

TMD REVISITED: APPRECIATING THE WORK OF ILLNESS, THE BALANCING  
OF RISKS, AND THE CONSTRUCTION OF MORAL IDENTITY INVOLVED IN  
DEALING WITH CHRONIC PAIN

by

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## ABSTRACT

Temporomandibular Disorder(s) (TMD), a common cause of chronic pain affecting the face and jaw, profoundly impacts interactions as fundamental to human existence as smiling, laughing, speaking, eating, and intimacy. Since landmark anthropological research on TMD in the 1990s, considerable changes have occurred in the way TMD is thought about and responded to. Knowledge about TMD among dentists and physicians has increased since publication of the Research Diagnostic Criteria (RDC-TMD), and a well-funded TMJ association now advocates for research and support of the condition. On the other hand, concerns in the medical world about increases in chronic pain and associated risks of misuse of pain medications have increased. Physicians are trained to perform a gatekeeper role, preventing those patients at-risk of becoming drug abusers from gaining access to opioid pain medications. These differing contextual factors and my focus on a group of participants drawn from a complementary and alternative medicine (CAM) trial, rather than from a pain clinic, provide an expanded and updated view of TMD. I present analyses of semi-structured, open-ended interviews with 44 participants interviewed multiple times over the course of their participation in an NIH-funded trial evaluating Traditional Chinese Medicine (TCM) for TMD. In contrast to earlier studies of participants who were consumed by an endless search for diagnosis and treatment, these participants were largely focused on coping and “just dealing with” the daily experience of severe pain. Three articles comprise the body of work presented in this dissertation. Topics include the Works of Illness, the Paradox of Hope, and the construction of moral identity through consumption of over-the-counter (OTC) medications.

First, using a “works of illness” framework, I draw attention to the considerable work sufferers undertook to manage competing demands of social and physical risk imposed by chronic pain. I refer to these forms of work as the *work of stoicism* and the *work of vigilance* and identify double binds created in contexts that call for both. Multiple voices in the narratives of sufferers are highlighted as essential to the construction of a positive identity in the face of illness.

In more in-depth exploration of the work of hope, hope is revealed as a fundamental and paradoxical aspect of autobiographical work. I describe multiple forms of hope in a typology of *ways of hoping* and raise as an issue the manner in which the paradox of hope—keeping hopes in check while also avoiding despair— intersects with participant expectations in the trial. I suggest this may have an impact on the placebo effect.

Trade-offs between physical harm reduction and reducing potential harm to one’s identity produce narratives of *harm justification* as pain sufferers work to describe their use of OTC medications as minimal and responsible. Sufferers in this study, describing medications as “just over-the-counter” or “not real pain medication” distanced, themselves from association with the addictive potential of prescription pain medications. Participants avoided harm to their identities by consuming OTC pain medications as idioms of self-care.

This case study provides important lessons about the experience of chronic pain in the USA. While much attention has been directed at overuse and addiction to pain medication, less has focused on the experience of those soldiering through pain and navigating paradoxes between social and physical demands. This study also directs

attention to anthropology's potential contribution to drug trials, to the necessity of studying hope as well as expectations, and to how both impact the placebo response.

## INTRODUCTION

This research, conducted as part of a larger study, considers the perspectives of individuals living with chronic temporomandibular pain who were not seeking care in a Western Medical context. I explore their experiences of pain over time in the context of a complementary and alternative medicine (CAM) treatment study. Research questions included: (1) What do participants believe about illness causality and prognosis and how does this relate to prior experience? (2) How are expectations and hopes for the future involved in experience and how do they change over the course of a treatment experience? (3) How is medication use undertaken and explained in ongoing pain management? (4) How do people living with chronic pain understand their experience in a treatment-oriented study in relation to identity, pain management, and living up to family obligations and cultural expectations?

Although many of the theoretical conclusions in this research apply to chronic pain and chronic illness more broadly, I focus on a particular chronic pain disorder affecting the face and jaw that is commonly referred to as Temporomandibular Disorder(s) (TMD).<sup>1</sup> This research is focused on interviews with 95 participants, 44 of whom completed 4 or 5 interviews each over the course of their participation in a study offering Traditional Chinese Medicine (TCM). I interviewed participants from 2007 to 2010. Contact with each individual participant typically ranged from 1 year to 18 months, depending on the speed with which they completed study activities. In the articles that comprise the main body of this dissertation, I focus on three aspects of living with

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<sup>1</sup> In the past, this disorder was referred to as “TMJ”, for Temporomandibular Joint. Many participants still use this term in their descriptions.

chronic TMD pain. First, I describe the role of pain in identity construction, and the interaction of social and physical risk with the “Works of Illness” (Nichter 2005; Corbin and Strauss 1985). Second, I consider the complex and multifaceted nature of finding hope amidst chronic pain or illness. Third, I interweave analysis of over-the-counter pharmaceutical pain reliever marketing with analysis of participants’ explanations of their use of these medications and the profound interconnections between these medications and the construction of moral identities.

The larger study context was a multi-sited clinical trial offering Traditional Chinese Medicine (TCM) to people with Temporomandibular Disorder(s) (TMD). The broader study aimed to measure the effectiveness of a pain self-management program (Dworkin et al. 2002; Suvinen et al. 2005) in combination with Traditional Chinese Medicine Treatment. I followed participants to learn how their understandings and explanations adapted over time and in relation to experience with what was, for many, a novel treatment. The TCM treatment offered new ways of relating to the body and illness and challenged participants to adapt their explanatory models and strategies for making sense of their experience in the broader context of their lives.

### *Chronic Pain in Biomedical Perspective*

Over the past 20 years, there have been significant changes in both research and treatment related to chronic pain. Organizations such as the American Pain Society, the International Association for the Study of Pain (IASP), and the NIH Pain Consortium have gained recognition in their efforts to improve pain treatment worldwide. Pain medicine has emerged as a medical specialization (Crowley-Matoka and True 2012;

Jackson 2011) and there are currently a number of prominent scholarly journals dedicated to the study of pain.<sup>2</sup> Web-based information sharing, medical advice and self-diagnosis websites, and the explosion of social media sites connect consumers to information about their illness and related options that were not available prior to the internet (Rice and Katz 2001; Ziebland, Lavie-Ajayi, and Lucius-Hoene 2014). Stigma in relation to chronic pain is likely to have, if not lessened, at least shifted a bit as the neurological underpinnings of chronic pain are increasingly understood (American Pain Society Guidelines 2009).

Official treatment guidelines define chronic pain as “any pain that persists beyond normal tissue healing time, which is assumed to be three months” (American Pain Society 2009; CA Workers Compensation Guidelines 2009).<sup>3</sup> Although research into the etiology of chronic pain has improved understanding of the factors contributing to it (Fine 2011), efforts to standardize the treatment of chronic pain focus almost exclusively on standards for opioid prescribing. Between 1999 and 2006, Nuchols et al. (2014) report, the use of opioids in the treatment of pain went from being discouraged to being included in standards of care. An “epidemic” of adverse outcomes resulting from increases in opioid use is the subject of considerable research (Nuckols et al. 2014). The lived experience of pain outside the context of a pain clinic, including the work of living

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<sup>2</sup> For example: *The Journal of Pain*; *Pain*; *The American Academy of Pain’s Pain Medicine Journal*; *Clinical Journal of Pain*; *Pain and Symptom Management*; *British Journal of Pain*; *Journal of Pain Research*; and *The Scandinavian Journal of Pain*, to name a few.

<sup>3</sup> Definitions of what constitutes chronic pain in research typically varies from three months to six months of constant pain with average pain requirements either of a particular rating or constant level of experience.

with illness and self-management of pain using OTC medications, however, has received less attention.

TMD, one of the most prevalent chronic pain conditions in the developed world, is estimated to affect 5% to 12% of the general U.S. population. TMD pain impacts daily activities, social functioning, and multiple aspects of quality of life (Schiffman et al. 2014; Dworkin 2011; Glass et al. 1993; Dworkin 2007). Research Diagnostic Criteria for TMD (RDC-TMD) were first published in 1992 and have become standard for clinical diagnosis of the disorder (Schiffman et al. 2014). The RDC-TMD was replaced in 2014 by the DC-TMD (Diagnostic Criteria), an updated version of the tool that is used in both research and clinical contexts (<http://www.rdc-tmdinternational.org/>). The TMJ Association (TMJA), founded in 1986, is a major patient advocacy organization dedicated to promoting awareness about the condition, advocating for continued research into the causes and treatments of the disorder, and to offering support and resources for those living with TMD (TMJ) (<http://www.tmj.org>).

#### *Chronic Pain in Anthropology: Overview of Relevant Literatures*

DelVecchio Good et al.'s (1992) landmark volume on the anthropology of chronic pain, "Pain as Human Experience," was published the same year as the RDC-TMD was first available. The authors present research on several chronic pain disorders, including two chapters specifically focused on TMD. At the time, TMD was a little known and poorly understood condition. Patients struggled with the lack of any frame of reference with which to make sense of their experience of persistent pain. Good (1992) and Garro (1992) found that TMD sufferers were remarkably persistent in their search for diagnosis

and then for effective treatment. Their research participants, recruited from the context of a pain clinic, were caught in an all-consuming search for legitimacy and recognition for the reality of their pain. Many sufferers in their research described feeling doubt and uncertainty surrounding the authenticity of their experience as an affront to the self. Seeking treatment was therefore also a search for legitimacy, self-hood, and meaning in illness.

More than 20 years later, although chronic pain is a widely known condition and increasingly common diagnosis (Elder et al. 2012; Jackson 2011; Crowley-Matoka and True 2012), Jackson (2005) reports that pain clinic participants continue to experience considerable stigma. Further, many of Jackson's participants drew upon the same negative stereotypes when describing others with chronic pain. Growing recognition for the existence of chronic pain does not necessarily mean increased acceptance of sufferers, as the authenticity of their subjective experience continues to be difficult to establish. Physicians often describe these patients as "a pain" in themselves (Jackson 2011), calling them "pain-seekers." Courses for clinicians treating chronic pain include titles such as "How to Say 'No': Holding Challenging Conversations with Patients on Opioids for Chronic Pain" (Furlan 2014). Clinicians trained as gatekeepers often view chronic pain patients with suspicion. Those who do ask for medications for their pain are suspected of trying to "dupe" clinicians into participating in a street drug market (Crowley-Matoka and True 2012).

Alan Young (1982) observed that culture is most clearly observed in the places where it breaks down (cf. Jackson 2011; Good et al. 1992). Where culture fails to assist individuals in making sense of illness, its relation to individual experience may be

explored with unique insight (Hilbert 1984). Chronic pain presents a particularly rich area of such inquiry, as more and more aspects of human life are medicalized or brought under medical jurisdiction (Clarke and Shim 2011; Kaufman, Shim, and Russ 2004; Lock 2004). Unlike other illness, chronic pain has consistently failed to be fully incorporated into medical jurisdiction (Crowley-Matoka and True 2012). For this reason, seeking alternative treatment may have additional implications for sufferers in terms of achieving a meaningful sense of self and eschewing stigmatized identities. Not only does pain resist description, it has also been characterized as resisting cultural categories, or as not being amenable to the “work of culture” (Obeyesekere 1985) for providing meaningful ways of interpreting experience (Good et al. 1992; Hilbert 1984). Csordas (1990) describes the body as the existential ground of culture. In the lived experience of chronic pain, then, the work of describing one’s pain may be synonymous with describing one’s place in the world and one’s experience of the workings, or failings, of culture.

