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## The Experience of Chronic Pain Management: A Multi-Voiced Narrative Analysis

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The Experience of Chronic Pain Management:  
A Multi-Voiced Narrative Analysis

by

Loren E. Wilbers

A dissertation submitted in partial fulfillment  
of the requirements for the degree of  
Doctor of Philosophy  
Department of Sociology  
College of Arts and Sciences  
University of South Florida

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## **Dedication**

To my mother, the participants in this study, and all people living with chronic pain.

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## Abstract

Since the late 1990s, the abuse of prescription opioid painkillers has been constructed as a major social problem in the United States, commonly referred to in the media as the “prescription painkiller epidemic.” Stories of addiction, overdose deaths, robberies, and other tragedies related to prescription opioids have been, and continue to be, commonly featured in the media. In response to public outcry regarding the “epidemic,” government and medical institutions have enforced strict regulations on the distribution of opioids, targeting most of these regulations at the treatment of chronic pain in particular. In this dissertation, I examine the experience of chronic pain management with opioids amid this cultural environment, using the personal, cultural, and institutional levels of narrative outlined by Loseke (2007) as an organizing theme. The dissertation is comprised of four distinct but interrelated chapters that explore the topic of chronic pain management with opioids in four different ways.

In the first substantive chapter, I share a personal narrative of my own experience as the daughter of a mother with chronic pain who relies on opioids, in order to provide context for the rest of the dissertation, disclose my own positionality, and *show* rather than *tell* how the stigma and regulations surrounding opioids are experienced in the lives of people with chronic pain and their families. In the following chapter, I shift away from the personal and use Loseke’s (2012) method for the empirical analysis of formula stories to examine cultural narratives about prescription opioids published in the *New York Times* between 2000 and 2013. I argue that the narratives contribute to an environment in which people with chronic pain who rely on opioids are made vulnerable to stigma and discrimination. I use Loseke’s method again in the third

substantive chapter to examine institutional narratives about opioids told in an FDA public hearing. I argue that the narratives serve to construct moral boundaries between different types of pain patients and justify a label change that disproportionately burdens patients with chronic pain. In the final substantive chapter, I share personal narratives acquired through in-depth interviews with twelve people currently living with chronic pain. I find that the dominant cultural and institutional narratives surrounding prescription opioids translate into stigma and barriers experienced in the lives of people seeking chronic pain treatment, and serve to silence their personal narratives which are resistant and subversive. I conclude by urging for the removal of barriers to chronic pain treatment with opioids and for the wider dissemination of personal narratives of chronic pain patients at the cultural and institutional levels.

## **Chapter One:**

### **Introduction**

Scholars across a variety of disciplines have increasingly written about the importance of narratives. Narratives are “the means and medium through which humans learn who they are, what their relation is to those around them...and what sort of actions they are expected to perform under which circumstances” (Frank 2010:665). It is through narratives that humans are able to explain cause and effect and give coherence to complex situations and events. It is through narratives that we can make sense of the past and give advice about the future. It is through narratives that culture is transmitted, maintained, and shaped. Narratives are particularly useful for sociological study because they serve to “bridge the gap between daily interaction and large-scale social structures” (Ewick and Silbey 1995:198).

Loseke (2007) identifies four different levels at which narratives operate in social life. Some narratives are told at the cultural level, such as in the news media, and serve to influence public opinion and mobilize social movements. Some narratives are told at the institutional level, such as in public policy hearings, to support or oppose government action. Some narratives are told at the organizational level, to justify social service provisions to the types of clients served by organizations. Finally, some narratives are told by individuals at the personal level, to make sense of their own experiences and the experiences of others. The relationships between these levels of narrative are inherently reflexive, as each type of narrative can influence the other (Loseke 2007). For example, cultural narratives can seep into the institutional sphere and inform public policy, public policy can affect the lives of individuals who then tell personal narratives

about their experiences, and these personal narratives can be re-told at the cultural and institutional levels.

In this dissertation, I explore how narratives about prescription opioids told at the cultural, institutional, and personal levels both reflect and affect the experience of chronic pain management. The body of this dissertation is comprised of four distinct but interrelated chapters that explore the topic of chronic pain management with prescription opioids amid a culture of “opiophobia” that exists in contemporary American society. My approach to this project is both constructionist and emancipatory, and the goals of my dissertation are twofold. First, I aim to uncover how cultural and institutional narratives about opioids told in the public sphere serve to justify the stigmatization and marginalization of patients with chronic pain who rely on opioids. Second, I aim to reduce the stigmatization and marginalization of chronic pain patients by making personal narratives of their experiences more visible and accessible. Each chapter approaches the topic of chronic pain management with opioids using a different level of narrative as the focal point.

In Chapter Two, entitled, “She has a Pain Problem, Not a Pill Problem: Chronic Pain Management, Stigma, and the Family – An Autoethnography,” I offer a personal narrative of my own experience as the daughter of a mother with severe chronic pain who relies on opioids. The goal of my autoethnography is to *show* rather than *tell* how the dominant narrative of opioids as drugs of abuse and addiction translates into stigma and barriers experienced by people with chronic pain and their families. I begin the dissertation with autoethnography for a few reasons. First, to provide context for the rest of the project and give readers an overview of the current situation regarding chronic pain and prescription opioids in the United States. Second, to disclose my own positionality as a researcher who is personally invested in the topic and seeks to

advocate for the removal of cultural and structural barriers faced by people with chronic pain. Finally, in line with the evocative style of autoethnography, I aim to create an engaging, accessible, and heartfelt text that highlights connections between personal experience and aspects of the wider society (Ellis, Adams, and Bochner 2011).

In Chapter Three, entitled, “Narratives Regarding Prescription Opioids in the *New York Times*: Implications for the Treatment of Chronic Pain,” I move away from the personal and analyze cultural narratives about prescription opioids told in the national news. Cultural narratives are widely shared stories about what it means to be a specific type of person or engage in a certain activity (Loseke 2007). Cultural narratives told in the news play an important role in shaping our reality by influencing public opinion, shaping the implementation of public policy, and influencing the lives of individuals (Clawson and Trice 2000; Kelly 1996; Loseke 2007; Shah et al. 2002). To examine cultural narratives about prescription opioids, I employ Loseke’s (2012) method for the empirical analysis of formula stories to analyze 203 stories about opioids published in the *New York Times* between 2000 and 2013. I find that two overarching narratives emerge in the articles – a predominant narrative about the “prescription painkiller epidemic” and a less common narrative about the “crisis of unrelieved pain.” I examine the characteristics (i.e. plots, characters, and morals) of these stories and consider how they contribute to an environment in which people with chronic pain who rely on opioids are stigmatized and marginalized both within and outside of the health care system (Gardner and Sandhu 1997; Peppin 2009; Vallerund and Nowak 2010).

In Chapter Four, entitled, “Deserving Patients or Potential Addicts? Using Narrative Analysis to Examine an FDA Hearing on the Labeling of Prescription Opioids,” I examine institutional narratives told in an FDA hearing that resulted in a label change intended to reduce

opioid prescribing to patients with chronic pain. Institutional narratives are stories produced at policy-making levels that construct political and policy boundaries around groups and individuals (Kusow and Eno 2015; Loseke 2007). Institutional narratives often take the form of causal stories that define problems, diagnose causes, and justify policy (Stone 1989).

Institutional narratives are important because they construct target populations – the “types” of people who will be benefitted or burdened by policy action (Schneider and Ingram 1993). Again I employ Loseke’s (2012) method for the empirical analysis of formula stories to examine the stories told at the hearing. And again I find two overarching narratives – a predominant narrative about the dangers of opioids and a less common narrative about the benefits of opioids. I examine the plots, characters, and morals of these narratives and consider how they serve to construct moral boundaries between different types of pain patients and justify a label change that disproportionately burdens patients with chronic pain.

In Chapter Five, entitled, “They Make You Feel Like a Criminal: Patients’ Narratives of Managing Chronic Pain amid the Prescription Painkiller Epidemic,” I share personal narratives acquired through in-depth interviews with twelve people currently living with chronic pain. Personal narratives are stories that social actors tell in order to locate themselves in the narratives produced at the cultural, institutional, and organizational levels (Kusow and Eno 2015; Loseke 2007). Personal narratives portray events as experienced by people in particular times and social locations (Mattingly, Lawlor, and Jacobs-Huey 2002). Personal narratives are important because they allow storytellers to give voice to their suffering and provide testimony to a wider social audience (Frank 1995). Personal narratives can also incite social change when they are resistant and subvert the hegemonic (Ewick and Silbey 1995). By sharing my participants’ stories, I aim to show how the dominant cultural and institutional narratives surrounding prescription opioids

translate into stigma and barriers experienced in the lives of people with chronic pain. I consider how the participants' stories both reflect and challenge the dominant narratives regarding opioids, and I argue that more attention should be paid to the stories of people with chronic pain in order to reduce stigma, eliminate barriers, and improve chronic pain treatment.

In the discussion section, I review the major findings from each chapter and consider what they demonstrate about the importance of narratives for the experience of chronic pain management. I also consider what the findings reveal about the relationships between different levels of narrative and the usefulness of narrative as a method for social inquiry. Finally, I make suggestions for future research to expand on what I have accomplished in this project.

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## Chapter Two:

### **She Has a Pain Problem, Not a Pill Problem: Chronic Pain Management, Stigma, and the Family – An Autoethnography<sup>1</sup>**

“She has a *pain* problem, not a *pill* problem,” I say, a statement I have made countless times before, but it never seems to sink in. The student stares back at me blankly. He clearly doesn’t get it. I’ve just lectured to my undergraduate medical sociology class about some of the struggles experienced by people with chronic non-cancer pain, including difficulties accessing prescription painkillers and the constant battle to convince doctors and others that they are legitimate pain patients and not opioid addicts. As I often do in these situations, I used my mother’s experience as an example.

“But you said your mom takes methadone and morphine every day, so *obviously* she’s an addict,” the student declares with disgust. He looks around at his classmates for support. Most of them are staring down at their desks, not wanting to be dragged in to this. They probably agree with their outspoken classmate, but after listening to my hour-long talk on how the “war on prescription painkillers” hurts people with chronic pain, people like my mom, they know better than to speak up about it. He’s on his own.

“There’s a difference between addiction and dependence,” I explain for what seems like the zillionth time. “My mom is *dependent* on painkillers, which means she needs to take them regularly and would experience withdrawal if she stopped them suddenly, but she isn’t *addicted*

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<sup>1</sup> A version of this chapter has been previously published in *Humanity and Society*, 2015, 39(1):86-111 (DOI: 10.1177/0160597614555979) and has been reproduced with permission from SAGE Publications. A copy of the Author Use Document is included in Appendix A.

in the sense that she has a psychological compulsion to abuse them (Heit 2003). She takes the amount prescribed by her doctor, nor more, no less, and is able to function normally.”

“But she’s high all of the time, right? That’s not *functioning normally*.” He mocks me by flashing air quotes with his fingers when he says “functioning normally.” I feel a familiar anger bubbling up within me, a primal urge to lash out in defense of my mom’s honor.

“No, she’s not *high all of the time*,” I respond with my own air quotes. “In fact, she’s still in pain all of the time. The pills just dull it enough so she can make it through the day.”

“Whatever you say.” He slumps in his chair and rolls his eyes. It’s obvious I haven’t convinced him. I scan the classroom hoping that at least one person will meet my gaze with understanding and empathy. I’m disappointed, but not surprised, when none do.

The clock saves me when it strikes five minutes from the hour, and the students begin prematurely capping their pens and closing their notebooks in preparation for departure. It’s a pet peeve of mine that I would normally scold them for, but today I go along with it. “Alright, I’ll see you all after Spring Break,” I announce, my voice muffled by the sounds of desks shifting and backpacks zipping. I’m relieved as the head for the exit en masse, none lingering to argue with me further. When the door closes behind the last student, the hot, frustrated tears I’d been holding back are free to roll down my cheeks.

In this chapter, I provide an autoethnographic account of my experience as the daughter of a mother with severe chronic pain who manages her condition with prescription opioid painkillers. When I was a freshman in high school, my mom developed extensive spinal disc degeneration that caused irreparable nerve damage, resulting in constant and severe pain in her lower back and legs. She has since relied on the continuous use of high doses of methadone and morphine to manage the pain. The challenges my mom has faced, and continues to face, in

accessing appropriate treatment have spurred my desire to share her story with others, with the goal of informing efforts to improve pain management, an essential form of care.

### **Chronic Pain, Opioids, and Stigma**

Chronic non-cancer pain is a major public health problem in the United States, affecting approximately 100 million people, and is the leading cause of disability in Americans under 45 years of age (National Centers for Health Statistics 2006). Chronic non-cancer pain (hereafter referred to as chronic pain) is any pain that persists longer than three months or beyond the expected healing time and is not related to active cancer of the end of life (Chou et al. 2009). Chronic pain can occur in the context of many different diseases and syndromes. Some conditions involving chronic pain include chronic low back pain, chronic migraine, arthritis, chronic neuropathic pain, phantom limb pain, and fibromyalgia. In some cases, chronic pain stems from an underlying disease or injury that can be detected by medical tests. In other cases, the pain is deemed “medically unexplained,” meaning the origin is unknown. Regardless of its cause, chronic pain has a range of negative physical, psychological, and social consequences and profoundly influences the quality of life for those who experience it.

Aside from prolonged physical suffering, other major effects of chronic pain on patients’ lives can include depression, anxiety, anger, job loss, marital and family problems, and an increased risk of suicide (Fishbain 1999; Strunin and Boden 2004). All of these effects, of course, are compounded when pain is poorly controlled. Chronic pain has also been found to have negative consequences for the family members of patients. Research shows that spouses, parents, siblings, and children of chronic pain patients often experience high levels of psychological distress (Dura and Beck 1998; Flor, Turk, and Scholz 1987).

Much of the sociological literature on chronic pain deals with the stigmatization its sufferers face (Goldberg 2010; Holloway, Sofaer-Bennett, and Walker 2007; Jackson 2005; Lennon et al. 1989; Slade, Molloy, and Keating 2009). Stigma, as defined by Goffman (1963), is the process by which the reaction of others spoils normal identity. People with illnesses or characteristics viewed as undesirable by society, including people with chronic pain, are susceptible to negative and devaluing responses of others. Stigmatizing attitudes can lead to their poor treatment and exclusion from the activities of daily life, along with increased distress, anxiety, isolation, and decreased life satisfaction.

Several scholars point to the invisibility of chronic pain as a source of stigma (Glenton 2003; Holloway et al. 2007; Lennon et al. 1989; Slade et al. 2009). Because doctors often cannot find an underlying injury or disease to explain the presence of chronic pain, and because there is no medical test that can prove the level of pain a patient is experiencing, this makes it difficult for people with chronic pain to convince others that their pain is “real” or as severe as they are reporting. When pain persists for an extended period of time with no improvement and no medical “proof,” doctors and others may begin to suspect the patient of malingering and exaggerating their symptoms for “secondary gain,” which refers to any social advantage afforded to patients as a consequence of illness (e.g., sympathy, freedom from work obligations, financial benefits, or access to drugs) (Fishbain 1994). The difficulties faced by people with chronic pain in proving their legitimacy are also faced by those with other medically invisible conditions, including Gulf War Syndrome, Chronic Fatigue Syndrome, and Multiple Chemical Sensitivity (Japp and Japp 2005; Ware 1992). The chronicity of these conditions along with a lack of diagnostic certainty and agreed upon treatment exposes sufferers to stigma in ways that uncontested illnesses, such as cancer, do not.

Chronic pain patients who rely on prescription opioids for treatment are often doubly stigmatized as people with chronic, invisible conditions and as potential drug addicts (Gardner and Sandhu 1997). Opioid analgesics (e.g. morphine, oxycodone, fentanyl, and hydrocodone), the most potent class of painkillers, have been shown to significantly decrease pain, restore function, and improve the quality of life for many people, like my mom, who suffer from severe chronic pain (Portenoy and Foley 1986; Zenz, Strumpf, and Tryba 1992). Unfortunately, opioids are also widely abused narcotics and are regarded by the general public with a great deal of stigma. Opioids, like illegal drugs, are most often portrayed in the media as addictive and deadly, rather than as legitimate medications for the treatment of pain (Whalen, Asbridge, and Haydt 2011).

Opioids have long been mainstays for managing cancer pain, severe acute pain, and pain at the end of life, but the use of opioids for the treatment of chronic non-cancer pain is controversial. While opioids can be effective in treating chronic pain, there is also widespread concern both within and outside the health care community that the long-term use of opioids will eventually lead to addiction and therefore, chronic opioid therapy is an unacceptable treatment option (Franklin 2014). People with persistent pain who use opioids “too long” (a subjective determination) are vulnerable to accusations that they have a “pill problem” rather than a “pain problem,” meaning they are assumed to be opioid addicts rather than pain patients who genuinely need opioids to relieve their suffering.

McCaffery and Pasero (2001) report that the reason most often given by health care providers for not accepting and action on a patient’s report of pain is the suspicion that the patient is an addict, even though addiction occurs in only a small minority of chronic pain patients using opioids prescribed for pain relief (Fishbain et al. 2008). Vallerand and Nowak (2010)

found that the chronic pain patients they interviewed reported much stigma surrounding their opioid regimen from the health care system, family, and society at large and that stigma was a significant barrier for them in accessing treatment. Another study by Shah and Diwan (2010) found that a majority of doctors were hesitant to prescribe methadone, a synthetic opioid, to their patients due to the social stigma of its use in the treatment of heroin addiction.

In addition to stigma, chronic pain patients face a number of structural barriers that make it challenging for them to access appropriate pain management with opioids. First and foremost, it is often difficult for people with chronic pain to find a doctor who is willing to treat them. There is a major shortage of pain specialists in the United States (Breuer et al. 2007), and many physicians who do not specialize in pain are reluctant or unwilling to prescribe opioids to chronic pain patients (Colwell 2011). This fear of treating chronic pain with opioids occurs for several reasons. One reason involves the lack of pain management training among doctors. In 2011, only four medical schools in the United States required a course on treating pain (Mezei and Murinson 2011), and many doctors feel they lack the knowledge to appropriately treat chronic pain with opioids (Weinstein et al. 2000). Many physicians also fear that they risk legal prosecution or sanctioning by medical boards for prescribing opioids to patients with chronic pain and/or worry that pain patients on chronic opioid therapy will become addicted, overdose, or experience other negative side effects (Nwokeji et al. 2007). Interestingly, these fears arise even in cases when the cause of pain is medically visible (e.g. spinal injury and arthritis), but most doctors do not report the same level of fear regarding treating cancer pain with opioids (Roth, Burgess, and Mahowald 2007).

Even when a chronic pain patient is fortunate enough to find a doctor who is willing to prescribe opioids, he or she is often met with another set of difficulties. Increasingly, doctors are

requiring chronic pain patients to sign opioid contracts, which are formal written agreements between physicians and patients that outline the rules patients must follow in order to receive chronic opioid therapy. These can include rules about how often the patient must see the doctor (typically every one to three months) and where they can fill their prescriptions (usually at only one pharmacy). Often, opioid contracts stipulate that patients must submit to random drug tests. The purpose of these urine screenings is to verify that the patient is taking the prescribed medication (i.e. not selling it or otherwise distributing it) and to identify any other substance that should not be present, including illegal drugs. All of these regulations can be burdensome to patients, both financially and emotionally, and perhaps more importantly, can compromise trust between patients and doctors and hinder the availability of patients to fully benefit from their treatment (Collen 2009).

While it is widely recognized that there are barriers, both cultural and structural, which hinder the ability of many people with chronic pain to access effective treatment, little research addresses how these barriers are experienced in the everyday lives of patients and their families.

### **Autoethnography as Method**

Scholars across a variety of disciplines are increasingly incorporating autoethnography into their research. Autoethnography is a method of writing that explores the author's personal experience and connects it to wider cultural, social, and political issues (Ellis, Adams, and Bochner 2011). Autoethnographers attempt to produce texts that are meaningful, accessible, and evocative to audiences, often with the purpose of inciting positive social change. As Ellis and colleagues (2011:277) explain:

The autoethnographer not only tries to make personal experience meaningful and cultural experience engaging, but also, by producing accessible texts, she or he may be able to reach wider and more diverse mass audiences that traditional research usually disregards, a move that can make personal and social change possible for more people.

There are many ways to do autoethnography, and autoethnographers vary in the extent to which they emphasize the self (auto), the wider culture (ethno), and the research process (graphy) (Reed-Danahay 1997). While some autoethnographers lean toward the analytical and strive to develop theoretical explanations for broader social phenomena, others take a more evocative approach and aim to make emotional connections with their readers (Ellingson and Ellis 2008). Personal narrative is one approach to autoethnographic writing in which the author treats himself or herself as the phenomenon under study and writes an evocative story about his or her lived experience (Ellis et al. 2011). Personal narratives invite readers to enter the author's world and to use what they learn there to reflect on and understand not only the author's individual experience but also some aspect of the wider culture.

Frank (1995) argues that personal narratives about illness allow storytellers to give voice to their suffering and provide testimony to a wider social audience. Japp and Japp (2005) argue that illness narratives can serve political ends by raising awareness, destigmatizing various illnesses, influencing legislation, and lobbying for increased medical research. According to Japp and Japp (2005:107-8), personal narratives about illness benefit not just storytellers but also their readers:

If readers share the illness, they find reinforcement and community. If not, they learn how others experience the world of illness, and prepare for the day when they too will need to adjust to an illness of their own or one they love.

The importance of personal narratives is becoming more recognized in health care contexts as well. Charon (2006) argues that physicians should practice "narrative medicine" and that listening to patients' stories will allow doctors to treat them more effectively and compassionately. Illness narratives can provide physicians with insight into patients' lifeworlds; their contextualized and meaningful accounts of illness experience, which are too often

suppressed and fragmented by the voice of medicine (Mishler 1984). As Early and DeCosta (2009) explain:

The voice of medicine...belongs to doctors who are trained to think and act in a highly scientific manner. The lifeworld represents the voice of patients who share their personal lives through emotions and stories...If doctors discount the stories and feelings of their patients by relying only on their technical rational training, then they may miss important opportunities to communicate and connect with patients, and, perhaps, to discover information relevant to their patients' health.

A study by Barry and colleagues (2001) found that the poorest patient outcomes occurred when patients used the voice of the lifeworld but were ignored or blocked by doctor's use of the voice of medicine. When both doctor and patient engaged with the lifeworld, patients were recognized as unique individuals, were treated more humanely, and had better health outcomes.

If personal narratives about illness can hold such potential for benefiting storytellers, readers, and medical care in general, perhaps the same is true for narratives about chronic pain. In this article, I offer a personal narrative with the goal of showing how I, and others in my family, experience and interpret barriers to adequate pain treatment, and how even now, over a decade after my mom's pain started, the stigma surrounding prescription opioids continues to permeate every facet of our lives.

### **Talking Pills on the Plane**

"Excuse me," the red-headed, heavy-set woman says as she scoots past me to claim the window seat. "I swear these planes keep getting smaller and smaller." She lets out a loud, exasperated gasp as she plops down and attempts to get comfortable. Once settled, she meets my gaze and flashes a warm smile. "Hi, I'm Betty," she says.

"I'm Loren. It's nice to meet you," I reply, reaching for a handshake. I'm relieved to be sharing a flight with someone who seems genuinely nice for once.

“Were you on vacation down here too?” Betty asks. “It’s a shame to leave this warm weather behind.” She reaches into her purse and pulls out a bottle of diet Pepsi. Just like my mom, I think to myself, picturing the mini-fridge in the basement of my parents’ house. It’s always stocked with the stuff.

“Actually, I go to school here in Tampa,” I explain. “It’s Spring Break and I’m headed up north to visit my family for the week.”

“Oh, that’s lovely!” Betty replies. “I was here visiting my son for a few days. Now I’m on my way home.” She sighs before taking a long, slow sip of soda. I wonder if she sees her son even less often than I see my family. I know how lonely it can be living far away from loved ones.

“So, what do you study in school?” she asks.

“I’m working on my PhD in sociology,” I explain. “I’m about to start my dissertation research on the experience of chronic pain management.”

“Good for you! That’s fascinating,” she says. “I’m a nurse practitioner, you know, so I deal with pain a lot.”

“Wow, that’s great,” I reply. “The nurse part, I mean. Not the pain part.”

Betty chuckles softly. “So, what is it that interests you about chronic pain?”

“Well, I’m especially interested in the experiences of pain patients who use opioid painkillers, as well as the experiences of the doctors and nurses who prescribe them.”

“Opioids, huh?” she raises her eyebrows, exaggerating the wrinkles in her forehead.

“Well, I can tell you how *I* feel about them.”

Uh oh, here it comes, I think.

“I won’t even prescribe that stuff anymore,” Betty declares, matter-of-factly. “Most people who come in asking for pills just want to get high. I won’t deal with patients like *that* anymore.” She scowls and shakes her head, disgusted by the mere thought of a “drug-seeking” patient. My heart sinks the way it always does in these encounters.

“Well, what about people who really are in pain? What are they supposed to do for relief?” I challenge.

Betty shrugs her shoulders.

“My mom suffers from chronic pain,” I continue. “She takes methadone and morphine every day and she manages quite well. She couldn’t live without those pills!” My eyes start to burn like they always do when I try to hold back unwanted tears.

An all-too familiar look appears on Betty’s face. Disbelief. Suspicion. Judgment. I know what she’s thinking. Well, I *assume* I know what she’s thinking...*Her mom’s probably a drug addict.* Betty continues, not sensing my discomfort. “I think chronic pain should be managed in other ways, not with drugs. Like with exercise, meditation . . . stuff like that.”

“Well, isn’t it possible that some pain is too severe for those methods to relieve?” I plead defensively.

“Well, sure, cancer pain,” Betty says, as if it’s the most obvious thing in the world. My mind wanders to the time when a close friend of mine was dying of cancer. In his apartment he had a plastic trunk, full of bottles of every type of painkiller imaginable...OxyContin, morphine, hydrocodone. You name it, he had it. The doctors threw the stuff at him like candy from a parade float. He couldn’t take any of it, however. It made him feel too nauseous. So his trunk full of unwanted pills sat on a shelf in the closet while others with the “wrong” kind of pain were allowed to suffer. Near the end, one of the only things providing him with any quality of life was

marijuana. When he smoked, he could eat, laugh, play his guitar, and have long conversations about the meaning of life and death. He found peace in pot, until it was time to go to the hospital where he was forced to spend his final days without it. He shriveled away, nauseous and scared, while others patted themselves on the back for making the world a safer place by criminalizing marijuana. Just like Betty, who congratulates herself for denying pain patients pain relievers.

“I think I’m going to read for a while,” I say, deciding it best not to continue the conversation. I reach under my seat to retrieve the novel I brought along.

“Oh...OK, sure,” Betty says, surprised by my reaction. “I’m sorry if I offended you.” She grabs the in-flight magazine from the pouch behind the chair in front of her and buries her now-red face in it. I follow suit and attempt to seek refuge in Stephen King’s *Needful Things*. That is, until I turn to the part when Alan, the protagonist, questions whether his girlfriend Polly is taking too many pain pills for her arthritis. I paid no mind to this scene when I first read the book many years ago. Now the words read as if they were written to offend me personally.

“On second thought,” I announce, breaking the awkward silence. “I think I’ll nap for the rest of the flight.” I close the book without bothering to earmark the page.

### **An Unwelcome Phone Call**

Spring Break is already drawing to a close and the leisurely breakfast I’d been sharing with my mother and sister has been interrupted by an unwelcome phone call. When mom saw the words “Pain Clinic” flash on the caller ID, she flipped on the speaker so we could listen in on the conversation.

“It’s *policy*,” the nurse explains. “Patients on narcotics must come in every 28 days to have their prescriptions refilled.”

“I wish someone would have told me that sooner,” my mom responds, with a hint of desperation in her voice. “I only have enough medicine to get me through tomorrow, and then it will be the weekend. I can’t wait until Monday.” She doesn’t go on to explain that waiting until Monday would mean excruciating pain, withdrawal, and possible hospitalization.

The nurse, likely aware of the potential consequences, is silent for a moment before replying, “He has an opening at 7:30 tomorrow morning. Can you come in then?”

“What choice do I have?” mom sighs. “Pencil me in.” She presses the red button to end the call and turns to Rachel and me. “Can you believe that?” she asks. “I have to see the pain doctor tomorrow or he won’t refill my prescription. I was just there a few weeks ago.”

“That’s bullshit!” I reply, slamming my coffee cup down in protest. “Isn’t it the same prescription as always?”

“My dosage hasn’t changed in years, but it doesn’t matter. This new doctor wants to see me once a month now instead of every three months like before. My insurance company is going to *flip*.”

Mom moves from the living room to the kitchen and pours herself a cup of the gourmet coffee I bought dad for Christmas. I follow her and watch as she stirs in a package of hot chocolate mix. I want to comment that she’s ruining the integrity of the coffee by doing that, but then I notice how she’s lifting her right foot and rubbing it against her left leg—a sign that she’s hurting. I know the pain-relieving effects of the sugar will be comforting to her, so I keep the thought to myself.

“What happened to your last doctor?” I ask, wanting to know more. “I thought you liked her.”

“I loved her, but she quit practicing a couple of months ago.”

“Oh no!” I gasp. “Why would she do that?”

“All the hype about painkiller abuse, the new regulations...a few of her colleagues were accused of overprescribing and had their clinics shut down. She couldn’t take it anymore.”

“Jesus,” I mutter under my breath.

“So now I have a new doctor, and he’s making me come in tomorrow.”

