pain because, when the body is experiencing physical pain the mind is “[wiped] clean and [the individual] is only thinking of that physical pain” (1985:34). After Maria’s father had committed suicide, she grappled with intense emotional pain, created by devastation and confusion. When Maria cut herself, she was able to quiet her mind and escape the emotional pain and thoughts for a brief period. Sometimes it is easier to deal with a tangible pain that you can see rather than an abstract pain (like devastation) that you can only describe.
In the 19th century, people who suffered mental distress would sometimes wish for a physical and tangible pain to avoid self-mutilation, and to “escape the maddening mind pain” (Scarry 1985:33). Understanding why Maria cut herself can be understood by Scarry’s explanation of trying to escape mental pain, but also by Anthropologist Rebecca Lester’s explanation of self-harm serving as a form of communication. Deliberate self-harm is common amongst female teenagers and young adults in the west (Lester 2012:724). Self-harm, such as in Maria’s case, should not be confused with attempting suicide. In fact, most individuals who self-harm, such as cutting, do not want to die. Instead, an individual may harm himself or herself in an attempt to alleviate emotional pain while communicating this pain to others (Lester 2012:724-5). Maria lacked an outlet for her emotional pain. She went to therapy only a few times, did not trust her doctors, and had a rocky relationship with her mother. Cutting became a brief outlet for Maria that allowed her “psychological pain to be transformed into physical pain, which can feel more concrete and time-limited, therefore, more manageable” (Lester 2012:725).

I argue that self-harm along with Maria’s eating disorder offered her control in addition to being a form of communication and making her pain feel more concrete. Religion, God, and medication did not offer Maria control over her pain or body. She inflicted physical pain by cutting her wrists and limiting her food intake because it allowed her the ability to have control over something that her body experienced. Medical Anthropologist Csordas explains that “control of one’s feelings, actions, thoughts, life course, health, occupations, [and] relationships is a pervasive theme in the North American cultural context of this healing system” (Csordas 1990:16).

Luckily, Maria stopped harming herself and sought control in a different form. Maria uses spiritual coping strategies now instead of self-harm that utilize optimism and high hope, which empower and allow her to take back control in a positive way (Wachholz and Lynn
Optimism or high hope is found in individuals who “actively problem solve. In addition, individuals who have high hope use more problem-focused strategies such as acceptance, reframing, and humor” (Wachholz and Lynn 2011:18-20). Maria has high hope that her pain will be better when she graduates, and this hope provides healing properties in addition to giving her control of her pain tolerance and stress level.

**Stress and Chronic Pain**

In her ethnography of child patients with chronic pain, Buchbinder interviews Allan, a 13-year-old suffering with chronic migraines, whose story reminded me of Maria’s complex health case (2009). Allan discusses with his doctor that he suffers from stress, takes antidepressants, that his mother suffers from health issues, and like Maria grapples with problems surrounding his father (Buchbinder 2009:114). Both of these cases cause problems when trying to treat through a biomedical approach, because biomedicine tends to ignore the role that social factors play in health and illness (Scheper-Hughes and Lock 1987:8). This is exemplified in the article *The Mindful Body* when a medical student is frustrated about a woman’s illness, after being asked to discuss the social dimensions affect a patient’s health. The medical student asks her professor, “What is the REAL underlying cause?” (Scheper-Hughes and Locke 1987:8). The underlying cause is not limited to biological etiology or one social dimension, making cases like Maria’s difficult to treat and fully understand because her emotional pain is a part of her suffering.

Wilkinson, in his book *The Impact Of Inequality*, briefly explains why the physical manifestations of stress are no quick fix. He points out that stress can come from early childhood experiences, such as in Allan’s case, like a parent abandoning a child. Stressors, especially those experienced early in life, can “raise cortisol levels” and create other issues
Essentially, stress elicits a “real” physiological response that is physically and psychologically damaging (Sapolsky 2004:9). When stressed, the body centralizes all energy to move towards the muscles in a fight or flight response (Wilkinson 2005:272). In order to efficiently and quickly move the body’s energy for mobilization digestion stops, tissues stop growing, and the immune system stops battling harmful pathogens (Wilkinson 2005:271-5). All of the body’s resources divert and respond to stress instead of functioning properly. Because of this, individuals who experience stress frequently are more likely to get sick. If the body must constantly push all of its nutrients to feed the liver and battle stressful situations, then it will experience fatigue, making it difficult to perform everyday mundane tasks and fight infection (Sapolsky 2004:34).