Central to the articles presented in this dissertation is a concept I refer to as *pain identities*. I use this term to describe the ways people living with chronic pain explain themselves in the context of an interview, through multivocal descriptions and narrative selves. The subjective, private, hidden experience of pain makes the interview experience a site for the construction of moral identities. Existing in a state of risk for becoming a drug abuser, of being seen as a malingerer or even just a whiner, people living with chronic pain must construct themselves as moral individuals. Constructing pain identities involves explanation of choices and limitations as warranted by the severity of one’s condition. As Buchbinder (2010) explains, in narratives about pain, “the moral character of the protagonist is always at stake” (111). Explaining one’s choices prior to beginning a

new form of treatment and explaining one's reactions to new experience are not statements of fact, but are rather narratives of ongoing personal formation.

Participants rarely produced narratives about their history, their treatment seeking experience, their families, or their social networks without giving considerable attention to their identity as pain sufferer, or conversely, as not "one of those chronic pain people". As Byron Good (1994) has described, chronic pain forces awareness inward. Sufferers find it difficult to focus on anything outside of the pain itself. At the same time, they often describe struggling to ignore it and explain that during interviews, talking about pain makes it worse. During my interviews, participants often visibly struggled to explain themselves cringing and slouching to express what they could not put into words. As with many aspects of life with chronic pain, sufferers balanced their explanations between the severity of the pain and the limitations it imposes while at the same time performing a self that is separate from the pain. Although working to live up to many social roles, much description is focused on the self. It may be that this self-focus is in part produced by the interview context. The extent of focus on constructing the self was striking in these interviews, however, as a central aspect of the experience of chronic pain.

#### *Narrative Construction of Pain Identities*

Pain sufferers' morality, identity, legitimacy, and cultural roles are called into question by a medical system in which pain is incompletely medicalized (Crowley-Matoka and True 2012). Stories of causation are thus important ways that sufferers are able to make sense of chronic pain (Eccleston, Williams, and Rogers 1997; Garro 1992). The characteristic performative and public speech that is gathered in the interview

context (Buchbinder 2011; Goffman 1959; Labov 2013; Miczo 2003) is a useful way to understand how chronic pain patients construct themselves as believable narrators of their own pain experiences (Ong et al. 2004). Illness narratives are a way for people to explain and contextualize their selves and lives (Reissman 2003). Ochs and Capps (1996) noted that narrative situations, like in-depth interviews, challenge people to make sense of difficult situations and allow them to create their own meaning or coherence. For people with chronic pain, the self is threatened not only by the pain, but also because sufferers cannot expect validation of their experience to come from others who are unable see, to imagine, or to relate to the pain (Jackson 1994). The narrative construction of self therefore comes to the forefront as a means of validating the self and constructing one's experience as "authentic suffering" (Ecks 2005; Kirmayer 2002).

Much research has focused on the relationship between pain and language. Some have argued that narratives of pain as well as pain symptoms share characteristics with human language (Brodwin 1992; Good et al. 1992). According to Bourdieu (1977), the language of the body is broader and richer than words. Body language, he argues, is more useful for communicating as "bodily experienced symbols" (120) to describe experiences that cannot be put into words. Pain is more easily described or shared through body language, as the pain itself seems to "shatter language" and leave sufferers with cries, groans or descriptions of bodily damage to describe their experience (Jackson 1994; Scarry 1985; Semino 2010). Researchers suggest that pain is impossible to describe using everyday language (Emad 2003; Jackson 1994), that it resists or even destroys language (Jackson 2011; Scarry 1985; Throop 2002), and that any description of pain is inadequate

as such a private and subjective experience cannot be shared (Good et al. 1992; Hilbert 1984).

Simply accepting that the sensation of pain cannot be shared through language, however, may not take us far enough in considering the narratives of chronic pain sufferers. As Hilbert (1984) argues,

“For pain sufferers, trendy notions of pain as private reality undermine the very possibility of their ever ‘knowing’ that reality. There can be none of the interpretive work, linguistic use, of social negotiation essential to knowable reality ... if pain is private and unknowable to others, nothing counts as verification or as correct description of ‘how’ the pain feels” (374).

Describing the experience of pain employs voices used in different contexts and for different audiences as part of a dialogical construction of self (Goffman 1959; Hermans, Kempen, and VanLoon 1992; Hermans 2001; Smith and Sparkes 2008). Constructing the self while also navigating the difficulty of describing pain in interviews leads to multivocality in sufferers’ narratives. The performance of multiple selves when describing different aspects of experience reveals the difficulty of both making sense of and describing the experience of chronic pain. Pain narratives are intended not only to describe experience, but also to present the sufferer as a moral individual (Buchbinder 2011; Butler 2005). In this context, therefore, the multi-voiced polyphonic nature of narratives and construction of moral selves can be observed (Holquist 1990; Clark and Holquist 1984; Labov 2013; Miczo 2003).

The presence of multiple social selves is not unique to the experience of chronic pain. Kopytoff argues that a person not only has numerous social selves, but also that these selves are often conflicting. In complex societies, “The drama of personal

biographies has become more and more the drama of identities – of their clashes, of the impossibility of choosing between them” (Kopytoff 1986:89). Selves are not organized by any hierarchy or level of importance. Each is specifically tailored to its particular context. Goffman (1959) quotes William James in saying “...we may practically say that [a person] has as many different social selves as there are groups of persons about whose opinion he cares. He generally shows a different side of himself to each of these different groups.”<sup>4</sup> (quoted in Goffman 1959:48) Conflicts between selves are generally avoided, however, through audience segregation. In the ethnographic interview context, therefore, “the central analytical unit is not a bounded and static self but rather the diverse discursive repertoires spoken by persons within particular social settings; that is, interviewing provides a context for revealing how language ‘makes’ people, produces and changes social life” (Tangaard 1999:1499). Tangaard refers to Bakhtin’s proposal that we can view interviewing as a social setting that enables the performance of polyphonic dialogues to be seen in one context. The existence of multiple voices and discourses cross each other and produce knowledge about personal narratives and social life.

Unending pain challenges the identity and social position of the sufferer (Jackson 1992, 2011). Jackson (1994) asserts that pain, in its extensive rewriting of the self and the lifeworld of the sufferer, is “the quintessential symbol of disorder”. Because of this disorderliness and profound disruption of the sufferer’s place within a particular culture, identity construction may be more central a project for pain sufferers than for others

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<sup>4</sup> James, W. (1950). *The principles of psychology*. New York : Dover. (Original work published 1890)

(Garro 1992). Eckert (2000) explains that an individual's engagement in the world is a constant process of negotiating individual identity in relation to group identities. Identity in this context is defined as:

“one's ‘meaning in the world.’ A person's place in relation to other people, a person's perspective on the rest of the world, and person's understanding of his or her value to others – all of these are integral to the individual experience of the self, and are constructed in collaboration with others and those others engage in the same construction for themselves” (Eckert 2000:41).

The “chronic” aspect of chronic pain adds an additional level of disorder to the temporality of lived experience (Antelius 2007; Garro 1992, 1994; Honkasalo 2001). According to Bulow (2003), suffering from a chronic illness or affliction overturns the temporal frameworks of our daily lives. Its very chronicity violates a basic assumption of the sick role; that it is temporary (Varul 2010). In situations where pain or illness becomes chronic, temporality is altered as sufferers attempt to make sense of their experiences in a life in which the everyday experience of pain provides no temporal context, no stages or patterns on which to pin one's sense of a life process.

As Nichter and Vukovic (1994) argue, sufferers may be unwilling to accept a technical fix for their illness if that illness is an idiom of distress or a symbol of a broader set of untenable life circumstances. Although many with chronic pain are seeking treatment for a physical ailment, others may be communicating distress. Pain may be symbolic of a life situation that cannot be remedied by treatment. In such cases, the description of pain is particularly important to consider, as sufferers communicate more than physical sensation in their descriptions of pain. Hay (2010), alternatively, explains that adopting a “John Wayne Model” of illness as something to be wrestled into submission leads those sufferers who are able to adopt a stoic position and work in spite

of illness. Those who fail to meet culturally sanctioned expectations are limited to a “cultured response” in which their sense of self is devalued by the culturally patterned model of stoicism and productivity as measures of moral worth that sufferers themselves buy into. As Ecks (2005) points out, because what people say they do is not always representative of what they actually do, interview narratives must be viewed as a space for construction of an idealized conception of self. Attention even to the most mundane details of how people living with pain attempt to describe their experience can shed light on the way pain is felt and meaning constructed in daily life (Jain 2007). As Frank (1998) suggests, “we live stories whether we want to or not, and the only real questions are how aware we are of the stories we are living and how effectively we try to tell some kinds of stories and avoid telling/living others” (330).

The articles presented in this dissertation explore the work involved in constructing pain identities, living with illness, and constructing selves appropriate to role requirements in multiple contexts. Debates surrounding expressions of agency versus the hegemonic control of culture have long been central to anthropology. Here, rather than join this debate and thus attempt to decipher the actions of those living with chronic pain as expressions of agency or of social control, I draw attention to what is left out of these debates. I consider what is left as sufferers move through life, confronting layers of paradox as they attempt to cope and hope with chronic pain.

At issue is the risk of being lumped in with “those people with chronic pain,” a label participants actively avoid. Instead, they worked to cultivate a stoic persona and “just deal with” the pain. Through the Works of Illness Framework (Corbin and Strauss 1985; Nichter 2005), I explore ongoing efforts to juggle social risk—the demands of

participating in family and social interaction—with physical risk—the body-centered experience of managing a chronic condition.

That participants did not report experiencing stigma, yet spent considerable effort differentiating the self from a label they clearly recognized, offers new perspectives on stigma and the ways in which people are socialized to understand mental illness (Link & Phelan 2013). Rather than facing the tainted, discounted identity that comes with stigmatized illness (Goffman 1963), sufferers in this study worked to distance themselves from it in multiple ways. Biomedical culture provides a range of moral imperatives to guide those with chronic pain. Sufferers are expected to be realistic and yet hopeful in the face of difficult odds (Adams, Murphy, and Clarke 2009; Sulmasy et al. 2010; DelVecchio Good et al. 1990), part of living up to specific cultural codes of “affective decorum” (Brown 2015: 121). Unlike other illness, in which not accepting prescribed medications is labeled “noncompliance,” those living with pain are congratulated for refusing prescription pain medications (Crowley-Matoka and True 2013).

Despite increasing visibility, prevalence, and legitimacy at least in terms of recognition for being a widespread problem, the lack of a medical cure (pain medication notwithstanding) relegates chronic pain to a status of being not-quite-medical (Jackson 2011). This failure of medicalization challenges patients to achieve legitimacy, not for their symptoms, but for their ability to handle them. The social and biomedical context constructs barriers against access not only to medication, but also to seeking other treatment for chronic pain. Managing one’s own medication, avoiding prescriptions altogether, finding hope where it can be found, and maintaining a stoic identity, become

means of reducing harm and making do in living with and describing the experience of chronic pain.