“But mom, we were supposed to have a marathon tomorrow,” my sister, Rachel whines, pointing to the House M.D. DVD box set resting on the TV stand. The three of us have been die-hard fans of the show since it came out over 10 years ago. Dr. House, the main character, is a brilliant diagnostician with a sarcastic wit who saves the life of at least one patient an episode, all while suffering from severe chronic leg pain which he manages with Vicodin. He’s the perfect fictional hero for a family like mine. We actively ignore the story line about him being an addict.

“Yeah mom,” I add, also sounding whiny, “I have to fly back to Tampa on Saturday, so tomorrow is our last day to spend time together.”

“I know, Sweeties, and I’m sorry, but I don’t have a choice.” Mom sighs. “Do you girls want to come with me to the appointment? It’s an hour and a half drive so we should leave around six.”

“It’s that far from here?” I ask, already dreading waking up early.

“It’s the nearest clinic I can go to. The next closest is four hours away.”

“That’s ridiculous!” I shudder at the thought of mom making such a long drive every month. “Doesn’t the doctor know that your pain is always worse in the car?”

“He doesn’t care,” she answers nonchalantly before sipping her chocolaty concoction.

“I’ll go with you, mom.” Rachel offers. “That way I can yell at him if he’s a jerk to you again.”

“If who’s a jerk? The doctor?” I ask, a little jealous that I’ve been left out of the loop while away at school.

“Yeah, he treated me like crap last time,” mom explains. “It was horrible.”

“What happened? What did he say?”

“Well, first he accused me of faking my X-rays,” mom begins. “He held up the image and said, ‘If this is really you...’”

“Who else would it be? Why would he even say that?” I interrupt, already disliking the new doctor. An image of Dr. Giggles, the creepy villain from the 90s horror movie comes to mind. It’s the way I picture all the doctors who treat mom poorly.

“Who knows,” she continues. “He took one look at the spine on the image and didn’t believe it was mine. He probably assumed I found the X-rays online and snuck them into my file in some elaborate attempt at drug seeking. It was bizarre.”

“What an asshole. What else did he say?”

“Oh I don’t know. Several insulting things...”

“Like what?” I probe.

“Well, he asked how many milligrams of Ketamine I took after my last surgery, and I told him I couldn’t remember. I only took it for a month over a year ago, you know. I said I knew it was a low dose, but I couldn’t recall the exact number. His response was, ‘That methadone is really affecting your memory, huh?’ He made me feel like dirt . . . worse than that even.” Mom sighs.

I feel my nails dig into my palms as my hands become tightly clenched fists. “At least he refilled your prescription, right? That’s the most important thing.”

“Well yes . . . for now. He got on my case about being on the methadone for so long though. He insisted that it isn’t meant for long-term pain management.”

“Then what is?”

“That’s exactly what I asked him. If not methadone, then what drug is meant for pain like mine? His response was, ‘There isn’t one.’”

“Unbelievable,” I say. “Did you tell him how well you’ve been managing on it for the last decade?” My mind flashes back to the time before methadone, when mom could do nothing but writhe in agony. “You have to leave me,” I overheard her telling my dad on a particularly bad night. “Take the kids with you. They can’t live like this anymore.” Dad held her tightly, muffling her sobs with his chest and letting her tears soak his shirt. “We’re not going anywhere,” he said. “We’ll find something that helps. I promise.” And then one afternoon, a few months later, I came home from school to find mom outside, walking up and down our driveway, relishing each step as if it was her first. “You won’t believe it, Sweetie!” she shouted when I approached, flashing a giant smile. “The new medicine the doctor gave me...it works! It really works!” She hugged me tightly and assured me that everything was going to be OK from now on. Back then none of us could have predicted that the stigma surrounding her miracle cure would eventually cause as much distress as her pain.

“I tried to tell him how well the methadone works for me,” mom continues. “But he refused to listen. Then he got all caught up on this idea that I’m constipated.”

“Constipated?” I can’t help but laugh. “What does that have to do with anything?”

“It’s the most common side effect of painkillers. That’s why I always eat so much fiber. I told him I haven’t been having any trouble with that, but he wouldn’t believe me...as if I’ve been bound up for a decade and didn’t know it!” She shakes her head and chuckles at the absurdity of

the doctor's behavior. "I think he's just looking for any excuse to stop prescribing the methadone."

"I can't believe this."

"Tell her the rest, mom," Rachel urges.

"Oh, it gets even worse," mom continues. "At one point near the end of the appointment when the doctor wasn't looking, I peeked at my file and saw that he had written, *Patient denies constipation*. So now it says that I'm a liar on my permanent medical record. Can you believe *that*?"

"How dare he treat you that way!" I shout.

"I hope you gave him a piece of your mind, mom," Rachel says.

"No. I was very calm and polite," mom replies, sounding defeated. "I couldn't give him any reason not to take on my case."

"You should have told him you're a lawyer," Rachel suggests. "Maybe he would've respected you more if he knew."

"It doesn't work that way, honey," mom explains. "Doctors don't always like lawyers. Besides, it isn't entirely his fault. He could get in big trouble for prescribing that kind of medicine to the wrong person. He has to watch his back."

"Well your back needs watching too, mom. We are definitely coming with you tomorrow," Rachel concludes. I nod in agreement.

"That would be great," mom answers. "But I think it's best if you both wait in the car."

"Darn," Rachel sighs. "I wanted to witness the drama."

"We can go out for breakfast afterward and I'll tell you the whole story," mom offers.

"Although I hope there won't be much of a story this time."

## A Family Affair

Later that evening my mom, dad, brother, sister, and I gather at my grandparents' house for a family dinner.

"Mom has to go to the clinic tomorrow," Rachel announces as we take our seats at the table. "Me and Loren are going with her."

"Loren and *I*," Grandma corrects, as she serves each of us from a large platter full of Midwestern favorites. "You wouldn't say, 'Me is going with her.'"

"*Okay* Grandma," Rachel responds, not masking her frustration. "You know what I mean."

"Didn't you just see him a few weeks ago?" Dad asks, interrupting the grammar lesson. "Why are you going back so soon?" He reaches for the bottle of red wine on the center of the table and tops off his glass, careful not to spill on Grandma's white tablecloth.

"She has to go in every month now or they won't refill her prescription," I answer, before mom has a chance to. "Isn't that ridiculous?"

"That's downright unethical!" Dad declares. He catches himself before slamming a fist on the table. "Did you tell him how long your commute is? Is our insurance company even going to cover all of these appointments?"

"They'll have to," mom answers, matter-of-factly. "But they aren't going to like it." She looks down at her plate and moves a few bites of food from one side to the other with her fork. The savory meat and vegetables aren't appealing when she's hurting so much.

"Did the doctor give a reason for this? Are you starting a new treatment?" Dad probes, needing to know the whole story.

“No, it’s just his policy,” mom explains, shrugging her shoulders. “He expects all new patients to come in that often.”

“He wants to make sure she isn’t a junkie,” I interject. “It’s bullshit.”

“Watch your language, young lady,” Dad warns, pretending to be serious. “But you’re right, it is bullshit.” He winks at me and reaches with his fork to “steal” a morsel of rare steak off my plate.

“The doctor was a real jerk to mom last time,” Rachel says, determined not to change the subject. “You wouldn’t believe the way he treated her.”

“What did he do? Tell me!” Dad commands. His eyes widen and his face grows redder as Rachel recounts the details of mom’s last visit to the clinic. I’m surprised that it’s the first time he’s hearing this story, until his rising anger reminds me why mom didn’t tell him about the appointment earlier. She didn’t want to upset him.

“I’d like to give that guy a fist-full!” Dad proclaims when the story is over. At 6’5” and 275 pounds, this threat would be terrifying to anyone who heard it. Although I’m strongly opposed to violence, I can’t help but feel proud of Dad and comforted by his desire to defend mom’s honor. He is as sensitive to the injustices mom suffers as I am. His rage is my rage. Besides, it’s not like he would ever act on it.

“Let’s all calm down,” Mom orders, not wanting our growing anger to ruin the evening. “There’s no reason to fuss over something we can’t change.”

“But we should try to change it, mom,” I argue. “It isn’t right.”

“I know, honey. But getting upset won’t solve anything. Just work hard on your research, that’s what matters.” She reaches across the table and lovingly takes my hand in hers.

“I will mom,” I promise, squeezing her hand in return. Knots form in my stomach with fear of disappointing her. Will what I write even matter? Will anyone read it? Did I choose the wrong discipline?

“That’s why I’m specializing in pain management,” Rachel announces, as if she had read my mind. “So I can help people like mom.” I feel both pride and jealousy as she discusses her plans to become a nurse practitioner and start her own pain clinic. Will she do more good than I? Will mom be more proud of her career than mine? She always said she never envisioned any of her children becoming academics.

“That’s great, sweetie” mom says, moving her other hand to hold one of Rachel’s. “I’m so proud of all of my children.” She directs her gaze at my brother, Eric, to make sure he feels included too. Eric has been quiet since the conversation started, and I wonder if his silence has to do with a close friend of his who passed away from an opioid overdose last year. Unlike the rest of us, my brother has witnessed the dark side of prescription painkillers. I want to discuss these things with him, to ask him whether he still feels the same way about mom’s pills as the rest of us do, but it never feels like the right time.

Grandpa also has been quiet all night, which isn’t out of character for him. He and Grandma tend to sit back and listen as the rest of us chat, interjecting only occasionally to talk about grammar, church, or conservative politics. I wonder how they feel about the conversation we’re having. For years after mom’s diagnosis, they pestered her about taking painkillers. “When are you going to get off of those pills?” they would ask. “Won’t you get addicted?” Although I now feel ashamed when I think of it, I was afraid mom would become addicted too when I first learned that her pain medications were also dangerous street drugs.

“It’s made from the same stuff as heroin, you know,” my high school health teacher said about morphine, just over a month after mom started taking it. He had recently undergone knee surgery and was describing to our class how afraid he was of becoming addicted to the morphine they gave him for postoperative pain. “I’d rather hurt than get hooked on that garbage,” he proclaimed. My heart sank into my stomach and stayed there until I expressed my concerns to mom later that evening. She assured me that while her medicine certainly had the potential to become addictive, that it wouldn’t happen in her case. “It doesn’t make me feel high,” she explained. “I still have pain when I take it, just not as much. If a better, safer pain treatment ever comes along, I’ll get off of these pills without a second thought.”

Fourteen years and countless experimental therapies later, the morphine and methadone are still the only drugs that provide mom with adequate relief, and the benefits of her treatment continue to outweigh the potential risks. The choice is simple: She can function with the pills or suffer greatly without them. Unfortunately, for our family and others like us, the rest of the world doesn’t see it that way.

“You know what I really hate?” mom asks, returning my attention to the dinner conversation. “The random urine tests. All of the pain doctors require them. That’s the policy you should try to change first.”

“That bothers me too,” Dad agrees. “They treat you like you’re on parole.” I picture a nurse handing mom a cup to pee in so they can check her system for drugs—the assumption being that if she is on pain medication, she might be an illegal drug addict, or perhaps isn’t taking her prescription at all and is selling her pills on the street. My own cheeks burn red as I imagine the humiliation mom feels each time they ask this of her. Years ago, when the policy was first implemented, mom’s doctor told her that they were measuring whether the correct

levels of methadone were in her system. She was a little annoyed by this but thought it seemed reasonable enough. Later on, she discovered that they were also checking for illegal drugs, like marijuana, crack, and meth. She was infuriated by the invasion of privacy and the implication that she was a criminal but was powerless to stop it. “It’s policy,” the nurse told her when she complained. To make matters worse, these mandatory urine screenings aren’t always covered by health insurance, and they are pretty pricey at \$400 a pop.

“You should be innocent until proven guilty,” Rachel declares. “They shouldn’t be allowed to force you to . . . “

“Let’s change the subject now!” Grandma interrupts. I knew it would only be a matter of time after the word “urine” was uttered that she would insist we talk about something more dinner-appropriate. If there’s one thing Grandma takes seriously, it is table manners.

“How many of you activists are ready for dessert?”

### **A True Nightmare**

That night in my old bedroom, I slip into a nightmare I’ve had many times before. In it, I’m trapped in a hospital, in a maze of bright hallways full of doors that all look the same. An impending sense of doom crushes my chest, making it difficult to breathe. I know only one thing. My mom is in danger. She is somewhere in the building and it is up to me to rescue her before it’s too late, before the surgeon starts cutting.

I think I see a map on the wall ahead of me. I walk toward it, hoping it will lead me to mom’s room. But the closer I get, the more blurry the map becomes. I squint my eyes, trying to make the fuzzy shapes form letters, to no avail. I soon begin to doubt whether what I’m looking at is even a map.

Suddenly, a shadowy figure brushes past me. I realize that it's a nurse. "Please help me!" I try to shout, but my words come out in whispers. The nurse doesn't hear me. I start to run after her, but it feels like I'm stuck in quick sand. The harder I try, the less I'm able to move. I'll never catch up.

And then I hear it. The screaming. It's coming from behind the door to my left. I force my hand to move for the handle and turn it. I have only enough strength to open the door a few inches, just enough to peek inside. What I see is the same horrific scene I always find when I open this door. My mom is lying on a surgery table surrounded by men in blue scrubs. Three of them are holding her down while the other is cutting her abdomen open with a scalpel. I'm paralyzed, powerless to do anything but watch. With each motion of the knife my mom's screams grow louder and louder, until she is silent.

Suddenly, my voice and mobility return to me. I rush into the room and plead with the surgeons, "Please, give her more pain medicine before she wakes up! You didn't give her enough!"

"We gave her plenty already," one of the men responds from behind his white mask. "No one needs more than that."

"You don't understand," I croak. "You didn't give her enough."

My knees buckle as I see my mom's eyelashes begin to twitch. "Oh God, it's too late," I say. "She's waking up."

As soon as her eyes open, my mom's chest ignites, engulfing her in flames. Her screams begin again as she burns and writhes in anguish. An evil energy holds me still, forcing me to watch. The surgeons do nothing. They don't seem concerned.

The buzzing of the alarm clock jolts me back to reality. I sit up in bed, panting and coated in cold sweat, trying to forget the horror I witnessed. But this particular nightmare cannot be forgotten, because it wasn't "just a dream."

Ten years ago, my mom had a neurostimulator device surgically implanted in her abdomen. The device was designed to interrupt some of the pain signals between her brain and spine. During that procedure, she was supposed to be awake, but numb from the waist down (similar to how many women have cesarean sections). Unfortunately, only the former was achieved before they started operating. She felt everything as the surgeon cut open her mid-section.

A few years later, she underwent breast reduction surgery to take some of the pressure off her back. This time she took extra precautions before going in for the operation by double and triple checking with the anesthesiologist to make sure that he had the correct information about her medication regimen. She made sure he knew that she took 100 milligrams of methadone twice per day.

Somehow, on the day of the surgery, the anesthesiologist decided that there was "no way" a person could take that much methadone every day. He assumed mom was confused about her dosage and that she really took 10, rather than 100 milligrams. He administered her anesthetic accordingly. Mom stayed under through the duration of the procedure (thank goodness), but the nightmare ensued when she came to. She awoke from the surgery with zero pain relief. She said it felt like someone had poured gasoline over her chest and lit it on fire. She screamed and screamed before passing out. My dad reportedly heard her from the waiting area and sprinted toward her recovery room, ready to swing fists at whoever was responsible. Even though I wasn't actually at the hospital on either occasion, these events still haunt my dreams

over a decade later, a testament to the ripple effects that chronic pain and its mistreatment can have on family members.

### **A Trip to the Clinic**

Early the next morning, mom, Rachel, and I groggily pile into the Suburban and begin our journey to the pain clinic.

“Let’s get some air flowing in here,” mom says as she moves her right hand from the steering wheel and flips on the A/C, “I’m roasting.”

“Seriously, mom? I’m freezing!” Rachel complains from the back seat. “Why are you always so hot?”

“Because she’s in pain. Duh!” I turn around and shoot Rachel a nasty look, which she counters with an exaggerated eye-roll. I know she’s just grumpy because we woke up so early, but I hate it when she gives mom a hard time.

“Come on girls, please don’t ruin the day before it even starts,” mom pleads. She grabs Dad’s Carhartt sweatshirt off the center console and tosses it over her right shoulder to Rachel. “If you’re cold, put this on. I don’t want to hear about it anymore.”

Mom reaches for the A/C a second time, turning the fan up two notches higher. I notice her long brown hair is sweaty and sticking to the back of her neck, and I silently curse her new doctor for demanding that she come in this morning.

“Are you nervous about your appointment?” Rachel asks, sounding concerned. “Do you think the doctor will be mean this time?”

“No, I’m not nervous,” mom answers. “What will be, will be.” She sounds confident, and I can’t help but wonder if perhaps I am more bothered by the way she’s treated than she is.

I look out my window and watch as we pass acre upon acre of brown, frozen cornfields, the only attraction on the 90-mile trek to the pain clinic. I shiver, as the icy air from the car's A/C unit pierces my winter coat and think that mom must be hurting pretty bad to feel hot in this weather. I try to recall whether she packed the bottle of liquid morphine in her purse before we left the house this morning. The methadone might not be enough to get her through the long drive.

"Hey girls, I love this song!" mom announces cheerfully, interrupting my thoughts. She reaches for the radio and turns up the volume. "Be My Lover" by La Bouche blares through the factory speakers. *A ha ye heyee. Wanna be my lover. A ha ye heyee. Wanna be my lover.* I close my eyes and let the music take me back to a time before mom got hurt, to a night when she and her girlfriends drank white zinfandel and danced for hours to the 90s hit in our living room. A little girl at the time, I snuck out of bed and peeked at them from the stairs.

Mom moved so gracefully to that beat; clearly the best dancer among them. And her smile was big enough to make my own cheeks hurt. I yearned to be a grown-up so I could join them.

Now it's been years since those friends have visited. I try to recall when and why they stopped coming around. Maybe they were turned down one too many times when mom wasn't feeling well and decided to quit trying? Maybe they were uncomfortable because they didn't know how to act around someone in pain? Maybe they were never "real" friends in the first place? I consider each scenario, as the song fades into another...and another. I begin to wonder if my own friends would stick around if I ever became disabled.

"We're here!" mom's voice invades my daydream. I open my eyes to find we are already approaching our destination.

The clinic looks smaller and more hidden than I remember. It's tucked behind a gas station on the edge of town, and has no visible sign from the road, as if treating pain is something to be ashamed of. We turn into the empty parking lot and claim a space in front of the door with the words "Pain Clinic" on it in small white print.

Mom puts the car in park and reaches for her purse. She pauses for a moment, clutching the bag to her chest and taking a slow, meditative breath before reaching for the door handle. "Here goes nothing," she says.

"Good luck, mom!" I cheer.

"Text us if you need backup." Rachel adds.

"Thanks girls. I'm sure I will be fine."

I notice how stiff mom looks as she leaves the car and heads toward the entrance. My own back twinges as I try to imagine how intensely hers hurts. With each step she takes, I imagine the excruciating electric shock of nerve pain that must be coursing up through her left leg and into her lower back, causing her muscles to spasm. It occurs to me, like it has many times before, that I would want to kill myself if that happened to me. Just a little extra methadone and my heart would stop...

I regret the thought as soon as it enters my mind. I shake my head briskly in an attempt to force it out. I'm sure mom would be horrified if she knew what I was thinking. An eternal optimist, she would find such utter pessimism weak, deplorable, even sinful. I don't want to disappoint her. *Buck up, Loren*, I think to myself. *You're not even the one in pain*. I watch as mom opens the door to the clinic and enters. Now we wait.

Rachel plugs in her iPod and Lil Wayne, a popular rapper comes through the speakers. He sings that he's "got no worries" because he has his "sizzurp"—a cocktail of cough syrup,

codeine (an opioid), and soda. I look at my window and try to forget my own worries as I wait for mom to emerge from the clinic. I cross my fingers and hope that the appointment goes smoothly and that it ends with a renewed prescription.

“Do you think it’s going OK?” Rachel asks, after a few moments have passed. I can hear the concern in her voice.

“I hope so,” I answer. “Mom’s tough. She can handle it.”

We are no longer alone in the parking lot when an old, filthy Chevy pickup pulls into the spot next to us. The driver is a woman about mom’s age and next to her is a twentysomething male. I assume he is her son. The woman is smoking a cigarette and sipping from a koozie covered can. The distinct silver and blue lid peeking out from the top of the koozie tells me she’s drinking a Busch Light . . . at 8:00 in the morning. I continue to stare, as she finishes the drink, tosses the empty can behind her into the back seat, and flicks her cigarette butt out the driver’s side window. She then gets out of the truck and heads for the clinic while the man stays behind and waits.

As I watch the woman, I start to wonder whether she is really in pain, or if she’s an addict. Maybe the guy in the truck isn’t her son at all, but a drug dealer. Or maybe they’re lovers, and he’s just using her for pills.

Then it hits me like a ton of bricks. I’ve just done the very thing that I’ve been fighting against. I’ve stigmatized this poor woman who is probably in pain like my mom and just trying to make it through. Even her early morning beer could be an attempt at self-medication, something to tide her over until her prescription was renewed. How could I be such a hypocrite? Were my suspicions about her fueled by class bias? And if the woman is an addict, does that mean she is any less deserving of my sympathy and respect? I don’t think so.

I notice that Rachel had also been watching the woman. “Were you just thinking what I was thinking?” I ask.

“I was wondering whether that lady is faking it for pills,” she answers, sounding guilty.

“I was too,” I confess. “We should know better than that.”

“Why is it so hard,” Rachel asks, “to give people the benefit of the doubt?”

“I don’t know. I guess the stereotype is too powerful,” I respond. “Let’s not tell mom about this.”

“Deal,” Rachel agrees.

We pass the rest of the time chatting about more pleasant things. Rachel tells me about her last year at college, the friends she’s made, and the boy she likes. I discuss my upcoming wedding plans and the dog my fiancé and I rescued from the local shelter. I glance toward the clinic entrance every few minutes to see if mom has emerged yet, until finally, she does.

“Look, here she comes now!” I announce, pointing out my window.

“She looks happy,” Rachel speculates. I hope she’s right.

I notice the slip of paper mom is clutching in her hand. “Is that a prescription she’s holding?” I ask.

“I guess we’re about to find out.”

Mom opens the door and climbs into the driver’s seat. “Guess what, girls...” she says. “I had a different doctor this time, and he was wonderful! He said he would handle my case from now on.”

“That’s awesome, mom! What happened to the jerk?” Rachel asks.

“I don’t know. He wasn’t even there today,” mom explains. “But this new doctor actually listened to me. He didn’t treat me like a criminal.”

“I’m so happy for you,” I say, reaching for a hug. “So I guess there’s not much of a story this time, huh?”

“No, and thank goodness!” mom answers. “Now who’s ready for breakfast?”

As we drive away from the clinic, the feeling is bittersweet. I am thrilled and relieved that mom’s appointment went smoothly (this time) and that she has a new, compassionate doctor. But I worry the joy will be short-lived. What happens when the new doctor retires or if he moves away? What if he chooses to stop prescribing opioids because the social and legal difficulties involved are too great? Will mom be able to find another doctor? Will she be trapped in excruciating pain, indefinitely, without effective treatment?

I *cannot* let that happen.

### **A Call to Autoethnography**

“She has a *pain* problem, not a *pill* problem.” It’s a statement I’ve made countless times before, but it never seems to sink in. The sociologists stare back at me blankly. I don’t think they get it.

A few months have passed since my visit home, and now I’m standing in a hotel meeting room where I’ve just presented a conference paper on the experience of chronic pain to an audience of seasoned social scientists. During my talk, I briefly mentioned that accessing opioid medications is a structural barrier people in pain often face; and, as I am inclined to do, I used my mom’s experience to illustrate the argument.

“I’m sorry that happened to your mom,” an audience member commented after I finished my presentation. “Those doctors prescribe painkillers so irresponsibly. It’s no wonder she got addicted.”

*Did this person hear a word I said?* I wonder, struggling to keep my cool. I offer my usual mini-lecture on the difference between addiction and dependence and once again I explain that the problem for people, like my mom, with chronic non-cancer pain is that the stigma surrounding opioids makes it difficult for them to access appropriate treatment.

“Well I imagine there has to be other, safer ways to manage pain besides opioids,” a distinguished-looking man in the front row suggests. “Shouldn’t doctors be focusing on alternative methods anyway? Perhaps this hesitation to prescribe narcotic painkillers is really a step forward.”

*A step forward? Did he really just say that?* Hot, restrained tears poach the backs of my eyeballs. It takes every ounce of my willpower to refrain from screaming, “You damn sadists!” at everyone in the room.

Instead, I nod, force a half-smile, and politely reply, “Of course, doctors should consider alternative methods as well. However, it’s important to keep in mind that opioids are the most effective pain relievers currently available, and not utilizing them would mean forcing millions of people to suffer needlessly.”

The presider saves me when she announces that it’s time to wrap things up so the next group of presenters can claim the room. As I’m packing up my laptop and preparing to leave, I am approached by an audience member who had been silent during the discussion segment.

“Thank you for your talk. I really enjoyed it,” he says softly. I notice how white his knuckles are and how tightly he is clutching the handle of his briefcase.

“You’re very welcome,” I reply. “I’m so glad you liked it.”

He sighs. “I can’t tell you how much it means to me to know that someone else understands what I’m going through. I’ve been hurting for 10 years and it’s so hard to find a doctor who will treat me. They always assume that I’m an addict.”

“An assumption not just limited to doctors apparently,” I tease, motioning to the empty seats where the opinionated audience members had been sitting. “What can we do to make people understand?”

My new acquaintance is silent for a moment before replying. “Maybe the answer lies in our stories,” he says. “If people could see . . . if they could just feel, even for a moment, what it’s like to live like your mom and me. If they only understood what we went through . . . maybe things would change.”

“Yes, perhaps you’re right,” I say. My pulse quickens at the thought of writing such a story—not the typical qualitative piece with codes and themes and small chunks of participants’ stories separated by academic jargon and strings of citations— but a real story—the kind that invites the reader into the experience and (hopefully) evokes their emotions—the kind that autoethnographers are writing.

Could I write that way? I can’t write my mom’s story. I can’t tell the story of living with chronic pain. But could I write my own story? Could I tell the story of living with chronic pain in the family? Nervous sweat and goose bumps share space on my skin as I rush with purpose back to the solitude of my hotel room. Once there, I power up my laptop, open a blank word document, and let the story unfold. *She has a pain problem, not a pill problem...*

## **Future Directions**

For the past 15 years, my mother’s experience with chronic pain and opioids has profoundly impacted nearly every aspect of my life. Each time I read a news story about the

“prescription painkiller epidemic” or see an image of opioid addiction in the media, my heart races and my mind is flooded with fear about what the future holds for my mom and for our family. I am terrified that someday the negative public perception of opioids will so far outweigh the positive that my mom will no longer have access to her medication and will be trapped in excruciating pain, indefinitely, with no hope for relief.

With her medicine, my mom’s life is as fulfilling as anyone without a serious health condition could expect. Aside from the pain, she is in excellent health and is more active than most people I know. A former lawyer, she now runs an Internet business from home. She is also a successful dog trainer and people from all over the country call her day and night for advice. She is a wonderful mother, loving wife, and has been happily married to my dad for 28 years. When I tell people these things, they are often shocked; not shocked that someone in pain can do these things (sometimes they are) but surprised that a person could function at such a level while on high doses of opioids. I am not sure what they imagine someone on opioids must be like. Perhaps they envision the opioid addicts on the TV show *Intervention*, who spend all day getting high and committing crimes to obtain pills. Aside from the two times a day (5:00 a.m. and 5:00 p.m.) that my mom takes her methadone and rests for an hour until it takes effect, her daily routine is nothing out of the ordinary. She is still in pain all of the time, but with her medicine, it is manageable.

There was a popular film released in 2002 called, *Panic Room*, in which a woman, played by Jodie Foster, and her young daughter, played by Kristen Stewart, hide in their home’s secret room (the “panic room”) after three armed men break in to rob them.

One of the most dramatic scenes in the film is when the daughter, a diabetic, becomes severely hypoglycemic and her life depends on receiving a shot of glucagon, which is just out of

reach outside the panic room. The terror the mother feels during this scene is just how I feel each time my mom's pain medicine prescription is threatened. Mom needs her medicine to survive, just as a diabetic would need glucagon or insulin. But society does not view opioids the same way they view medicine for diabetes. Unlike insulin, people can get addicted to opioids, and every year thousands of people overdose on them and die. In an effort to prevent such tragic consequences, well-meaning legislators, doctors, and others create barriers to make it more difficult for people to access opioids. Unfortunately, even the most well-meaning actions can have damaging, unintended consequences. My aim in writing this autoethnography has been to shed light on some of those consequences.

For a long time, I was angry at people who misused opioids, as if they were to blame for my mom's struggles. In conversations with others, I emphasized the distinction between my mom's "legitimate" use of opioids from "illegitimate" use. This form of boundary maintenance has been noted in a number of qualitative studies on stigma. For example, Kowalewski (1988) found that the gay men he interviewed actively distanced themselves from gay men who also had AIDS, as a means to avoid being doubly stigmatized. Similarly, Lavin (2013) describes how strippers employ particular strategies to avoid being doubly stigmatized as both sex workers and drug users. Through writing this autoethnography, I have come to realize that I have been guilty of attempting to legitimize medical opioid use at the expense of further delegitimizing opioid addiction. This is highly problematic, as it serves no other purpose than to pit two similarly marginalized groups against each other while further enhancing the stigma surrounding opioids. This vilification of opioid addiction harms pain patients and addicts alike and was not my intention in writing this autoethnography.

So where, then, do we go from here? One issue that needs immediate attention is the lack of pain management training among doctors. Many doctors simply do not have the knowledge or experience necessary to appropriately deliver opioid therapy to people with chronic pain.