Chronic pain is amplified by stress-induced hyperalgesia, which comes from damage to the peripheral nerves as a result of the body experiencing repeated stressful events or known as chronic stress (Sapolsky 2004:104). This is when, instead of becoming numb to pain when facing a stressful situation, an individual actually becomes hypersensitive to it. The brain causes one to experience a more intense emotional reaction to pain that is a heightened experience. This is why anti-anxiety drugs tend to help chronic pain patients because they block stress-induced hyperalgesia (Sapolsky 2004:105). So, not only does stress cause and enhance infection, disease, and the breakdown of the immune system, but it also can cause one to be extra sensitive to perceived pain. This helps to explain why so many individuals who experience high levels of stress as a result of traumatic events also suffer from debilitating chronic pain (Sapolsky 2004:103-5).

Maria experiences significant stress and does not deny that stress negatively affects her chronic pain and illnesses. During times of heightened stress, like when she found out about her father’s infidelity, Maria’s doctor and hospital visits increased as a result of an increase in pain.
and Raynaud’s symptoms. However, Maria has found ways to reduce her stress level and although she lives with chronic pain, it is more manageable. Her stress level has declined as a result of her environment, increased social support, and increased financial support.
Chapter 6: Illness Narrative #4
Lisa - The Power of Prayer

I spoke with Lisa, a 30-something Pastoral Associate at a local Catholic church, who suffers from chronic back pain. Lisa is a unique individual to discuss chronic pain with because, as she suffers from it herself, she also holds a position in her church that’s core responsibility is to keep people “connected” to the church who do not feel well enough to attend services. My conversation with Lisa was centered on her personal perception and the Catholic Church’s perception on the subject of experiencing and dealing with chronic pain. This narrative is different from the prior narratives because it focuses more on the Catholic Church and Lisa’s congregation’s perspective on chronic pain and less on her personal experience.

First, I asked Lisa about how many individuals she knew of in her congregation that currently experience chronic pain. At first she told me that she couldn’t think of many, but after asking again she said that there are a few elderly with MS (multiple sclerosis) and Fibromyalgia. I asked her if she could recall anyone else, perhaps children, teens, young mothers, anyone that is under 60, simply because chronic pain affects all ages, and she is a member of an exceptionally large Catholic Church. She paused to think for a moment, then told me about a few teenage boys who suffer from severe migraines. The boys are very involved in the church (altar boys), and since developing migraines have missed church and a lot of their normal day-to-day activities. Despite trying numerous treatment options, she said they experience pain all the time.

This led me to question what Catholicism says about individuals taking pain medication for health issues like migraines, joint pain, etc. Lisa replied, “God works through science and medicine to bring healing. He works through technological advancements to bring comfort and
healing when people need it. The line is crossed in taking medication when there is addiction, and it is used for the purpose of pleasure rather than for the alleviation of pain.” I wanted to better understand how God works through science and medicine to heal. Before Lisa explained this, she told me that prayer and communion are the most powerful ways in treating and alleviating chronic pain. She believes that praying next to the individual in pain, and taking communion (a ritual of receiving God into the body from the wine and bread) is paramount to any other form of healing or treatment. The church members give communal support indirectly through prayer. “At liturgy and mass we pray by name for chronic pain patients, those with mental illness, and the sick.” It is her job as Pastoral Associate to go to the homes of individuals for about half an hour, to visit with them, and to pray with them or over them. “Science works through God, and we pray for it to work. When I (or someone else) prays for this one might say: God please work through this medication to bring me comfort. Church, please pray for me, that I will find a hospital to restore my body and soul.”

The prayer seems to insinuate that there is something at fault with the soul when a person is sick. When she prays to restore the soul and the body she makes a differentiation between the two, and that a person’s sickness is not bodily confined but is a part of the soul/spirit as well. This led me to ask whether or not she believes that pain is a result of God’s punishment. She clarified by telling me that “possibly God is punishing someone and that is why they experience pain, but it is on an individual basis. For example: children do not deserve to suffer, so I don’t think that it is God who forces them to suffer. People who get lung cancer and don’t smoke are not suffering as a result of their sin.” Basically, Lisa explained that chronic pain or pain and suffering, in general, is not necessarily the result of immorality, but that it can be in certain cases.