## **METHODS**

Participants for this study were recruited to a clinical trial of a combination of pain self-management training (Dworkin et al. 2002; Suvinen et al. 2005) and Traditional Chinese Medicine (TCM) for people living with chronic jaw pain from Temporomandibular Disorders (TMD). The context of a research study recruiting people from the community offered a unique perspective for considering the lived and embodied experience of pain, hopes and expectations, identity, and other factors impacting individuals as they entered and contemplated a research trial. For full description of the overall study and sample characteristics, see Ritenbaugh et al. (2012). One hundred sixty-eight participants entered the trial. Of those, every second participant was asked to participate in interviews up to five times over the course of their experience in the study. Ninety-five people completed baseline interviews. Forty-four of those continued to participate in up to four additional follow-up interviews over the course of their experience in the study. Interviews were designed to occur at 5 points: prior to any treatment, after self-care training and prior to TCM treatment, approximately 2 months after starting TCM treatment, 6 months after starting TCM treatment, and 3 months after the end of treatment. Eligibility criteria included ages 18 - 70, worst facial pain  $\geq 5$  on a 0-10 scale, and research confirmation of TMD diagnosis (<http://www.rdc-tmdinternational.org/>). All procedures were approved by the University of Arizona and Oregon College of Oriental Medicine Institutional Review Boards and all participants provided informed consent.

### *Research Context*

The study involved research with participants in two locations: The University of Arizona in Tucson, Arizona and Oregon College of Oriental Medicine in Portland, Oregon. Participants were recruited in both locations through newspaper advertisements and fliers advertising a study offering a modified behavioral therapy combined with Traditional Chinese Medicine for TMD. The response was greater than expected, with many people joining the study even though not actively seeking care. I conducted all interviews in Tucson and over half of the interviews with participants in Portland (by telephone). I was also responsible for transcription of most interviews, which allowed me to gain an intimate knowledge of what was contained in each transcript. Multiple interviews over time provided depth to my understanding of how participants made sense of a new treatment and adapted their understandings of illness in light of new experience (Hunt, Jordan, and Irwin 1989). The process of conducting multiple interviews also allowed participants to reflect back on what they had described in earlier interviews and in many cases I was aware of changing life circumstances and prior expectations in ways that participants may not have noted. Over the course of four or five interviews with each participant during their eighteen month participation in the study, I became familiar with their stories and was attuned to changes over time as well as performed voices that arose differently at varying points during the study and in regard to different topics. In more than five years of analysis on these transcripts, I have committed to memory many of the stories they contain. Despite this depth of awareness of each story, I continue to be surprised by the richness of experience and the new understanding to be gained from these narratives.

In addition to managing the qualitative component of the study, I attended final TCM visits with some participants. In these visits, a TCM practitioner not involved in providing treatment examined patients and asked questions about their experience in the study. During these visits I was able to observe participants in a different context, to hear their explanations of outcome as described to a practitioner, and to hear their impressions of the study as told to a practitioner, rather than to me as qualitative interviewer. I gained a broader perspective and increased depth of understanding of participants' experience through involvement with study activities beyond qualitative interviewing, such as entering the data from TCM evaluation forms, self-care check-in forms, and other quantitative data collection tools. As research assistant I had the opportunity to observe the research study context and to gain insight into the intricacies of a large research trial, including both limitations and benefits to participants of receiving care in this way.

Due to limited space and parking on campus, interviews were conducted off-site at a rented facility a few miles away. Although we worked to make the space appear both official and inviting, shortcomings of the space warrant mention. First, the room was located inside a courtyard-style office building in which most of the office suites were empty. Empty offices gave the place a deserted feel that participants often commented on, sometimes describing it as "creepy". Many of the researchers who used the space shared this opinion of it and therefore kept the door locked at all times. Although I was conscious about unlocking the door when possible, the locked door at some times of day and depending who was sharing the office likely contributed to unease about the study overall for some participants upon their arrival. I did not observe any difference in how comfortable participants were in talking to me about their pain and their expectations

about the study. I did, however, have the sense that for some participants, the credibility of the study overall may have been less certain as a result of this choice of interviewing location. Although I did not visit the location where interviews were conducted in Portland, participants' reactions and descriptions indicate that it was similar and the similarity therefore precludes analysis of the impact of such a site on participants' narratives.

### *Interviews*

Semi-structured, open-ended interviews were designed to elicit information about a range of topics of potential interest. Interviewers, including myself and two others, were trained by Mark Nichter, PhD, MPH, in Tucson, Arizona. Interview guides were designed to capture patients' illness experience prior to study interventions and at multiple points throughout treatment. Baseline interviews covered broad themes such as family and social support, work situation, stress, illness history, medication use, expectations, hope, explanatory models of illness, experience of stigma, and past treatment seeking to understand participants' experience of illness and coping prior to entering the study. Follow-up interviews explored treatment experiences, changes in coping, changes in illness experience, changes in ideas about illness, additional treatment seeking, and other topics varying by relevance to the participant. Basic code structure consisted of a set of themes that encompassed descriptions of patients' pain and its predictability/unpredictability, stressors that led to pain flare-ups, behaviors that fell under all three works of illness (everyday life work, illness work, and autobiographical work (Corbin & Strauss 1985), medication use, and social relationships.

In initial interviews, interview experiences were communicated to the whole research team and any problems that arose were discussed in regular conference calls to maintain consistency across sites and to improve interviewing skills.

Informants were primarily Anglo-American middle class, ranged in age from 18 to 69 years old and approximately 70% were women.<sup>5</sup> Most participants held steady jobs and lived with families or in long-term relationships. TMD pain onset had occurred within the past few years for some and as early as adolescence for others.<sup>6</sup> Although over-the-counter analgesic medication use was common, only about ten percent of participants reported regular use of prescription pain medications (see Elder et al. 2012, for detailed analysis of medication use). A few reported using sleep medications. For many, lack of adequate health insurance coverage for TMD (which often requires dental coverage) or complementary therapies was a primary reason to join the study.

### *Analysis*

All interviews were transcribed verbatim and coded using ATLAS.ti 6.0 (Muhr 2011). Based on initial impressions and hand coding of the first several transcripts, I developed an extensive list of codes, guided by my advisors and organized based on the Works of Illness framework. The codebook was shared with the research team for feedback and to assure the appropriateness of codes for analysis in this very large data set. Analysis also involved considerable recontextualization by hand coding and referring back to individual transcripts over the course of approximately five years of analysis.

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<sup>5</sup> The ratio of women to men in this study is roughly equivalent to estimates of TMD prevalence in the general population.

<sup>6</sup> See Ritenbaugh et al (2012) for full sample details.

Focus on the considerable work involved in living with illness and finding meaning in one's experience—the Works of Illness—arose early. After initial interview experiences I was surprised by what I perceived as a deficiency in the data. The narratives I expected to find, based on the work of anthropologists such as Byron Good, Linda Garro, and Arthur Kleinman (Good et al. 1992) who found that chronic pain sufferers were often involved in an endless and all-consuming search for treatment and legitimacy, were largely absent. I was frustrated by repeated narratives of participants who told me they “just live with it” while describing intense and ever-present pain. Using the Works of Illness as a lens shifted the focus to understanding sufferers' narratives as multi-voiced presentations of self that were part of a process of coping with double binds at every level of experience.

My focus on hope emerged out of the primary focus of another study I was involved in. Consideration of hope was completed as a secondary analysis in which we searched initially for patterns that could be compared with quantitative data surrounding prior experience, expectations, and many other measures we assumed would correlate with expectations or hopes among participants. After several iterations of statistical analysis of every measure we could think of, comparison of pain score graphs, and quotes drawn from the transcripts of every participant included in the analysis, the search for patterns proved fruitless. Only after this initial attempt to write a mixed methods paper about expectations among TMD sufferers in a CAM study did I decide to delve into a theoretical reconceptualization of hope, prompted in part by an article by Darren Webb (2007) entitled, “Modes of Hoping”. A newly conceptualized idea of hope led to a typological consideration in which the narratives of sufferers appeared not as random, but

as pieces of a complex process of coping with illness and avoiding biographical disruption (see Bury 1982; Williams 2000).

Medication use and beliefs about medication were central topics in interview guides. A focus on medication use was therefore expected and as the focus of a manuscript, unsurprising. The focus on over-the-counter (OTC) analgesics rather than prescription opioids, however, arose after multiple iterations of coding and analysis. Re-coding of all mentions of medications in the dataset into more detailed codes revealed that not only were participants using OTC medications in relatively large and regular doses, descriptions of their use were an intricate feature in multivocal constructions of self. The way participants described OTC medications inspired me to explore the way these medications were advertised as a supplementary analysis to understand how sufferers were interpreting the messages contained in these advertisements, and whether they seemed to adopt or reject such messages in their understandings and use of these medications.

## CONCLUSION

*“I mean it's just so in your head. It's so in your head. Because you've got all your messages about oh, don't be a whiner and be brave and, you hear all that stuff, as well as, you know, I'm a child, please comfort me, I'm in pain. (Helen, 57, Interview 5)*

Kentucky Senator Rand Paul (and 2016 Republican presidential hopeful) said recently that “over half the people on disability are either anxious or their back hurts. Join the Club... Everybody over 40 has a little back pain<sup>7</sup>.” Paul referred to such pain

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<sup>7</sup> “Rand Paul: Disability Insurance Wasted On People With Anxiety And Back Pain.” July 14, 2014. *The Huffington Post*. Accessed January 29, 2015

sufferers as “gaming the system” at the expense of those who are “deserving.” In a similar vein, the American Medical Association and medical researchers from institutions around the U.S. are attempting to combat an “opioid epidemic” that is the result of changing regulations and treatment guidelines to address a growing “chronic pain epidemic” (Manchikanti et al. 2012, 2014; Franklin 2014; Chou et al. 2015).<sup>8</sup> Literature on opioids in pain management centers around the issue of how to target the significant percentage of pain sufferers described as at-risk for developing aberrant behaviors such as drug dependence or abuse (Turk et al. 2008; Sullivan et al. 2010; Manchikanti et al. 2014; Nuchols et al. 2014; Chou et al. 2015). The implication is not that pain sufferers are suspected of being drug abusers, but rather, that a medical treatment associated with a market of street drugs places these individuals at-risk for such behaviors.

In this broader context, the work of stoicism and “just handling pain” described at length in this dissertation comes to the forefront as more than trying to be tough and live up to cultural ideals. Participants in this study, in every topic I have highlighted, focused considerable attention on constructing their identities as “not one of those people.” In the context of recent comments by Rand Paul along with the focus on prevention in medical publications, it is clear why these individuals wish to avoid being “one of those people” Rand Paul, or the researchers cited above, are referring to.

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[http://www.huffingtonpost.com/2015/01/14/rand-paul-disability-insurance\\_n\\_6470890.html](http://www.huffingtonpost.com/2015/01/14/rand-paul-disability-insurance_n_6470890.html).

<sup>8</sup> Further, the effect of the War on Drugs in the U.S. has made illegal opiates more difficult to obtain. This difficulty makes prescription opioids simultaneously more appealing as drugs that are relatively easy to obtain and perceived as safer due to their association with the medical profession (Crowley-Matoka & True 2013; Quintero & Nichter 2011).