Another pressing issue is the shortage of doctors specializing in pain management. In 2007, there were only four board certified pain physicians per 100,000 patients with chronic pain in the United States (Breuer et al. 2007). As the number of people with chronic pain grows, so must the number of pain specialists. Along with increasing access to pain treatment, it is also important to increase access to treatment for opioid addiction and to mental health care in general. A study by S. S. Martins and colleagues (2012) found that many people who become addicted to opioids use them to self-medicate for mood and anxiety disorders. If mental health treatment was more widely available, it is likely that rates of opioid addiction and overdose would decline.

Most importantly, I believe the answer lies in reducing the stigma surrounding opioids; not only for people like my mom, but for all parties involved. A similar thing is already happening around the country with marijuana, a substance the Drug Enforcement Administration still classifies as more dangerous than prescription opioids. So far, 21 states and the District of Columbia have legalized marijuana for medicinal purposes and that number is likely to continue to grow as more stories of people benefiting from marijuana seep into the public sphere. We need to make visible those same types of stories about opioids. While some people who use opioids do develop problems with them, most do not. Yet, I have never seen or read a positive story about opioid use in the media. The images of opioids that dominate are the most extreme, the most tragic, and the most stigmatizing. What I attempted to do in this autoethnography was to tell a different story about opioids; to give readers a glimpse of a lifeworld in which the problem

is not drugs, but the stigma surrounding them; and to demonstrate the myriad ways this stigma can harm people with chronic pain and their families.

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### **Chapter Three:**

## **Narratives Regarding Prescription Opioids in the *New York Times*: Implications for the Treatment of Chronic Pain**

The news media play an active role in shaping our reality by circulating stories that define problems, identify causes, make moral judgments, and suggest solutions (Dubriwny 2009). Stories about prescription opioids told in the news have the potential to influence public opinion and policy decisions that affect all parties involved in the treatment of chronic non-cancer pain (hereafter referred to as chronic pain). A growing body of research demonstrates that people with chronic pain who rely on opioids experience stigma and barriers to treatment that hinder their ability to achieve adequate pain relief (Gardner and Sandhu 1997; McCaffery and Pasero 2001; Peppin 2009; Vallerand and Nowak 2010; White and Seibold 2008). News coverage of predominantly negative stories about the distribution and use of prescription opioids may compound these struggles for people with chronic pain.

In this chapter, I report on a qualitative analysis of national news articles regarding prescription opioids published in the *New York Times* between 2000 and 2013. Two competing narratives emerge in the data: a story about the “prescription painkiller epidemic” and a story about the “crisis of unrelieved pain.” While on the surface these narratives seem to oppose each other, taken together they construct the treatment of chronic pain with opioids as inherently different and more dangerous than the use of opioids for the treatment of pain associated with cancer or at the end of life. I argue that these narratives may contribute to an environment in which people with chronic pain who rely on opioids for pain relief are singled out, stigmatized,

and discriminated against both within and outside of the health care system. In the following sections, I will summarize the current controversy surrounding the use of opioids for chronic pain, synthesize the literature on the importance of narratives told in the news, and employ Loseke's (2012) method for the empirical analysis of formula stories to examine my data. Finally, I discuss the implications of my findings for the treatment of chronic pain.

### **The Treatment of Chronic Pain with Opioids**

Prescription opioids have long been mainstays for treating severe acute pain, pain related to cancer, and pain at the end of life, but the treatment of chronic pain with opioids is controversial (Chou et al. 2009). First publications advocating the use of opioids for chronic pain appeared in the medical literature in the mid-1980s, and the prescribing of opioids for chronic pain rose sharply over the following decade (Portenoy and Foley 1986; Sng and Schug 2009). Not long after doctors began prescribing opioids more liberally for patients with chronic pain, public concern grew over the "street use" of prescription opioids, and the media widely reported rising rates of opioid abuse, addiction, and overdose deaths. Since the turn of the century, media attention has constructed the widespread use of prescription opioids as a major social problem, deemed the "prescription painkiller epidemic." Public outcry surrounding the "epidemic" has spurred actions by legislators and doctors to limit the distribution of opioids with the goal of curbing diversion, abuse, and addiction (Libby 2005; Manchikanti 2006; Rigg et al. 2010). Most of these actions have specifically targeted the treatment of chronic pain.

The current consensus in the medical community is that doctors should take a series of precautions when prescribing opioids to chronic pain patients, with the goal of reducing opioid-related abuses and harms (Reuben et al. 2015). Medical guidelines recommend that chronic pain patients receiving opioid therapy visit their doctor frequently (every 30 to 90 days), submit to

regular or random urine drug screenings, and/or receive routine psychological evaluations. Chronic pain patients are often prohibited from using more than one doctor or pharmacy, having prescriptions faxed, or filling prescriptions early (Buchman and Ho 2013; Chou et al. 2009; Collen 2009). Many doctors are hesitant to prescribe opioids to chronic pain patients due to fears of abuse, diversion, addiction, adverse side effects, and encountering regulatory scrutiny (Colwell 2011; Libby 2005; Nwokeji et al. 2007). Thus, people with chronic pain face numerous barriers to accessing treatment with opioids.

In addition to barriers to access, patients with chronic pain who rely on opioids often experience a great deal of stigma surrounding their treatment. Vallerand and Nowak (2010) report that the chronic pain patients they interviewed felt stigmatized as addicted or morally weak and encountered negativity and disdain surrounding their medication use from family and friends, employers and coworkers, and the media. A number of studies also report negative attitudes of physicians and staff toward patients with chronic pain who use or seek opioids (Peppin 2009; Roth, Burgess, and Mahowald 2007; White and Seibold 2008). The literature suggests that while patients with cancer and terminal illness have also been affected by the stigma surrounding opioids (Schuster 1989), doctors are more willing to prescribe opioids for patients with cancer than for those with chronic pain. For example, Roth, Burgess, and Mahowald (2007) found that medical residents expressed greater concern that treating chronic pain (compared with cancer pain) with opioids would cause addiction, abuse, and side-effects, and would draw criticism from faculty or risk sanctioning. The medical residents also showed more empathy for cancer pain and more willingness to give whatever doses necessary for pain control, and were less likely to be annoyed when cancer patients asked for refills.

The question I seek to address in this chapter is, why are chronic pain patients singled out for differential treatment with regards to opioids? One possibility is that people with chronic pain are especially vulnerable to addiction. However, Fishbain and colleagues (2008) found that only a small percentage of people with chronic pain using opioids had abused them or struggled with addiction. They report that risk was less than 1% in people who had never abused drugs or been addicted (Fishbain et al. 2008).

Another possible reason chronic pain patients are singled out is because of the invisibility of chronic pain. Often there is no detectable injury or disease at the source of a patient's chronic pain and there is no medical test to objectively measure pain level. Over time, doctors and others may have trouble believing that a patient's chronic pain is "real" or might suspect the pain is "all in the patient's head." However, this does not explain why people with chronic pain with a known source (e.g. arthritis) or whose doctors agree that their pain is legitimate are also subjected to stigma and barriers to opioid therapy. It also does not explain why people with cancer, who cannot "prove" that they are in pain either, are not similarly marginalized. It seems to be a culturally shared "truth" that patients with cancer and at the end of life are deserving of treatment with opioids, but for some reason, this is not the case for patients with chronic pain. Roth, Burgess, and Mahowald (2007:266) argue:

Certain beliefs, attitudes, and disease models about pain and how it should be handled by patients and treated by physicians are formed long before students arrive in medical school and are molded by ethnic and cultural values and norms.

One source of these cultural values and norms is narratives told in the news media.

### **Narratives and the News Media**

Numerous scholars have argued that narratives are the essence of human meaning-making and identity construction (Bruner 1987; Ewick and Silbey 1995; Loseke 2007; Mishler

1995). The stories people tell contain *symbolic codes*, or “systems of ideas about how the world does work, how the world should work, and about the rights and responsibilities among people in this world” (Loseke 2012:253). Narratives both reflect and effect shared cultural understandings about the way life is and should be.

Narratives are especially important in heterogeneous societies, such as the U.S., where individuals spend increasing amounts of time interacting with unfamiliar and diverse peoples. According to Loseke (2012:252), “The more social relations involve people who are strangers to one another, the more these relations are – and must be – informed by preexisting images.” One source of these pre-existing images is narratives told in the public sphere. When individuals are confronted with an unfamiliar person or issue, they must rely on culturally circulating stories about that “type” of person or issue in order to make evaluations or decisions for action.

Social problems claimsmakers often use narratives to convince the public that “morally intolerable conditions exist and must be eliminated” (Loseke 2007:678). The melodrama is the typical genre in social problems narratives (Nelson-Rowe 1995). Melodramatic plots feature the principle identities of extreme villains and victims. They portray power relations, interests, values, and motives in terms of good and evil, weak and strong characters (Nelson-Rowe 1995). These are the kinds of stories that have potential to convince audience members that a problem is at hand that is intolerable and something must be done about it.

The news media are an important source of social problems narratives. According to Dubriwny (2009:107):

News plays an active role in shaping our everyday reality...News is used by scholars to construct and transform reality; to frame that reality by defining problems, diagnosing causes, making moral judgments, and suggesting remedies; and to circulate meanings that reproduce social and economic relationships.

Narratives found in newspapers may be especially salient, because this form of media largely attempts to reflect and construct dominant cultural values, and politicians and other members of the elite openly favor the newspaper as a source of news (Kelly 1996). According to Connolly-Ahern and Broadway (2008:362), “understanding how the media frame an issue provides a context for understanding how the public may view an issue or, at least, what types of sense-making patterns may influence public perception.” In their study on public opinion of drug policy, Blendon and Young (1998) conclude that the American public’s views on drugs are greatly influenced by the content and extent of media coverage on drug-related issues.

Narratives told in the news offer a depiction of the world from a particular point of view, and are an arena in which public vocabularies develop and subsequently inform our lives (Dubriwny 2009). These stories are not just practical and symbolic actions; they are also part of the political process (Jones and MacBeth 2010). Newspapers construct images of types of characters that influence public opinion and debate, shape the implementation of public policy, and influence the lived experiences of individuals (Clawson and Trice 2000; Kelly 1996; Shah et al. 2002). Popular narratives, such as those found in newspapers, “exclude the experiences and views of some sectors of society while including and privileging others” (Mishler 1995:109), and in doing so, affect who society views as “legitimate” or “worthy” of help (Brush 1997). Whether it is intentional or not, newspapers can also be a source of structural stigma which, according to Corrigan and colleagues (2005:551), “is formed by sociopolitical forces and represents policies of private and government institutions that restrict the opportunities of the groups that are stigmatized.” Unfortunately, “when the news media frames a group in a negative light, it propagates prejudice and discrimination” (Corrigan et al. 2005:551).

Few studies have examined the representation of prescription opioids in the news. A study by Whelan, Asbridge, and Haydt (2011) on newspaper portrayals of OxyContin (a widely prescribed opioid) found that news coverage of the drug emphasized the problems of abuse, addiction, crime, and death rather than the use of OxyContin for the treatment of pain. Baumrucker (2001:155) also highlights the media emphasis on crime with regards to OxyContin, and argues that, “Since OxyContin is an excellent drug that is having big problems with the media...the result is to cause physicians and other health professionals to steer clear of prescribing it for patients who actually need it.” The current study will contribute to the existing literature on opioids and the media by examining the characteristics (i.e. plots, characters, and morals) of newspaper stories regarding prescription opioids and considering their implications for the treatment of chronic pain.

## **Methods**

The data for this study are national newspaper articles, including news stories, editorials, and letters to the editor, published in the *New York Times*. I chose the *New York Times* because it is the most popular newspaper in the United States and is widely regarded as a national newspaper of record. I used the LexisNexis Academic database to acquire all articles about prescription opioid painkillers published in the *New York Times* between 2000 and 2013. This timeline is appropriate because news coverage regarding prescription painkillers became widespread at the turn of the century and has continued to be a popular topic in the news (Whelan, Asbridge, and Haydt 2011). I used the following search terms to locate relevant articles: opioids, prescription painkillers, prescription drugs, pain management, pain treatment, pain clinics, chronic pain, and OxyContin. In my final sample, I only included articles with stories written in a narrative format, with settings, plots, and characters. In total, my search

yielded 203 publications relevant to the topic that were published between April 6, 2000 and September 14, 2013.

I used Loseke's (2012) method for the empirical analysis of formula stories to analyze my data. This method involves four steps. The first step is *establishing story context*. At this stage I considered the following questions: who authored the stories? Are the stories being claimed as fact or fiction? What audience are the stories intended for? What was the author's purpose in telling each story? Since most of the data were news stories, the authors of these articles were journalists who presented the stories as "factual" accounts of "real" things happening to real people – and each story was told with the purpose of "informing" the general public about an opioid-related issue. Because a disproportionate amount of news stories about drug incidents and policies are told from the perspectives of police and court officials, I assumed that many of the stories were told from the perspective of law enforcement agencies (Chermak 1997). Editorials and letters to the editor also included stories of "real" things happening to "real" people, but unlike in the news stories, the authors of these articles openly expressed their opinions. Some authors expressed positive attitudes towards opioids (i.e. emphasized the necessity of their use for the treatment of pain) and others expressed more negative attitudes (i.e. emphasized the dangers of opioid abuse and addiction).

The second step is *close reading*. At this stage I attempted to get a sense of the data as a story. I read through the articles multiple times, noting the plots, characters, and morals that emerged. What I found was that each of the 203 individual articles could be categorized into one of two larger narratives: a story about the "prescription painkiller epidemic," which was the dominant narrative that appeared in the majority of the articles, and a less common narrative

about the “crisis of unrelieved pain” that appeared in the remaining articles. From this point on, I treated the data as if there were two, rather than 203 narratives present in the articles.

The third step is *categorize explicit descriptions of major characters*. At this stage I made note of all statements about the characters in each story, and paid attention to similarities and differences between the characters across the stories. I found that the story of the “prescription painkiller epidemic” involved several characters, including opioid addicts and doctors as villains; and children, women, the elderly, and chronic pain patients as victims. The story of the “crisis of unrelieved pain” also included several characters, including legislators, law enforcement officials, and doctors as villains; and “legitimate” pain patients as victims.

The fourth and final step is *unpack symbolic codes*. At this point I asked about the statements made in each story: “What knowledge about the world does this statement assume? What would I need to believe about the world for this statement to be believable and important? What specific values are being reflected/transmitted?” (Loseke 2012:262). I found that in order for the stories to make sense, the readers must have shared understandings of the nature of addiction and the nature of pain, as well as shared understandings of the responsibilities of doctors in dealing with addiction and pain.

My aim in the analysis was not to assess the “truth” of the stories or to argue for the “superiority” of one narrative over the other, but rather to look for generalities and patterns in order to uncover the underlying cultural assumptions which might serve to justify the marginalization of people with chronic pain. In my analysis I considered questions like: What themes were similar across the stories? What did the plots, characters, and morals of the stories have in common with one another, and how were they different? Also, what plots, characters, and morals could have been present, but were not? Finally, I considered the types pain treatment

that were, and were not, supported by the stories, and how this might translate into stigmatization and barriers faced by people with chronic pain.

## **Findings**

Two overarching narratives emerged in the data – a story about the “prescription painkiller epidemic” and a story about the “crisis of unrelieved pain.” In the following sections, I will describe the plots, characters, and morals of each story, using quotes from the articles to illustrate story characteristics along the way.

### **The Prescription Painkiller Epidemic Story**

**The plot.** An overwhelming majority of the newspaper articles tell stories about prescription opioid abuse, constructed as a serious, widespread social problem requiring immediate public attention. Many of the articles begin with a sense of urgency regarding the prevalence of prescription opioid abuse and dramatize the scope of the problem with statements such as, “Prescription drug abuse is rampant in all parts of this country” (July 21, 2007)<sup>2</sup>, and, “The problem of prescription painkiller abuse is much bigger than people realize” (April 20, 2004). The articles imply that opioid abuse, like an infectious disease, is contagious, out of control, and spreading to every corner of the United States. Readers are warned that opioid overdoses have become “epidemic” and that the problem is “bad and getting worse” (May 9, 2012). According to one story, “Prescription painkillers are so readily accessible, so easy to obtain, that they are ravaging society and ending many young lives” (June 19, 2012). Many of the articles claim that prescription painkiller abuse is far worse than any other social problem. One article states, “If you look at the problem, it’s the darkest, most malevolent thing you’ve ever seen” (April 20, 2011).

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<sup>2</sup> I reference each article by date in the body of this chapter and have included a list of all bylines in Appendix B.

A number of articles compare the “prescription painkiller epidemic” to problems with illegal drugs. With titles like, *Legal Drugs Kill Far More than Illegal* (June 14, 2008), readers are encouraged to believe that there is a “prescription painkiller problem” and that this problem is worse than the illegal drug problem. One article, for example, claims that, “America’s drug problem is shifting from illicit substances like cocaine to abuse of prescription painkillers” (July 17, 2012). Another reports, “Painkillers now take the lives of more Americans than heroin and cocaine combined” (January 26, 2013). An underlying assumption throughout the articles is that readers share an understanding of illegal drug use as an unacceptable, dangerous behavior that leads somewhat inevitably to addiction and death. Readers are encouraged to believe that they have more to fear from prescription drug abuse than illegal drug abuse, because prescription drug abuse is more widespread. As one article states, “And whereas cocaine and heroin have been concentrated in big cities, prescription drug abuse has spread nearly everywhere” (July 17, 2012).

Many articles discuss the economic toll of prescription painkillers on the country and stress that the problem costs not only lives, but money as well. As one article reports, “The economic costs associated with the painkiller boom have also proved enormous, giving rise to a host of unanticipated medical, legal and social costs” (June 23, 2013). Another argues, “Even for those of us who don’t inhale, the misuse and abuse of prescription painkillers called opioids should matter because, putting moral and ethics aside for the moment, it’s costing us billions of dollars” (September 20, 2009). Another article notes, “When you think about the cost involved in lives and families, not to mention dollars, it’s pretty startling” (January 6, 2011).

**The characters.** There are villains and victims in the story of the “prescription painkiller epidemic.” The villains are opioid addicts and doctors accused of overprescribing opioids, and the victims are children, women, the elderly, and chronic pain patients.

*Opioid addicts as villains.* Opioid addicts are portrayed as desperate and dangerous criminals who will lie, manipulate, steal, and even use violence to satisfy their need to get high. Readers are warned that “robberies, burglaries and homicides have been committed by those seeking addictive pills” (April 17, 2012), and, “if someone breaks into your home and steals your flat-screen TV...they’re not looking to make a mortgage payment. They’re looking to buy Percocet” (August 8, 2011). One article claims, “We’re seeing people desperately and aggressively trying to get their hands on these pills...Home invasions, robberies, assaults, homicides, thefts – all kinds of crimes are being linked to prescription drugs” (September 24, 2010). Another article tells three, shocking stories about crimes committed by opioid addicts: “In Rockland, Maine, one wielded a machete as he leapt over a pharmacy counter to snatch the painkiller oxycodone, gulping some before he fled...In Satellite Beach, Florida, a robber threatened a pharmacist with a cordless drill...and in North Highlands, California, a holdup led to a shootout that left a pharmacy worker dead” (February 7, 2011).

*Doctors as villains.* The second type of villain, doctors accused of overprescribing opioids, are portrayed as irresponsible, greedy, and unconcerned with the safety of their patients. Article titles such as, *Doctor or Drug Pusher* (June 17, 2007) and *When Teenagers Abuse Prescription Drugs, the Fault May Be the Doctor’s* (December 27, 2005), point to opioid-prescribing doctors as the primary cause of the “painkiller epidemic.” Articles make claims such as, “Doctors are prescribing [opioids] like crazy” (April 9, 2012) and, doctors are “giving high

daily dosages of powerful drugs for ailments like back pain for far too long without evidence that the drugs worked” (July 29, 2010).

There are many stories featuring villain doctor characters. One article tells of villain doctors who “write fraudulent prescriptions to support their own substance abuse, exchange prescriptions for sexual favors or monetary kickbacks, and grossly overprescribe opioids, causing grave harm to patients” (July 29, 2005). Another article reports, “A small number of doctors willingly prescribe potentially lethal doses of narcotic drugs for no medical reason” (April 17, 2012). According to these articles, the motive is financial: “Doctors who prescribe in bad faith are drug dealers with a medical license” (April 17, 2012). “There are bad apples among members of the medical profession. There are some doctors who charge for medical exams that they never do and provide phony patients with prescriptions for narcotics to feed their habits or sell on the street” (January 10, 2006).

Other articles present doctors as lazy villains. These doctors wrongfully prescribe opioids, not out of greed, but because they simply are simply too lazy to spend the necessary amount of time and energy necessary to determine whether or not their patients are “legitimate.” As one article observes, “Often it’s easier just...to give a narcotic rather than taking the time to have a conversation. It’s not always easy to do the right thing” (August 6, 2013).

Occasionally, doctors are portrayed as unwitting villains. They prescribe opioids when they shouldn’t, not out of greed, but because they are too easily manipulated by opioid addicts, the other type of villain in the “prescription painkiller epidemic” story. In one article, a physician describes his experience treating patients addicted to opioids. He writes:

A mentor had cautioned me that addicts are often creative, ruthless, persistent and even seductive to get what they need. But as a new practitioner, I was like a blossoming teenage girl, startled by my sudden power and vulnerable to experienced advances (July 20, 2006).

Another article claims, “Most of these physicians are compassionate people trying to help suffering patients but are sometimes fooled by clever addicts, drug dealers or undercover agents who fake their pain” (January 10, 2006).

*Children as victims.* A common tactic used by social problems claimsmakers is to highlight the innocence of victims. In American society, children epitomize innocence, and crimes against children are considered especially heinous. In line with this tactic, with titles like, *Newly Born, and Withdrawing from Painkillers* (April 10, 2011) and *Pain Drugs May Lead to Birth Defects* (March 22, 2011), many of the newspaper articles emphasize the harm that prescription painkiller abuse poses to children. For example, in one article, “a 13-month-old boy died after he apparently swallowed pills from a bottle of prescription drugs that his parents had given him to play with as a rattle” (October 15, 2011). In another article, “a high school athlete became addicted to prescription painkillers after a series of injuries. Eventually, he turned to heroin because it was easier to get. He died from an overdose at age 18” (June 9, 2012). This example demonstrates what the overarching story is claiming about opioids – that they are inherently addictive and dangerous drugs that lead almost inevitably to death. In an article authored by the mother of a son addicted to OxyContin, she writes, “It’s really no different than having a loaded gun just lying around the house” (September 24, 2010).

In line with a typical social problems story tactic, readers are warned that the painkiller problem is so widespread that *all* youth are in danger and *no* children are safe. A quote from one article reads, “Around here, everyone has a kid who’s addicted...It doesn’t matter if you’re a police chief, a judge or a Baptist preacher. It’s kind of like a rite of passage” (April 20, 2011). Another reports, “Almost one out of every 10 high school seniors has abused prescription drugs” (July 29, 2005).

*Women as victims.* Women also are constructed as a group that is particularly victimized by the “prescription painkiller epidemic.” One article argues, “Women are dying from prescription painkillers at rates that we have never seen before” (July 8, 2013). Another states, “More women now die of overdoses from pain pills like OxyContin than from cervical cancer or homicide” (July 3, 2013).

*The elderly as victims.* Crimes against the elderly also are emphasized. As one article claims, “Opiate painkillers and other prescription drugs, officials say, are driving addiction and crime like never before; with addicts singling out the homes of sick or elderly people” (September 24, 2010). Another article claims, “This is not just about addicts, but little old ladies with arthritis starting to die because of this kind of medical practice” (July 29, 2010).

*Chronic pain patients as victims.* Several articles portray chronic pain patients as victims who were prescribed opioids by doctors and then became addicted or overdosed as a direct result. For example, one article tells the story of J., a construction worker who was prescribed oxycodone to treat the pain caused by osteoarthritis. The oxycodone treated his pain effectively, but soon “J. was looking forward more to the buzz than to the relief the pills brought.” He went to see two other physicians who, unaware that he was double-dipping, prescribed similar medications. Eventually, J.’s use spiraled out of control. “He was taking dozens of pills a day, often crushing and snorting them to speed the onset of his high...the drugs had marred every facet of his life, from days of missed work to increasing debt, deteriorating health and marital strain” (October 2, 2012).

Another article tells the story of Robby Garvin who, suffering from excruciating spinal deterioration, tried many painkillers before his doctor prescribed methadone. At first the methadone was tremendously effective. Robby called his mother the day after he started taking it

to say, “Mama, this is the first time I have been pain free, this medicine just might really help me.” The next day, as directed, he took two more tablets and then he lay down for a nap. He died of an overdose while asleep (August 17, 2008). Another article tells a similar story: Margaret Moore, who suffered from chronic back pain from a car accident and relied on methadone and valium to manage the pain, was found deceased at home. Her death was declared an accident from methadone toxicity (July 24, 2010).

It should be noted that in *every* story in which a pain patient was prescribed opioids and subsequently became addicted or overdosed, the patient suffered from chronic pain. There were no stories of patients with cancer or terminal illness suffering detrimental consequences from opioids. Such stories imply that even when the source of a patient’s pain is medically visible (e.g. rheumatoid arthritis, spinal deterioration, and injury resulting from a car accident), and even when the opioids initially appear to provide relief, the risks of opioids still outweigh the potential benefits for people with chronic pain.

**The moral.** The tale of the “prescription painkiller epidemic” constructs prescription opioids as highly addictive and deadly drugs that cause extreme harm to society. Any opioid use leads inevitably to addiction and/or overdose, and even when doctors are well-intentioned in prescribing painkillers, negative consequences ensue. Thus, the stories encourage readers to assume that it is rarely (if ever) acceptable to use or prescribe opioids, and *all* pain patients and doctors associated with opioids are suspect. The only acceptable solution to the problem is to enforce strict regulations on the distribution and use of opioids.

### **The Crisis of Unrelieved Pain Story**

**The plot.** A significant minority of newspaper articles construct a narrative that competes with the tale of the “prescription painkiller epidemic.” In this alternative story, there is a

worldwide “crisis of unrelieved pain” in which too many “legitimate” pain patients are suffering because they cannot access the opioid medications they need to relieve their symptoms. Articles make claims such as, “The under-treatment of pain is the meta-problem” (June 23, 2002), and, “The severe under-treatment of pain is an urgent worldwide crisis. Corrective action can wait no longer” (September 17, 2007). One article reports, “Studies in the United States found that up to 41 percent of all cancer patients are in pain and that some 50 percent of seriously ill and dying patients did not have their pain managed” (September 17, 2007).

Many of the stories highlight the immense suffering experienced by those whose pain is undertreated. For example, one article tells the story of patients from Africa whose pain was so bad that they hanged themselves or threw themselves in front of trucks (September 10, 2007). Another article reports, “Undertreated pain destroys lives. As one young woman put it in an e-mail message: ‘The effect of pain had an insidious effect on my life, my outlook, my well-being and my relationships. It affected every sphere of my life’” (March 8, 2005).

**The characters.** In the story of the “crisis of unrelieved pain,” there are several characters: legislators, law enforcement officials, and doctors as villains; and “legitimate” pain patients as victims.

*Legislators and law enforcement officials as villains.* With titles like *Drugs Banned, World’s Poor Suffer in Pain* (September 10, 2007), legislators and law enforcers are accused of victimizing pain patients by making it more difficult for them to get the treatment they need. As one story reports:

Patients with debilitating pain from chronic illness, accidents, surgery or advanced cancer have long had problems getting adequate medication to control their pain and make life worth living. Now the federal government, and especially the Drug Enforcement Administration, is working overtime to make it even harder for doctors to manage serious pain, including that of dying patients trying to exit this world gracefully (January 10, 2006).

Articles about the “crisis of unrelieved pain” argue that, “Pain management has become a crime story when it really should be a health care story” (October 19, 2004), “The war on drugs is a failure that imprisons people who really need treatment” (July 17, 2012), and, “There is a greater chance that patients with a legitimate clinical need would be unnecessarily forced to endure symptoms of pain for a longer period of time” (June 19, 2012).

*Doctors as villains.* Doctors are also portrayed as villains in the “crisis of unrelieved pain” story. While the “epidemic” narrative blames doctors for overprescribing opioids, the “crisis” narrative accuses doctors of making the opposite mistake – wrongfully withholding pain medication from patients who need it. As one article argues, “Many doctors are simply unwilling to prescribe narcotics, no matter how much a patient suffers” (January 10, 2006). A number of stories highlighting the villainy of doctors appear throughout the data. For example, one article tells the story of Christine Link, who says that several doctors had refused to refill the prescription for painkillers she had taken for years for a degenerative joint disease. “I am suffering, and I know I am not the only one,” she says (April 9, 2012). Another article written by a pain patient tells a similar story:

I suffered severe back pain some years ago and remember well on several occasions being talked out of the opioid prescription I knew would work. Even though I had been prescribed opioid drugs before and shown no tendency to abuse or overuse, the doctors showered guilt and fear upon me until I gave into their safer preference. (Was that done for my benefit or their own?). Now I worry about liver damage from years of doctor-recommended high doses of acetaminophen. “You may have to live with some pain,” a doctor is quoted as saying. Some? I wonder how that doctor might feel if he had to live with a pain level of 5 or more every day for years and be told the pain was considered adequately managed (July 1, 2007).

*Legitimate pain patients as victims.* In the “crisis of unrelieved pain” story, the victims are pain patients who are suffering and unable to access appropriate treatment due to the actions of the villains. As one article argues, “Pain patients are the collateral victims here” (June 17,

2007). A number of articles portray racial minorities as particularly victimized by the “crisis of unrelieved pain.” For example, one article states, “Cancer patients and others with severe pain who live in black, Asian and Hispanic neighborhoods may have trouble getting medicine for their pain” (April 6, 2000). Another article reports, “The researchers said that if two groups of a dozen patients sought treatment for pain, one group all white and the other all minority, one fewer patient in the minority group would get the medication” (January 8, 2008).