I asked if members in her particular congregation question chronic pain patients or blame the person for their pain? I realized shortly after asking the question that her congregation has
thousands of members. I rephrased and asked: do the majority of members within the congregation question chronic pain patients or blame the person for their pain? After a long uncomfortable pause her tone changed and she responded as if reading lines from a court document, “I can’t comment on that.” Noticing that I had upset Lisa with this question and sensing our conversation ending, I changed my approach. I asked if chronic pain is different from other illnesses like cancer or a tumor, and if so exactly how? The conversation went back on track and more comfortably that time she replied, “Cancer gets more attention for sure-chronic pain isn’t spoken about as much. You don’t want to bring people meals every day; you’re looking for an end in sight. People start to think, what is the matter with this person? There is more judgment and a question of whether it is psychiatric.” Her answer was genuine, and I sensed personal experience and reflection from her response. Lisa was right- with a disease like cancer the individual either goes into remission, or it is fatal. Ultimately, with a disease that has a clear trajectory of symptoms and development there is an end in sight. For individuals in chronic pain, it can last a lifetime and is continuous.

I asked if an individual is to live with chronic pain, then how is someone within the Catholic faith supposed to respond to pain and suffering? Lisa told me that, “ideally you try to align your sufferings with Christ and to lift your pain up to God as a sacrifice and offering hope.” I was confused about what exactly offering hope meant, and she explained that it is in offering our pain and our experience with pain to God that we have hope to be healed and renewed. She then went on to tell me that not everyone aligns their suffering with God and some respond angrily and feel like their pain is a test. But, she said that there is a righteous anger, and this stems from a Psalms model of dealing with pain. However, the goal is to get past the anger and to come to a state of acceptance and hope.
Wanting to know more about Lisa, I attempted to ask questions about her experience with chronic pain. She politely steered our conversation towards the power of prayer and explained that her pain is not as bad as the individuals she prays for or helps. But, it is her back pain that helps her to have empathy towards others in chronic pain and is partly why she is a Pastoral Associate. It is clear that Lisa does not judge those in pain. She was careful not to speak poorly about the principles of the Catholic Church or the members of her congregation in our conversation. I reassured her that we are all human and making assumptions about an individual’s morality and questioning something like pain (that we cannot see) is something that we all at some point are guilty of—whether Catholic, Protestant, Muslim, Hindi, atheist, etc. Like chronic pain patients who may be careful to construct their illness narratives in front of their doctor, Lisa was careful in how she discussed her church’s views on chronic pain in front of me. Her honesty and perspective are appreciated, even more so because she experiences chronic back pain herself.

The Invisibility of Chronic Pain

When I asked Lisa about how many individuals in her church’s congregation experienced chronic pain she had trouble answering, and did not think that it affected a significant amount of people. This is not an uncommon response and exemplifies that “chronic pain generally escapes notice even though 1 in 10 Americans suffers with it” (Morris 1991:60). It goes unnoticed partly because it appears as a part of what people consider the “normal.” Because so many individuals experience chronic pain, it becomes “absorbed into the routine conditions of modern life;” and because it is an ongoing experience it does not seem out of the ordinary, making it difficult for others to recognize (Morris 1991:19). Even if we notice that something seems abnormal about someone experiencing chronic pain, it is typically a shift in behavior noticed, like if the
individual is moodier or grumpier than usual (Morris 1991:73). As described in previous chapters, changes in behavior are typically attributed to issues concerning character, not chronic pain. A behavioral shift is not something people become exceptionally concerned with because many people experience mood shifts throughout the day or week.

Instead, fatal diseases like cancer or AIDS are more likely to elicit a reaction and gain visibility from others. Ultimately, chronic pain is easy to ignore because most people do not understand or perceive of it as something serious (Morris 1991:66). Fatality elicits visibility, sympathy, empathy, and understanding from others. Because chronic pain is not fatal or a threat to public health (like AIDS), it is not understood by outsiders as serious. However, it can be as detrimental as cancer emotionally, because of its continuity and the length of time (sometimes a lifetime) it persists. Chronic pain does not have a list of expected symptoms that can be googled. It is only through the individual’s personal description of their experience with chronic pain that others can attempt to understand and empathize with. It also does not fit neatly into a box with signs, symptoms, prescribed treatment, and defined etiology as other diseases do. This makes chronic pain somewhat abstract and obscure to those not directly experiencing it.