Anthropological studies of chronic pain carried out in the 1980s and 1990s focused on sufferers in search of a diagnosis who felt their legitimacy as illness sufferers was in question (Good et al. 1992). TMD was one of the ambiguous illness categories considered at length in these studies (e.g. Good 1992; Garro 1992; Jackson 1992). A few decades later in my research on patients in the context of an alternative medicine trial, I found significant changes in the lived experience of TMD pain. In this dissertation I have shown how participants attended to the works of illness and managed multiple double binds created by competing demands of body, family, self, and society. Competing needs—social, familial, and physical—and contradictions characterize the lifeworld of sufferers (Hilbert 1984). Over the course of several interviews, different voices emerged as each individual described the conflicting demands that influenced their decisions of whether to bear or retreat from social interaction. Performed selves were juxtaposed (Labov 2013; Miczo 2003) as informants described and reflected on their experiences and adaptations as well as means of coping, hoping, and maintaining a moral identity they could live with.

I have shown how in each area of work—everyday life work, illness work, and autobiographical work—the cross cutting of social risk and physical risk lead to double binds. Sufferers actively worked to manage these conflicts on a daily basis, facing both types of risk and privileging one or the other depending on the particular demands of each arena of life. I call these two areas of narrative and interactional work *the work of stoicism* and *the work of vigilance*. The work of stoicism involves keeping a tough exterior, working to not burden others, and working to appear as though one is able to soldier through and “just deal with” pain. The work of vigilance, conversely, stems from

the fear of triggering an acute episode or “flare-up” and requires constant vigilance against any activity, food, or life event that may cause increased pain.

The double binds or paradoxes of being both stoic and vigilant on a constant basis extend to the three originally outlined works of illness (Corbin and Strauss 1985). As I describe in article 1, they also impact the work of hope, encountered in multiple *ways of hoping*, as well as in the ways participants use and talk about their use of medications for pain. Particularly in the case of autobiographical work, participants expend considerable energy to appear and feel normal in the present. When I asked them to map a typical day in terms of pain and activity patterns, participants refused to complete the exercise. They expressed reluctance to consider the future or any time other than the present and worked to suppress any expectations that would lead to a sense of what Bury (1982) describes as a disrupted biography. Although chronic pain is defined by physical suffering, the suffering entailed by biographical disruption (Williams 2000), loss of hope (Cassel 1982), or from experiencing the stigma associated with illness (Link & Phelan 2013; Goffman 1963) are purposefully kept at bay through consistent vigilance work. At the same time, avoiding social interaction or other expected social roles is a risk in itself, also threatening to disrupt the biography of the sufferer.

This conflict—between too much and too little—hope has been called “the paradox of hope” (Mattingly 2010; Barnard 1995; Chesla 2005). Although hope is sometimes described as a singular experience, participants’ narratives revealed that hope is a multifaceted and variable experience. From a tacit knowing perspective, *ways of hoping* is a lens for understanding how individuals living with chronic pain navigate the paradox of hope to avoid despair while living with enough hope to continue with daily

living. I described Webb's (2007) "Modes of Hoping" framework as a preliminary step in understanding the relationship between expectations and hope in the context of a CAM study.

By hoping in multiple ways, sufferers can be realistic and stave off the ever-present threat of despair, while still being hopeful and finding meaning in the present. Sufferers in this study reported constant fear, not of the pain becoming worse as much as of the pain becoming what it had been at some time in their past. The fear is not of the unknown, as in terminal illness, but of the known, an experience in the body. Even the act of describing past experiences of pain made sufferers cringe as they recounted "flare-ups" in their pain history and the fear they felt at the thought of returning to such a point.

Summing up the interconnectedness between the experiences of fear and hope, Pema Chödrön writes,

"The word in Tibetan for hope is *rewa*; the word for fear is *dopka*. More commonly, the word *re-dok* is used, which combines the two. Hope and fear is a feeling with two sides. As long as there's one, there's always the other. This *re-dok* is the root of our pain." (2002, 40-1)

Despite its connection to fear and to the possibility of despair, Pruyser (1963) explains hope as a continuous re-evaluation of reality in light of new experiences. I have presented a typology of *ways of hoping* that describes a few of the multiple forms of hope. In article 3, hope is characterized as wishful, realistic, transcendent, and as a diverse experience of faith. I consider the relationship between hope and faith not only from a religious perspective, but also as faith felt in the ability of biomedicine, or conversely, in CAM, to offer hope in the face of pain. I also consider a form of faith in the body's ability to

spontaneously heal. This faith in the body itself is at times cognitive and at others embodied, sometimes a way to find hope when not available from other sources.

In this dissertation I have focused on TMD sufferers who attempt to fulfill role requirements, to meet both the demands of both culture and family and to still attend to the demands of the body. Use of over-the-counter (OTC) pain medication is one area of such work. In previous research clinicians have been presented as gatekeepers and patients as often asking for prescription medications. I found an entirely different scenario. Discussion of medication use revealed a preference for using OTC meds and how and why they chose to use OTC rather than prescription medications. Few participants reported having difficulty obtaining prescription medications. Instead, many recounted having been prescribed medications but choosing not to use them. Requests for prescription medications, along with patients' credibility, were saved for times when they were "really needed." Often, when medications were really needed depended on context and social demands rather than pain level. Participants worked meds into their stoic social personas both by avoiding prescription meds and by taking meds when they had to, as one participant described it, "pay the price" for continuing to participate in social interaction. OTC medication use was another area in which sufferers worked to avoid being "one of those people", in this case, one of those people who likes taking pain medication. The implication being that there is a thriving street market for these drugs and sufferers do not wish to be associated with the stigmatized chronic pain sufferer/addict that many physicians dread working with (Quintero and Nichter 2011; Crowley-Matoka and True 2012)

Writing about the works of illness with multiple co-authors, particularly from other disciplines, presented challenges. There was considerable skepticism about the possibility that participants in this study could have the pain levels they reported at baseline, and cope in the ways they described. I started exploring these narratives from the perspective of the three works of illness as originally described. The paper went through multiple iterations of revisions, however, as I struggled to convey my observation that participants could describe stoically accepting pain while at the same time the presence of pain fundamentally altered every aspect of how sufferers “move in the world”. It was through these iterations of revisions and going back to participants’ transcripts over and over to check and re-check these observations, that the work of stoicism and work of vigilance came to my attention as a way to clarify the reasons for the double-binds that so strongly surfaced in participants narratives, and in their body language—slouching, pointing to parts of the body, and cringing—in interviews.

As a cultural anthropologist on a multidisciplinary research team, I was tasked with being the “qualitative” researcher on the team, working to contribute participants’ words to a quantitative description of their experiences. Through this role, I became immersed in the world of CAM research, which has been a backdrop and source of interest as I focused on the lived experience of chronic pain from an anthropological perspective in my own writing. Although in many cases CAM researchers aim to understand whether and how CAM therapies work for chronic pain, participants searched for other forms of understanding as well. Some sought to be involved in research to feel as though they were doing something about pain. Many expressed disillusionment with biomedicine, and were therefore seeking an alternative. Some sought to appease family

members who wanted assurance they were doing all they could to return to “normal”. These and others reasons for joining the study guided participants’ experiences as they navigated the research study. Although many seekers of CAM outside of a research setting have been described as more “open” or “proactive” or “aware of the need to participate in their own care” than those seeking traditional care (Sasagawa et al. 2008; Murthy et al. 2014), many participants in this study had not tried CAM therapies previously. Some expressed weariness at the idea of trying them. A few even dropped out prior to ever going to a TCM appointment. Their reasons for doing so are unclear, but it would be an incomplete picture to describe study participants as uniformly open to alternative care.

In earlier research on the lived experience of chronic pain, anthropologists reported that sufferers searched endlessly for treatment and legitimacy (Good et al. 1992). Among participants in this study, participants rarely expressed such a sentiment. Although chronic pain still occupies an ambiguous position in biomedicine, few of these participants, living in an age of self-help and internet medicine (Ziebland, Lavie-Ajayi, and Lucius-Hoene 2014; Rice and Katz 2001), reported feeling as though the legitimacy of their experience was in question. Despite clear awareness of stigma and the questionable status of chronic pain in general, participants focused on questioning the legitimacy of the diagnoses they had been given. They questioned the authority of western medical practitioners to treat chronic pain and the technological advancement of pharmaceuticals in the treatment of pain and other ailments. For the most part, rather than undertaking an unending search for legitimacy through biomedical validation, these

participants sought legitimacy in illness by carefully constructing their identities as stoic bearers of pain, living with and in spite of pain day to day.

### *Limitations*

There are several potential limitations of this data. One is that it was not collected among chronic pain sufferers who were “randomly selected” from the community, but rather from a group of participants who opted to join a trial offering Traditional Chinese Medicine. It is possible that these participants were therefore not representative of a general population of sufferers of chronic pain. Since many of those who participated in baseline interviews, however, did not ultimately participate in TCM, it may be more accurate to describe the majority of these sufferers as willing to participate in a study, or optimistic that for one reason or another, being in a study might produce a positive effect. Another potential limitation is that these observations are based almost solely on interviews with participants about a condition that, as I mention in the introduction, resists description. Therefore, the interview context itself plays a major role in the analysis, having a major impact on the ways in which sufferers choose to present themselves as moral and capable individuals. The relatively small percentage of men in the study (reflective of national TMD prevalence estimates overall) precludes detailed analysis of these themes by gender. I did not observe any differences in the importance of being stoic, avoiding medications, or other works of illness between men and women, but that is not to say they are not present. I cannot comment on whether the small number of men in the study is truly a product of fewer men living with TMD, or of gendered use of CAM therapies, or other unknown factors. Whether performance of masculinity, femininity, or other ascribed cultural roles influenced the ways participants described

their experience or presented their stoic personas in interviews warrants further research. Although sufferers from multiple ethnicities are represented in the data, I do not have enough information to comment on cultural differences in pain coping or identity construction. This is another important area for additional research.

Although not a focus of my analysis, some differences in context between Oregon and Arizona should be mentioned. First, weather can profoundly affect chronic pain sufferers, both in terms of the way joints respond to varying levels of damp and dryness, and also the way emotional states are impacted by sunlight and darkness. The climate in Portland, overcast and cool for much of the winter, has a profoundly different impact on TMD sufferers than that of Tucson, where the sun shines almost every day and half the year is characterized by desert heat. For this reason, the emotional component of TMD may be experienced differently with different seasons in these locations, with more participants in Portland attributing depressive symptoms to dull weather.

A second major distinction between the two research sites is the availability of insurance to cover CAM treatments (Ritenbaugh et al. 2008). Participants in Portland were more likely to report previous experience with other CAM therapies, likely due to health insurance coverage for some of these therapies. Note, however, that this difference is likely to be less than for the general populations of these two geographic locations because the majority of participants seeking TCM treatment in the context of this study from either location were doing so because it was offered for no cost and most did not have access to this type of care from other contexts.