With titles like, *Painkillers in Short Supply in Poor Countries* (October 9, 2007), other stories highlight how the problem of undertreated pain affects the poor. One article tells the story of a woman from Sierra Leone who, without access to opioids, is suffering tremendously from pain caused by breast cancer. The article reads, “Like millions of others in the world’s poorest countries, she is destined to die in pain. She cannot get the drug she needs” (July 31, 2007).

While the “crisis of unrelieved pain” narrative clearly argues that many pain patients are victims harmed by the actions of legislators, law enforcement officials, and doctors who limit access to opioids, not all actions to regulate opioids are condemned in this story, nor or *all* pain patients portrayed as victims. Rather, most of the articles written from this perspective imply that some regulatory action is acceptable and needed, as long as these actions do not harm pain patients viewed as “legitimate.” Many of the stories include qualifiers when describing the types of pain patients that are harmed by restrictions on opioids. For example, one article claims:

Any efforts to recalibrate guidelines for pain management must not carry the unintended consequence of worsening the already frightening under-treatment of pain in people living with serious and life-threatening medical illnesses like cancer, dementia, organ failure and stroke (April 17, 2012).

Another states, “The regulations should not affect how narcotics are used to treat patients with cancer or those at the end of life, because experts agree that such patients should receive as much pain medication as necessary” (July 29, 2010). By specifying that pain patients with certain

conditions perceived as “legitimate,” (e.g. patients with dementia, organ failure, stroke, or those at the end of life) deserve treatment with opioids, these articles reinforce the idea that there are other “illegitimate” patients who are not deserving of opioid therapy.

**The moral.** The story of the “crisis of unrelieved pain” portrays prescription opioids as essential medications that are being wrongfully withheld from people in pain. This narrative accuses legislators and doctors of allowing “legitimate” patients to suffer needlessly by making it difficult for these patients to access opioids. While this narrative urges fewer restrictions on opioids for patients deemed “legitimate,” it perpetuates the notion that there are “illegitimate” patients who are not deserving of the pain relief opioids can provide.

## **Discussion**

My goals in analyzing the plots, characters, and morals of the stories told in the *New York Times* articles were to uncover the underlying cultural assumptions present and to consider how these assumptions justify the marginalization of patients with chronic pain. Taken together, the stories told in these articles offer a complex portrait of cultural attitudes surrounding pain and prescription opioids in the United States. In the tale of the “prescription painkiller epidemic,” opioids are portrayed as addictive, dangerous narcotics, their users as desperate, violent addicts, and their prescribers as greedy, irresponsible drug dealers. In contrast, the story about the “crisis of unrelieved pain” portrays opioids as essential, life-saving medicines, their users as deserving sufferers, and doctors who refuse to prescribe opioids as uncaring violators of their Hippocratic Oath. While the plots and portrayal of characters are different, they do not entirely contradict each other. Across the data what remains constant is the assumption that some pain and patients are “legitimate,” and deserving of the relief opioids can provide, while others are “illegitimate,” not to be trusted, and not deserving of treatment with opioids.

For patients whose pain has been deemed “legitimate,” the need for pain relief is portrayed as more important than the risk of addiction or overdose posed by opioids. For this minority of patients, treatment with opioids is portrayed as necessary and acceptable, and not to be stigmatized in the same way as is illegal drug use. In order to access opioids and avoid stigma, patients must prove that their pain is “legitimate.” The problem is that “legitimate” is never objectively defined in either narrative. For patients with certain conditions (e.g. cancer and at the end of life), the medical diagnosis is assumed to be automatic proof enough, and the authenticity and severity of these patients’ suffering is not questioned. For people with chronic pain, however, this is not the case. In every news story about a patient spiraling into addiction and/or overdosing, the patients suffered from chronic pain. There are no stories about patients with cancer experiencing negative consequences from using opioids. I argue that these narratives both reflect and contribute to an environment in which people with chronic pain experience stigma and barriers to accessing pain treatment with opioids.

Portrayed as villains in both narratives, doctors seem to be stuck between a rock and a hard place. While in one story they are blamed for opioid abuse and are encouraged to limit their prescribing habits, in the other story they are blamed for the under-treatment of pain and are urged to prescribe more. Doctors seem to have no choice but to prescribe opioids *only* to patients whose conditions are universally perceived as legitimate, and to be suspicious of patients with chronic pain.

Because widely circulating narratives can influence public opinion, shape public policy, and affect the lived experiences of individuals (Clawson and Trice 2000; Kelly 1996; Loseke 2007; Shah et al. 2002), we may assume that the newspaper stories surrounding prescription opioids have consequences for the parties involved with the treatment of chronic non-cancer

pain. Because the legitimacy of chronic pain is questioned, people with these conditions are vulnerable to stigmatization and accusations of malingering or faking their condition to feed an opioid addiction. Melodramatic cultural narratives about prescription opioids in the news likely exacerbate the already-existing struggles with stigma and access to medication that chronic pain patients face.

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## **Chapter Four:**

### **Deserving Patients or Potential Addicts? Using Narrative Analysis to Examine an FDA Hearing on the Labeling of Prescription Opioids**

A growing body of scholarship suggests that decisions made in public policy hearings are not solely shaped by material and political interests, as scholars have previously argued, but that policy decisions are, to a great extent, shaped by socially circulating stories which justify the need for policy action (Fischer 2003; Kaplan 1986; Loseke 2007; Roe 1989; Stone 1989). This is a social constructionist view which holds that decisions about which phenomena require what sorts of policy action are not necessarily made based entirely on any underlying “truth.” Rather, these decisions are guided by cultural beliefs about what makes something a pressing social issue and what the responsibilities of government are in addressing pressing social issues. These beliefs are both reflected and affected through narratives. Speakers in public policy hearings tell stories that draw on widely shared assumptions about how the world works and should work, which types of people are deserving of help and which are deserving of punishment, and what sorts of government interventions are appropriate, in order to convince legislators and the public that policy action is necessary and justified.

My goal in this chapter is to demonstrate, through qualitative narrative analysis, how stories told in an FDA public hearing on the labeling of prescription opioids justified a label change which was intended to reduce the prescribing of opioids to people with chronic non-cancer pain, while preserving access for people with pain associated with cancer and terminal illness. I argue that by drawing on widely held cultural beliefs about pain, addiction, and the

responsibilities of doctors and government regulators, the stories told by the speakers in the hearing had great rhetorical power and were effective in marginalizing the stories of chronic non-cancer pain patients who rely on opioids and who would be most burdened by the label change. In the following sections, I briefly summarize the purpose of the hearing and its outcome, synthesize the literature on the importance of narrative in public policy, and employ Loseke's (2012) method for the empirical analysis of formula stories to examine my data (the full text of the stories told at the hearing). Finally, I discuss the implications of my findings for the treatment of chronic pain, as well as for the narrative approach to exploring policymaking in general.

### **Pain, Opioids, and Public Policy**

Throughout history, opioids have been used to treat a wide range of symptoms, including pain. In the United States, the status of opioids has transitioned through periods of liberal use and periods of relative prohibition (Savage 1996). During the late 1800s, opioids such as morphine were widely available for purchase at drug stores and grocery stores and were commonly used to soothe a number of ailments. At the turn of the century, public concern began to grow over the habit-forming nature of opioids and the U.S. government took action to criminalize their nonmedical use. In 1914, legislators passed the Harrison Act, which granted doctors a gatekeeping role over the legal use of opioids and made it criminal for doctors to prescribe opioids to anyone considered an "addict." Between 1914 and 1938, approximately 25,000 doctors were arrested under the terms of the Harrison Act (Libby 2005). As a result, for the next several decades, doctors prescribed opioids rarely and in the lowest dosages possible for fear of producing addiction in their patients and/or attracting unwanted legal attention.

In the 1980s, a shift took place in the medical profession as concern grew over the under-treatment of pain – particularly among patients with cancer. Doctors, patient advocacy groups,

and others argued that the public fear surrounding opioid addiction in “street addicts” had unjustly outweighed concern over the suffering of patients with cancer. They argued that doctors should be further educated on the distinction between “acceptable” physical dependence in cancer patients and “unacceptable” compulsive behavior in addicts, so that opioids would be more readily relinquished to the former (Schuster 1989; Weissman and Haddox 1989).

Concerns about the under-treatment of pain were also extended to chronic pain not related to cancer; albeit to a lesser extent. First publications on the use of opioids in chronic non-cancer pain appeared in the medical literature in the mid-1980s. In 1986, Portenoy and Foley published a seminal article in which they argued that opioids were safe to use for the treatment of chronic non-cancer pain and that the concern over addiction for these patients had been overrated. The dissemination of this article and others like it were followed by changes in clinical recommendations and marketing activities which led a stark rise in the prescribing of opioids for chronic non-cancer pain beginning in the early 1990s (Sng and Schug 2009). Soon thereafter, however, this new willingness to prescribe opioids for non-cancer pain was fraught with controversy.

In 1996, Purdue Pharma released OxyContin, an extended release long-acting version of oxycodone, a commonly prescribed pain reliever. Soon after the drug’s release, recreational users found that crushing and snorting or injecting OxyContin would produce a euphoric feeling similar to that of heroin, and OxyContin became a popular street drug. A media firestorm quickly ensued, and rates of overdose deaths and addictions related to OxyContin were widely publicized. This led to lawsuit against Purdue Pharma and public outcry for the DEA and FDA to “do something” about the problem, which was extended to include all prescription opioids. Under pressure from the public, the DEA enacted an aggressive plan to suppress the illegal use

of opioids, which involved the public pursuit and prosecution of doctors accused of prescribing opioids inappropriately – a strategy reminiscent of the Harrison act in the early 20<sup>th</sup> century. Deemed the “war on the prescription painkillers,” these actions cast a chill over the doctor-pain patient relationship and scared many doctors away from pain management altogether (Libby 2005).

At the same time that there was renewed public outcry over addiction and death related to opioids, there was also a resurgence of public attention afforded to the under-treatment of pain – particularly with regards to pain related to cancer and terminal illness. As in the 1980s, critics of the “war on prescription painkillers” again argued that the fear and stigma surrounding opioids which had soared in the late 1990s had resulted in many “legitimate” patients not receiving adequate pain treatment (Ferrell 1997). Thus, government regulators and policymakers were tasked with engaging in efforts to curb the “prescription painkiller epidemic” while simultaneously reserving access for “legitimate” patients in need of opioids for pain relief.

### **The Role of the FDA**

The Food and Drug Administration (FDA) is mandated by federal law to assure the safety and efficacy of prescription drugs and to minimize risks to the public health through designing safety programs and placing restrictions on drug prescribing, dispensing, and use. With regards to prescription opioids, the FDA is tasked with assuring that patients who need opioids for pain control maintain appropriate access to them, while also limiting the misuse and abuse of opioids to the extent that is possible. The FDA is also responsible for monitoring the advertising of prescription opioids by pharmaceutical companies (Manchikanti 2006).

The public hearing I examine in this chapter, entitled, “Impact of Approved Labeling on Chronic Opioid Therapy” (Part 15 Hearing, February 7-8, 2013), is one example of an attempt by

the FDA to fulfill their public mandate to “do something” about the “prescription painkiller epidemic.” According to the *Federal Register* bulletin in which the hearing was announced, the purpose of the hearing was to “obtain information – particularly scientific evidence, such as study data or peer-reviewed analyses – from expert members of the public, on issues pertaining to the use of opioid drugs in the treatment of chronic pain” (DHHS 2012:75178). And, “to find a balance between minimizing opioid drug abuse and misuse, while simultaneously enabling appropriate access to pain-relieving drugs” (DHHS 2012:75178).

Testimony at the hearing was provided by a range of individuals and groups representing different views regarding changes to the current prescription opioid labeling, including: doctors, family members of loved ones lost to opioid-related deaths, pain patient advocates, public health advocates, pharmaceutical manufacturers, pharmacists, academics, and chronic pain patients. Seven months after the hearing in September 2013, the FDA made safety labeling changes aimed at reducing the prescribing of extended-release, long-acting (ER/LA) opioids in ways that would be particularly burdensome for patients with chronic non-cancer pain.

The label changes enacted after the public hearing were intended to “more effectively communicate to prescribers the serious risks associated with these drugs, and to more clearly describe the population in whom these drugs should be used in light of these serious risks” (FDA 2013:6). The first sentence of the new boxed warning states that ER/LA opioids “expose patients and other users to the risks of opioid addiction, abuse, and misuse which can lead to overdose and death.” The label urges prescribers to “assess each patient’s risk” for addiction before prescribing. It also states that decisions about using ER/LA opioids should not be made solely based on patient’s rating on a pain intensity scale, but also “on a more thoughtful determination that their pain is *severe enough* to require daily, around-the-clock, long-term opioid treatment,

*and* for which alternative treatment options are inadequate” (FDA 2013:7-8, emphasis in original). Finally, the new label recommends that when an ER/LA opioid analgesic is prescribed, prescribers should “monitor patients carefully for signs of abuse and addiction” (FDA 2013:8).

While the FDA did not explicitly single out chronic non-cancer pain in the label change, the new label was likely to affect the treatment of chronic non-cancer patients in particular. This is evidenced first and foremost by the fact that ER/LA opioids, which are often prescribed for chronic non-cancer pain, were the only drugs targeted by the label change. Furthermore, the recommendation that doctors assess each patient’s risk of addiction before prescribing is problematic for patients with chronic non-cancer pain because it has been well-documented that doctors are often too quick to label these patients as “drug-seeking” or as “addicts” (Reuben et al. 2015). The second recommendation, that doctors only prescribe opioids to patients with *severe* pain, is also troublesome for chronic non-cancer pain patients, who often struggle to “prove” that their pain is as severe as they are reporting. Doctors can only assess the severity of a patient’s pain by listening to what that patient says; and research has shown that doctors often take some patients’ (e.g. those with cancer) reports of pain more seriously than others (e.g. those with chronic non-cancer pain) (Roth, Burgess, and Mahowald 2007). The third recommendation, that ER/LA opioids only be prescribed when no other alternative treatments are adequate, can also pose a problem for patients who are managing well on the ER/LA opioid treatment they are currently receiving, but find themselves coerced by their doctors into experimenting with new treatments, which may be less effective and have more side effects.

The final recommendation that doctors should closely monitor patients who use ER/LA opioids for signs of abuse and addiction can be especially difficult for patients. As I wrote about in Chapter Two regarding my mother’s experience as a chronic non-cancer pain patient who

relies on ER/LA opioids, the frequent doctor's visits, random pill counts, urine drug tests, and other monitoring techniques can be experienced as highly stigmatizing and financially and emotionally burdensome for people with chronic non-cancer pain. For many chronic non-cancer pain patients like my mother, the label change is not perceived as a welcome solution to the "prescription painkiller epidemic," but rather as a misguided and unjustified punishment. This was evidenced by the hundreds of chronic non-cancer pain patients who wrote to the FDA after the hearing to express concern that a label change would negatively impact their access to treatment (FDA 2013). Regardless, the label change was made.

As both a sociologist interested in narrative and as a daughter of a mother with chronic non-cancer pain who relies on ER/LA opioids, the question I seek to answer in this chapter is, how was the label change justified? In other words, how was it that the FDA officials came to agree that a necessary and logical solution to the "prescription painkiller epidemic" would be to approve a label that would make it more difficult for patients with chronic non-cancer pain to access pain treatment with opioids? And, more specifically, how was this justification accomplished through the stories told in the hearing? In order to begin to address these questions, I will first review the literature on narrative and public policy.

### **Narrative and Public Policy**

Scholars across a variety of disciplines have written about the importance of narratives for human meaning-making, identity construction, and politics (Bruner 1987; Ewick and Silbey 1995; Loseke 2007; Mishler 1995; Plummer 1995). In this chapter, I take a constructionist approach to narrative, and assume that "actions, events, and identities do not exist 'out there' for us to see; rather, they are constituted through story creating and telling" (Ramirez-Valles 1999:86). The constructionist approach to narrative holds that stories are the way through which

humans make sense of our own identities, the identities of others, and the events that take place in the world around us. It is through stories that we are able to explain cause and effect and give coherence to complex situations and events. It is through stories that we can make sense of the past and give advice about the future. It is through stories that culture is transmitted, maintained, and shaped.

Policy-making is an arena in which stories are particularly important. As Fischer (2003:168) argues, stories “are the means – the only means – by which policymakers can negotiate the realities that confront them.” Speakers in public policy hearings tell stories in order to persuade policymakers that a problem is at hand, that policy intervention is necessary, and that some types of interventions are desirable and others are not. According to Campbell (2002), it is often the case that there is no conclusive evidence about which policy option is likely to work best in addressing a particular issue. Therefore, policymakers cannot make decisions based on objective “truth” regarding which policy actions are “right” and which are “wrong.” Instead, they must rely on evaluating stories to decide which policy decisions are appropriate. These stories contain culturally shared values, norms, and principled beliefs. In short, these stories contain culture (Padamsee 2009).

Stories told in policy hearings contain symbolic codes, or “systems of ideas about how the world does work, how the world should work, and about the rights and responsibilities among people in this world” (Loseke, 2012:253). In other words, these stories both reflect and effect shared cultural understandings about the way life is and should be. Speakers in policy hearings tell stories to give moral meaning to the issues at hand. When a speaker narrates about a past event, she does not simply recount the “facts” of the event, but also conveys a moral attitude toward the event; i.e. “the protagonist of the story acted well, acted badly, is to be praised or

blamed, can be taken as a model for the hearer's own behavior" (Linde 2001:163). Speakers in policy hearings tell stories aimed at convincing policymakers that the policy action they are supporting is the *moral* thing to do. Likewise, policymakers use stories to morally justify the policy decisions they make. In this way, debates in public policy hearings can be viewed as "competing visions of the moral order" (Steensland 2010:467).

The stories told in public policy hearings usually take the form of causal stories, which define problems, identify causes, and explain the need for particular types of policy action. According to Stone (1989:283), causal stories told in policy hearings are neither right nor wrong, nor mutually exclusive – "They are ideas about causation, and policy politics involves strategically portraying issues so that they can fit one causal idea or another." Speakers in policy hearings define problems they want solved and goals they want achieved through telling causal stories that speak to audiences' shared assumptions about the way things work and the way things should work. These causal stories also serve to construct target populations – the "types" of people whom policy should target in order to achieve the desired goals, and to identify what should be done with, for, or to these people (Schneider and Ingram 1993).

Solutions to policy problems typically involve ascribing benefits and burdens to differently constructed target populations (Schneider and Ingram 1993). Speakers in policy hearings tell stories about characters, often identified as "types" of people, such as victims, villains, and heroes. These characters represent the people associated with the issue the policymakers are seeking to address. Whether a character is constructed as a victim, villain, or hero in the dominant story told at the hearing will influence the way actual people are treated by the outcome of the policy. Policy burdens will most likely be ascribed to negatively constructed

characters and policy benefits will most likely be distributed to positively constructed characters (Loseke 2007; Schneider and Ingram 1993).

The stories told in policy hearings battle each other for dominance. The “best” story wins. The reward for telling the winning story is the power to affect the outcome of a policy that will have real consequences for real people. As Ramirez-Vallez (1999:87) states, “Those who succeed in promulgating a particular narrative...are those who exercise power over others.” But not all stories can be winners, and not all stories even make it onto the agenda in the first place. The stories which are most likely to be persuasive in policy are those that have certain characteristics. First, the storytellers must be viewed as “credible.” Usually stories told by high status “experts” are taken more seriously than those told by those with lower status (Loseke 2007). Persuasive stories will also have “cultural resonance” (Loseke 2007:668) – they will “make sense given what audiences think they know, what they value, and what they regard as appropriate or promising” (Loseke 2007:665). Simply put, for a story to win, the audience has to evaluate it as believable and important.

## **Methods**

The data for this study come from the full text of the FDA public hearing entitled, “Impacted of Approved Labeling of Opioid Therapy – Part 15 Hearing,” which took place in Bethesda, MD, on February 7-8, 2013. I retrieved the full transcript of the hearing through the FDA website (<http://www.fda.gov/Drugs/NewsEvents/ucm326450.htm>) where it is available to the public in PDF format. In total, the transcripts totaled 527 double-spaced pages. In order to make the transcripts searchable, I copied the entire text of the hearing into a word document which resulted in 206 single-spaced pages.

Once the data had been transformed into a searchable document, my next task was to narrow the sample by isolating the stories told in the hearing. I read through the data multiple times, and pulled out only those segments of text that constituted stories about particular, named people. Of the 50 presentations given at the hearing, 16 unique stories were told. These stories became my data.

With my data assembled, I proceeded to employ Loseke's (2012) method for the empirical analysis of formula stories, which involves four steps. I began with step one, *establishing story context*, and considered the questions: Who authored each story? Are the stories being claimed as fact or fiction? What audience(s) are the stories intended for? What was each speaker's purpose in telling each story? I found that the stories in my sample were told by 14 different speakers, including nine family members of loved ones lost to opioid-related deaths, one physician, three chronic pain sufferers, and one patient advocate. Each story was presented as "fact" – an account of "real" things happening to real people – and each was told with the purpose of convincing the audience – the FDA decision-makers – to approve (or not) the proposed label change. Of the 16 stories told, 11 were offered explicitly to support the new label, and five to oppose it.

I then moved on to the second step, *close reading*, and I attempted to get a sense of the data as narrative. I read through the stories multiple times, noting the plots, characters, and morals that emerged. What I found was that each of the 16 individual stories could be categorized into one of two larger stories: a story about the dangers of opioids, which was the dominant narrative told in 11 of the 16 stories, and a much less common narrative about the benefits of opioids, told in the five remaining stories.

Next, I *categorized explicit descriptions of story characters*. I made note of all statements about the characters in each story, and paid attention to similarities and differences between characters across the stories. I found that the story about the dangers of opioids included several characters, including two types of victims – opioid users and their families – and three types of victims: pharmaceutical companies, doctors, and the FDA. The second story about the benefits of opioids, on the other hand, included only one type of character – pain patients who rely on opioids, constructed as victims.

In the fourth and final step, I *unpacked symbolic and emotion codes* by asking about the statements made in each story: “What knowledge about the world does this statement assume? What would I need to believe about the world for this statement to be believable and important? What specific values are being reflected/transmitted?” (Loseke 2012:262). I found that in order for the stories to make sense, the audience members must have shared understandings of the nature of addiction and the nature of pain, as well as shared understandings of the responsibilities of doctors and government officials in dealing with addiction and pain.

My goal in analyzing the data was not to evaluate the “truth” of the stories or to suggest that any one narrative was “superior” to another, but rather to look for generalities and patterns in order to uncover the underlying cultural assumptions which served to justify the outcome of the hearing. In my analysis I considered questions like: What themes were similar across the stories? What did the plots, characters, and morals of the stories have in common with one another? In what ways did they contradict one another? Also, what was missing from the stories that could have been included? In other words, what plots, characters, and morals could have been present, but were not? Finally, I considered the types of policies that were, and were not,

supported by the stories, and how this translated into the distribution of benefits and burdens to chronic pain patients targeted by the label change.

## **Findings**

Two overarching narratives emerged in the data – one about the dangers of opioids, and the other about the benefits of opioids. In the following sections, I will describe the plots, characters, and morals of each story, using quotes from the speakers to illustrate story characteristics along the way.

### **The Dangers of Opioids Story**

**The plot.** In this story, the United States is experiencing a “massive epidemic” in which “one person every 19 minutes dies from an opioid drug” (Lexi Reed Holtum, day two, p. 57). But unlike previous drug epidemics, “This is not an epidemic of abuse. It is an epidemic of overprescribing” (Pete Jackson, day one, p. 35). Pete Jackson (day one, p. 34-35) offers an account of the problem:

Between 1999 and 2010 there was a fourfold increase in the sale of prescription opioids...The result has been a fourfold increase in deaths and a six-fold increase in treatments for addiction to prescription opioids over the past decade...The correlation between sales on the one hand and deaths and treatment admissions on the other is irrefutable evidence that overprescribing is driving this epidemic.

Speakers construct the epidemic as stemming from the increase in opioid prescribing for chronic non-cancer pain in particular. This is illustrated when Ada Guidice-Thompson (day one, p. 22) observes, “In 1992, almost 90 percent of physicians recognized the very real risk of opioid addiction. Then came a shift in practice and opioids began to be prescribed widely for chronic non-cancer pain.” The problem with this shift in opioid prescribing, according to Lexi Reed Holtum (day two, p. 59), is that “there is no scientific evidence backing up long-term use of opioid prescription medicine for non-cancer pain.” In addition to being ineffective for long-term use,

opioids are highly dangerous. “All opioids are highly addictive...all opioids cause depression and thoughts of suicide” (Avi Israel, day one, p. 29).

In short, the plot of the dangers of opioids story is as follows: Doctors began prescribing opioids more readily to patients with chronic non-cancer pain, and an “epidemic of addiction and death” (Ada Guidice-Tompson, day one, p. 23) ensued as a direct result.

**The characters.** There are victims and villains in this story. The victims are people who have been harmed by opioids, along with their loved ones, and the villains are those held responsible for this harm, including: pharmaceutical companies, doctors, and the FDA.

*Opioid users as victims.* The majority of stories about the dangers of opioids are told by family members of young people who died opioid-related deaths. These family members recount in heart-wrenching detail the loss of their loved ones who died much too young. Each of these stories begins with a positive description of the deceased. Teri Kroll (day one, p. 15-16) describes her son Tim as “always a happy kid. He was the source of lots of pride and laughter. He was always my good boy... he loved his family.” Pete Jackson (day one, p. 33-34) describes his daughter Emily as “a wonderful young lady, the babysitter next-door, the pitcher on her softball team, the friendliest girl you could ever possibly meet.” Daniel Placek is described by his parents as “a Navy veteran who was every parent’s dream” (Cheryl and Daniel Placek, day two, p. 141). Similarly, Lexi Reed Holtum (day two, p. 53) describes her late fiancé, Steve Rummler, as “the kind of man that you wanted to be the father of your child.”

Each of these victims’ stories follow a similar format. Their lives were perfect until they were introduced to prescription opioids, either for pain or out of innocent curiosity, and tragic consequences ensued. Most victims were chronic non-cancer pain patients who were prescribed opioids by doctors, became addicted, and eventually died by overdose or suicide. Teri Kroll tells

a story about her son, Tim, who began suffering from severe headaches and was prescribed pain medicine by his doctor. When the pills weren't working, the doctor prescribed a stronger opioid, oxycodone. "Before long, Tim became addicted and fell into a life of psychological despair and torment" (Teri Kroll, day one, p. 18) and soon after died of an overdose. Another parent, Avi Israel (day one, p. 28), shares a dramatic account of his son Michael's death:

After two years of being prescribed hydrocodone for Crohn's disease, Michael got to a point where he saw no way out of his addiction and hated what he was becoming. Michael put a shotgun under his chin and blew half his head off.

Ada Guidice-Tompson's son, also named Michael, was prescribed opioids for pain caused by kidney stones. "The prescriptions continued for two years, until he died in his sleep from prescribed hydromorphone" (Ada Guidice-Tompson, day one, p. 24). In each case, opioids are presented as the direct cause of the person's death, with no other context provided. This is evidenced when Avi Israel (day one, p. 30-31) states, "My son was taking hydrocodone. This is my son's grave."

An important common denominator in all of these stories is the way the speakers construct their lost loved ones as pure innocents who were not to blame for what happened to them. They succumbed to their fate not by choice, but by the inherently dangerous and powerful nature of the drugs. "For some patients, their very first exposure to an opioid starts them on a slippery slope," Ada Guidice-Tompson (day one, p. 24) argues. Similarly, Pete Jackson (day one, p. 33-34) notes "how easily and how innocently an unspeakable accidental tragedy can happen with these dangerous opioid medications." Tish Westrup (day two, p. 45) urges the audience to consider the following:

There's kids who try things at high school, or there's kids like Michael, my son, who followed doctors' directions. None of them got up that morning and said I want to be an addict. None of them wants to be an addict. None of them wanted to die.

Judy Rummler (day two, p. 52) highlights the innocence of her son when she says, “Steve did not want to be an addict. He tried very hard to fight the disease of addiction.” Similarly, Teri Kroll (day one, p. 20) says of her son Tim, “When he could make his own choices, he made the right choice to be a straight edge kid.”

By emphasizing their positive qualities and innocence, the speakers construct their loved ones as pure victims. According to Loseke (2009:503), “Victim is a symbolic code requiring cognitive appraisals that *moral* people have been harmed through *no fault* of their own” (emphasis in original). Pure victims must have “unquestionable morality” and “their virtue and innocence are dramatized in melodramatic narratives” (Loseke 2009:504). By constructing their lost loved ones as pure victims, the speakers likely evoke an emotional response in the FDA decision-makers.

While most of the dangers of opioids stories are told by loved ones of opioid victims, two stories are told by chronic non-cancer pain patients who identify as former opioid addicts. These patients offer detailed accounts of their own experiences with opioids. The following story, read by Jane Ballantyne (day two, p. 101), was written by a patient named Karen:

My experience with opioids has been terrible. It felt like I was a walking zombie. At first, I didn't mind that because it took the pain away, but after a while, I didn't like it. It was not me. It was not my personality. My skin was dry, my hair was falling out my teeth hurt. I was not feeling pain, not feeling life, not feeling anything.

Another chronic non-cancer pain sufferer gives an account of her experience with opioids. Sarah Bowker explains that she had been prescribed hydrocodone by her doctor for pain caused by rheumatoid arthritis. The medication worked well, at first, until she developed a tolerance and needed higher doses to achieve the same relief. Before long, things spiraled out of control:

At this point, I literally couldn't finish a sentence. Words would not come out of my mouth. I was losing my memory. Emotionally, I felt nothing. I had become severely depressed. I convinced myself that my husband and two-year-old daughter were better off without the burden of my being (Sarah Bowker, day two, p. 39).