Due to these reasons and because it may not change a person’s physical appearance like cancer, it can go unnoticed and blend into society. Not everyone has empathy like Lisa does for those in chronic pain. The subjective experience is frustrating because there really is no expected illness narrative of the chronic pain patient like there are for other diseases like cancer (Morris 1991:61-73). Therefore, chronic pain can seem invisible to outsiders not as a result of people’s conscious choice to ignore it, but because it is difficult to identify its severity is often misunderstood.
God Complex: Voice and Body

Lisa’s prayer to God, asking him to heal through mechanisms of science and biomedicine, makes the doctor and biomedicine a vessel for God’s work. To better understand Lisa’s prayer, I turned to Elaine Scarry’s discussion of the body and the voice. In her book The Body in Pain, the human body is described as weak, material, finite, and the voice as powerful and God-like, so the two are divided representing humanity and the divine (1985:192). But, the body and voice are not always kept completely separate, because “the verbal acts of man and God are braided together” when a man acts on behalf of God (Scarry 1985:196-7). Scarry gives the example of humans having a voice when God speaks through him or her, exemplified by Abraham praying and God’s power illuminating through his prayers (1985:195).

The idea of God working through man is carried into contemporary thought, especially in regards to biomedicine. Prayers like, “God please work through this doctor or medicine to heal me” or “Give this doctor the wisdom to diagnose me” are common said prayers of Christians when an individual is sick. The idea of God working through the doctor gives the doctor power, and unconsciously sometimes we associate doctors with Gods by assigning them God-like power and the ability to heal. In the Old Testament, it is “through the human body that belief is substantiated” and healing is a sign of God in (Scarry 1985:188). It can be interpreted that God is working through the doctor through voice and physical alteration of the body, which are evidence of his power and work according to the Old Testament. God says things like, “I will make you….I will multiply you” and using repetition, establish power through language that assert the ability to alter the body (Scarry 1985:192). Doctors also use repetition and the focus is on changing the patient’s body or bringing it back to a state of homeostasis. Doctors may ask repetitive questions like, “Does this hurt, does that hurt and where does this hurt?” Within the context of biomedicine, the patient is the body, and the doctor is the voice. Assigning this type
of power to doctors, it can help to reaffirm belief in God if they are healed or to lose faith in God when they are not. For those in chronic pain, it can cause them to question God when biomedicine seemingly fails to rid them of their pain, and in turn can challenge their belief system. When the expectation is to be healed, and God is the healer by the mechanism biomedicine, then both can be seen as failures to someone experiencing chronic pain. Perhaps a prayer that focuses on reducing chronic pain and better coping instead of completely alleviating it would be more productive.
Chapter 7: Conclusion

I began this study with the confidence that I would find something profound and enlightening about chronic pain and its relation to religion. I hypothesized that religion (as a social world) would have a definitive negative or positive impact on a person’s experience and understanding of chronic pain. From here, I thought I would be able to identify factors within religious institutions that perpetuate or mitigate chronic pain. Ultimately, I aimed to come to a conclusion that would offer a better understanding of the language, experience, and meaning of chronic pain. However, what I have found is that although chronic pain is a complex topic to understand and explain, entangled as it is in one’s biology, environment, and social world, many of my informants seemed to suggest that some of the best methods they have found to cope and live with chronic pain are actually quite simple in theory. These methods include relying on social support, being hopeful, having an altruistic spirit, laughing, and creating new norms.

In my interviews, I found that some individuals with chronic pain viewed themselves as a “problem” as a person with a condition needing to be “fixed.” Many of my informants who felt they were a “problem” or had a condition needing to be fixed described similar stories about censoring their language. Some stopped telling others about their symptoms and became more isolated, so as not to become a societal burden. Many struggled with relationships and friendships, because they felt as if they were difficult patients or problem children. Abigail mentioned that her church found her to be a “problem child” and her parents said she was difficult. As a result, Abigail was careful not to talk about her pain with her new Life Group. Maria told me that she initially worried that her fiancé, Peter, might find her health issues too difficult to deal with and not want to date her. Many of the chronic pain patients I have spoken with share a fear of being difficult and a burden.
For some whom I interviewed, this fear of being a burden on others worsened their condition. It hindered their ability to form meaningful relationships and tell their doctors exactly how they felt, and it could cause some to censor their language. Thus, for some, rather than destroying language, chronic pain teaches individuals to censor their language. They do so in response to societal expectations. People censored their language differently depending on what others expected of them. Those expectations are shaped by social roles. So a mother, for instance, might be more inclined to censor her complaints about her pain because it is socially expected for her to maintain a household and bear the burden of pain silently. A child may become a “problem” child in certain medical and behavioral health contexts because his or her behavior is seen as needing to be disciplined because of his or her role as a child.