### *Future Directions*

My involvement in quantitative data entry and early analysis of study results spurred my interest in the pain scores participants were reporting and how they were evaluating their pain in study surveys. In later interviews I began asking participants to describe their use of the pain scores with questions about what a score of “ten” would represent (i.e. how were they choosing the number they reported). Many participants expressed surprise at the question and were unable to explain how they’d chosen the pain scores they’d been reporting throughout their participation in the study. Additionally, it was clear that participants were using the scale to communicate more than just pain level and that the number depended on what they were seeking, how they were feeling in general, and various other factors. Because of the ubiquitous nature of the Likert pain scale in medical practice—from rating cancer pain to the pain of a broken bone to chronic nonspecific pain—future research should explore the decision-making process that goes into choosing a number to describe one’s pain. Patients who have never encountered the pain scale, for instance, may have different understandings than veteran patients whose treatment and medication regimen depends on the rating they provide. Likewise, physicians’ perspectives on the utility of, and issues that arise with the use of the pain scale might lead to improved ways of understanding the experience of pain in the lives of individuals.

The centrality of hope to the experience of illness is an important area for anthropologists or ethnographers to contribute to greater understanding of the placebo phenomenon. In placebo research, Dein (2002) suggests, patients’ own explanations of how faith or religious healing produce effects are rarely considered, although their own

explanations are key to understanding descriptions of satisfaction or treatment “outcome”. For ethnographers studying placebo, patients’ descriptions of their healing are the “data” collected to understand such effects. Questions for future research include: Is a patient’s reported level of satisfaction with a treatment the same as a placebo effect? If a patient experiences a reinterpretation or renewed sense of meaning as a result of a ritual or encounter and then reports a positive outcome, is this “outcome” comparable a positive response after receiving an ostensibly inert pill? The experience of pain is subjective. Measuring brain activity cannot tell us any more about how a person experiences their pain than can their own description of it. In this instance, a patient’s report that pain has improved as a result of an inert treatment may have to do with change in the meaning of illness. Or, it could be a conditioned response to a particular stimulus that produced a physiological response. Are these both placebo effects? Are they the same but with different interpretations of the mechanism? Further, by asking direct questions about hope and forcing awareness of it, are we, as anthropologists, capable (or culpable) of impacting the outcome of a treatment, or the possibility that the patient will benefit from the experience? Bound up with faith, despair, connectedness with community, and other central features of the human experience, hope, particularly as an embodied or pre-intentional experience, and its relationship to spontaneous healing and the placebo effect, is an important area for future research.

Over-the-counter (OTC) medication emerged from participant narratives as a crucial arena for symbolic consumption and the creation of moral identities in chronic pain. Future research, specifically designed to consider the use of OTC pain medication, could more closely study the actual use and intake of OTC meds. Although participants

often mentioned potential harms and side effects associated with taking such medications, more inquiry into how participants understand and navigate perceived risks might provide a clearer picture of how OTC pain meds are consumed. Not only the quantity of medications, but also the reasons for their use, the justification of particular dosages, and decisions of when and how to take medication are fascinating places for future inquiry.

When I have mentioned this study in casual conversation, I have been surprised by what people say about their own use of OTC pain meds, whether for chronic pain or other reasons. Although clinically defined chronic musculoskeletal pain may impact only a small percentage of the general population, the regular use of OTC pain meds may be much more widespread. In contrast to studies of chronic pain in pain clinics, I found many chronic pain sufferers who were focused on “just dealing with” the pain of TMD rather than seeking a cure or diagnosis. Future research should consider the range of people who, for various reasons, may be regularly involved in consumption OTC pain medications whether they subscribe to the identity of chronic pain sufferer or not.

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**APPENDIX A: Works of Illness and the challenges of social risk and the specter of pain in the lived experience of TMD**

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*ABSTRACT*

Temporomandibular Disorders (TMD) represent a particular form of chronic pain that, while not outwardly debilitating, profoundly impacts interactions as fundamental to human existence as smiling, laughing, speaking, eating, and intimacy. Our analysis, informed by an expanded “works of illness” assessment draws attention to work surrounding social and physical risk. We refer to these as the *work of stoicism* and the *work of vigilance* and identify double binds created in contexts that call for both. Conflicting authorial stances in informants’ narratives are shown to be essential in maintaining a positive identity in the face of illness. While earlier ethnographic studies report TMD sufferers’ experience of stigma and search for diagnosis and legitimacy, we present a group of individuals who have accepted diagnosis at face value and soldier through pain as a fundamental aspect of their identity.

**KEY WORDS:** chronic pain, works of illness, risk, double binds, temporomandibular disorders]

## **Introduction**

Temporomandibular disorder(s) (TMD) is a common source of chronic pain affecting the face and jaw. Although not physically debilitating per se, TMD is often associated with intense pain, aggravated by activities taken for granted in everyday life—talking, laughing, smiling, eating, kissing, intimacy—that are nevertheless fundamental to both public and personal social interaction. We consider the challenges and double binds faced by sufferers constantly weighing the physical risk of increased pain with the social risk of avoiding meaningful social interaction. In this study, participants had often accepted diagnosis at face value, rarely expressed a sense of threatened legitimacy, and were instead involved in cultivating self-identities while coping with unpredictable, intense, and ongoing pain.

Earlier anthropological studies of TMD among individuals seeking treatment in pain clinics found that sufferers had often consulted several practitioners and spent considerable energy searching for diagnosis and legitimization that their ailment was not “just psychological” (Garro 1992; Good 1992; Lennon et al. 1989; Ostermann et al. 1999). Fifteen years after this first wave of anthropological research on TMD, we encountered a very different health care-seeking scenario that included greater access to health information via the Internet (Bury 2001), changing definitions of “normal” (Williams 2000), and more widespread familiarity with TMD as an ailment. Many study participants, recruited from the community rather than from pain clinics, were not seeking legitimization but rather had already self-diagnosed with TMD or had been

diagnosed by dentists or physicians based on clicking sounds in their jaws prior to experiencing any pain. Whether or not their diagnosis was accurate, being informed early that there was “little or nothing one could do” about TMD influenced health care-seeking behavior. Some of those afflicted never sought additional diagnosis, legitimacy, or treatment for pain.

Coping with constant, albeit unpredictable, pain entails many life adjustments and is a constant source of concern. Minimizing physical and emotional risk through constant vigilance is challenging as sufferers attempt to be stoic in the face of pain, avoid social risk, and maintain meaningful social roles. Living in a state of embodied risk (Kavanagh and Broom 1998) and constant vulnerability to symptom flare-ups (Hunt et al. 1998; Nichter 2003) affects interpersonal relationships and leads those with TMD to adopt an “at risk role” (Nichter 2003, 2010). We draw attention to contexts in which physical risk is weighed against social risk (risk to present and possible future social relations), and to how those in pain balance multiple “risk roles” within hierarchies of risk (Connors 1992).

Chronic pain or illness introduces disorder to the temporality of lived experience (Antelius 2007; Bulow 2003; Garro 1992, 1994; Honkasalo 2001). Unlike terminal illness or cancer in which sufferers “live in prognosis,” ordered by the stages of illness (Jain 2007), the everyday experience of chronic pain provides no temporal context, no stages or patterns on which to pin one’s sense of a life process. TMD sufferers are not at risk for becoming ill or for an unknown future. But they are at risk for a previously experienced level of pain. The temporality of experience, or lack thereof, influences the daily experience of those with chronic TMD.

The “works of illness” conceptual framework originally outlined by Corbin and Strauss (1985) and further developed and used in medical resident training by Nichter (2002, 2005) provides a useful lens to examine the work engaged in by those living with TMD pain in addition to or as an alternative to seeking treatment. The works of illness framework encompasses three general lines of work: (1) everyday life work; (2) illness work; and (3) autobiographical work.<sup>1</sup> Each line of work requires specific adaptations and levels of effort. Everyday life work includes domestic chores, occupational work, marital and social relations work, child rearing, and the emotional work of both managing one’s own emotions and not overburdening others. Illness work involves diagnosis and monitoring, routine symptom management, flare-ups and crisis prevention, health care-seeking, and assessment and information gathering. Autobiographical work involves coming to terms with illness and adjusting one’s identity accordingly, revising one’s illness narrative in different contexts and for different purposes, and adjusting how one thinks about and plans for the future.

The works-of-illness conceptual framework is useful as it identifies the challenges and tasks those with TMD face regardless of disability and pain severity (Nichter 2002). In this article, we describe ways in which people living with TMD manage the risk and impact of pain throughout their lives. Areas of particular salience that emerged in informant narratives include works we refer to as the *work of stoicism*—managing multiple arenas of social risk and attempting to appear normal—and the *work of vigilance*—maintaining constant awareness of pain, eliminating triggers, and managing the physical risk of acute pain episodes.

We use the heuristic “work” when describing vigilance and stoicism for three reasons. Work implies that purposeful effort is being expended. Work is respected and it entails social relations and responsibilities. Further, the meaning and implications of work are readily understandable and applicable to the experience of both patients and clinicians. Hay (2010) considers increased suffering experienced by chronic illness sufferers unable to live up to culturally patterned expectations of stoicism. Employing the frame of the work of illness, we consider the experience of sufferers who, at least outwardly and in the present, meet such expectations. There is more involved than resolve, as vigilance and stoicism are entangled with all three lines of work noted above. This entanglement entails hierarchies of risk (Connors 1992) that often involve double binds (as illustrated in Table 1).

The concept of the double bind has been described (Bateson et al. 1956) in terms of primary and secondary injunctions, and usefully applied to chronic illness and disability (e.g., Alexander 1981; Ingram and Hutchinson 2000; Krefting 1990) as well as sexual decision-making (Muehlenhard and McCoy 1991). Double binds occur when adaptation in one domain of life paradoxically proves problematic in another. Those living with TMD often employ multiple voices, selves, or social identities (Goffman 1959; Strauss 1997) when describing different works and the double binds they face. Identifying these voices and appreciating these double binds adds to our understanding of the challenges TMD sufferers face as they attempt to minimize stressors, negotiate social relationships and maintain some modicum of control by attending to states of subjective risk (Tulloch and Lupton 2003).

## **Materials and Methods**

TMD, colloquially called “TMJ,” is the third most common chronic pain disorder in the United States after chronic low back pain and muscle-tension headache. Estimated lifetime prevalence is between 10 to 25% of the general population, with higher rates reported for women than men (Dworkin 2011; Glass et al. 1993). The primary symptoms of TMD, including chronic pain affecting the face’s muscles and temporomandibular joint (TMJ), negatively affect everyday activities, social relationships, and the emotional states of sufferers. TMD is frequently associated with depression and other health problems (Dworkin 2007; Slade et al. 2013).

The semi-structured, open-ended interviews on which this analysis is based were conducted as part of a dual-site (Tucson, AZ; Portland, OR) randomized phase 2 trial of traditional Chinese medicine (TCM) with or without self-care training for TMD (For full description of the overall study and sample characteristics, see Ritenbaugh et al. 2012). Participants were recruited through community outreach and newspaper advertisements that described a study evaluating TCM for jaw and facial pain. One hundred eighty-six participants (approximately 85% female) consented to the trial. Of those, we asked approximately every other participant to be interviewed up to five times over the course of their experience in the study. Due to the small number of men in the study, we interviewed as many of them as possible, in addition to including every other participant. Although some did not continue through all follow-up interviews, no participants declined to be interviewed at baseline. A series of five interviews were designed to be conducted: (1) prior to any treatment; (2) after self-care training and prior to TCM

treatment; (3) approximately 2 months after starting TCM treatment; (3) 6 months after starting TCM treatment; and (4) 2–3 months after the end of treatment. Eligibility criteria included ages 18–70, worst facial pain  $\geq 5$  on a 0–10 scale, and research confirmation of TMD diagnosis (<http://www.rdc-tmdinternational.org/>). All procedures were approved by the University of Arizona and Oregon College of Oriental Medicine institutional review boards, and all participants provided informed consent.