In both of these cases, opioids began as an effective treatment for chronic non-cancer pain, but eventually resulted in terrible consequences. Once again, no additional context surrounding their addictions is provided. The opioids are constructed as directly to blame for the troubles that followed.

*The families of opioid users as victims.* The other victims in this story are the families of those harmed by opioids. Several of the speakers describe the terrible suffering they experienced due to the addictions and deaths of their loved ones. Teri Kroll (day one, p. 20) describes herself as “a parent who will forever grieve the loss of my child.” Patricia McDonald (day one, p. 48) illustrates the profound sense of grief she endures after her daughter, Adrienne, passed away from an opioid overdose:

I will never see Adrienne’s beautiful face again. I will never hear Adrienne’s giggling laughter. I will never watch as she gets married and share in the joy of becoming a mother. I will never again hug her. I will never again have the joy of hearing her voice on the other side of the phone saying, “Hi, Mom.” I will never ever see Adrienne again.

Lexi Reed Holtum (day two, p. 56) offers a heartbreaking account of how she comforted her daughter after her fiancé, Steve, died from an opioid overdose: “I held her for weeks as she cried in my arms and said, Mommy, why didn’t he just listen to us? Why didn’t he stop taking the pills?” Sarah Bowker (day two, p. 42) asks of the audience, “As you continue to research into this matter, think of my daughter, Ava, who nearly lost her mother because she was so heavily drugged.”

The speakers stress that they are not alone in their grief, and that the opioid problem affects the American family in general. Avi Israel (day one, p. 28-29) asks the audience to consider “what opioids and addiction do to the American family, the unspeakable devastation it leaves behind.” Patricia McDonald (day one, p. 46-47) proclaims, “Across America, my daughter, myself, and the thousands of other kids lost and their grieving families are the statistics. I am a statistic.” Avi Israel (day one, p. 31) quantifies the problem when he says:

Over the last 10 years or so we have had over 100,000 people who have died, we have over 20 million people who are addicted. That brings us to about 500,000 people in this country who have been destroyed because of addiction. That's half a million people.

In addition to describing the grief they endure as a result of their loved ones' opioid use, the family members also suggest that they are not to blame for what happened. They insist that they would have intervened to help their loved ones, had they been given more information. As Patricia McDonald (day one, p. 45) states, "I didn't know Adrienne was in trouble." Similarly, Avi Israel (day two, p. 45) explains, "I, as a parent, did not know how bad the addiction got ahold of my son...All I knew is Michael was taking pain pills." Teri Kroll (day one, p. 20) says to the audience, "Look at me. I'm just a normal mom. I'm not an absentee mom. I was involved, I asked questions." By including these details, the family members also construct themselves as pure victims. They were not "bad" parents who contributed to their children's drug use through abuse or neglect. They were "good" parents who wanted what was best for their children and could not have anticipated the trouble to come. The blame falls elsewhere.

*Pharmaceutical companies as villains.* Villains are characters that are blamed for causing harm to victims. In the dangers of opioids story, pharmaceutical companies, referred to frequently as "Big Pharma" throughout the hearing, are constructed unanimously as villains. Speakers assert that Big Pharma is to blame for the prescription painkiller epidemic because these companies intentionally "downplayed the risks and exaggerated the benefits" of opioids (Ada Guidice-Tompson, day one, p. 24), and "continue to misrepresent data and deflect attention away from the inherent addictive quality of opioids" (Ada Guidice-Tompson, day one, p. 25).

One company in particular, Purdue Pharma, the manufacturer of OxyContin, is often mentioned by name. Avi Israel (day one, p. 32) asks, "Purdue was fined \$600 million for lying to

the American public. How can we trust any pill that they put out is safe? How can we believe anything they say?” Pete Jackson (day one, p. 36) also targets Purdue Pharma when he argues:

Books, medical literature, and court documents all describe in detail the all-expense-paid symposia held at resorts, branded promotional items, targeting the highest prescribers of opioids, manipulating and mischaracterizing clinical data, and intentionally misleading doctors about the true risk of OxyContin.

Similarly, Judy Rummier (day two, p. 50) says, “I don’t mean to pick on Purdue Pharma, but this is a chart of the 200 top drugs in the U.S. market by sales in the year 2010...Purdue made \$3.08 billion selling their drug in this year.”

Big Pharma is constructed as a villain who knowingly and intentionally misled the public regarding the safety of opioids for no reason other than monetary greed. Big Pharma was “focused on nothing but profits” (Avi Israel, day one, p. 30). According to the story, Big Pharma was well aware that opioids were addictive, dangerous, and deadly, but continued to market them and downplay the risks for monetary gain, without regard for the suffering of victims.

*Doctors as villains.* Doctors are also constructed as villains in this story, and their villainy stems from overprescribing. Avi Israel (day one, p. 30) claims, “Opioids are prescribed today just like Halloween candy, every doctor gives them out, everybody hands them out.” Avi also asserts that the victims “all got addicted by following doctors’ directions and taking the pill as prescribed” (Avi Israel, day one, p. 27). Teri Kroll (day one, p. 20) supports this assumption when she says, “It was a doctor who led my son down the path that would ultimately kill him.”

The villainy of doctors is not as straight-forward as is the villainy of Big Pharma. Some doctors are constructed as pure villains, knowingly harming their patients for the sake of profit. For example, Teri Kroll (day one, p. 16) describes the doctor who prescribed opioids to her son as “a drug dealer hiding behind a certificate the indicated he had completed medical school.” However, other doctors are portrayed as simply negligent. These doctors should have “known

better” and prescribed opioids more sparingly, but instead were too quick to write prescriptions.

Patricia McDonald (day one, p. 45) describes her daughter’s encounter with this type of doctor:

Adrienne was prescribed hydrocodone for lower back pain by her primary care physician. Not once did he refer her to physical therapy or a specialty consultation. Not once did he order a simple diagnostic radiology exam. Not once did he suggest she titrate off the hydrocodone to a non-addictive pain medication. But most importantly, not once did he inform her of the addictive nature of hydrocodone. Instead, he kept refilling her scripts and sending her on her way.

Similarly, Sarah Bowker (day two, p. 37) describes an experience with a specialist who treated her rheumatoid arthritis pain. She says, “The first thing they did was increase my hydrocodone. They didn’t even ask if I was comfortable with that increase. They didn’t ask what I did for work, if I cared for children, if I drove a car.” Sarah goes on to describe how even after she was “obviously addicted to the hydrocodone” (day two, p. 38), the specialist continued to prescribe and even increased her dose of the medication.

Finally, other doctors are constructed as well-intentioned, but ignorant of the danger because of misinformation and/or a lack of training. “There are so many doctors who are not trained and will give it to you for a pulled tooth, for a twisted toe. They’ll give it to you for anything,” Tish Westrup (day two, p. 45) proclaims. Judy Rummler describes the doctor who treated her son, Steve, as “well-intentioned and highly regarded,” and explains that “he believed that this medication would help Steve. This doctor believed that these medications would be safe and effective for long-term use” (Judy Rummler, day two, p. 47). Steve’s fiancé, Lexi Reed Holtum (day two, p. 55) asks, “If these doctors are unaware, because of the current labeling, and because of the relentless education that big pharma has done around the safety of these drugs...how can they possibly help their patients?”

*The FDA as a villain.* In the dangers of opioids story, the FDA is portrayed as a villain who allowed the prescription painkiller epidemic to happen through lax legislation. Speakers blame the

FDA for failing the American people by not properly regulating the marketing and distribution of opioids. Pete Jackson (day one, p. 34) argues, “During the past decade or longer, policy changes at FDA have not been responsive to the escalation in deaths and addiction from opioids.” Judy Rummeler (day two, p. 52) blames the FDA for the opioid epidemic when she says, “So the current labeling has led to the overprescribing of opioids and, in my opinion, has led to the overtreatment of pain with opioids.” Lexi Reed Holtum (day two, p. 56) claims that her fiancé, Steve, overdosed and died “as a direct result of the labeling of opioid pills.”

The speakers talk of frustration with what they perceive to be apathy on the part of the FDA. Patricia McDonald (day one, p. 47) asks:

Why is it that the FDA, an organization designed to protect us, finds it acceptable that every 19 minutes in America someone dies from prescription pill-related deaths?...Why has the FDA not acted sooner and more aggressively to save lives lost to unnecessary addiction to these drugs?

Similarly, Avi Israel (day two, p. 143) says, “I mean every time there’s a problem with a bag of lettuce, the FDA’s right on TV and we’re calling back all the lettuce. But here we have people who are dying every day, every day, and nobody’s doing anything.” Lexi Reed Holtum (day two, p. 54) laments, “I am not a doctor. I am not a judge. I am not a lawyer. I’m not a government official. I am an American citizen who is deeply disturbed by the lack of change happening at the FDA.” Sometimes the speakers talk directly to the FDA officials in the audience. For example, Avi Israel (day one, p. 32) says, “You’ve been entrusted with this job to serve as the people’s protector. Stop passing the ball around and do your job.” Pete Jackson (day one, p. 34) warns that if label changes are not made, “The loss of life will continue to rise each year and it will be on your watch, FDA.”

**The moral.** Since the dangers of opioids story is about a problem of opioid overprescribing, the logical solution to the problem is to reduce opioid prescribing. All speakers telling this story agree that reducing prescribing is the appropriate goal, and they offer a number

of suggestions for how this should be accomplished. First, they argue that the public must be made more aware of the danger of opioids. Avi Israel (day two, p. 144) argues, “The problem is we need to inform the people. We need to let the people know what is in those pills, how bad addiction is.” He pleads with the FDA, “Please, please have a strong warning on the bottle. ‘This medication can be addictive’” (day two, p. 144). Similarly, Patricia McDonald (day one, p. 46) says, “I don’t need scientific facts to prove the point that opioids need stringent warning labels.”

The speakers also agree that a fundamental shift must be made in the public’s perception of when opioid use is appropriate. Pete Jackson (day one, p. 34) argues, “We are fooling ourselves if we continue to believe that these medications can be widely prescribed across the board for virtually all types of levels of pain and not result in many more tragedies.” Sarah Bowker (day two, p. 42) asserts that opioids should be reserved for “severe, immobilizing pain.” And what constitutes “severe” pain? Tish Westrup (day two, p. 45) defines it when she says, “Severe pain is for somebody who is really at the end of their rope, somebody who there’s nothing else that works for them.”

A common thread throughout these stories is that some conditions are viewed as more painful than others and therefore some patients are viewed as more deserving of pain treatment with opioids than others. Sarah Bowker (day two, p. 41) illustrates this assumption when she says:

I was given Lortab after my C-section when they cut open my abdominal wall, took out my organs, a baby, and then put me back together and stitched me up. How is it that the same medication is written for a toothache, bursitis, frozen shoulder, and ankle sprain?

Avi Israel (day two, p.145) further captures the sentiment that some pain sufferers are more deserving of opioids than others when he states, “If you have cancer, yes, take that medication. But if you twisted your ankle, take two aspirins and call me tomorrow. That will work a lot better.” Similarly, Sarah Bowker (day two, p. 41) asks, “I understand that there are some who need the

drug, cancer patients, veterans with their limbs blown off, accident victims, but a continuous supply of hydrocodone for chronic, unexplained pain that isn't getting better?" Avi Israel (day one, p. 32) puts it bluntly, "Let's stop the long-term non-cancer use of this medication."

**Summary.** In the dangers of opioids story, opioids are constructed as addictive and deadly drugs causing extreme harm to society, as a result of over-marketing by greedy pharmaceutical companies, overprescribing by negligent doctors, and a lack of action by the FDA. The victims are young people, especially those with chronic non-cancer pain, who were introduced to opioids by doctors, family members, or peers, and subsequently became addicted, died, or both. These were good, innocent people who succumbed to the inherently addictive and dangerous nature of opioids. Their families are broken and devastated by the loss. The only way to put an end to the epidemic is for the FDA to take action that would reduce the prescribing of opioids to patients with chronic non-cancer pain.

### **The Benefits of Opioids Story**

**The plot.** In the less common story about the benefits of opioids, the heightened fear surrounding opioids as a result of the prescription painkiller epidemic is preventing many legitimate pain patients from getting the opioid treatment they need. According to Rebecca Kirch (day two, p. 126-127), "Strong messages about painkillers and risks of addiction...outright scare many patients and families facing unrelenting pain. And often also chill prescribing by practitioners that patients are relying on to help them relieve it." The speakers do not deny that there is a prescription painkiller epidemic. Amy Abernethy (day one, p. 63) says, "I don't think anyone would disagree that there is a public health imperative to address the scourge of prescription drug misuse and abuse." However, they express concern that public attention to the

epidemic is causing legitimate patients to suffer. In this story, opioids are both dangerous drugs *and* needed medications, and the speakers argue that more attention should be afforded to the latter.

**The characters.** There is only one type of character in this story: pain patients constructed as victims.

*Pain patients as victims.* Amy Abernethy tells three stories about patients whom are greatly benefitted by medical treatment with opioids. The first story is about Janet, a 44 year-old woman whose treatment for metastatic melanoma has left her with “a horrible peripheral neuropathy and leg pain” (Amy Abernethy, day one, p. 60). After exhausting all other treatment options, Janet now relies on high-dose opiates which “allow her to be able to function as a hair dresser, act as a wife, and mother of her two children” (Amy Abernethy, day one, p. 61). The second story is about James, an 82 year-old man with chronic ischemic heart disease. “The combination of his heart drugs and opiates has allowed James to stay off of the floor crying like a baby in response to his continuous chest pain and, instead, sit on his front porch, waving at people as they go by in their cars” (Amy Abernethy day one, p. 61). The third story is about Steve, a 57 year-old man with recurrent lymphoma who suffers from breathlessness. Steve could not even open his newspaper because of the breathlessness, but after taking morphine, Steve is able to “talk to his wife and really have some relief from the suffering...in his last days of life” (Amy Abernethy, day one, p. 61-62).

Wendy Foster is the only self-identified opioid-reliant chronic pain patient to share her story at the hearing. Wendy explains that she suffers from severe migraines, mild strokes, spinal stenosis, and a muscle condition that makes it difficult for her to breathe. She also requires the use of a service dog. She describes her pain level as “astronomically high” (Wendy Foster, day one, p. 40-41). Wendy also says that in her case, it is “most difficult to obtain the necessary help via pain medicine” (day one, p. 40). She instructs the audience:

Imagine yourself as a person with intense, unrelenting chronic pain. Now imagine taking years to find the right medication to help with your pain. Oftentimes the pain does not leave but merely has the edge taken off. Now imagine that you've been able to take the medication without many adverse side effects and you're beginning to feel that you can start to live your life even a little more fully. Now imagine that just when you've begun to feel that you may one day feel whole again... You're forced to end the treatment. You now find yourself back where you started, in excruciating pain, looking for another medication to help.

Wendy's story dramatizes the harm that can be caused to a legitimate pain patient when access to opioid treatment is taken away.

Rebecca Kirch (day two, p. 132-133), a director for the American Cancer Society, tells a story about her brother Eric, who died a painful death due to lung cancer at age 47:

His oncologist had prescribed pain medicine, but Eric was afraid of becoming addicted, even when he was dying. So he took those meds rarely and reluctantly, and got very little relief... There was no way we could be prepared for the destruction of Eric caused by the unrelenting and unrelieved pain he suffered right until the night he died.

In her story, it is not opioids, but the fear surrounding them that causes harm to victims.

**The moral.** The moral of the benefits of opioids story is that while "horrible things have happened to real people because of misuse of opioids," the public must "beware of putting that fact first" (Amy Abernethy, day one, p. 67), and make sure that negative attention to opioids does not hinder the care of people in pain. According to Rebecca Kirch (day two, p. 127):

The solution to this problem involves crafting and communicating responsible and balanced messages for consumers that cover both sides of the story, explaining the risks of addiction and misuse, as well as the effectiveness of these medicine as a lifeline to restoring function and quality of life when used appropriately.

In other words, patients who legitimately need opioids should have access to them. Examples of "legitimate" patients include: "individuals with serious and life-limiting illness – illness such as cancer, COPD, AIDS, end stage kidney disease, heart failure, hemophilia, and sickle cell" (Amy Abernethy, day one, p. 63). Also, doctors alone should have the authority to decide which of these patients should receive opioids, and for how long and at what dosage. As Wendy Foster (day one,

p. 41) argues, “If a patient is fortunate enough to find a medication that works for their pain, it is the doctor who should make the decision of what medication is right for that patient.”

**Summary.** In the story about the benefits of opioids, there is a prescription painkiller epidemic that society must deal with, but not at the expense of patients with legitimate pain. These patients, including those with cancer and other life-threatening conditions, benefit greatly from opioids and will suffer greatly if access is limited. It is doctors who have the knowledge and responsibility to care for these patients in whatever way they deem fit. Thus, it is doctors should be trusted to make decisions about the appropriate use of opioids.

## **Discussion**

My goals in analyzing the plots, characters, and morals of the stories told at the hearing were to uncover the underlying cultural assumptions present and to consider how these assumptions morally justified a label change which disproportionately targeted people with chronic non-cancer pain. What I found in the data were two overarching stories – a dominant story about the dangers of opioids, and a much less common story about the benefits of opioids – each attempting to influence the outcome of the hearing in different ways. While on the surface these stories seemed to oppose one another, they shared similar assumptions about the nature of opioid addiction, the severity of pain, and the responsibilities of doctors and government regulators. These assumptions allowed the stories to have cultural resonance and be persuasive to the FDA decision-makers. I argue that these assumptions also served to marginalize the stories of people with chronic non-cancer pain who rely on opioids.

Assumption #1: The first assumption shared by the stories is that there is indeed a “prescription painkiller epidemic” occurring in the United States. Speakers both supporting and opposing the label change attested to this. Perhaps this is not surprising, given that the speakers

came to the hearing to talk specifically about opioids. However, it remains unclear why this particular problem was pressing enough to warrant the label “epidemic” in the first place. What makes opioids different than the other FDA regulated substances that kill people each year? What about Acetaminophen (i.e. Tylenol), a painkiller that is the leading cause of acute liver failure in the country (Larson et al. 2005)? Or tobacco, another substance regulated by the FDA, which accounts for more than 480,000 deaths per year (DHHS 2014)? What is “special” about opioids?

From a social constructionist perspective, what is considered a major social problem or “epidemic” is not based on measurable damage, but rather on the types of things that the public finds important and open to critique in a particular social context. Out of the countless phenomena that could be defined as “problems requiring government intervention,” only some things are defined this way. There is something about opioids, aside from the rates of addiction and death associated with them, which makes them targets for public persecution. The public views opioids differently than they do Tylenol or cigarettes. As Schuster (1989:2) observed, there is a widely held cultural belief that opioids are drugs with a “mysterious power to enslave” their users.

The assumption that opioids are inherently addictive went unchallenged in the stories. This was most clearly demonstrated in the dangers of opioid stories in which victims were shown experiencing devastating harm after consuming opioids, with no other context provided. As I read the stories, I imagined myself as a person who had never heard of opioids before. I considered that if the only information I ever had about opioids came from these stories, what would I believe about them? I would probably believe that consuming opioids inevitably leads to addiction, the ruining of one’s life, and eventually death. I would be afraid of opioids, and I

would pity the people who used them. I would be comforted by government efforts to make opioids less available.

But this is not the only story about opioids. It does not resemble my mother's story, nor the stories of the hundreds of patients who wrote to the FDA after the hearing to oppose the label change. Nor does it resemble the stories of the millions (or perhaps even billions) of people who consume opioids and never experience any negative consequences. But the stories told at the hearing construct a reality in which one opioid pill is the first step toward disaster. They construct a reality in which prohibition is the only *moral* solution.

Assumption #2: The stories also reflect a shared assumption that people with chronic non-cancer pain are *especially* at risk for opioid-related harm. In the dangers of opioids story, the increased prescribing of opioids for chronic non-cancer pain is constructed as the direct cause of the prescription painkiller epidemic. Almost all of the victims that appear in the dangers of opioids story are people with chronic non-cancer pain. The stories give the impression that *most* people with chronic non-cancer pain will become addicted and suffer terrible consequences. None of the stories even suggest that only a small minority of people with chronic non-cancer pain experience addiction, as research has demonstrated (Fishbain et al. 2008). It is taken for granted that these patients are at greater risk, and because they are at greater risk, they are in need of greater protection.

When I had originally approached the data, I expected to find chronic pain patients being constructed as villains, which would justify why they were disproportionately burdened by the label change. But instead I found the opposite – they are constructed as victims. The stories call for reducing opioid prescribing for patients with chronic non-cancer pain in order to *help* them, not punish them. The assumption is that opioids *hurt* people with chronic non-cancer pain;

therefore, reducing access to opioids is a form of *protection*. This assumption closely resembles the “perversity thesis” identified by Somers and Block (2005) in their work on welfare debates. They observe that proposals to cut welfare spending are justified by claims that welfare harms poor people by “creating perverse incentives toward welfare dependency and exploitation” (Somers and Block 2005:265). In other words, claimsmakers argue that welfare hurts poor people by making them dependent and therefore “denying it is not cruel but compassionate” (Somers and Block 2005:265). The same logic is applied to opioids in the hearing. The stories construct withholding opioids from pain patients as the moral thing to do, in order to prevent addiction. This points to another underlying assumption – that protecting patients from addiction is more important than protecting them from pain.

But for some forms of suffering, the severity of pain does outweigh concerns of addiction. The stories told at the hearing also share an assumption that sometimes allowing access to opioids *is* the moral thing to do. Just as opioids are endowed with the power to enslave, they also are also endowed with the power to ease the suffering of people who are “truly needy.” In this way, the stories told at the hearing preformed moral boundary work between different types of pain patients. Anagnostopoulos (2006:8) defines boundary work:

Boundary work refers to the strategies that groups and individuals employ and the evaluative criteria they draw upon to construct distinctions between themselves and others. It serves as a mechanism both for inclusion, in that it helps to create social groups and generate feelings of group membership, and for exclusion, as people seek to distinguish them-selves as different from and “above” others.

In the stories told at the hearing, some patients are constructed as deserving of opioids, while others are constructed as potential addicts who must be protected from opioid-related harm. People with certain diagnoses, such as cancer and other life limiting illnesses, are given a “special status” in the stories. These patients’ claims to suffering are constructed as

unquestionably legitimate, and their use of opioids as decidedly moral. On the other hand, the use of opioids by chronic non-cancer pain patients is suspect. It is the role of doctors to determine which of these patients are “legitimate” and which are not; and it is the role of government regulators to enforce these distinctions.

Assumption #3: The unchallenged view that doctors and government officials should regulate the “appropriate” use of opioids points to yet another assumption – that patients should not have a say in their own care. Nowhere in the stories is it suggested that pain patients themselves should decide whether or not to use opioids, or that their own claims to “deservingness” matter. None of the stories afford any agency on the part of opioid users. In fact, the entire hearing contained virtually no stories told by people with chronic non-cancer pain who rely on opioids. How could this be? How could the hearing not have included testimony from the very people whom would be most affected by the outcome?

It is not uncommon for policy hearings to exclude testimony from the people being targeted by the policy (Loseke 2007). This can happen for a number of reasons. Checkoway (1981) notes that hearings are not always held at times and places that are convenient and accessible for those wanting to participate; nor are citizens always informed that a hearing is taking place. Also, citizens might believe that only highly qualified experts can present at hearings and may not feel confident that they can give an adequate presentation (Checkoway 1981). We can also assume that the people invited to speak at hearings are selected precisely because their stories support the policy agenda in a particular way, and those who oppose the agenda may be intentionally excluded (Loseke 2007).

There is another reason why some stories are not told at policy hearings that I believe has particular relevance for the hearing under examination in this chapter. Sometimes, people are

not invited to give testimony in policy hearings because they are not viewed as “credible” witnesses. Ewick and Silbey (1995) offer an example of this in the policymaking process surrounding the Vietnam War. During this process, Vietnam veterans were disqualified as witnesses because they were constructed as not capable of telling “true” stories because of their war traumas. Similarly, people with chronic pain who rely on opioids are constructed as not credible witnesses in the stories told in the FDA hearing. The stories portray opioids as dangerous drugs that automatically transform users, especially those with chronic non-cancer pain, into addicts. Therefore, chronic pain patients who rely on opioids are constructed as potential addicts and any claims they might make about needing or benefitting from opioids are discredited. A quote from one of the speakers demonstrates this profoundly:

It scares me when I hear about other chronic pain patients take the defensive accusatory stance about taking their pills away. It is such a transparent statement of addiction. They don't even know what they are saying because these drugs, they cause so much confusion, lethargy, memory loss, and a depressed mental state (Sarah Bowker, day two, p. 41-42).

By constructing opioids as inherently addictive drugs, and chronic non-cancer pain patients as potential addicts in need of government and medical protection, the stories told in the hearing effectively marginalized the stories of people with chronic-non cancer pain who rely on opioids, leaving the policymakers free to make decisions about them, without them.

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## **Chapter Five:**

### **They Make You Feel Like a Criminal: Patients' Narratives of Managing Chronic Pain amid the Prescription Painkiller Epidemic**

*It's a story we've come to expect. A patient with persistent back pain visits his doctor and is prescribed hydrocodone, an opioid pain reliever. When he takes the medication, he experiences relief. More than that, he feels euphoric, even "high." He continues taking the medicine, enjoying the pleasure it gives him and no longer worrying about his aching back. After a while, he realizes that the dose the doctor prescribed – one pill every four to six hours – is no longer enough to give him the same euphoric feeling. So, he takes two pills instead. That works for a while, until he needs three, then four, and so on, until the bottle runs out. His back pain is no longer a primary concern, but his desire for more pills is overwhelming.*

*The patient returns to the doctor and complains that his pain has gotten worse – he needs something stronger. This time, the doctor prescribes oxycodone, and the cycle repeats. Soon the patient is back in the doctor's office, begging for more pills. The doctor, becoming suspicious, refuses, and sends him on his way. So the patient visits another doctor who, unfamiliar with the patient's history, writes the prescription. This continues until the patient has exhausted nearly every doctor in the city, and is now taking so many pills that one prescription only lasts a couple of days. So, he begins buying painkillers illegally from a drug dealer he met through a mutual friend. That is, until he loses his job and runs low on money. The dealer suggests heroin, "It's cheaper, and will give you the same feeling," he says. The patient, terrified of withdrawal and desperate for a "fix," heeds the dealer's advice. He uses the heroin, and is instantly hooked. A*

*few months later, the former-patient-turned-addict's life is in shambles, and he dies in his sleep from an opiate overdose.*

This tragic story illustrates one version of the dominant narrative about prescription opioids that currently prevails in the United States. The plot begins with a doctor prescribing opioid medicine to a patient with chronic non-cancer pain which, as the story goes, leads inevitably to tolerance, addiction, street use of heroin, and eventually death by overdose. If only the doctor would have been more cautious and not prescribed such a powerful and dangerous narcotic in the first place, the patient's life could have been saved. If only the government would have more strictly regulated opioid prescribing, such a tragic ending may have been avoided. This is the story of prescription opioids that most Americans are familiar with, and is the story that has informed legal and medical decisions made across the country since the late 1990s to curb the "prescription painkiller epidemic" (Manchikanti 2006; Rigg et al. 2010). Yet, this story represents only a small percentage of the estimated 5 to 8 million Americans with chronic pain who rely on opioids for treatment (Fishbain et al. 2008; Reuben et al. 2015). The question I address in this chapter is, how does the dominant narrative about prescription opioids impact the lives of people with chronic pain?

### **The Power of Narrative**

Narratives are powerful forces in social life. We use narratives to teach each other "right" from "wrong," "good" from "bad," and to distinguish "us" from "them" (Bruner 1987; Loseke 2007; Plummer 1995). We use narratives to evoke emotion in other people and to justify our own emotions and actions (Loseke 2009). We use narratives to rationalize and oppose public policy (Fischer 2003; Kaplan 1986; Stone 1989). We use narratives to stigmatize, glorify, justify, advocate, silence, and oppress (Ewick and Silbey 1995). We use narratives to accomplish just

about everything in the social world, and by studying narratives, we can learn much about ourselves and society.

For sociologists, narratives are especially important because they “bridge the gap between daily social interaction and large-scale social structures” (Ewick and Silbey 1995:198). Through studying narratives, we are able to exercise a “sociological imagination” and answer Mills’ (1959) call to connect personal troubles to public issues. That is because “the stories people tell, of course, are not simply personal...but a reflection of the culture and society that ‘speak’ through the lives of individuals” (Berger et al. 2013:370). By studying a personal story, we can learn as much about society as we can about the storyteller.

Loseke (2007) identifies four types of narratives that circulate in social life. First, there are *cultural narratives*, often found in the mass media, that construct symbolic boundaries around “types” of people, such as “the addict,” “the welfare mother,” and “the terrorist.” These stories are powerful shapers of public opinion and can drive social movements. Next there are *institutional narratives*, which also construct boundaries around types of people, but do so with the explicit goal of supporting or opposing legal and public policy decisions. *Organizational narratives* are similar to institutional narratives, and are used to justify social service provisions to the types of clients served by organizations. Finally, there are *personal narratives*, defined as “stories that social actors tell to locate themselves into those narratives produced at the cultural, institutional, and organizational levels” (Kusow and Eno 2015:4; Loseke 2007).