Gender, age, class, race, and ethnicity also can play important roles in shaping how people censor their language and thus how others see chronic pain as a “problem.” Maria censored her language by choosing which symptoms to tell her doctor and which to leave out. She chose words and descriptions surrounding her symptoms that she thought the doctors could understand and treat. Maria’s censorship of certain pains and symptoms enabled her to receive treatment for specific issues like a cold, in addition to avoiding certain stigmatizing labels such as “hypochondriac.” Had Maria listed all of her symptoms, her doctor might have thought that her list was too burdensome to tackle or that she was too difficult of a patient to treat. Abigail also censored her language. She filtered what she shared with her life group, perhaps in order to maintain a particular social role or to avoid judgment. Members of Abigail’s life group depended on her as their leader to offer guidance and support. Abigail censored discussions surrounding her health, maybe in part to maintain certain expectations attached to her leadership role. This censorship also potentially allowed her to avoid skepticism surrounding the legitimacy of her pain. Although almost all of the informants I spoke with censor their language due to chronic
pain, the ways in which they censor their language and the reasons for doing so vary. Whether
the goal is to maintain legitimacy or morality or to receive care from a doctor, the censorship of
language has a purpose. And how this purpose is achieved through censorship is shaped by a
variety of factors that are ultimately situated in context.

My research on chronic pain patients has allowed me to discover three major themes that
I will elaborate in this conclusion. First, I will explain how chronic illness poses a challenge to
biomedicine because, for many of my informants, there is no clear biomedical etiology for their
condition, and so each person’s morality and character become suspect. In the case of chronic
pain, American ideas about “rugged individualism” and a Protestant work ethic or productivity
exacerbate this questioning of a person’s morality and character. Second, I will discuss how it is
not the role of religion per se that creates or destroys pain, but a multitude of factors within one’s
religion that affect a person’s experience and understanding of pain. In particular, I will focus on
the role of social support found within religious affiliations. Next, I will expand upon methods
of coping that were shared by many informants in my study and that informants identified as
most effective. The efficacy of these methods rival science, biomedicine, and technology.
Coping methods are by far the most important finding within my research because the methods I
found most effective are accessible to all regardless of income, race, class, gender, or geographic
location. Finally, I will discuss how we can use this research as a medical community and as a
community, in general, to help improve people’s experience with chronic pain and to better
understand chronic pain in general.

Coping in Place of Overcoming

Chronic pain poses a challenge in contemporary American society, where individual
worth is bound up in ideas about productivity and the Protestant work ethic—the notion that if
one simply works hard enough, one can succeed (Martin 2009). It is culturally ingrained and can become embodied, exemplified as a common theme in children’s books. These stories center on individuals overcoming illness, poverty, and major limitations to become victorious. Stories of these heroes—such as Olympian Wilma Rudolph, a child who overcame polio and the inability to walk to win a gold model in track—present individuals whom children aspire to emulate. Thus, in American society, we are taught that if someone else can overcome his or her limitation, then so should we. However, for many of my informants, chronic pain is not about overcoming; rather, it is about coping. Almost all of the individuals I spoke with were focused on coping (not fighting their pain) and living life the best and most full way they could.

An American middle-class understanding of what it means to be a winner and victorious is based on war-like metaphors in which every obstacle is approached as a battle, especially in regards to health (Good et al. 1992). We must “win” a fight against cancer (ridding oneself of the disease) and run in local 5K races to help “beat” cancer.

Chronic pain, however, is not a battle or a fight. As Pastoral Associate Lisa said, people bring food to those with cancer and sympathize. There is a definite linear trajectory of cancer as a disease, and people want to help participate in the “fight” against it through efforts such as bringing the individual foods, offering sympathy, and praying. The people I interviewed did not speak of needing an army around them to fight or battle their pain; instead, they spoke of the need for support and love. Sophia said that the doctor at the book signing encouraged her and showed her care, which allowed her to cope better with pain. The power of support was reaffirmed when Sophia was able to sit through a long book signing in minimal pain. She was also able to race her walker to the front of the book signing line with ease. Although Sophia still experienced chronic pain that day, the support and love that she remembered receiving from the doctor visibly increased her pain tolerance to the point that her ability to walk (even though it
was just for a few minutes) improved drastically. Maria found that, when she realized Peter accepted and loved her regardless of her health or pain, she felt better and visited the doctor and hospital less. Like Maria and Sophia, Abigail also found social support to be therapeutic. When Abigail joined a new church and was the leader of her life group, she felt supported by the members and was able to handle her pain in a positive way that did not involve abusing drugs or alcohol. Each of these individuals, when supported, saw noticeable improvements in their pain’s severity or their pain tolerance, allowing their pain to become somewhat more manageable.