Interview guides were designed to capture patients' illness experience prior to study interventions and throughout treatment. Baseline interviews covered broad themes such as family and social support, work situation, stress, illness history, medication use, expectations, hope, explanatory models of illness, experience of stigma, and past treatment seeking prior to entering the study. Follow-up interviews explored treatment experiences, changes in coping, changes in illness experience, changes in ideas about illness, additional treatment seeking, and other topics varying by relevance to the participant.

Emery Eaves conducted all interviews with participants in Tucson and some via telephone with participants in Portland. Elizabeth Sutherland and an additional interviewer conducted in-person interviews in Portland. All baseline interviews were conducted in person. Some follow-up interviews were conducted over the telephone to reduce participant burden. Interviewers were trained and monitored by Mark Nichter, an anthropologist with significant experience in ethnographic interviewing in clinical as well as community contexts. Interview experiences were exchanged and problems discussed in regular conference calls to maintain consistency across sites. Early interview experiences were discussed and frustrations elicited in order to train interviewers to

expect performative and rhetorical aspects of illness narrative construction in the context of the interview (Buchbinder 2011; Goffman 1959; Labov 1972, 2013; Miczo 2003) and to encourage participants to speak reflexively in a way that freed them to employ several different “voices” representing various aspects of their lives (Tanggaard 2009).

Ninety-five participants participated in baseline (pre-randomization) interviews; 44 completed four or five interviews for a total of 271 interviews. Eaves transcribed interviews transcribed verbatim and coded them using ATLAS.ti 6.0 (Muhr 2011). Basic code structure consisted of a set of themes that encompassed descriptions of patients’ pain and its predictability/unpredictability, stressors that led to pain flare-ups, behaviors that fell under all three aforementioned works of illness, medication use, and social relationships. Aspects of TCM treatment and changes in many areas of participants’ lives were also carefully coded and will be the subject of in-depth analysis in forthcoming articles. Eaves, Cheryl Ritenbaugh, and Nichter held regular meetings to discuss code descriptions and emergent themes, to maintain consistency, and to interpret findings.

Informants were mostly women 18–69 years of age, primarily middle-class Anglo-Americans with steady jobs. Most lived with families or in long-term relationships. TMD pain onset had occurred recently for some and as early as adolescence for others. Our gender distribution matched estimates for population distribution overall (see Ritenbaugh et al [2012] for full sample details). Use of over-the-counter analgesic medications was common, while routine use of prescription pain medications occurred in about ten percent of participants (see Elder et al. [2012] for medications analysis). A few reported using sleep medications. Lack of adequate health

insurance coverage for TMD or complementary therapies was often a motivating factor to join the study.

Quotes have been assigned to “named” individuals to indicate gender and differentiate between participants; all names have been changed to protect anonymity. In the following section, we first describe the work of stoicism and then the work of vigilance. We then consider how they interact with one another to create double binds and hierarchies of risk as they collide with original works of illness.

### **The Work of Living with TMD: Participant Experiences**

#### *Stoicism and Vigilance in the Context of Other Works of Illness*

Table 1 provides an illustrative summary of how the work of stoicism and the work of vigilance, discussed in detail below, interact to create multiple hierarchies of risk and double binds. Vigilance and stoicism lead to situations requiring continual trade-offs as they intertwine with the three originally conceptualized lines of work described above. We found that participants faced double binds that forced them to privilege one type of risk over another. In many social contexts, for example, engaging in the work of stoicism meant that concerns about social risk outweighed physical risk. In the case of vigilance work, avoiding social situations altogether involved the work of declining to participate in activities while still trying to maintain social ties.

<b>Table 1. Interactions between stoicism and vigilance across 3 lines of work</b>		
	<b>Work of Stoicism</b>	<b>Work of Vigilance</b>
	Working to appear normal, to live normally in spite of pain, and to hide pain from others; “just dealing with it”; soldiering through any amount of pain	Working to avoid pain triggers, avoiding increased pain – “flare-ups”; hyper-awareness of physical body and pain levels

	<i>Managing Social Risk</i>	<i>Managing Physical Risk</i>
Everyday Life Work	<p>Working to minimize the <i>impact</i> of pain on social relationships and activities; participating in social activities and making a “payment” of increased pain</p> <p>In professional and public situations: Eating and talking normally; smiling to avoid appearing anti-social;</p> <p>With significant others: Managing others’ emotions; not burdening others with pain; participating in family activities; maintaining intimate relationships</p> <p>Sleeping enough to avoid being irritable and to be productive</p>	<p>Working to avoid situations likely to result in pain flare-ups; eliminating activities known to cause/increase pain</p> <p>Avoiding crunchy/chewy foods; not talking too much/too long; not smiling or laughing too much; avoiding intimate activities involving mouth;</p> <p>Hyper-vigilance against clenching/grinding during sleep</p>
Illness Work	<p>Not seeking care; accepting original diagnosis, and “just handling” pain; self-diagnosis with books or internet; not mentioning TMD to PCP to avoid stigma of being a chronic pain patient</p> <p>Avoiding being “someone who likes taking pain medication<sup>3</sup>” by avoiding prescription pain meds (or if taking them, emphasizing severity of pain)</p>	<p>Reliance on mouthguard; working to describe pain severity to family members or physicians when necessary</p> <p>Taking large doses of OTC meds to manage pain (working to construct them as not pain medication<sup>4</sup>); Not taking pain meds to retain bodily awareness and ability to monitor pain</p>
Autobiographical Work	<p>Working to create stoic moral identity; avoiding stigma by not drawing attention to pain</p> <p>Keeping up hope for improvement<sup>5</sup>; expressing hopefulness and positive attitude to significant others; Denial that TMD impacts future plans</p> <p>Working to accept pain and to care for the self and the body on one’s own; requires knowledge about the condition</p>	<p>Working to stay focused on the present; – maintaining “at risk role” always attentive to pain</p> <p>Keeping hopes in check, not hoping for too much as a form of vigilance against possibility of despair</p> <p>Avoiding prognosis; Working to keep hopes up by avoiding too much negative information or accepting that pain is “chronic”</p>

*The Work of Stoicism: “Just Dealing with Pain”*

Our community-based sample was recruited for a clinical trial of TCM. Eligible participants had worst facial pain levels of 5 or above on a 0–10 scale. Notably, over 40% of 186 participants had not sought care for TMD pain within the past six months, and more than 10% had never sought care. We report here on the entire study sample to highlight the fact that despite entrance criteria requiring high pain levels, many entering the study were not actively seeking care. In contrast to earlier anthropological studies of patients seeking diagnosis and legitimacy for chronic pain in pain clinics (DelVecchio Good et al. 1992; Jackson 2005), many participants in this study reported being diagnosed with TMD by dentists or general practitioners based on clicking sounds in their jaw *before* experiencing pain. One said:

Well my uh, my family dentist was the one that, you know, noticed it cause it's squeaky while he's touching me and, he was very understanding and, “Do you know have TM- TMD”?—He called it “TMJ.” But uh, I just tried to relax it.  
(Carol, 61)

Receiving a diagnosis before pain onset curtailed treatment-seeking for many participants who were told by clinicians there was little they could do. Unlike Garro's informants (1994), many people in our study had seen only one practitioner. In addition, several were self-diagnosed with TMD based on books, Internet research, or hearsay and had never sought treatment.

I don't really know, um, I think it was just someone talking about, “Well that's the way TMD is, it's that your jaws pop.” And probably the first time I figured

out that I had it was when I yawned and it—you know when you yawn and all of a sudden it hurts? ... That's probably when I figured it out. (Margaret, 63)

After receiving a diagnosis of TMD from their dentist or PCP, most participants in this study had been offered dental splints, muscle-relaxing medications, or narcotic pain medications. Several participants who chose to try recommended treatments and found them inadequate reported a process of being referred back and forth between doctors, dentists, and specialists (see Ostermann et al. 1999) until they became discouraged and discontinued searching for a medical fix to their problem.

And so I was in some intense pain ... and it was so funny because as soon as I got to the doctors they tell me I should go to the dentist, and then as soon as I go to the dentist they tell me they can't do anything for me, I have to go back to the doctors. And so it's a lot of shifting back and forth, and I didn't have a lot of time as a student and working full time and so ... I've just kind of dealt with the pain. (Lisa, 30)

Others chose not to seek recommended treatments or interventions, knowing they were cost prohibitive and chose instead to “just let it go.”

I'd been discussing the jaw problem with my dentist for a couple of years. ... And he had been recommending that I go see this specialist that creates some kinda really high-tech splint. But, I never could afford it and it wasn't gonna be paid by my insurance. So, I just let it go. (Bonnie, 57)

When asked about TMD in daily life, many participants initially responded that TMD does not interfere with their lives. Despite reports of high levels of pain, the majority insisted that they “just deal with it,” “just handle it,” or “just ignore it” and continue to live “normally” in spite of pain.

No reason to concern anybody else and have anybody else get upset about it. Uh, no, I just put up with it, that’s all. (Hank, 65)

Most participants stated matter-of-factly that TMD pain was something they had to soldier through because it is not outwardly debilitating and because other matters (such as family and friends, work, or other illnesses) warranted greater attention.

When it’s really bad, I can’t sleep and I can’t eat so my energy level and my outlook on life at that moment is a little bit less than thrilling. But my lifestyle doesn’t change because of it. (Melanie, 30)

While virtually all of our informants at some point downplayed limitations and employed a voice of stoicism, they also shifted back and forth from the “voice of the normal” to “voices of affliction” as they went on to talk about TMD’s major *impact* on their physical, social, and emotional lives.

Pain to me is something that’s debilitating in a sense. It changes the way that you move in the world. (Melanie, 30) [quoted above saying “my lifestyle doesn’t change because of [pain]”]

Participants emphasized their silence in dealing with pain. They worked to keep pain to themselves, even while bringing attention to a range of impacts on their lives.

Attempting to convey the severity of pain places sufferers at risk of violating social proscriptions against whining or complaining about pain (Hilbert 1984; Werner et al. 2004). A voice of stoicism—of soldiering through any amount of pain—is culturally sanctioned and central to sustaining a positive sense of self (Hay 2010; Hermans 2001; Smith and Sparkes 2008; Wilce 1998). This voice at once articulates inner strength and confirms the ability to maintain meaningful social roles despite varying degrees of impairment. Further, many participants in this study referred to “people who have chronic pain” as different from themselves. As noted by Jackson (2005), they distance themselves from what they perceive to be a stigmatized chronic pain identity associated with medication dependency if not abuse.

Linda, quoted below, reported being unable to work due to severe pain. Pain limited her participation in household tasks, and she described exasperation on her husband’s part over her refusal to continue seeking treatment. Despite this, she referred to herself as someone more able to handle chronic pain than others.