Personal narratives are important because they “allow us to attend to the collective *and* the personal, the intersubjective and the individual. A story portrays events as experienced by someone situated in a particular time and place and from a particular social location” (Mattingly, Lawlor, and Jacobs-Huey 2002:745). Personal narratives “are epistemologically both a means of

knowing and a way of revealing the world of ‘problematic lived experience’” (Berger et al. 2013:370). Stevens (1993:40) argues that personal narratives told by patients are especially important, because “in telling stories of their health care encounters, individuals not only convey personal interpretations of what happened to them, but also describe health care environments and communicate social, economic, and political consequences of the structuring of health care.”

In previous chapters, I examined cultural narratives about prescription opioids published in the *New York Times* between 2000 and 2013, and institutional narratives told in an FDA public hearing on prescription opioid labeling. I found that in each case the dominant story portrays opioids as inherently addictive and deadly drugs that have been overprescribed to people with chronic pain, leading to an “epidemic” of opioid addiction and death in the United States. The story calls on government officials and doctors to limit the prescribing of opioids to people with chronic pain in order to solve the “epidemic.” At the same time, however, the story warns that opioid prescribing should not be entirely prohibited, because the pain relieving effects of opioids are needed for some patients whose suffering is “truly severe.” The moral of the story, then, is that doctors must be more diligent in making distinctions between “deserving patients” and “potential addicts.”

This process of making distinctions does not occur in a vacuum – it involves subjecting real people to differential treatment and coercing them to do things they would not normally do. It involves making assumptions about whose pain is legitimate, which as Bell and Salmon (2009) observe, is a process that is as moral as it is clinical. The dominant story holds that a good doctor can, and should, make distinctions between patients who deserve opioids and those who must be protected from opioid-related harm – but what does that mean for the lived experience of patients made subject to this scrutiny? Examining stories told by people with chronic pain provides an

opportunity to analyze the connections between stories told at the cultural, institutional, and personal levels. In this chapter, I examine how the dominant narrative about opioids translates into the stigmatization of people with chronic pain.

### **Stigma, Chronic Pain, and Opioids**

There is a wealth of literature documenting the stigma that people with chronic pain face (Glenton 2003; Goldberg 2010; Holloway, Sofaer-Bennett, and Walker 2007; Jackson 2005; Lennon et al. 1989; Slade, Molloy, and Keating 2009). Stigma, as defined by Goffman (1963), is a negative reaction to a socially devalued trait. People with conditions or behaviors that society defines as undesirable or problematic, such as chronic pain or the use of narcotics, become vulnerable to exclusion and negative treatment.

Link and Phelan (2001) expand on Goffman's definition and identify four components of stigma. The first component is *labeling*, which occurs when a difference is recognized as socially significant. For example, the "chronic pain patient" is singled out as a particular "type" of patient. This leads to the second component, *stereotyping*, in which a negative meaning is attached to the difference. *Separation*, the third component of stigma, occurs when the perceived negative difference leads to a feeling of "us" versus "them. Finally, the fourth component, *status loss and discrimination*, occurs when people with the difference are subjected to negative treatment and are denied access to valued social resources.

The experience of stigma can severely impact a person's quality of life and ability to fully participate in society (Green et al. 2005; Link et al. 1989). According to modified labeling theory, the perception of stigma can cause individuals to adopt stigma management strategies, such as being secretive about their stigmatized condition, trying to educate others about their situation, or withdrawing from social situations they perceive as potentially stigmatizing (Link et

al. 1989). Link and colleagues (1989:400) argue that these strategies can lead to social isolation and other negative consequences, because “the more patients believe that they will be devalued and discriminated against, the more they feel threatened by interacting with others.”

Jackson (2005:332) asks, “Why is pain, something experienced by everyone, so often stigmatizing in its chronic form?” Several scholars argue that the answer lies in the invisibility of chronic pain (Glenton 2003; Holloway et al. 2007; Lennon et al. 1989; Slade et al. 2009). Many people with chronic pain have no outward physical signs to indicate that they are hurting and there is no medical test that can objectively measure pain. People with chronic pain must rely on words and appearance to convince others of their suffering and as a result, they are vulnerable to accusations that they are feigning or exaggerating their pain for ulterior motives, such as to gain sympathy, release from work, disability benefits, or access to narcotics (Fishbain 1994).

Public concern over prescription opioid abuse and addiction has magnified the stigmatization of people with chronic pain. Chronic pain sufferers have been singled out as the population driving the “prescription painkiller epidemic” and are subjected to differential treatment within and outside of the health care system (Gardner and Sandhu 1997; Peppin 2009; Sullivan and Ferrell 2005; Vallerund and Nowak 2010). While the dominant story about opioids constructs patients with cancer or at the end of life as unquestionably deserving of opioids, patients with chronic pain are constructed as especially vulnerable to opioid addiction (Sullivan and Ferrell 2005). To mitigate risk of addiction, doctors are encouraged to take “universal precautions” when prescribing opioids for chronic pain patients (Gourlay et al. 2005). Some of these precautions include using risk assessment measures to evaluate the propensity for addiction before and after prescribing, and enforcing strict control and surveillance over chronic pain patients receiving opioid medications (Chou et al. 2009).

Not all chronic pain patients benefit from opioids, but many do, and a growing body of literature documents that seeking treatment with opioids entails a number of challenges for people with chronic pain. Many health care providers are hesitant or unwilling to prescribe opioids to chronic pain patients, so finding a doctor can be difficult (Libby 2005; Nwokeji et al. 2007). When a chronic pain patient is able to find a provider who is willing and able to prescribe opioids, they must jump through a number of hoops. First, they must convince the provider that their pain is severe enough to require treatment with opioids, and that they are not likely to abuse the medication. This can be tricky, as health care providers are sometimes “quick to label patients as ‘drug-seeking’ or as ‘addicts’ who overestimate their pain” (Reuben et al. 2015:1).

Once they have convinced the provider to prescribe opioids the patient will likely be required to sign an “opioid contract” – an agreement that stipulates what the patient must do and not do in order to continue receiving medication (Buchman and Ho 2013; Collen 2009). Usually, patients are allowed to receive prescriptions from only one doctor, whom they must visit in person at frequent intervals, usually every 30 to 90 days. They may also be limited to using only one pharmacy and subjected to random pill counts, regular urine drug screenings, and/or mandatory psychological evaluations. All of these procedures have been implemented with the goal of protecting chronic pain patients from the harms of opioids. They align with the dominant story of opioids as inherently addictive and dangerous drugs and of chronic pain patients as especially vulnerable to addiction. The question I address in this chapter is, how do chronic pain patients experience these procedures in their everyday lives as they attempt to manage their pain?

## **Methods**

The data presented in this chapter are drawn from in-depth interviews I conducted with 12 people currently living with chronic non-cancer pain in the United States. After receiving

approval from the University of South Florida Institutional Review Board (see Appendix C), I began the recruitment process. I drew on my own social networks and used a combination of convenience and snowball sampling to locate potential participants. To be included in the research, I required that participants be over the age of 18 and currently receiving medical treatment for chronic pain not related to cancer or terminal illness. I began by asking everyone I knew whether they, or someone they knew, suffered from chronic pain, and whether they might be willing to share their story with me in a tape-recorded interview.

Since there are approximately 100 million chronic pain sufferers in the U.S. (Reuben et al. 2015), locating people who fit my recruitment criteria was not difficult. However, finding people who were willing and able to schedule an interview with me proved much more challenging. There were a few reasons for this. First and foremost, committing to an in-person interview was too burdensome for several potential participants. Four individuals who had originally expressed interest in participating later changed their minds, and apologetically explained that they were already overwhelmed with managing their day-to-day responsibilities while struggling with pain and that they simply could not afford to take the time to meet with me. Three other potential participants who had initially agreed to be interviewed were forced to cancel due to health crises that arose near the time we were scheduled to meet. One person who declined my invitation to participate explained that her experience with chronic pain was too traumatic and something she would rather not re-live in an interview. Several others simply did not respond to my invitation to participate at all, for unknown reasons. Although I cannot speculate as to why they chose not to respond, I suspect that some were hesitant to discuss their pain management regimens due to concern about the stigma surrounding prescription painkillers.

The recruitment process went much more smoothly once I gave potential participants the option of being interviewed over the telephone. This gave respondents more flexibility in the time of day they could be interviewed and allowed them to speak with me from the privacy and comfort of their own home. It also made rescheduling much easier in instances when a participant's pain level was especially high on the day we had planned to talk and they preferred to move the interview to a more convenient time. In these cases the participant could simply say, "I'm hurting too much right now, can we talk tomorrow instead?" which they may not have felt comfortable asking had I travelled to meet with them in person. The telephone option also allowed me to interview people from across the United States, so I was no longer geographically limited to areas within driving distance. While I initially worried that the quality of the interviews would be compromised if not done face-to-face, I found the opposite to be true. Participants shared their stories freely on the phone and our conversations yielded rich and detailed accounts of their experiences. Like Holt (2010), I found interviewing over the telephone to be a beneficial and perhaps even preferable way to elicit narratives from this particular group of respondents whose physical limitations and desire for flexibility and privacy made face-to-face interviewing an inconvenient option.

In total, I interviewed 12 chronic pain patients (four face-to-face and eight over the telephone) with a wide range of diagnoses, including: trigeminal neuralgia, chronic pain due to injuries resulting from motor vehicle accidents, fibromyalgia, endometriosis, migraine headaches, lupus, osteoarthritis, rheumatoid arthritis, Ehlers-Danlos syndrome, and chronic fatigue syndrome. The length of time living with chronic pain ranged from two years to over 30 years. At the time of the interview, nine participants currently relied on opioid medications to manage their pain; one had previously used opioid medications but now managed his pain with

non-opioid pain relievers; one had never used opioids but relied on another controlled substance, clonazepam; and one participant had never taken prescription pain medication. Participants ranged in age from 27 to 75, and most were in their 40s or 50s. Seven lived in the southeastern U.S., four in the West, and one in the Midwest. Eleven of the respondents were female and one was male. Of those I interviewed in person, three were white and one was African-American. I did not collect information about race over the telephone. All respondents identified as middle class and all had completed at least some college.

I began each interview by asking the respondent to share their story with me, beginning with when the pain first started. I used an interview guide (see Appendix D) to assist me in directing the interviews, but I followed it loosely to allow the participants to focus on the topics they found most important and to create a more conversational interview experience. Some of the topics covered included: the initial onset of pain, the effects of pain on their personal and professional lives, encounters with doctors and other medical professionals, experiences with medication, and attitudes regarding prescription opioid regulation. The interviews lasted between one and four and a half hours, with an average length of two hours. Interviews were tape-recorded and later transcribed and I assigned pseudonyms to all participants to ensure confidentiality.

I took an emancipatory approach to research in this project and I began with the explicit goal of shedding light on cultural and structural barriers faced by people with chronic pain (Oliver 1992). I wanted to “give voice” to my participants’ stories which have too often been marginalized and silenced both within and outside of the health care system. As I discuss in more detail later in the chapter, many of my participants shared with me opinions and experiences that they have been reluctant or unable to voice to others due to fears that they would be stigmatized

or would lose access to their treatment. I sought to give my respondents a “safe space” and platform to share their stories without fear of reprisal. All participants were aware of my status as the daughter of a mother who suffers from chronic pain at the time of the interview, and all were aware of my activist agenda. Several participants expressed that they were initially hesitant to speak with me, but felt more comfortable sharing their experiences once they learned of my own positionality. Three respondents reached out to me and volunteered to participate precisely because they had read my autoethnography (Chapter Two).

Although I do not believe it would be possible to remain “objective” or “unbiased” when approaching my participants’ stories, I made a conscious effort to put my own feelings and judgments aside when analyzing the data. The first step I took was to closely read and re-read all of the transcripts, until I was familiar with each story as a distinct whole. I asked about each story: What is the plot? Who are the characters (i.e. victims, villains, and heroes)? What are the morals? I also paid attention to any contradictions that became apparent within each story. Once I had become familiar with the stories individually, I began to consider the similarities that emerged between them. I asked, what plots, characters, and morals were similar across the stories? Which shared messages did the stories convey? I also paid attention to the ways in which the stories differed from one another or conveyed conflicting information (Green forthcoming). Finally, I considered how the stories served to reflect, sustain, and/or subvert the dominant narratives regarding pain, opioids, and addiction that currently prevail in the United States.

## **Findings**

While the participants varied with regards to age, location, medical diagnosis, and treatment modalities, several commonalities emerged between their stories. In this section, I will describe the following dimensions of the participants’ experiences: 1) the impact of chronic pain,

2) experiences with medication, 3) managing stigma, and 4) navigating barriers. I will then discuss what their stories reveal about how the dominant narrative about opioids impacts the experience of chronic pain.

### **The Impact of Chronic Pain**

Kathy, a woman in her early fifties who suffers from trigeminal neuralgia, a severe type of facial pain, described the extreme desperation she felt during the time before her pain was adequately controlled:

So in the beginning, the pain from the trigeminal neuralgia...I can hardly keep from crying when I think about how bad it was. I mean, there is not a number, there is not a way to describe how awful that level of pain was. For all of my faith in God, and I have a lot of faith in God, and I have a great love for my family, and I'm filled with hope in so many ways. But there were moments when I would've crawled to the medicine cabinet and taken any drug in any combination to make it stop. It was so horrible. I thought, I cannot live. I never entertained killing myself, I just thought, I cannot live. I hope they diagnose me with some condition that I am going to die from because I cannot live in this amount of pain.

Other participants discussed how the pain made it impossible to perform activities of daily living. Leslie, also a woman in her early-fifties, described how her pain resulting from lupus and fibromyalgia was so bad when it first started that she could barely move:

I remember in the beginning I couldn't even turn over in bed to get to my medication. I would hurt so badly. I would wake up and be in so much pain, and I'd call my son on my cell phone. His room was down the hall. And I'd say can you come in here and get my pain medication out for me? And he'd come in and get it out for me and help me take it, and I'd just lie there and wait for it to work.

Stacey, a woman in her early sixties who suffers from chronic fatigue syndrome and fibromyalgia, explained that the pain made it nearly impossible for her to perform most daily tasks, including personal hygiene and housework:

Sometimes the pain was so bad that I literally couldn't stand to take a shower, because the water just beating on my chest, my hair, it was just too painful... And I know to some people it probably sounds ridiculous, but just putting dishes in the dishwasher, I couldn't

do it. Some days just getting out of bed to go to the restroom and making sure that I had some nourishment was about all I could do for the day.

For Monica, a woman in her mid-fifties, the pain from lupus and fibromyalgia is so bad that any physical contact with others causes her to experience excruciating pain. During the interview, she lamented the fact that her pain limits the physical affection she can share with her grandchildren:

My pain feels like somebody stabbing me. Just like the slightest touch I get the stab and the longer they touch it just digs in further. So my grandkids know not to touch me unless they warn me before they come, or else I will scream.

The participants also discussed the ways that chronic pain has affected their social lives and relationships. Stacey explained that because the severity of her pain varies from day to day, committing to plans in advance can be difficult, and this has caused her friendships to suffer:

I did lose people who I thought were my friends, because they would call and ask me if I wanted to get together for lunch or something, and I would say that it would have to depend on how I felt that day. And at first I think they were OK with that, but then when I had to cancel on them more than once, I could just kind of tell that they were starting to pull away.

Marcia, a woman in her mid-fifties who also suffers from fibromyalgia, shared a similar account:

I've lost a lot of friends. You know when you make appointments to go out to lunch or do something with a friend and you cancel at the last minute because you just can't do it. People don't put up with that for forever.

While most struggled with losing friends as a result of their pain, the participants generally described supportive relationships with spouses. During the interview, Kathy said of her husband, "There's nothing that my husband wouldn't do to make the pain go away. Nothing he wouldn't pay for. Nothing he wouldn't do to try to make it better." Similarly, Evelyn said, "My husband is very supportive. He seems to understand on days when things aren't going well and I'm in a lot of pain. I'll just say this is not a good day and he kind of backs off and leaves me alone." Sometimes, however, the pain took a toll on even the most supportive relationships.

Debbie, a woman in her early forties who suffers from chronic pain due to endometriosis and degenerative disc disease, described how the pain affected her relationship with her husband:

As my pain's gotten worse I've been trying to get my husband to talk to someone about it, someone else who has gone through the same thing. Because I can look at his face and see that he just feels helpless, that he doesn't know how to handle it. There was some animosity between us for a little while, and it was stupid because he was just trying to be nice and helpful and supportive, and all I saw was pity, and I didn't want that.

In addition to the effects of chronic pain on their personal lives, the participants also discussed how the pain affected their work. Kimberly, a graduate student in her late twenties who suffers from chronic back pain resulting from an automobile accident, was concerned about the negative toll that pain has taken on her academic performance:

It was so horrible because I couldn't get any work done. You have to sit for a long time to write a 40 page paper and I just couldn't do that. After 15 minutes the pain would be excruciating and I would have to get up. So then I'd standing at the bar in my kitchen trying to work and it just wasn't happening. So it was disrupting my grades, and my ability to teach, and to make progress in my program, which are all things that are extremely important to me.

Evelyn, a woman in her mid-seventies who has lived with fibromyalgia for over twenty years, spoke sadly of the day she decided to quit her job because her pain had become too overwhelming:

The pain got worse, and I remember walking through the airport one day and I was just sobbing. I was so tired, I hurt, I'm dragging this suitcase and I'm thinking, I can't do this anymore. As much as I love this job, I have to quit. So that's when I went on disability.

Many participants expressed a feeling that they had lost their previous identities. They emphasized how active they were before the pain started and how dramatically the pain has limited their ability to do many of the things they used to enjoy. Monica said:

Before the pain started I did a whole lot of things. I loved to shop. I loved to go out. I loved to do all sorts of things. I was always really active in my kids' schooling. I even tried to be active when my daughter went to college, but after the pain got bad I wasn't able to do that anymore.

Similarly, Marcia, a woman in her early fifties who suffers from fibromyalgia, mourned the loss of her ability to be active in church and in her children's athletic events:

The pain has taken a lot from me. I was very active in our church. I did quilting, I spoke at worship services, and I helped organize the different committees and things like that. When my daughter was young I was a soccer mom and I did all of the traveling. I was so determined that I didn't want this to interfere with my life, but slowly but surely I can hardly do anything anymore.

After identifying herself as a "Type A personality" and listing the many activities she was involved in before the pain started, Stacey said, "All of the sudden I just became this person who spent her life going to doctors and coming home and going to bed."

For the participants in this study, living with chronic pain, especially when it was poorly controlled, had a profound effect on all aspects of their lives. In addition to the experience of relentless physical pain, they also experienced significant physical limitations, an inability to perform activities of daily living, social isolation, and a loss of identity.

### **Experiences with Medication**

The journey to achieve adequate pain control was long and arduous for all participants in this study. Most saw multiple doctors and tried numerous treatments before finding a medication that provided enough relief. Emily, a woman in her early forties who suffers from chronic head and neck pain resulting from injuries she sustained in a car accident, described how for years after her accident she tried every therapy imaginable with hope that she would not have to rely permanently on medication:

I tried all of those things, chiropractic manipulation, exercise, aquatic therapy, massage therapy, meditation, yoga, dietary supplements. I consulted with several different neurologists. I went to see other types of doctors. And I was doing everything that all of the doctors told me to do. I was working out. I was taking care of myself. I was making sure I got enough sleep. I was exercising. I was eating healthy. I had a great support system. I was doing everything that they told me to do. Because I didn't want to be taking drugs for the rest of my life.

When none of those modalities were effective, Emily managed as well as she could on one of the weaker prescription opioids, tramadol (i.e. Ultram), but found it was not enough to give her a good quality of life. Eventually, she went to her doctor and asked for a stronger prescription:

The tramadol was working for a while but it got to a point where I realized I'm just in a lot of pain all of the time. It just wasn't working well enough. So I went to my doctor and I said I can't take this anymore. I can't take the pain anymore. The tramadol just isn't cutting it. I asked, is there anything else I could try? Anything stronger? She was hesitant at first, but eventually she started me on the Dilaudid. It was like a godsend. I was like, oh my God, why didn't you give me this before? Because it made such a huge difference in my pain levels. Thank God she was willing to try that because it literally saved my life.

After she began taking the Dilaudid, Emily's pain was so well-controlled that she was able to return to work full-time and, in addition, begin taking graduate classes toward her PhD. During the interview she said, "I think without control of my pain there's no way I would have been able to do any of that. I would've had to go on disability."

While she was initially concerned with the possible long-term effects the medication might have on her body, Emily soon came to the conclusion that the prospect of remaining in pain would be more devastating than any risks the Dilaudid might pose:

If you weigh all of the risks and benefits, the risks of the drugs to me are nowhere near what the risks would be if I didn't take them, you know? If I didn't take them, the risk would be suicide, it absolutely would be. It's like, would you rather have a functional life where your pain is managed, or would you rather not have a functional life and live in horrible pain in order to make sure that you don't get these possible long-term effects? I'm sorry, but there's not even a choice there. It's not even a question.

The fear of medication side effects was a common theme throughout the participants' stories. Kimberly, the only participant in the study who has never taken prescription pain medication, was concerned that prescription painkillers would cause drowsiness and make it difficult for her to complete her schoolwork. She said, "The biggest fear for me was they have the side effect of making you tired, which I can't afford to be as a graduate student who is already tired and overwhelmed all of the time anyway."

Tim also expressed concerns about the effects of painkillers on his ability to function.

Tim is a man in his mid-forties who suffers from chronic nerve pain in his hands and feet resulting from injuries he sustained in a motorcycle accident. He took oxycodone for pain for a few months after his injury. Although it gave him adequate relief, he worried the medicine was negatively interfering with his work as an automobile mechanic:

I know it messed up at work when I was taking that. I don't know if it was just because I had so much pain or if it's because I was taking those drugs, but I started making a lot of mistakes and forgetting stuff at work. So that wasn't good. So you can't really take those and work.

Tim eventually found a combination of non-opioid medications, gabapentin (i.e. Neurontin) and cyclobenzaprine (i.e. Flexeril), that works well to manage his pain and does not seem to affect his work performance. However, he did complain that the medicine makes him drowsy. He said, "The thing that's hard is the medicine because it makes me tired. If I take a Neurontin and a muscle relaxer and I sit down, I'm out in like ten minutes. If I'm busy doing something I'm fine, but if I sit down I'm down for the count."

Sandra, a woman in her mid-sixties who lives with chronic pain related to rheumatoid arthritis and osteoarthritis, also noted that the hydrocodone and oxycodone she takes as needed cause drowsiness and interferes with her studies. At the time of the interview, Sandra was completing her last semester towards her bachelor's degree, something she had always wanted to do. She explained that the medicine worked well to manage her pain, but she would avoid taking it for as long as possible when she had homework to complete:

I only took them only when it was absolutely necessary because the truth of the matter is sometimes they can, depending on the day, make you feel kind of drowsy or kind of lightheaded, and when you want to study or write a report, it's very difficult for you to be able to be as focused as you want.

While Tim and Sandra reported negative effects of pain medicine on their ability to function, other participants described a totally different experience. Jill, a woman in her mid-forties who suffers from chronic pain related to Ehlers-Danlos syndrome, said:

For some reason the hydrocodone had almost a paradoxical effect with me. Some people who take it will say it knocks them out and they get tired. But it kind of motivated me. I would feel less pain and then on top of it I actually felt like I had a little bit of energy.

Leslie also said about the oxycodone she takes regularly for pain, “It really doesn't make me feel sleepy or anything. It just gets rid of my pain.” Similarly, Evelyn said, “If anything it makes my mood better, but it doesn't make me tired, and I don't feel groggy or drunk or anything like that.”

Kathy was especially vocal about the positive effect the clonazepam (i.e. Klonopin) she takes for pain has on her ability to function:

That was one of the things that convinced them to let me take the medicine that I'm taking. Because they were like, “Well you may become dependent and it's going to make you really sleepy.” And I said listen, this makes me a lot less sleepy than a lot of the medicines I've tried. And I finished my dissertation and learned a foreign language while taking this medication, so don't talk to me about, “You're not going to be able to function.” I can't function with the pain. I can function with this medication.

Another concern the participants voiced is that they would eventually become tolerant to their pain medication and would need higher and higher doses to achieve the same relief. This is one of the reasons Kimberly resisted taking prescription painkillers:

And that's another fear I have I guess is that if I build up a tolerance will it ever be enough? Will I eventually have to take higher and higher doses and will it ever be enough to address the pain? Is it better for me to just live without treating it?

Kathy, also concerned about tolerance, explained that she takes less of her medication than she needs from time to time to prevent the possibility of becoming tolerant:

I back off of it from time to time so I don't have to keep increasing the dosage. My biggest fear is that I would have to take more and more. And in 5 years I haven't taken any greater dosage. And when I back off of it I hurt a lot, but it is worth it to me not to become more and more medicated.

While several participants expressed that they were initially hesitant to take pain medication for fear of tolerance, most discovered that tolerance was not an issue. Once they found an effective dose, many stayed on the same amount of medication for a long period of time without increasing it. This was the case for Evelyn, who takes hydrocodone for her fibromyalgia pain. Evelyn said:

You know I'm taking the same dosage that I was taking at the beginning. I have not increased it. I don't feel like I need to increase it. It's keeping everything at kind of a low roar. It just makes it so much easier to tolerate.

Leslie shared a similar experience with her medication:

They say oxycodone eventually doesn't work, but I've been on the same dosage for many years and it's always worked for me so far. So I have a lot more faith in it than what people say. I definitely have hit a plateau that is absolutely perfect.

Addiction was another concern shared by many of the participants. Kimberly explained that she is afraid of taking prescription painkillers because she has witnessed others in her life struggle with addiction to opiates:

My fear comes from my friends who have drug issues. Some of them have a history of first being addicted to painkillers and then moving to something like heroin, and then going back off of that and back on to prescriptions. And some of these people are very much like myself. They are educated and they have significant positions in society. So it all plays into this fear that addiction is possible with these types of drugs and that it can happen to anyone.

Monica also expressed a concern about addiction, which stemmed from her previous experience working for a substance abuse agency:

So every month I'm going back and getting more and more medication, and I don't like pills. I don't like taking medication because I used to work for a substance abuse agency and I know that you get hooked when you're taking oxycodone and all of that and I don't want to take it.

While addiction was an initial concern for most participants in this study, none reported experiencing any problems with addiction while taking opioid medications. Debbie stressed that while she is dependent on painkillers, she is not “addicted” in the colloquial sense:

I’m not addicted in the way people think of when they hear the word addiction. My body has gotten so used to it that I can’t just stop taking it today. If I stopped taking my medicine right now, I would be in the hospital. But I’m not jonesing for it. It’s not like oh God I wish I could get more of it. I just know that if I have it, the pain is manageable, and I can continue to function day to day.

Evelyn shares a similar account:

I don’t know what being addicted to this stuff is like, but I don’t think I’m addicted to it, because I’ve never increased the dosage. But on the other hand, just the thought of getting up in the morning and not getting that relief from the pain, and then having to go through a day...

A final reservation they had about taking opioid medications was the fear that they might be stigmatized. Kimberly said:

There was a significant part of me that worried about the impression of being a drug-seeker. Because there’s a stigma associated with being somebody that is a regular narcotic painkiller user...I think if I took pain pills the general public would think that I have a drug addiction. That I was Dr. House and I was popping pills everywhere I went like it was candy.

Jill described the anxiety she felt when her doctor recommended daily use of hydrocodone to manage her pain:

I just had this fear that I would be seen as an addict or drug-seeking, even though I knew that what I was taking it for was completely legitimate. I wasn’t abusing it. I was taking it as prescribed. I wasn’t selling it on the corner. I wasn’t handing it out. But I remember when my doctor said, “Why don’t you just take it regularly?” I was like, really? I can’t believe I would be allowed to do that. Because there’s such a stigma about taking them on a regular basis.

When I asked Jill why she thought there was such a stigma attached to prescription opioids, she answered, “Our society has this idea that if you take this for more than three days then you’re

gonna be hooked and your life is gonna be ruined and you're gonna be doing heroin three years down the road."

Stacey was also concerned about stigma when she began taking oxycodone for pain, but after exhausting dozens of other treatment options, she was willing to try anything that would allow her to regain function:

So they started me on oxycodone, and that was another thing that I did not want to go on, because of the stigma and the labeling that went on with oxycodone. Because basically that was stuff that drug addicts took. So that was a hard pill to swallow, but I knew that I couldn't worry about what other people were saying. I just needed to get myself to a place where I could function.

Unfortunately, the fear of stigma was something that materialized for most participants in this study.

### **Managing Stigma**

The stigma surrounding prescription painkillers had a profound impact on the lives of almost all participants. Many expressed frustration with the way other people automatically attach negative meanings to their medication use, even when the observers have no personal experience with chronic pain themselves. Leslie said:

A lot of people don't understand. They're very judgmental, with three exclamation points. It's usually people that don't have any pain, or that don't have any family members with pain. And they're always so disapproving. "I can't believe you take oxycodone. What a terrible thing!" And I tell them I guarantee you wouldn't think that way if you were in my shoes.

Leslie observed that the people who are most judgmental of her opioid use are people without pain themselves. Stacey, on the other hand, discovered that even the other pain patients in her support group whom she relied on for support and comfort expressed stigmatizing attitudes towards her medication use:

And then she [the doctor] added the methadone to the mix. And that's when I really felt the stigma of being on a drug like that. Because when I went to my support group and

had to share with them what was going on, there were a lot of sighs and gasps and all those kinds of things, because everyone associates methadone with drug addicts.

The primary reason for the stigmatization the participants experienced was the association of pain medication with drug addiction. Most participants expressed that the first reaction they received from others when revealing their medication use was the suspicion that they were using the drugs to “get high” or to feed an addiction, rather than to treat pain. Debbie said:

Is there a stereotype placed on people like me and other people that I see at my pain management place? Yep. All you need to say is I have a pain management doctor and, “Oh, you have a problem.” Yeah I have a problem, I have a pain problem. “No, you’re a druggie.” It’s a horrible feeling and nobody should ever have to feel that way.