Instead of fighting, the individuals I have spoken with are managing. They have adjusted their lives and what they consider normal to live purposefully with chronic pain. Sophia did not attend church as much and stayed home more, in part due to her pain. She created new norms and adjusted to living in an assisted living home by focusing on making friends and creating new routines for herself, such as playing pinochle with a group. Sophia wished that she felt well enough to do her hair and makeup as her neighbor down the hall did. But, instead of focusing on what she could not do, she focused on what she could do. Strength and character are reflected in Sophia’s and many of my informants’ abilities to adjust, create new norms, and focus on what they have the ability to do.

A Different Kind of Support

In interviews, chronic pain patients made it clear that they still need the same support as a cancer patient or a person with a tumor does, but a different kind of support.

They need support that is not battle centered and focused on the illness, but simply characterized by others being positive and focusing on the individual in pain, not the pain itself. Abigail told me that it was frustrating when her parents and others would ask questions such as, “What doesn’t hurt?” Such questioning unconsciously treats the pain and the individual in pain
as if they are the same. This is a problem because, as the pain and person become interchangeable, the person in need of support can become invisible. Multiple informants told me that they wished they had something like a broken leg, because then people would understand that their pain is real, it hurts, and they need support. Because biomedicine has yet to understand truly chronic pain, and there is no formula or magic bullet to treat chronic pain, we must try to understand the entangled social factors that alleviate and perpetuate chronic pain. This requires a revised approach in which care is more than biomedical treatment.

My research and these narratives illuminate the true complexity of chronic pain. Chronic pain is dynamic, and it encompasses every part of a person’s experience, including religion, stress, trauma, upbringing, work, and family life. After speaking with so many different individuals in chronic pain, I conclude that because each person experiences and understands pain differently, the way he or she copes with and reacts to pain is also different. I have found that how people experience, understand, cope with, and discuss pain is most heavily influenced by their social world. To better understand a person who experiences chronic pain and considers religion and God to be a large part of his or her life, I analyzed dimensions of each one’s religious, social world.

During this study, I spoke with individuals in chronic pain who were angry with God, but I also spoke with those who believed God helped to ease their pain and did not want them to suffer. The responses in relating God to one’s experience with pain were unique, as was each person’s interpretation of God. Some people believed in a kind and merciful God, who suffers with them. Others found God to be vengeful, and their pain to be some form of punishment. I did not expect to hear people interpret God so differently, and one individual’s understandings of pain to be so different in relation to that of another chronic pain sufferer within the same religion. Ultimately, I found that we cannot blame religion, God, or the people in a church’s congregation.
for causing chronic pain. Nor can we give religion, God, or the congregation credit for healing pain. Each congregation, even within the same religion, is ultimately made up of people who have different opinions, personalities, and interpretations of God. From the same Bible, people can quote God saving and healing, as well as damning and condemning. Humans use and manipulate text, even biblical holy text. The ways in which biblical codes are held to and interpreted affect a person’s experience of, understanding of, and method in coping with pain.

For example, the rigidity of religion, as in Abigail’s case, actually amplified her suffering. In contrast, Sophia felt that her church was supportive of her and did not mind that she was unable to attend most days. In Sophia’s case, church was a place that offered social support. I found that churches within five miles of one another, claiming to worship the same God and to be the same religious denomination, understand and interpret God and how God would respond to situations differently. It is not religion directly, but people’s interpretation of religion, that affects how the people within that particular congregation react to and treat someone in chronic pain. In addition, this interpretation affects how the individual in pain experiences, understands, and copes with pain. Ultimately, the people within a particular congregation determine whether a member in chronic pain has true social support, and this can provide a beneficial mechanism for coping. It is not the building of the church or the biblical text, but rather the individuals who interpret the text and who worship within the church who can alleviate or amplify suffering.