People who have chronic pain, can’t, don’t know how to manage their pain. Um, it can be very discouraging for them. I think I know how to manage my pain because I turn it off as much as I can. And I do a lot of things to make it better, like yoga or walking. But people, a lot of times, haven’t explored that. So the people that will be coming through [the study], and I’m not one of those, I think I’m going to be a little different for you, but I’m not one that gets real discouraged. (Linda, 62)

“I’m not the type of person who” commonly prefaced statements in which participants worked to position themselves as different from stereotypical pain sufferers.

Individuals in other studies of chronic pain reported facing considerable stigma at work and in social situations (Jackson 2005; Lillrank 2003; Reid et al. 1991). Most participants in our study, however, said they rarely spoke to others about their pain.

I don't like attention drawn to things like [TMD]. I once hurt my knee and had to wear a brace and I hated that. You know, like people coming up to you, "Oh, what's wrong with you?" I'm not somebody that tries to have injuries and get attention. I'd rather be out there and just fine and nobody knows what's wrong with me. (Patricia, 58)

I don't go out of my way to explain to people that I have it. I'm not proud of it. It's not something that I carry around like a badge of courage. It's just, I live with it. I'm not looking for sympathy. (Larry, 52)

Although when describing our research on TMD in varying situations, researchers commonly heard phrases such as "Oh, I have TMD" or "I know someone with terrible TMD," several participants in this study reported never having met anyone else with the condition. Although somewhat isolating, a positive outcome of resistance to ever discussing pain with others was a lack of any reported experiences of stigma associated with TMD. Participants were aware, however, of stigma surrounding other conditions such as fibromyalgia or chronic fatigue syndrome and were careful to construct their experience of TMD pain as categorically distinct from other conditions considered socially or medically suspect.

It's nice to know people are researching this. That it's, it's not like fibromyalgia or something where people think it's just, um, either just in your head, or they

think it's just stress that causes it or, I think there's more to it. For some people it's stress, for some people it's muscular, some people it's arthritic. (David, 54)

Remaining stoic and not becoming “somebody that tries to ... get attention” requires significant work. Social interactions are weighed in terms of risk and opportunity cost. Often, the physical risk of increased pain is eclipsed by the “social risk” (Castañeda et al. 2010; Nichter 1994) of avoiding some of the simplest of social activities, including talking, smiling, laughing, and eating with friends and family. Further, we identified two arenas of social risk that arise in living with TMD and differ from each other: social risk in public and work contexts and social risk in family and intimate contexts. In work and other public contexts, participants work to hide pain or illness altogether, thus avoiding the social risk of assuming a chronic pain identity.

I'd be walking down the aisle [at work] and somebody'd say, “Go ahead and smile. It doesn't hurt.” And I thought about that later and I thought, you know, it does hurt. It hurts to smile. (Lloyd, 54)

The repercussions of failing to smile at others in a work environment and thus being perceived as unfriendly or even hostile are easily apparent. Laughing, smiling, and talking, which lead to pain, are key elements in maintaining work relationships and place sufferers in a double bind. Similarly, many work and social encounters revolve around food and eating, another area of particular difficulty for those living with TMD. To avoid offending well-meaning friends or family members, our informants presented a stoic self, eating what was prepared for them, knowing it will cause a pain flare-up later. Hiding

pain, while involving physical risk, allows sufferers to live normally in social contexts and make their own decisions about balancing risks.

It takes the spark out of life. I'm very easy-going, and I'm a joker and I just don't talk as much as I used to. ... Smiling is (cringes) but laughing is a killer. ... And I'm always joking around and playing around with my daughter and, I still do but I always know, and I do, and I pay for it later ... but you know, you gotta make that payment. (David, 54)

In relationships with significant others, however, the experience of pain cannot be entirely hidden. As significant others become involved in attempting to manage risks, or shelter sufferers from perceived risks, additional double binds are often confronted. Sufferers now also must work to avoid burdening significant others with their experience of pain.

You know, so I feel that kind of guilt ... dragging them down too. And they overcompensate. "Well, we don't have to go, what can you eat tonight?" like "What restaurant do you want to go to." And I say "I'll go anywhere. I, you know I'll find something on the menu that I can eat." "Oh no, no, no, we can't go for that. ..." And, and you get into that argument almost, where I'm saying, "I don't want you to do this, like don't do this because of me. 'Cause it makes me feel worse by you not having what you want." (David, 54)

Juggling risks of pain with other forms of risk continues into the most intimate areas of individuals' lives. Sexuality is another area of significant work for these

informants. The experience and fear of chronic pain can have profound effects on intimate relationships (Bral et al. 2002; Schlesinger 1996; Smith 2003).

When I want to make love with my lover, but my jaws hurt so bad that I can't kiss her, well, that's an effect that it has. ... There are times when an explanation just, you know, isn't quite enough. ... The first [few] times we had to deal with it, it's, for somebody who's never experienced it, "Waddaya mean (breathes into her hand and smells, as though she is checking for bad breath) you can't kiss me right now? What?" (Taylor, 53)

The communication work involved in explaining to partners that lessened sexual desire results from the pain of the disorder, not from relationship problems, is particularly challenging and introduces double binds for all involved. Abstaining from sexual contact means denying partners the experience of pleasure, compromising one's stoic posture, and burdening one's significant other with pain. To engage, however, is to suffer in the moment or after the act. Partners are also caught in a double bind. Partners may be afraid of initiating sex for fear of causing pain. On the other hand, not initiating sex can be read as distance.

As much as they could, participants often chose to bear pain in social and intimate situations and pay the price later in the form of increased pain and inability to work the next day, difficulty sleeping, and so on. Many also chose to not to discuss pain with medical practitioners to avoid calling too much attention to TMD and risk assuming the stigma of being a chronic pain patient. They maintained credibility as stoic patients for some unknown future time when they would need to be taken seriously. "Medicine talk" or discourse on avoiding pain medications as a personal choice was integral to

constructing a stoic self. Narratives about choosing not to use prescribed medications were common and provided yet another means of distancing oneself from stigmatized illness careers as well as establishing moral identity.

I'm concerned about an entire culture being addicted to, you know, Pfizer. So I have political reasons that I'm concerned with medicine but, on a personal level I'm, I'm not the kind of person that's going to, I know this the classic answer, but I'm not the kind of person to be addicted to pain medicine. (Dennis, 32)

Amalia, a participant receiving a government-sponsored pension due to her disabled status from multiple chronic pain conditions including fibromyalgia, described pain as “a job.” Despite descriptions of debilitating pain, constructions of a stoic and positive self were essential elements of her narratives.

I take the good and brush the bad aside, you know? The negative. I try to stay positive. (short pause) Yeah, that's how I take life, I have to you know, with the pain and everything you know. ... So, that's how I live my life, and like the pain is just another job that I have to do every day and I just take care of it, 'cause there's not much more I can do about it. (Amalia, 61)

This voice of acceptance, of knowing there's “not much more I can do about it” and being positively resigned to living with pain was only one of the voices participants employed. In another voice, participants described rearranging lives around pain, avoiding any pain triggers, and being constantly aware of the risk of pain.

*Vigilance Work: Fear and the Work of Avoiding Triggers*

In opposition to the work of stoicism as a means of managing social risk is the work of vigilance as a means of managing physical risk. While most participants could soldier through pain on a daily basis, they expressed concern about flare-ups of acute pain that result in migraines, neck pain, and other ailments that disrupt daily routines and require retreat to dark, quiet places.

It can get pretty bad. To the point where it interferes with my ability to think, if that makes sense. It's just so painful that I ... it's hard to think about things and I just want to kind of be left alone and like, ow I'm hurting and and ... don't bother me, and I can't think about anything and I've got to make this pain go away before anything else can happen. And that's not the norm for me but it does happen. (Jessica, 30)

The knowledge that pain can intensify without warning makes it difficult for some with TMD to plan their lives. These TMD sufferers take on an “at risk” role rather than a sick role. Assuming an at risk role entails careful monitoring of bodily sensations and the work of remaining vigilant (Lupton 1999; Nichter 2003). To reduce anxiety, informants described rearranging their lives to avoid triggers associated with flare-ups as much as possible.

The importance of minimizing pain triggers was clear to the research team when we asked participants to map daily pain patterns. They rejected the exercise. While many reported that pain was worse in the morning (due to poor sleep and lack of bodily control, explored further below), patterns of pain were difficult to identify because if participants had previously noticed a pattern, they believed they would already have eliminated the pain triggers associated with it.

I wish I could see a pattern. For a while I thought it had to do with my pillow and my sleeping position. And I've tried a bunch of different things and ... it, if there is a pattern I haven't been able to notice it. Foods that I eat comfortably one day, another day might cause my jaw to lock. So, no, I haven't been able to discern a pattern. (Helen, 57)

The experience of chronic pain makes it difficult for sufferers to describe a timeline of pain in terms of when pain is felt and with what circumstances (Good 1992). Informants emphasized that not only did pain fluctuate unpredictably, but that even when not consciously aware of spikes in pain, pain was latent. They were not ready to identify pain-free times or map out daily pain patterns.

It could be a couple of weeks where I try to eat and my jaws will lock up or I yawn and I'll ... they'll lock up. It could happen, um, it could not happen at all. I'm still getting to know the stages, of what happens. The stage I'm in right now I'll get pain. Chewing pain, and mouth headaches, there's time I get terrible headaches from it, but right now I'm going through a stage where it's, um, shooting pain. It started being on the right side, it used to only be on the left side. So there's no, um, particular pattern, I just, I don't know what triggers it. (Shawna, 42)

*Refocusing on the Present: Vigilance against Biographical Disruption*

As Garro (1994) has also noted, imagining a future filled with pain may be too much to bear. Unlike cancer sufferers who are “living in prognosis” (Jain 2007) with lives defined by illness stages, chronic pain has no stages. There is no cyclicity at all as sufferers work

to live with pain on a daily basis with no knowledge about how one will feel from one day to the next. We found that our questions about the future were threatening. When participants in this study were asked about how their illness had affected long-term life plans as a means of probing biographical work, they often denied that TMD had affected future plans. They immediately refocused conversation on the daily experience of vigilance against increasing pain.

I wouldn't say it's affected [my future plans] at all. How it's affected my life? I just have to be more conscious, conscious of foods I eat, chewing gum. ... I sleep with a night guard every night and if I don't, I definitely wake up in pain. But, nothing that's changed my outcome for the future, just awareness, behavioral changes. (Cindy, 36)

As Williams (2000) points out, biographical disruption (disruption in the forms of knowledge that underpin structures of everyday life (see Bury 1982, 1991) occurs when one anticipates or is committed to certain events taking place. In this context, avoiding talk about the future is part of vigilance not only against pain triggers, but also against the repercussions of a disrupted biography or of failing to live up to one's own expectations by maintaining a sense of living a normal life in the present.

Thinking too much about the future was identified as threatening by several informants, and as leading to despair. It was deemed healthier to focus on the present and make do.