Participants lamented that their status as chronic pain patients has become synonymous with drug addicts, and in these encounters they have no way of proving their legitimacy because their pain is not outwardly visible. Jill talked about how the invisibility of the pain contributes to the stigmatization she experiences:

I’ve always thought that because I don’t have an arm missing or my intestines hanging out, it’s hard for other people to understand how bad I’m hurting. “How can you have chronic pain? You look fine.” And I think a lot of people who have chronic pain or chronic illnesses deal with that.

Similarly, Evelyn described a stigmatizing encounter she had with a nurse who appeared to question her need for pain medication:

The nurse wanted to know what medicines I was taking and I gave her the list, and she said why are you taking the Norco? And I said because of pain. And she said what kind of pain? And I could just tell that she was thinking, “You don’t need it, I know you don’t.” And that’s the one thing about fibro is that you don’t look sick, you don’t look like you’re in pain.

A common theme that arose in the interviews was the perceived acceptance of opioids for cancer pain and the “special status” of cancer patients with regards to pain treatment. Emily said:

I know it's horrible to say, but sometimes I wish I had cancer instead, just so I wouldn't be so stigmatized. My mom has cancer and I've said this to her before, and she totally understands because she has seen the way I'm treated and she knows how hard it is.

As a way to avoid stigmatizing reactions, most participants engaged in passing and kept their medication use hidden from others whenever possible. Like people with mental illness often do, they attempt to manage stigma by becoming secretive (Link et al. 1989). For example, when I asked Marcia whether she had felt stigmatized by other people because of her medication use, she said, "Nobody else has really given me a hard time about it. I mean, I don't share. A lot of people don't know how much I take, so it's not common knowledge." Similarly, Evelyn said, "I don't tell very many people what I'm on." Stacey explained that in the beginning, she was very forthcoming about her medication use with others, but over time, this changed:

I've learned to be very careful about what I say and who I say it to. Because in all reality, it's nobody's business but mine and my physician's. But people who I do trust and I do know that they suffer right along with me, then it's OK.

Sandra offered this advice to other patients managing chronic pain:

One thing I would recommend to people is that you don't need to tell everyone what's going on with you. Aside from your immediate family members, nobody needs to know what you're taking. It's none of their business.

Most participants were comfortable discussing their medication use only with family members or close friends. Again, like people with other stigmatized characteristics (Green et al 2005; Link et al 1989), they bear the burden of having to educate others before gaining acceptance. While many of their loved ones had initially expressed reservations about the medication, most came to understand that the benefits of the drugs outweigh the risks. Jill said:

My husband calls me a "junkie" which makes me laugh, because I know he's saying it in jest. I mean, I know he would love it if I didn't take it as much as I do, but I also know he would hate me if he had to live with me not taking it, if that makes sense?

Marcia described her brother's response to her medication use:

My brother has commented, “Oh my God, you take *that* much?” Because taking one Vicodin makes him totally loopy. But other than that he doesn’t look down on me for doing it. He understands that I need it.

The majority of problems with stigma arose in encounters with others outside of their immediate family in instances when medication use was disclosed or “found out.” Although she was hesitant to disclose her medical treatment with her employer, Debbie chose to reveal her medication use to her boss and Human Resources representative as a pre-emptive measure in case it was somehow discovered later and led to problems:

I had always kept my employer informed of my medical condition. Because I was on a narcotic I always made sure they were aware of what I was taking. For one, because I didn’t want them to accuse me at some point of hiding my “drug problem” or something like that.

Debbie worked for a security company that dealt with government projects, and she was concerned that her medication use could be a liability for the company. She explained:

We did a lot of contracts with government facilities and we had to guarantee that we were 100% drug free, so immediately I’m a red flag. So I had to tell them. Nowadays everybody is wanting to sue somebody for this or that. If I’m at work and I don’t let HR or my boss or somebody know, even though they don’t have the right to know, about my medical condition...if I don’t tell them, and somebody gets injured, is the company gonna stand behind me when they found out I’m on all this pain medicine? Even if it wasn’t directly my fault, there’s still that fear in the back of my mind.

Unfortunately, after disclosing her medication use, the boss responded by banning Debbie from dealing with any government contracts which, as Debbie explained, meant that she could no longer advance in the company. It also led to humiliating treatment from her co-workers that eventually played a role in her decision to quit:

That was one of the reasons I made the decision to leave my job, because it was like I was the joke of the office. I would come into work sometimes and there would be notes on my desk, little cartoons that said, “If you’re happy and you know it, share your meds,” or little things like that. And if I told someone to do something it was like, “Oh, just wait a little bit until her medicine kicks in and she’ll change her mind.”

Another factor influencing Debbie's resignation was the fear that the stigma attached to her medication use would affect her husband's status at the company:

Also with my husband being in the same industry, I always worried about how it looked for him. You know, having the druggie for a wife. How does that reflect on him and his chance of progressing? I know it's supposed to be separate and it's not supposed to be an issue, but we all know it doesn't work that way.

In Debbie's case, disclosing her medication use led to withdrawal, which is the most serious of the stigma outcomes identified by Link and colleagues (1989). The only option she felt she had for managing the stigma was to remove herself from the setting where the stigmatizing encounters occurred.

Sometimes, stigma proved to be entirely unmanageable. Stacey told a story about a recent traumatic incident she had after an automobile accident when a police officer discovered her medication:

I was lying there on the stretcher and I asked someone if they would go into my vehicle and retrieve my glasses for me. And when I looked up I saw them handing my bag of medicine to the police officer, and immediately my heart sank. And then they took me to the hospital and the police officer came in and he was really, really nasty. Just an arrogant asshole. And he started in on me about, "Well, you're taking some very potent drugs. You know, they give methadone to heroin addicts so that they can't take pain meds, and here you're taking pain meds *and* methadone. So, what's wrong with you? What are you taking these for?" He just was going on and on about "these drugs," and questioning me as to why I take them. And I just felt so vulnerable and so violated by the things that he was saying to me.

During this encounter at the hospital, the policeman pressured Stacey into submitting to a drug test and, although her prescriptions were legitimate, the officer threatened Stacey with arrest and prosecution if her urine came back "dirty." When Stacey asked how she would find out the results, the officer told her that she would never see the results and that "someday down the road" she would get a letter in the mail informing her of what she was being charged with. At the

time of the interview, Stacey had still not received such a letter and was terribly anxious about what might happen.

The participants also reported experiencing stigmatizing encounters with doctors and other health care professionals who questioned the legitimacy of their pain and need for medication. Kimberly described an encounter with such a doctor:

There was one office visit when I sat there and cried for almost two hours, like inconsolably sobbing and unable to speak because of the pain and the inability to work or sleep had just destroyed me emotionally. And he just immediately characterized me as drug-seeking. And I mean we're not talking about a fake cry, we are talking about a serious, ugly cry, but he seemed almost amused by that. Like amused that I would make such a dramatic deal out of it. And then I asked him about medication and he basically said he didn't believe that my injury caused enough pain to require a drug like that.

Kimberly made no specific mention of opioids, but the doctor automatically assumed that her complaints of pain were evidence of "drug-seeking" and responded by completely discounting her claims of suffering.

Emily explained that one of the most stigmatizing parts of being a chronic pain patient is the mandatory drugs tests she must take in order to continue accessing her medication:

People will say, "If you're not doing anything wrong, you don't have anything to hide." But you feel like you are being treated differently. Because why isn't the person getting medication for his heart being drug tested? You feel like you are being treated like a criminal. Because to me, if they're drug testing your urine, right away there is an assumption of guilt there no matter what they say.

Emily also described the stigmatizing attitudes she perceives from the staff at her doctor's office:

I have had the most disrespectful and rude staff. And you feel like they look at you like you're a criminal because you're on these drugs. And every time I have to call in to get a prescription I get this attitude, or whenever I go in, I get this look, like I'm doing something wrong. But I haven't done anything wrong!

For Debbie, the pharmacy is one of the locations where she feels most stigmatized:

It's hard going to the pharmacy. You know, 20 questions, "Why are you on this? How come you're having to take so much?" And then I blow up at them because it's like,

you're not my doctor. My doctor prescribed it. You don't need to worry about why I'm on it. I'm not a drug addict, but that's how they make you feel.

For Stacey, the stigma she felt surrounding her medication use had affected her so greatly that she considered going off of her medication, even though it had given her substantial relief.

In Stacey's case, it was a doctor who convinced her not to let the stigma affect her treatment:

So I went to pain management and I told the doctor what I was taking and that I wanted to get off of the methadone. And she looked at me and she said, "If it ain't broke, why fix it?" And I said because of the labeling and the stigma that goes along with it, and being made to feel like a drug addict. And she said, "Number one, you don't abuse it. You're not a drug addict. Forget all of those other people. You can't let other people do that to you, or make you feel like you're doing something wrong."

Stacey followed her doctor's advice, but at the time of the interview she was still very concerned about the stigma surrounding methadone and hoped to someday find an equally effective medication that did not carry the same stigma.

The dominant story of opioids as drugs of abuse and addiction manifested in the lives of participants in the form of stigmatizing treatment they received from others. While they did what they could to manage the stigma by educating others, they were often forced to attempt to pass or use the stigma management strategy of secrecy, disclosing their medication use only to certain people. Passing and secrecy were not always possible, however, nor did disclosing always have the intended result. Sometimes the only way to manage stigma was to withdraw from valued social relationships. Such withdrawal is known to carry serious risks of social isolation (Link et al 1989).

### **Navigating Barriers**

The stigma surrounding prescription painkillers has translated into actions taken by the government, medical boards, pharmacies, and doctors with the goal of making it more difficult for people with chronic pain to access prescription opioids, and to enforce increased surveillance

and control on patients already using opioid medications. Most participants' lives were greatly impacted by these barriers and navigating them took extreme effort and oftentimes subjected them to additional stigma.

For many participants, finding and keeping a doctor who was willing to prescribe pain medication was the primary barrier they encountered. Many doctors were simply unwilling to prescribe pain medication at all. Kimberly had been taking naproxen for her back pain for several months and was still experiencing significant pain. When she visited her doctor and inquired about a prescription for stronger pain medication, her request was immediately denied:

I asked him is there anything else I can take for the pain? And immediately he went on the defensive that I was a drug-seeker. He was like, "Do you mean hydrocodone or one of those types of drugs? Because I'm not going to prescribe those to you." And I wasn't even asking for a narcotic painkiller. I was just asking for something for pain other than the naproxen.

After this encounter, Kimberly sought out a new doctor whose response to her request for pain medication was, "We're not doing any medications." At the time of the interview, Kimberly had still not been prescribed any stronger medication and continued to experience significant pain.

Kathy encountered a similar situation on her journey to find relief from her debilitating trigeminal neuralgia pain. She sought out a neurologist who made his stance on opioids clear from the start:

He told me from the beginning, they won't help you. It won't heal anything that's wrong with you. It will just knock you out and then when you wake up the pain will still be right there. So he said there's no point in that and it will ruin your life so I'm not going to prescribe narcotics.

Fortunately for Kathy, the neurologist was willing to prescribe clonazepam, which after years of experimenting with different treatment modalities and dozens of medications, finally provided her with significant relief. Although clonazepam is not an opioid, it is a schedule IV controlled substance and Kathy soon discovered that maintaining regular access to it would not be easy:

The drug that I take isn't considered a narcotic, but it is considered an addictive drug, and I have to go through a lot of hoops to get it. I mean, I have to sign all kinds of forms and go every three months and have somebody sign off on it and play the twenty question game of "why do you want to keep taking this? Can't you take anything else?" So it's pretty frustrating.

After several months of seeing the neurologist who had initially prescribed the clonazepam, Kathy was managing well on the medication and was dismissed from his care. This meant she had to find another doctor who would prescribe it for her. She went from appointment to appointment with multiple doctors who refused to prescribe clonazepam and instead insisted on trying a different treatment option, to which Kathy responded:

It's the only drug I've been able to find that works for me. So I said to be honest with you, if you aren't going to be able to prescribe these I'm going to go wherever I need to go to find somebody that will. Because this is what works. And I've tried everything else. So I'm just going to keep going from place to place and until I find somebody that will prescribe them for me.

Eventually, Kathy's general practitioner agreed to prescribe clonazepam for her when she was satisfied that Kathy's reason for taking the medication was legitimate:

I finally convinced my general practitioner to prescribe it for me. But I had to go through a great deal of convincing. To be honest with you. I think what really convinced her was, for one thing, I've been taking it for five years and I've never upped the dose. But I'm also a happy person. So I think she finally came to believe that I wasn't seeking this drug to escape my life. Just to escape the pain.

Strategies for convincing doctors to prescribe was a common theme that emerged throughout the interviews. Sandra explained that her doctors were willing to continue prescribing hydrocodone for her after she "proved she could handle it":

The reason why my doctors are willing to prescribe that medicine for me is because they know that I would never ever abuse it. As a matter of fact, one time they only gave me 30 pills for a whole summer, and when I came back I showed them the bottle and that it wasn't empty and they said, "You did a good job. You probably hurt a lot."

Sandra's willingness to endure pain and resist using all of the medication was taken as evidence that she was in fact "deserving" of a continued prescription.

Evelyn's strategy for convincing her doctor to prescribe hydrocodone has been to tell him that she is taking the medicine for pain caused by hip replacement surgery. Evelyn explained that in reality, she takes the hydrocodone because it helps significantly with her fibromyalgia pain, but she is hesitant to be forthcoming about this:

The doctor asked me the last time I was in there, "You aren't taking this for the fibromyalgia pain are you?" And I knew enough to say no. Because I thought if I tell him I'm taking this for fibromyalgia, he will take it away from me. So I knew enough to say no.

While this covering strategy has worked so far, Evelyn knows that the doctor will not be willing to prescribe the hydrocodone indefinitely, because her hip will eventually be expected to heal. The prospect of losing access to the medication, and the relief it provides, is a source of great anxiety for her:

It's my internal medicine doctor who prescribes the Vicodin for me. I'm waiting for the cutoff and I've been trying to decide what I'm going to say when he says no more, because I really don't know how to convince him. I don't know what I'm going to do if he turns me down. Every time I go in I worry that this is the time he's going to say no. So I have this feeling we're gonna have a fight coming down the road, or I'm just gonna have to go off of it and try to find something else that would be as effective, but I haven't found anything else that works so well. So hopefully I'll be able to convince him.

Leslie lived with poorly controlled pain for years before she found an anesthesiologist who was willing to prescribe stronger medication. She was managing well on high doses of oxycodone until her doctor moved to a clinic in another city that was outside of her insurance network. Leslie visited every doctor in her area hoping to find someone else who would be willing to prescribe her medication, but was unsuccessful:

I went to appointment after appointment after appointment, and they would look at my records and they would say there is no way I'm going to write you a prescription for this much pain medication. Nobody would give me any medication because they were so afraid that they were going to go to jail or be in trouble themselves. Nobody would help me. I guess they just expected me to be in pain...That's what makes me so angry about doctors, because if they were in that much pain, I'm sure that they would take something for the pain.

Desperate and defeated, Leslie finally made the decision to continue treatment with her previous doctor, which meant paying out of pocket for each visit and driving to another city every month, which proved quite burdensome:

I have to see my doctor every 30 days because it's state law. Some states will let you go 90 days, but in mine it's 30. Boy it is hard! Because a while ago my doctor moved his office to another city which is like a 45 minute drive, and when I'm not feeling well, I'm telling you, it's hard. It's hard to do it. And sometimes I'll ask my son to drive me, but he and his wife are very busy. They both work so hard, and I don't want to burden them, so I try not to push it, but once in a while I just wish somebody could drive me.

While Leslie is able to continue her treatment for now, the fear of someday losing access to her current doctor is always on her mind:

I had a nightmare the other night that my doctor was moving, and I thought oh my God when I see him next week I'm gonna say to him, you aren't retiring or sick or going anywhere any time soon are you, or what am I gonna do? It scares me. Hopefully he's not going anywhere for a long time, because I don't know who I would go to. It's worrisome. Thank goodness for now I don't have to be concerned about that, but there may come a day when that might happen, and it scares me all of the time.

For a couple of years, Emily had a great relationship with her doctor and her pain was being well-controlled with Dilaudid. That is, until her husband's job transferred him to another state and they had to move across the country. In the new location, Emily went from doctor to doctor, searching for one that would agree to take her on as a patient and continue prescribing the medication. Every doctor she saw refused to continue the treatment:

So I went to quite a few doctors like that who just flat out refused to prescribe opiates. I went to one doctor who right away said, "We're going to get you off of your drugs completely. You're going to go through a detox program." And I'm like, are you kidding me? No way! I did find one doctor that would prescribe some opiates, but she refused to prescribe Dilaudid. She wanted to prescribe something weaker, even though I had been on the Dilaudid for a while by that time and it worked well for me. But she just refused.

With her medicine running low and no physician in the entire state who would refill it, Emily called her previous doctor and explained the situation. The doctor agreed to help and they worked out a solution. Emily flew across the country multiple times a year to see the doctor in

person, and the doctor sent the signed prescriptions to Emily every month through the mail.

While this solution worked and Emily was able to fill her out-of-state prescriptions without a problem, the system of sending the prescriptions through the mail caused her a great deal of anxiety, along with increased pain:

I was so worried about it and worried about her sending it, that I purposely took less than I needed to so that I could extend it out as long as I could. And I was so afraid that if it got lost in the mail, what would I do? Because her clinic probably wouldn't allow her to write another one and I would be screwed. Because they're not going to believe me that it got lost. Of course not. They assume that you're lying. They assume that you're doing something wrong. I was so afraid and I spent a lot of time in pain, because I was trying to take as little as possible because the restrictions made it so hard to get.

Eventually, Emily's husband was transferred again and they moved back to their home state. Emily continued to see the same doctor until, to her dismay, the doctor announced that she was retiring. Once again Emily had to search for a new doctor who would continue the treatment. Emily gathered every piece of documentation of her medical condition and carefully crafted a letter that chronologically outlined the details of her accident and resulting injuries and summarized every treatment she has tried over the years, highlighting the effectiveness of the current treatment. She anguished over the wording of the letter, wanting to get it just right. When she began her search for a new doctor, she presented the letter at the first appointment and urged the doctor to carefully consider it before making a decision about whether to continue her treatment. To her relief, a pain management specialist agreed to take on her case. However, when it came time for him to write the prescription, Emily was afraid to tell him how many pills she needed because she worried that the high dosage would compromise his willingness to prescribe them for her. Emily said:

I kind of made a big mistake because the nurse happened to ask me, how many do you take a day? And I kind of low-balled the number because I wanted it to be as low as possible because I worried about what she would think and what the doctor would think. But I shouldn't have done that, because now I've had to go into my emergency stash and

my emergency stash is starting to run low. So I know I have to say something soon. But I'm afraid to say anything because I'm so afraid that if I say I need more, automatically that's a red flag, you know? So I'm devising a plan about what to say to the doctor when I go in, but I don't want it to look like I'm thinking it out too much. You know what I mean? I don't want to look like I'm scheming about it. So this is what I'm worrying about. I'm spending so much time worrying about this. I'm so afraid that automatically that antenna is going to go up.

At the time of the interview, Emily was still experiencing increased pain and taking less medication than needed while trying to devise a plan to ask the new doctor for a higher prescription without triggering suspicion that she was abusing the medication.

Even when they were able to secure a doctor who was willing to prescribe pain medicine, the barriers to access did not end there for most participants. Once they had secured a prescription, the next obstacle was to find a pharmacy that would fill it. For a few participants, this was not a problem. According to Sandra, "I never had any trouble getting my prescriptions filled at the pharmacy because I always use the same pharmacy, and all of my doctors know each other, and they're all affiliated with the same hospital." Similarly, Stacey said, "I haven't had any trouble because I always use the same pharmacy."

Unfortunately, using the same pharmacy was not always possible. Several participants explained that when the restrictions on opioids were tightened, they began having trouble filling their prescriptions at their usual pharmacies. Leslie said:

I can remember when our attorney general first changed all of the rules about pain medication. My girlfriend drove me around to 20 different pharmacies one day trying to find a place that would fill my prescription and nobody would. We drove around and around and around, and there wasn't a single pharmacy that would fill it.

Debbie recounted a traumatic experience she had while trying to fill her prescription for Dilaudid at her usual pharmacy on a day when a substitute pharmacist was working:

I waited until it was my turn and I handed him my prescription, my insurance card, and my driver's license, because that's the law here in this state. He took one look at it and immediately handed everything back to me and said, "I can't fill this." And I'm like,

OK...? And my mother was with me and she had never been with me to fill any pain medications before, so she immediately started to get upset, and I said just hold on, because I know once you lose your temper it's over. So I maintained my calm and I said, I'm not sure what seems to be the issue, do you mean you don't have enough of the medication to fill it? Because if that's the case then I will try another pharmacy. And he said, "No, I'm just refusing to fill it." So I'm still trying to be nice and I'm trying to work with him, and I asked if I could pick it up tomorrow instead. And he said, "Look, I don't know what your game is, but I'm not filling it." And by this time he's yelling at me. He hasn't pulled me to the side or anything. There's a crowd now of like 20 people standing around and he is just making me feel like the biggest piece of crap, like I'm some kind of drug addict, and I mean he just went on and on. That man made me feel like I was doing something illegal, that I was a drug dealer, that I was a horrible person. I had never felt so ashamed and humiliated in my life.

After this encounter, Debbie attempted to fill her prescription at another pharmacy and discovered, to her horror, that the substitute pharmacist had called the other pharmacies in the city and "warned" them about Debbie and instructed them not to serve her. Fortunately, with the help of a friend, Debbie was eventually able to find a pharmacist outside of her city who would fill her prescriptions, but the memory of this incident still haunted her at the time of the interview.

Emily started having trouble filling her prescriptions when the pharmacies began limiting how often they would order the medicine she needed:

Because it's a controlled substance, the pharmacies will only order it once a week, so that means they are always running out. I can't tell you how many times I've gone to pick it up and they're like, "We're out." And a lot of times that's all they'll say, "We're out." And I'm like, OK, can you tell me what I can do? What do I need to do? How can I get it? And they won't even offer any information, because it's like they have this attitude that I shouldn't be on it anyway...I can't tell you how many times I've had to search around to find a pharmacy that will fill my prescription...and God forbid if you should call and ask first instead of driving around. I did that one time and I got the, "We're not going to tell you that. Why do you want to know?" Because they think that you're gonna go rob them or something. And I'm like, I'm only asking so that I don't have to spend my day driving around the city.

Emily finally found a grocery store pharmacy that would consistently fill her prescriptions. She went there for several months with no problems until one day the unexpected happened:

All of the sudden one day they told me that they weren't going to fill it anymore. And I asked why, and all they would say is, "According to our new policy, we will no longer fill your prescriptions for you." And it wasn't that they weren't filling prescriptions for opiates period, but apparently they had a checklist or something, and I must have failed it, but they wouldn't tell me what was on the checklist. So I was just mortified. I have not set foot in that store again and I will never go back there again.

Fortunately, Emily was able to find another pharmacist that would work with her, but the prospect of someday not being able to fill her prescription is a source of tremendous anxiety. She said, "And that's what is so scary. That's what I fear every day. That one day I'm not going to be able to get it filled, and then what am I gonna do? It scares me to death."

To manage the fear of losing access to her medicine, Emily explains that she keeps what she calls her "emergency stash":

I have what I call my emergency stash. I have saved up enough Dilaudid to hold me over in the event that I am not able to find a pharmacy that will fill my prescription, or if they have to order it and it might take a week. And that happens all of the time. I can't tell you how many times I've had to wait a week and I've had to go into my emergency stash.

Leslie also talked about her emergency stash, which she saves in case her pain increases in the future so she will not have to ask her doctor for more medication:

I always have medication left over thank goodness. I hold on to it in case I need it. I never use all of my medication every month, because I'm so worried that I'm gonna be in more pain in the future, so I try to take only what I absolutely need so that if I need more later on there's more for me to take. I don't tell my doctor that I don't take all of the medication because I don't want him to take any of it away from me. And then later down the line if I do need more I've got more already, and I don't have to ask him for it.

Even after securing enough medication, the battle does not end there. Many participants described a fear of being robbed. Leslie said:

Sometimes I worry because I live alone, and I have so much medication here, that somebody might try to rob me. I actually went and took a class on shooting a gun and I got my license to carry a firearm, and I have a gun, because I'm scared. Somebody could find out that I have all of this medication in my house and try to rob me. My doctor has actually told me not to mention to anyone what I'm taking. Because right now, especially people that are in a lot of pain that can't get any medication, you don't know what they'll do to get it.

Debbie described a similar worry:

Every time I get a prescription, as soon as that bottle is empty, I pull the label off and I shred it before I put it in the trash because I don't want anybody to know what I have in the house. It could be very dangerous, because it's something that people can't get, and so they want it.

Most participants directed blame for their situation at the government and the heightened restrictions on opioids, which they characterized as misguided efforts that punish people in pain, but do little to stop illegal activity. Jill explained:

I don't understand how changing Norco from schedule III to schedule II helps with the problems of overdose or people abusing it. It seems to me that the problem doesn't lie with the people who are following the rules. They aren't the ones who are overdosing on it. I mean everyone that I know who has a chronic pain condition and takes an opiate, they use it the way it's prescribed and it's just a hassle to get it. And the way it's regulated, they make you feel like a criminal. They make you feel like you're doing something wrong, and that you have to justify everything.

Similarly, Marcia said:

There's always gonna be street drugs, and when the legislature wants to get involved in making these laws, like the one now with the hydrocodone where I have to have a hand-written prescription every 30 days, all it's doing is hurting me. It's not taking drug addicts off of the street. It's not stopping the drug dealers. It's only hurting the people who truly need it. They're not eliminating the drug problem at all. They are hurting innocent people. Because like I said it is just as easy for me to get drugs off the street. I mean, I could go downtown and find drugs anywhere.

Leslie observed how the government regulation can backfire and cause more harm than good by forcing pain sufferers who cannot access their medicine legitimately to buy more dangerous drugs on the street:

Don't they realize what they have done to the sick people? That they can't even get their prescriptions filled? It's just crazy. Now people that are in this much pain are buying heroin off the street and they're ending up in the ER with heroin overdoses because they can't get their pain medications filled. And heroin is cheaper and easier to buy. And that's a problem the government created.

For many, the answer to the problem lies in "getting the story out." Emily said:

The day that happened at the grocery store pharmacy, I was just so angry. I mean, I wanted to get out there and launch a campaign. I wanted to write Rachel Maddow and say you've got to cover this. I still want to do it. I'm like, somebody's got to get this out, because this is ridiculous. We are being treated like criminals, and we didn't do anything wrong. The opiates have allowed me to live a functional life.

Similarly, Leslie said, "It's just been a constant fight over years to be able to continue to keep taking my medication, you know? I just don't understand. There's so many people with chronic pain. Why hasn't somebody stood up already?"

## **Discussion**

The dominant story of opioids as inherently addictive and dangerous drugs impacted the lives of the participants in several ways. First, many were initially fearful of using opioids to manage their pain and worried that the medication would hinder their ability to function and would lead inevitably to tolerance and addiction. While a few participants mentioned drowsiness as a bothersome side effect, most reported that the medication gave them more energy and allowed them to function better than they could when their pain was untreated. Fears of tolerance and addiction also did not come to fruition for the participants. Many stayed on the same dose for long periods of time and, although their bodies had become dependent on the medication, did not experience any problems with addiction.

The one fear that did materialize for most participants was stigma, and this was true even for Kimberly and Kathy, the two participants who had never taken opioids for chronic pain. This demonstrates that the stigma surrounding opioids is something that can affect chronic pain patients regardless of whether they use opioids or not. Simply being a chronic pain patient is enough to cast one under suspicion of "drug-seeking" or pursuing a prescription for motives other than pain relief. Many participants talked about stigmatizing encounters they had with medical professionals, co-workers, friends and family, law enforcement officials, pharmacists,

and other members of the general public. They lamented how others automatically attached negative meanings to their medication use and suspected them of taking opioids to “get high” or feed an addiction, rather than for the legitimate treatment of pain.

To manage stigma, most participants resorted to secrecy and kept their medication use hidden from others whenever possible, disclosing only to close friends and family. Ironically, by keeping their medication use secret, they also prevented their stories from reaching the public and further allowed the addiction narrative to be the only story about opioids that others are familiar with. However, by disclosing their use, they also risked perpetuating stigma if the consequences of disclosure interfered with their ability to function in society. For example, when Debbie disclosed her medication use at her job, the stigma she encountered eventually contributed to her decision to quit, which could be interpreted as evidence that people who use opioids cannot function in the workplace. These findings seem to support modified labeling theory, which holds that stigma management strategies can actually compound the social struggles faced by the stigmatized by leading to negative consequences for social support networks and employment (Link et al. 1989).

The dominant story of opioids as drugs of abuse and addiction also translated into tangible barriers the participants encountered in accessing their medication and achieving adequate pain relief. Many struggled to find a doctor who would treat them and endured humiliating treatment as they searched for a provider. The irony is that by going from doctor to doctor desperate to find one who would continue their treatment, the participants essentially reinforced the stereotype of the “doctor shopper” – a person, usually understood as an addict, who visits multiple providers to obtain narcotics. A similar problem arose as regulations were passed which made it difficult for many of the participants to find a pharmacy that would fill

their prescriptions. Often, while experiencing debilitating pain, they were forced to drive from pharmacy to pharmacy looking for one that would serve them, unwittingly reinforcing the stereotype of the “pharmacy hopper,” a common feature in the story of the “prescription painkiller epidemic.” It seems no matter what the participants did, nor how hard they attempted to follow the rules, every action they took could be taken as evidence of addiction.