However, religion is not the only factor at play here. Multiple dimensions, such as gender, ethnicity, class, and age, intersect with different ideas about God and pain. I found age to have a large role in relation to ideas about pain and God. For example, Lisa said that children who are ill or in chronic pain are not to blame for their pain. She believes that God does not want children to suffer because they are innocent, but that adults in chronic pain may be to blame for their suffering. Unlike that of children, an adult’s pain can be a result of God’s punishment.
But these intersecting factors are not clear cut, and they can be a bit more complex because they vary. Abigal experienced chronic pain as a child, and although her pain was not thought to be related to sin or punishment from God, her young age caused people to question her behavior in reaction to pain. Church members attributed her behavior to “acting out” and considered her in need of discipline for behavioral issues, not in need of support for pain.

Because of chronic pain’s complexity, I found this research very rewarding. Although we understand and experience pain differently, there are common factors within coping that reap therapeutic benefits. In a fee-for-service medical system, we easily associate healing with a price tag. However, my informants’ illness narratives suggest that some of the most beneficial ways to deal with chronic pain are free. In almost all of my discussions with chronic pain patients, I found social support, love, hope, altruism, and having a positive outlook by laughing or joking as ways to not only cope with pain but also increase pain tolerance. Religion can, therefore, help one to alleviate and cope with chronic pain if the individuals within a particular congregation offer empathy, compassion, love, and friendship. But this social support can also be found in many other settings that are not religious in nature: at school, in a neighborhood, at a club, or even at a chronic pain support group. Finding social support can be done through an act of altruism or giving others social support. By giving support, we are more likely to receive support. When Abigal became head of her Life Group, she provided members with support and guidance. And even though she did not discuss her pain with the members, she in turn received support from the group in the form of friendship and prayer. If we believe in a supportive, forgiving, and loving God, we experience and feel support, so our pain is mollified. Such support can also come from a relationship like the one Abigal has with her new boyfriend and the one Maria has with her fiancé. Social support involves cooperation and identifies how interconnected humans are.
A “We” Society

In a society that focuses on the success of the individual and competition, we are isolating people and perpetuating, possibly even creating, chronic pain. We began as hunters and foragers—a society that relied on gift giving, reciprocity, and community effort for survival. We worked together to succeed and survive, and it was possible only through cooperation. Now we are a competitive society that relies on science and technology to fix problems, and life is centered on efficiency and productivity rather than enjoyment and experience. But this research shows that we have not deviated so far from the cooperative society in which we began. We can fix some of the problems caused by an egocentric “me-me-me” society. Innately, we know how to share and work together, exemplified by children cooperating and helping one another when placed in group settings (Small 2001). Chronic pain is a product of and perpetuated by a “me” society in which, when surgery, pharmaceutical drugs, and a “let’s fix it” attitude do not rid a person of his or her pain, the pain becomes an annoying problem that is difficult and burdensome to society. Science and medicine, although they have helped to improve and advance lives, are unable to provide the tools to alleviate pain and heal that we are born with. We need one another—support from one another, friendship, love, laughter—because it is with people and support that the majority of the individuals I have spoken with are able to cope and live life fully with their pain. I thought that this study would prove to me that religion hinders or helps people in pain. But I found that it is not religion that helps, but rather the social support received from within religion that promotes kindness, empathy, and helping one another. Ultimately, my research and interviews prove that we are more communal than we know and function better as a society when in cooperation rather than in competition—we are better as a “we,” not a “me” society.
Active Hope

Out of the 29 individuals interviewed, all of the individuals had one thing in common: Hope. Whether it was hope to get better one day or hope to have a career helping others, hope gave each person a purpose or a reason to not give up. In *American Oncology And The Discourse on Hope* medical anthropologists argue that hope is intertwined in our biomedical system that ultimately “promotes a vision” that a disease, an illness, or a bodily state is curable (Good et al. 1990:60). In particular, the article discusses a prevailing attitude in ontology, an attitude of hope that surrounds the patient-doctor relationship within biomedicine. It is the premise of hope that “[shapes] current research, standards of practice, and efforts to provide anticancer therapies as well as humane and beneficial care” (Good et al. 1990:75). I argue that the prevalence of hope has an equally significant role in the lives of the chronic pain patients that I spoke with. There is a “deep cultural conviction that individualized will can influence bodily process” (Good et al. 75). Maria could get through, and is getting through, college with the hope that there is an end in sight to her suffering after graduation. Abigal lives her life fully, even after experiencing rape, going through substance abuse, and living in chronic pain, because she has hope that she can help others in her career.