This phenomenon became especially apparent during my interview with Emily, when she produced an “Addiction Behaviors Checklist” (see Appendix E) which used in some doctors’ offices and is intended to measure “possible inappropriate opioid use” in patients with chronic pain. The checklist includes 20 items, and if a patient receives a “yes” on three or more items, this “indicates possible inappropriate opioid use and should flag for further examination of specific signs of misuse and more careful patient monitoring.”

As I reviewed the checklist, I was struck by the number of items that aligned with the stories that Emily and the other participants had shared about their experiences. The first item that stood out was “patient indicated that he or she ‘needs’ or ‘must have’ analgesic meds.” In other words, according to the checklist, expressing need for pain medication is to be automatically interpreted by doctors as a possible sign of addiction. Similarly troubling was another item, “patient expressed a strong preference for a specific type of analgesic.” Many participants in this study had spent months or even years experimenting with different treatments before finding a medication that worked for their pain. Yet, telling this story to a doctor and requesting the particular medication they needed would be considered a possible addiction behavior according to the checklist. This is interesting because as Baruch (2008:8) points out, requesting a particular medication would not normally be viewed as problematic behavior:

Rarely in clinical medicine does the desire for a readily available treatment serve as a reason to dismiss a symptom. If a patient with a history of recurrent urinary tract

infections tells the emergency physician which antibiotic has been effective in the past and which were not, the physician is usually appreciative. But if the same patient has sickle cell disease or a migraine headache and informs the staff that Dilaudid usually works, he or she risks being stigmatized as a drug abuser.

Another item on the checklist, “patient reports minimal/inadequate relief from narcotic analgesic,” also serves to stigmatize patients who express concerns that the opioid they are currently receiving is not strong enough to adequately manage their pain. When Emily expressed to her doctor that the tramadol was not working well enough, an encounter that led to the stronger prescription for Dilaudid that Emily referred to as “life-saving,” she was, according the checklist, behaving in a way “possibly indicative of addiction.”

Another item on the checklist, “patient misrepresented analgesic prescription or use,” also occurred in a number of the participants’ stories. For example, Evelyn told her doctor that she was taking hydrocodone for hip pain, when she was really taking it for fibromyalgia pain, out of fear that if she told the truth the doctor would stop prescribing the hydrocodone and she would be left without an effective treatment. Emily also “misrepresented analgesic use” when she rounded down the number of pills she needed every month out of fear that the real number would scare the new doctor away from taking on her case. Even fearing the loss of access to medication itself is considered a possible addiction behavior according to the checklist, as one item reads, “patient expresses concern about the future availability of narcotic.” The only strategy available to the participants to manage fear of losing access – saving an emergency stash – also appears on the checklist under the item, “patient has hoarded meds.” Thus, the stigma and barriers surrounding prescription opioids effectively forced the participants into doing the very things that are considered indicative of addiction.

When a person with chronic pain asks a doctor for medication, the doctor is expected – even legally obligated – to automatically question the patient’s account and analyze it for signs

of abuse or addiction. They are obligated to compare the patient's story to the dominant story of what it means to be an "opioid addict." But what if the dominant story is wrong in the first place? What if the signs of addiction that doctors are expected to look for are not really indicative of addiction, but of inadequately treated pain? In the literature, this phenomenon is referred to as "pseudoaddiction," which occurs when seemingly aberrant behaviors stem from poor pain management rather than addiction, and doctors are encouraged to make distinctions between the two (Weissman and Haddox 1989). The problem with the concept of pseudoaddiction, according to Bell and Salmon (2009), is that it furthers the assumption that doctors should attempt to distinguish between patients that are "addicts" and those that are "pseudoaddicts," and reinforces the idea that people placed in the former category are not deserving of pain treatment. I argue that it also reinforces the idea that chronic pain patients' stories should be analyzed and questioned, rather than listened to and believed.

In *The Wounded Storyteller*, Frank (1995) argues that we need to think *with* patients' stories, rather than *about* them, and advocates for a moral duty "to listen to the voices of those who suffer" (Frank 1995:25). Similarly, Rita Charon (2006) argues that physicians should practice "narrative medicine" and that listening to patients' stories will allow doctors to treat them more compassionately and effectively. Jones (1999:253) calls stories told by patients "narratives of witness" and argues that they can, "with their experiential truth and passion, compel re-examination of accepted medical practices and ethical precepts," and can influence the practices of doctors and institutions. The current accepted medical practice is to make distinctions between patients who are "deserving" of opioids and those who are at risk of addiction. This is done under legal obligation as well as an ethical assumption that it is for

patients' "own good," and is guided by the dominant narrative of opioids as inherently addictive and dangerous and of chronic pain patients as especially vulnerable to addiction.

Frank (2010:665) argues that "anyone's sense of what counts as ethical is derived, first and often most pervasively, from the stories that a person knows." In the dominant story of the "prescription painkiller epidemic," the plot is a problem of overprescribing. Doctors are portrayed as villains who out of greed or ignorance, prescribe opioids too readily to chronic pain patients who almost inevitably succumb to addiction. The moral of this story is that doctors must be more cautious in opioid prescribing in order to protect patients from opioid-related harm. However, the stories told by the participants in this study portray a different plot – one in which chronic pain patients are not victims of overprescribing, but of stigma and barriers to treatment. The villains in their stories are doctors and others who doubt the severity of their pain and question their need for medication. The moral of their stories directly opposes the moral of the dominant story and calls the accepted "ethical" practices into question.

Ewick and Silbey (1995) argue that when parties whose voices are not normally heard are able to tell their narratives, these stories become "subversive" and are capable of countering and transforming the hegemonic. In other words, subversive narratives allow people to hear new stories about the experiences of "others" that can shift the direction of public opinion. By sharing the stories of patients with chronic pain and their struggles with stigma and barriers to medication, I hope to make the public more aware of their struggles and more likely to consider them when constructing their opinions and policies surrounding opioid medications.

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## **Chapter Six:**

### **Discussion**

For nearly two decades, the abuse of prescription opioid painkillers has been constructed as a major social problem in the United States. Stories of addiction, overdose deaths, robberies, and other tragedies related to prescription opioids have been, and continue to be, commonly featured in the media. Television shows like A&E's *Intervention* document the devastating consequences that opioid addiction can have on the lives of addicts and their loved ones. Parents of children lost to opioid-related deaths have spoken publicly about their terrible losses and demanded that those in power take action to end the "prescription painkiller epidemic." In response to the public outcry, government and medical institutions have taken actions to limit the distribution of opioids and, for reasons I explored in-depth in this dissertation, have targeted most of these restrictions at the treatment of chronic pain.

My goals in this dissertation were twofold. First, I aimed to uncover how cultural and institutional narratives about prescription opioids serve to justify the stigmatization and marginalization of patients with chronic pain who rely on opioid medications. Second, I aimed to reduce the stigmatization and marginalization of patients with chronic pain by making personal narratives of their experiences more visible and accessible.

I began to address the second goal in Chapter Two in which I shared my own story as a daughter of a mother with chronic pain who relies on prescription opioids. My intent was to *show* rather than *tell* how I experience and interpret the stigma and barriers surrounding my mother's treatment and to "set the stage" for the rest of the dissertation. I wanted to make visible

the tensions I have long felt between the dominant story of opioids as drugs of abuse and addiction and the story of opioids as essential medications that I have witnessed in my own life. I wanted to capture the deep sadness and anger I have felt as the result of the stigma surrounding my mother's treatment and the ever-present fear that she will lose her access to medication. In short, I wanted to show why I care about this topic in an evocative and heartfelt way that more traditional research methods would not allow.

While autoethnography was an effective tool for disclosing my own positionality and shedding light on how the stigma and barriers surrounding opioids can translate into lived experience, this method could not get at the *why* question that was also central to my dissertation project. That is, the question of why people with chronic pain (especially those who rely on opioid therapy) are stigmatized and marginalized within the health care system. According to Peppin (2009:497), "There has been little in the literature addressing the rationale behind the marginalization of chronic pain patients on opiate therapy."

As a sociologist interested in narrative, I suspected that answers to the *why* question could most likely be found in stories. More specifically, in stories about opioids circulating widely in the public sphere. I considered the constructionist argument that widely circulating narratives both reflect and sustain institutional and cultural arrangements (Ewick and Silbey 1995; Reissman 1993) and that widely circulating stories contain symbolic codes, or "systems of ideas about how the world does work, how the world should work, and about the rights and responsibilities among people in this world" (Loseke 2012:253). I thought that by analyzing widely circulating stories about opioids, I could uncover the underlying assumptions present and begin to answer the question of why people with chronic pain are singled out for stigmatization and differential treatment.

In Chapter Three, I began to answer the *why* question by analyzing national news articles about prescription opioids published in the *New York Times* between 2000 and 2013. In my analysis, I read through the articles multiple times, looking for the larger narrative or narratives that were told about pain and prescription opioids. What emerged in the data were two overarching narratives – a predominant narrative about the “prescription painkiller epidemic” and a less common narrative about the “crisis of unrelieved pain.” I examined the plot, characters, and moral of each narrative and then considered their underlying assumptions and implications for the treatment of chronic pain.

The plot of the “prescription painkiller epidemic” narrative was about an epidemic of opioid addiction and death that was ravaging American society. There were two types of villains in this story. The first and most common type was the dangerous opioid addict, who would lie, manipulate, steal and commit crimes (often violent) to support his or her habit. The second type of villain was the greedy, negligent doctor, who would write obscene amounts of opioid prescriptions for profit. The victims in the story were portrayed as pure innocents, usually children, who were harmed by the actions of opioid addicts who had been enabled by doctors’ reckless prescribing habits. The moral of this story was that the prescribing of opioids must be greatly reduced in order to protect society.

The plot of the second story that emerged in the news articles, about the “crisis of unrelieved pain,” directly opposed the plot of the “prescription painkiller epidemic” story. In the “crisis of unrelieved pain” story, it was the severe *under*-prescribing of opioids that was the problem. While in the “epidemic” story, opioids were portrayed as inherently addictive and dangerous drugs that must be prohibited, in the “crisis” story opioids were portrayed as essential medicines that must be more readily relinquished.

In the “crisis of unrelieved pain” story there were two types of villains. The first were overzealous legislators and law enforcement officers accused of limiting access to opioids for patients who truly needed them. The other villains were heartless doctors, accused of doing the same, by refusing to prescribe opioids to patients in pain. The victims in this story were legitimate patients, who suffered greatly due to the barriers to opioid access. The moral of this story was that access to opioids must be reserved for legitimate patients.

Taken together, the “prescription painkiller epidemic” story and “crisis of unrelieved pain” story encouraged readers to believe that there are two types of people who use opioids. The first are opioid addicts – dangerous villains that should not have access to opioids. The second are legitimate patients – innocent victims that must have access. But the stories give no explicit instructions on how to distinguish between a legitimate patient and an addict. This begs the question, how should such distinctions be made?

It was implicit in the narratives that patients with pain related to cancer and terminal illness should be automatically regarded as legitimate, as most of the “crisis of unrelieved pain” stories featured patients with cancer and terminal illness, and there were no stories in which patients with cancer or terminal illness experienced negative consequences from opioids. On the other hand, most stories of people succumbing to opioid addiction were about people with chronic pain. Thus, I argued, readers are encouraged to believe that patients with cancer or terminal illness are unquestionably legitimate and deserving of the relief opioids can provide, while people with chronic pain *might* be or become addicts, and therefore should be regarded with suspicion and more cautious prescribing.

My analysis of cultural narratives brought me closer to answering the *why* question. The stories portrayed a reality in which distinctions *must* be made between addicts and legitimate

patients. Because patients with chronic pain are not automatically afforded legitimacy in the same way that people with cancer and terminal illness are, I argued that they would likely be singled out for differential treatment and/or stigmatized as addicts. But exactly how this would happen could not be answered through analyzing narratives at the cultural level.

While I could assume that the cultural narratives both reflected and affected hegemonic beliefs about pain and prescription opioids and therefore justified stigmatization, at the cultural level they were still “just” stories, and may or may not have materialized into measurable consequences. In order to examine how these stories became social structure, I needed to examine narratives at the institutional level because, according to Loseke (2007:667), while cultural narratives “might – or might not – be evaluated as believable and important by a significant number of people and therefore might – or might not – shape the symbolic world, narratives of institutional identities are, by definition, consequential.”

In Chapter Four, I moved from the cultural level of the news media to the institutional level of public policy-making, and I examined stories about prescription opioids told in an FDA public hearing on opioid labeling. I read through the stories multiple times, looking for the larger narrative or narratives that were being told about pain and prescription opioids. Similar to what I found in my analysis of the *New York Times* articles, what emerged in the data were two overarching narratives – a story about the “dangers of opioids” and a story about the “benefits of opioids.” I examined the plot, characters, and moral of each narrative and then considered their underlying assumptions and implications for the treatment of chronic pain.

The plot of the “dangers of opioids” story was about an epidemic of addiction and death that was directly caused by an increase in prescribing of opioids to patients with chronic pain in particular. The prescribing of opioids to patients with pain related to cancer or terminal illness

was not included in the problem under discussion. As I suspected would be the case from my previous analysis of cultural narratives, chronic pain patients had been singled out as the target population to be dealt with through some sort of policy action.

Like in the “prescription painkiller epidemic” narrative told in the news articles, the “dangers of opioids” story told at the FDA hearing constructed doctors as villains, blaming them for causing harm to patients and the wider society through lax opioid prescribing. However, in the “dangers of opioids” story there are other villains as well, including pharmaceutical companies accused of over-marketing opioids for use in chronic pain and downplaying their risks, and the FDA for not sufficiently regulating the marketing and prescribing of opioids for chronic pain.

In contrast to the “prescription painkiller epidemic” story told in the news articles, the “dangers of opioids story” told at the FDA hearing did not include addict villains. Instead, the victims in this story were patients with chronic pain who had been prescribed opioids and became addicted and/or overdosed through no fault of their own. Thus, since the “dangers of opioids” story is about chronic pain patients being harmed by opioids, the logical moral of the story is to reduce the prescribing of opioids to patients with chronic pain.

In opposition to the “dangers of opioids” story, the FDA hearing also included a “benefits of opioids story.” Similar to the “crisis of unrelieved pain” story told in the news articles, the “benefits of opioids” story told in the hearing included accounts of patients (mostly patients with cancer and terminal illness) who benefit greatly from treatment with opioids and would suffer greatly if access to treatment was limited. Thus, the moral of the “benefits of opioids” story is that access to opioids must be preserved for *some* patients.

Taken together, the “dangers of opioids” story and the “benefits of opioids” story construct a reality in which doctors must be more cautious when prescribing opioids to patients with chronic pain and take measures to distinguish between chronic pain patients who might benefit from treatment with opioids and those who might become addicts. Again the question becomes, how should such distinctions be made?

The outcome of the hearing was an FDA label change that urged doctors to do three things when prescribing opioids to chronic pain patients: (1) assess each patient’s risk for addiction before prescribing; (2) make decisions about prescribing not solely based on each patient’s report of pain, but also on a more thoughtful determination that their pain is severe enough to require opioid treatment and for which alternative treatment options are inadequate; and (3) when opioids are prescribed, to monitor chronic pain patients carefully for signs of abuse and addiction (FDA 2013). In short, the hearing resulted in a label change that made doctors legally and ethically obligated to “weed out” the chronic pain patients who might become addicted through questioning the stories they tell about their pain and to exert control and surveillance over chronic pain patients receiving opioid medications. The label change was made under the shared assumptions that opioids are inherently addictive, that chronic pain patients are especially vulnerable to addiction, and that it is the responsibility of doctors and government regulators to protect chronic pain patients from addiction.

After my analyses of cultural and institutional narratives helped answer the *why* question by revealing the underlying assumptions by which chronic pain patients became singled out for differential treatment, I returned to the second goal of my research, which was to make chronic pain patients’ stories more visible and accessible as a means to reduce stigmatization and marginalization. In Chapter Five, I shared the stories of twelve chronic pain patients gathered

through in-depth interviews with them about their experiences. Their stories reveal how the dominant narrative of opioids impacted their everyday lives and in turn, serve to challenge the dominant narrative.

The dominant story of opioids as inherently addictive and dangerous drugs impacted the lives of the participants in several ways. First, they were initially fearful of using opioids to manage their pain and worried that the medication would hinder their ability to function and would lead inevitably to tolerance and addiction. However, most found that this was not the case and instead found that their lives were greatly improved by medication. The most significant problems they encountered did not stem from the treatment itself, but from the stigma and barriers surrounding opioids.

Many participants talked about stigmatizing encounters they had with medical professionals, co-workers, friends and family, law enforcement officials, pharmacists, and other members of the general public. They lamented how others automatically attached negative meanings to their medication use and suspected them of taking opioids to “get high” or feed an addiction, rather than for the legitimate treatment of pain. This was true even for the two participants who had never taken opioids, which demonstrates that the stigma surrounding opioids is something that can affect chronic pain patients regardless of whether they use opioids or not.

To manage stigma, most participants felt they had no other choice but to resort to secrecy and keep their medication use hidden from others whenever possible. Most disclosed only to close friends and family. However, by keeping their medication use secret, they also inadvertently prevented their stories from reaching the public and further allowed the addiction narrative to be the only story about opioids that others are familiar with.

The dominant story of opioids as drugs of abuse and addiction also translated into numerous barriers the participants encountered in accessing their medication and achieving adequate pain relief. Many struggled to find a doctor who would treat them and endured disparaging treatment as they searched for a provider. Once they found a doctor, they had to make sure they told the “right” story to continue receiving prescriptions, as well as endure humiliating urine drug screenings and drive long distances to the doctor’s office every month to continue receiving treatment. The barriers did not end once the written prescription was in hand, however. Several participants described the great lengths they went through to find a pharmacy that would serve them. Even after securing their medication, they lived in fear of being robbed or someday losing access to their treatment.

Ironically, the actions the participants took to manage barriers to treatment were often the very same behaviors that could be considered indicative of addiction and thus, could hinder their access to treatment. For example, the Addiction Behaviors Checklist I discussed in Chapter Five characterizes patients’ attempts to tell doctors the “right” story (i.e. “misrepresenting analgesic use”) as a behavior possibly indicative of addiction. Also, their fear of losing access is characterized as “patient expresses concern about future availability of narcotics,” and keeping an emergency stash is labeled “patient has hoarded meds.” The bottom line in the participants’ stories is that the mechanisms intended to help them by preventing addiction, in many ways harmed them, and also served to silence their stories by treating everything they said or did as evidence of addiction.

The personal narratives of participants in this study directly challenged the dominant story told at the cultural and institutional levels. In the dominant story, the moral is that doctors must be more cautious in opioid prescribing to chronic pain patients in order to prevent opioid-

related harm. However, the stories told by the participants in this study portray a different moral – that the stigma and barriers surrounding chronic pain treatment with opioids must be eliminated.

Loseke (2007:661) posits that the relationships between different levels are inherently reflexive, and argues that “exploring relationships between and among different types of narrative identity would yield a better understanding of how narratives work and the work narratives do.” Each type of narrative can influence the other. Cultural narratives can seep into the institutional sphere and inform public policy, public policy can affect the lives of individuals who then tell personal narratives about their experiences, and these personal narratives can be re-told at the cultural and institutional levels to affect change.

Ewick and Silbey (1995) write about two virtues of narratives – the ability to reveal truth and unsettle power. As objects of inquiry, narratives allow analysts to uncover widely shared assumptions about the world that both reflect and sustain cultural and institutional arrangements (Ewick and Silbey 1995; Reissman 1993). As a method of inquiry, narrative allows authors to show how cultural and institutional arrangements affect lived experience. Social change becomes possible when narratives are subversive and “challenge the taken-for-granted hegemony by making visible and explicit the connections between particular lives and social organization” (Ewick and Silbey 1995:197).

Findings of this study suggest that while chronic pain patients have subversive stories to tell, telling those stories and challenging the dominant narrative is not without risk. For most participants, the threat of losing access to medication that has made their pain bearable offers a powerful incentive for silence. Telling the “wrong” story to the wrong person could mean not only stigmatization, but also loss of access to treatment and a life of unbearable pain. The

riskiness of subversive stories in this context likely means that the dominance of the “prescription painkiller epidemic” narrative will continue unless the voices of chronic pain patients are included in stories told at the cultural and institutional levels.

In sum, the dominant narrative of opioids as dangerous and addictive drugs told at the cultural level has led to public outcry for more careful distinctions to be made between “legitimate patients” and “addicts” among people who rely on opioid medications. Patients with chronic pain, who have long struggled to achieve legitimacy, have been singled out as the population to be targeted. The dominant narrative has trickled down to the institutional level where it has influenced policy decisions intended to reduce the prescribing of opioids to patients with chronic pain by requiring doctors to enact barriers, such as mechanisms of surveillance and control, as a means to distinguish between “legitimate patients” and “addicts” among chronic pain patients. Patients with chronic pain who cannot or will not tell the “right” story and follow the rules imposed by these barriers are those most likely to be labeled illegitimate and denied pain treatment. Thus, in order to prove their deservingness and legitimize their claims to opioid medication, people with chronic pain must comply with the barriers no matter how humiliating, burdensome, or harmful they may be. They must also avoid telling stories that challenge the dominant narrative, lest they risk being stigmatized as illegitimate and losing access to pain treatment.

The dominant narrative about opioids told at the cultural and institutional levels has contributed to the creation of structures that serve to silence the personal narratives of patients with chronic pain. Change at the cultural and institutional levels will only be possible if chronic pain patients are actively encouraged to share their personal narratives. They are, however, unlikely to do so unless they receive assurance that they can share their stories without fear of

reprisal. In the face of the dominant cultural and institutional narratives and the barriers they justify, that kind of freedom will be hard won for patients with chronic pain. This dissertation represents a small step along the road to un-silencing their voices and bringing the stories of chronic pain patients into the discourse on chronic pain management.

Taken together, the findings of this dissertation suggest several avenues for future research. First, it is clear that in across levels of narrative, cancer patients are exempted from concerns about addiction. They are portrayed as worthy patients whose pain must be managed at any cost, and the legitimacy of opioid therapy for their pain is unchallenged. However, this has not always been the case. So, how did the transformation happen? What were the narratives used to legitimize opioid treatment for cancer pain and where did these narratives come from? How might similar stories be told to improve the situation for patients with chronic pain?

Second, in my analyses, I found that doctors were overwhelmingly portrayed as “villain” characters in all levels of narratives – the cultural and institutional narratives construct them as villains for too liberally prescribing opioids to chronic pain patients, and the personal narratives construct them as villains who stigmatize patients and enact barriers. Future research should address doctors’ experiences of being vilified in this way and the personal narratives they tell about practicing within the constraints of existing narratives of chronic pain.

Finally, the findings of this multi-narrative analysis reveal a great deal about how cultural and institutional narratives are interconnected, how they can serve to restrict the kinds of personal narratives individuals can share about their own experiences, and the risks associated with telling subversive narratives. This method could also be very helpful in understanding the experience of living with other kinds of stigmatized conditions, including other types of invisible disabilities and contested illnesses. This method might be especially useful for examining how

people with invisible disabilities and contested illnesses negotiate barriers to accessing needed funds and services.

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**Appendix C:**  
**Institutional Review Board Approval Letter**



RESEARCH INTEGRITY AND COMPLIANCE  
Institutional Review Boards, FWA No. 00001669  
12901 Bruce B. Downs Blvd., MDC035 • Tampa, FL 33612-4799  
(813) 974-5638 • FAX (813) 974-7091

8/9/2013

Loren Wilbers, M.A.  
University of South Florida  
Department of Sociology  
4202 E. Fowler Avenue, CPR 216  
Tampa, Florida 33620

**RE: Expedited Approval for Initial Review**  
**IRB#: Pro00002938**  
**Title: The Experience of Chronic Pain Management: A Multi-Voiced Narrative Analysis**  
**Study Approval Period: 8/9/2013 to 8/9/2014**

Dear Dr. Wilbers:

On 8/9/2013, the Institutional Review Board (IRB) reviewed and **APPROVED** the above application and all documents outlined below.

**Approved Item(s):**

**Protocol Document(s):**

[Loren Wilbers - IRB Research Protocol](#)  
[Loren-Wilbers-IRB-Interview-Protocol-1](#)  
[Loren-Wilbers-IRB-Interview-Protocol-2](#)

**Consent/Assent Document(s):**

[Loren-Wilbers-IRB-Consent-Form-1](#)  
[Loren-Wilbers-IRB-Consent-Form-2](#)

It was the determination of the IRB that your study qualified for expedited review which includes activities that (1) present no more than minimal risk to human subjects, and (2) involve only procedures listed in one or more of the categories outlined below. The IRB may review research through the expedited review procedure authorized by 45CFR46.110 and 21 CFR

56.110. The research proposed in this study is categorized under the following expedited review category:

(6) Collection of data from voice, video, digital, or image recordings made for research purposes.

(7) Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

Your study qualifies for a waiver of the requirements for the documentation of informed consent as outlined in the federal regulations at 45CFR46.117(c) which states that an IRB may waive the requirement for the investigator to obtain a signed consent form for some or all subjects.

As the principal investigator of this study, it is your responsibility to conduct this study in accordance with IRB policies and procedures and as approved by the IRB. Any changes to the approved research must be submitted to the IRB for review and approval by an amendment.

We appreciate your dedication to the ethical conduct of human subject research at the University of South Florida and your continued commitment to human research protections. If you have any questions regarding this matter, please call 813-974-5638.

Sincerely,

A handwritten signature in black ink that reads "John A. Schinka, Ph.D." The signature is written in a cursive, flowing style.

John Schinka, Ph.D., Chairperson  
USF Institutional Review Board

**Appendix D:**  
**Interview Guide**

*Thank you for consenting to participate in this study. I would like to record this interview so that the study can be as accurate as possible, and I would like to remind you that during any point during the course of the interview, you may request that the tape recorder be turned off. You may also choose to skip any of the questions or end the interview at any time, with no consequence to you.*

*The information you provide, aside from any identifying information, may be disseminated in a dissertation, conference presentations, or submitted to peer-reviewed journals for publication.*

Questions that the participants will be asked may include:

1. What led you to try opioids to manage your pain?
2. What, if any, hesitations did you have about managing your pain with opioids?
3. What was life like before pain management with opioids?
4. What does it feel like to take opioids for pain?
5. What challenges have you encountered with regards to managing your pain with opioids?
6. What is a typical day like?
7. What have your experiences with doctors been like?
8. How has your family responded to your opioid therapy?
9. How have your friends and acquaintances responded to your opioid therapy?
10. What are your thoughts about the future?

*Thank you for participating in this interview. Here is my contact information in case you would like to re-contact me to provide additional information or if you have any questions about the study: Loren Wilbers, [lwilbers@mail.usf.edu](mailto:lwilbers@mail.usf.edu).*

## Appendix E:

### Addiction Behaviors Checklist

#### Addiction Behaviors Checklist (ABC)

Designed to track behaviors characteristic of addiction related to prescription opioid medications in chronic pain patients. Items are focused on observable behaviors noted both during and between visits. ABC is focused on longitudinal assessment and tracking of problematic behaviors.

Addiction Behaviors Checklist			
<b>Instructions:</b> Code only for patients prescribed opioid or sedative analgesics on behaviors exhibited "since last visit" and "within the current visit" (NA = not assessed)			
<b>Addiction behaviors—since last visit</b>			
1. Patient used illicit drugs or evidences problem drinking*	Y	N	NA
2. Patient has hoarded meds	Y	N	NA
3. Patient used more narcotic than prescribed	Y	N	NA
4. Patient ran out of meds early	Y	N	NA
5. Patient has increased use of narcotics	Y	N	NA
6. Patient used analgesics PRN when prescription is for time contingent use	Y	N	NA
7. Patient received narcotics from more than one provider	Y	N	NA
8. Patient bought meds on the streets	Y	N	NA
<b>Addiction behaviors—within current visit</b>			
1. Patient appears sedated or confused (e.g., slurred speech, unresponsive)	Y	N	NA
2. Patient expresses worries about addiction	Y	N	NA
3. Patient expressed a strong preference for a specific type of analgesic or a specific route of administration	Y	N	NA
4. Patient expresses concern about future availability of narcotic	Y	N	NA
5. Patient reports worsened relationships with family	Y	N	NA
6. Patient misrepresented analgesic prescription or use	Y	N	NA
7. Patient indicated she or he "needs" or "must have" analgesic meds	Y	N	NA
8. Discussion of analgesic meds was the predominant issue of visit	Y	N	NA
9. Patient exhibited lack of interest in rehab or self-management	Y	N	NA
10. Patient reports minimal/inadequate relief from narcotic analgesic	Y	N	NA
11. Patient indicated difficulty with using medication agreement	Y	N	NA
<b>Other</b>			
1. Significant others express concern over patient's use of analgesics	Y	N	NA
<small>*Item 1 original phrasing: ("Patient used ETOH or illicit drugs"), had a low correlation with global clinical judgment. This is possibly associated with difficulty in content interpretation, in that if a patient endorsed highly infrequent alcohol use, he or she would receive a positive rating on this item, but not be considered as using the prescription opioid medications inappropriately. Therefore, we include in this version of the ABC a suggested wording change for this item that specifies problem drinking as the criterion for alcohol use.</small>			
<b>ABC Score:</b> _____ Score of $\geq 3$ indicates possible inappropriate opioid use and should flag for further examination of specific signs of misuse and more careful patient monitoring (i.e., urine screening, pill counts, removal of opioid).			

Checklist developed by Bruce D. Naliboff, Ph.D. with support from VA Health Services Research and Development. Used with permission.  
 Published in: Wu SM, Compton P, Bolus R, et al. The addiction behaviors checklist: validation of a new clinician-based measure of inappropriate opioid use in chronic pain. *J Pain Symptom Manage*. 2006;32(4):342-351.