For the individuals in this study, hope allows them the ability to better cope, to remain active in life, and to pursue goals. This study does not necessarily show a correlation between hope and healing, but it does show that hope helps the majority of my informants to persevere while in pain. Abigal hopes to become a patient advocate, and with this hope she actively pursues actions that will help her to reach this goal within her life group and within her studies. Therefore hope is more than simply a coping strategy for most of my informants; it is an active coping strategy that can become a positive lived and embodied experience.
A Revised Approach

These narratives highlight the need for change in understanding and treating chronic pain from within the medical community. A revised approach to deal with chronic pain is needed, one that heavily deviates from the current biomedical model, which is time constrained, biologically centered, and mechanistic in nature (Lock and Nguyen 2010). An approach that centers on listening to individuals’ stories is necessary to help those in chronic pain. The medical system must acknowledge that, when dealing with chronic pain, there may be no clear cause or origin of chronic pain, but that it is in part caused by experience. Listening to an individual’s story and the things that he or she feels are important will tell so much about a person’s pain, maybe more than a series of diagnostic tests will (Kleinman 1988).

Listening is one of the most important things our medical system can do to deal with chronic pain patients, and this is something that goes against the protocol doctors are taught in medical school—to look for symptoms, diagnose, and treat. Those in chronic pain, often through telling their illness narratives, find trends in their pain themselves, as exemplified by Maria’s illness narrative. When Maria discussed her illness narrative with me, she stopped mid-sentence at one point to tell me that she had not noticed prior to our conversation the clear correlation between finding out about her dad’s infidelity and her sudden increase in Raynaud’s symptoms. By simply discussing things that are important in her life and experiences leading up to her pain, she identified periods of high stress and potential triggers in amplifying her pain. This exemplifies how illness narratives hold patterns that are unique to each patient and should be included in a person’s medical history or at least listened to (Kleinman 1988). This could help doctors and patients to identify patterns and events in a patient’s life that may be stressful and create or perpetuate symptoms.
As a community, we can also change the way we approach and understand chronic pain by changing the language surrounding pain. **We can stop glorifying fighting illness as if it is a war, and stop comparing one person’s pain to that of another. I do not mean to say that we should not raise money or awareness for illnesses such as breast cancer, nor should we stop encouraging those with an illness to remain strong and positive.** However, we can stop behaving as if health is a choice and something we can all achieve. We should encourage individuals, regardless of their health state, and not pass judgment on those who say they are in pain. Instead of trying to fix chronic pain as a problem, we must approach it as a new norm and search for ways to better alleviate and tolerate pain through relying on one another and offering our support.

**Future Projects**

This research has inspired me to pursue more projects surrounding chronic pain. Truthfully, what has affected me most was hearing informants tell me over and over that they had hope.

It did not matter what the person had hope in or for, but hope gave a person purpose and the ability to move forward. A linear trajectory, a need to move forward in life, and belief in progress allows those in chronic pain to cope, to live, and to get through each day. Abigail hoped to make a difference in others’ lives as a patient advocate. Maria hoped that after she graduated from college, her pain would be better. And I hope that I can help chronic pain become visible so that people do not feel pressured to fake their health in public to avoid stigma and judgment, but instead receive social support. For this reason, in the future I plan to create a study that focuses on mechanisms to cope with chronic pain. I want to better understand how the imperical “why me” question (the causation of one’s pain) affects a person’s method of coping and ability
to cope. After speaking with many chronic pain patients, I have heard methods of coping that include self-harm, drugs, social support, and attempting to ignore the pain. In a society in which prescription drug addiction and self-harm are rampant, helping people to cope in a more positive and less physically harmful way is necessary. In particular, chronic pain patients who have told me they get to points where they are willing to try anything to get better or get rid of the pain are especially vulnerable to these destructive coping methods. More research is needed to analyze how one’s answer to the “why me” question and the factors that shape this response help explain how a person in chronic pain chooses to cope. From this research, there is potential to make treatment and therapy for chronic pain patients who abuse drugs and self-harm more effective. Focusing on changing how individuals understand their pain in turn can affect how they attempt to cope with their pain.

In closing, these illness narratives teach us that, if we want to help those in chronic pain, the medical community must restructure its approach and focus on listening to patients’ stories. As a community, we can make a cooperative effort to simply support one another, so that chronic pain patients do not feel they are difficult, to blame, or a problem. Our most valuable tool in alleviating and dealing with chronic pain is free—showing genuine care and support, so that those in pain know they are not alone.
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