I just feel like if I don't get things more in place now, that it's just going to be harder and I'm going to be less physically capable ... but it's hard. I don't really

have an answer besides just trying to prepare, or get as strong as I can now. ...  
I'm aware of my future but I don't want to be all like freaked out. (Chlöe, 31)

The risk role adopted by our participants is distinct from that assumed by someone at risk for illness but who is not yet ill. Those with TMD feel at risk of flare-ups they have already experienced and carry with them as an embodied memory. Avoiding this type of risk is a form of harm reduction associated with feelings of latent vulnerability linked to notions of both flare-up and possible illness transformation (Nichter 2003). The practice of harm reduction is limited to doing what one can to prevent preexisting health problems from worsening. Unlike progressive illness where the “worst is yet to come,” many in this study had already experienced the worst imaginable pain associated with the condition. Their sense of risk arose not out of fear of an unknown future, but fear of a known past, of returning to a previous experience of pain.

When it starts hurting a lot, then I remember how bad it's been at times and I have an emotional reaction instead of just the physical pain. Because once you've been through it a couple of times it's like (clenches teeth), *oh my gosh*. (Helen, 57)

Despite statements that TMD did not affect their plans for the future, many of our participants did employ a “voice of concern” about what would happen as they aged. Many worried that pain might worsen over time. Most forms of TMD are not considered degenerative and in many cases pain subsides with age (Egermark et al. 2001; Magnusson et al. 2005). Few participants we spoke to appeared to be aware of this, however, and this concern was not a subject they raised with health practitioners.<sup>2</sup> Too

much information could undermine one's ability to hope and to live "in the subjunctive mode" (Good and DelVecchio Good 1991; Simpson 2004). Participants worked to remain hopeful and "open" to the future by focusing on daily existence and not on prognosis (Eaves et al. 2014).

## **Discussion**

Previous ethnographic accounts of TMD have emphasized the search for pain diagnosis and the frustration often felt by patients seeking medical validation for illness. In contrast to earlier landmark studies (Garro 1992; Good 1992), those living with TMD in this study reported greater initial awareness of the existence of the condition, acceptance of the nature of the diagnosis, and resignation to the improbability of successful biomedical treatment. Instead of focusing on the search for legitimacy, these illness narratives centered on remaining vigilant to pain triggers and maintaining a stoic, present-oriented identity in the face of pain.

Pain is spoken about differently in varying contexts in keeping with different works of illness, audiences, and the dialogical construction of self (Goffman 1959; Hermans 2001; Hermans et al. 1992; Smith and Sparkes 2008). Interviews that are attentive to the lifeworld of the chronically ill invite reflection on many different aspects of life and result in multi-voiced polyphonic narratives (Clark and Holquist 1984; Holquist 1990). Within illness narratives, sufferers employ rhetorical devices not only to create meaning, but to present themselves as moral individuals (Buchbinder 2011; Butler 2005).

The presence of multiple voices in the narratives we collected was striking. Participants shifted between a voice of stoic sufferer—working to "just deal with it" and

keep pain from interfering with life—to a voice of vigilant sufferer working to recognize pain triggers and minimize sources of flare-up, ever aware of the risk of returning to a past experience of unbearable pain. Informants used different voices to describe myriad presentations of self in particular contexts. The unique context of open-ended interviews conducted by an interviewer one came to know over time and attentive to the many “works of illness” sufferers routinely engage afforded participants adequate space and time to share different aspects of their illness experience and identity struggles (Miczo 2003).

Others have observed contradictions inherent in the lived experience of chronic pain. Hilbert (1984), for example, has pointed out that “for sufferers in social settings, pain management is as ongoing as chronic pain itself. They do not engage willingly, nor can they abstain from it ... contradictory pressures to disclose and to conceal exist *simultaneously*, forcing sufferers to engage in an awkward ... balancing act between two extremes” (370; emphasis in the original). We found an expanded “works of illness” conceptual framework a productive heuristic to flesh out the multidimensional nature of the TMD experience, the ways sufferers cope with the unpredictability of symptoms, and the double binds they face while living their lives as best they can.

Two areas of narrative and interactional work emerged from our interviews. The work of stoicism requires soldiering through pain to navigate two arenas of social risk. Stoicism work involves both cultivating professional or public identities as well as maintaining family, social, and sexual relationships. Avoiding risk entails managing one’s own concerns while being attentive to role expectations and the emotional needs of others. The work of vigilance requires sufferers to maintain constant awareness of pain

and potential triggers. The unpredictability of pain complicates coping with TMD as the anticipation of pain is difficult to separate from the experience of pain itself (Jackson 2005). Fear of pain flare-ups and constant attention to bodily signs and symptoms involves a string of decisions such as whether or when to use pain medicine and how to contend with the opportunity costs of appearing ill or socially disengaged. Fear of symptom flare-ups leads to the adoption of an “at-risk” role. Sufferers are confronted with shifts in a hierarchy of physical and social risks and constantly weigh risks in terms of outcomes and priorities when deciding whether to avoid increased pain or to engage with family, friends, or significant others.

Vigilance and stoicism involve work in relation to one another, as well as in conjunction with each of the three originally conceptualized works of illness (Corbin and Strauss 1985; Nichter 2002, 2005). In everyday life, sufferers actively choose to mitigate pain or participate in social life on a constant basis. Pain was not always the principle concern, but rather was weighed against the social risk of avoiding smiling, talking, eating, and intimacy. In terms of illness work, treatment seeking, which could perhaps have mitigated physical pain, was complicated by the social risk of assuming a chronic pain identity or of admitting one could not “just deal with it.” On the other hand, seeking treatment was also a performance of appropriate hope and vigilance to significant others, regardless of individual expectations or prior experience. In autobiographical work, the risk of facing an altered biography, a life of illness, or unending pain led sufferers to refocus their attention on the present. Autobiographical work entailed effort to appear and to feel normal in the present through purposeful avoidance of expectations for oneself or

of the future that would entail a disrupted biography and thus increased suffering if not met (Hay 2010; Williams 2000).

Our ability to generalize about the experience of individuals with TMD is limited by the study context. Participants were recruited from the community, rather than a tertiary care pain clinic, to a research study offering TCM. Although these participants could be characterized as willing to try a complementary and alternative medicine (CAM) therapy, they are also not the same population who would be found already seeking care in complementary and alternative medical care settings since most were not already seeking CAM when they joined the study. It is possible, due to the nature of the intervention being studied, that the number of individuals not wanting to use pain medications is overrepresented in our sample. Attitudes toward medication as an example of stoicism work, however, applied to a broad range of our participants whether using pain medication or not. Additionally, observable differences between these individuals and those whose voices have been reported in studies of patients recruited from pain clinics provides an alternative and complementary perspective on the experience of living with this chronic pain condition. The small number of men ( $n=17$ ) in our sample is reflective of gender distribution of TMD in general, but precludes detailed analysis by gender. We note, however, that no gender differences were readily apparent among participants.

In sum, individuals with substantial chronic pain from TMD, recruited from the community, who joined a study offering no-cost TCM treatment, provide unique insights into the lived experience of TMD. Changes in medical treatment of chronic pain over time, as well as in the public's awareness of it, seem to have influenced the way TMD is

perceived and experienced. Rather than contradicting earlier anthropological insights into TMD, this research provides an updated account of TMD. Here, we have identified stoicism and vigilance as central works of illness and elucidated double binds created in situations where both are required. Significant effort, therefore, goes into living with ever-present pain, maintaining a meaningful identity, and retaining some modicum of hope for oneself and significant others. Future ethnographies attentive to the many works of illness beyond diagnosis and treatment seeking will provide us a more nuanced understanding of lived experience of chronic pain and the social risks of assuming a chronic pain identity.

## Notes

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1. Other forms of work engaged in by those affected include translational work (explaining one's ailments to others in terms they can understand), illness advocacy and support group work, and religious and spiritual work (Nichter 2005).
2. It is unlikely that even if participants had asked practitioners about the prognosis associated with TMD they would have learned of its common improvement with age

since most practitioners are not familiar with the specifics of the condition, particularly because of its ambiguous definition somewhere in-between medical and dental professions.

<sup>3</sup> Eaves, Emery R, Nichter, M, and Ritenbaugh, C. (2013) “I’m not the sort of person who takes pain medication. I just take Advil”: Over-the-counter Analgesic use among patients with chronic TMD pain. Poster presented at American Anthropological Association Annual Meeting in Chicago, IL 2013.

<sup>4</sup> Ibid.

<sup>5</sup> Multiple *ways of hoping* and the work of avoiding despair in chronic pain is also the topic of in-depth analysis in a forthcoming manuscript.

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**APPENDIX B: Modes of Hoping: Understanding hope and expectation in the context of a clinical trial of complementary and alternative medicine for chronic pain**

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**ABSTRACT**

This article explores the role of hope in participants' assessments of their expectations, experiences and treatment outcomes. Data analysis focused on semi-structured, open-ended interviews with 44 participants, interviewed 3-5 times each over the course of a study evaluating Traditional Chinese Medicine (TCM) for Temporomandibular Disorders (TMD, a form of chronic orofacial pain). Transcripts were coded and analyzed using qualitative and ethnographic methods. A "Modes of Hoping" (Webb 2007) framework informed our analysis. Five modes of hoping emerged from participant narratives: Realistic Hope; Wishful Hope; Utopian Hope; Technoscience Hope; and Transcendent Hope. Using this framework, hope is demonstrated as exerting a profound influence over how participants assess and report their expectations. This suggests that researchers interested in measuring expectations and understanding their role in treatment outcomes should consider hope as exercising a multifaceted and dynamic influence on participants' reporting of expectations and their experience and evaluation of treatment.

**KEYWORDS:** Hope; Expectation; TCM; TMD; qualitative

## INTRODUCTION

This paper explores the role of hope in moderating how participants assess and report expectations in the context of a research study of Traditional Chinese Medicine (TCM) for a chronic pain condition (Temporomandibular disorder; TMD). Participant responses to questions about expected and hoped for outcomes in the context of a novel treatment led to our interest in the following questions: (1) What role does hope play in how participants respond to questions eliciting their “expectations” for a treatment with which they have no prior experience for this condition? (2) What are the nuances of hope that allow participants to report increases and decreases in hope within a single interview? (3) What factors, other than inaccurate recall, might lead participants to report “no expectations” at baseline and later to report having entered the study expecting a “cure”?

Although the potential role of hope in the placebo effect is not a new idea (Hahn and Kleinman 1983; Pruyser 1963), the literature on the role of expectancy in the placebo effect rarely mentions hope. The few studies referring to hope parenthetically note that it is often mentioned by patients when asked about their expectations, but is not easily defined or investigated (Di Blasi, et al. 2005; Schrank, et al. 2011; Stone, et al. 2005). Several researchers have pointed out that conceptualizing hope as a type of expectation is problematic and that increased conceptual clarity is needed (Leung, et al. 2009; Ratcliffe 2011; Wiles, et al. 2008). The goal of the present analysis is to explore hope in the context of the lived experience of chronic pain. By investigating the role of hope in participants’ considerations and reporting of expectations, we aim to contribute increased

clarity to the concept of hope, and to its role in moderating the ways in which expectations are reported in the context of a complementary and alternative medicine (CAM) trial.

We draw from anthropology, psychology, philosophy and other disciplines for additional insights on the centrality of hope to patient narratives. As DelVecchio-Good et al. (1990) have pointed out, in cancer diagnosis, ideas surrounding hope and modes of disclosure are influenced by a “deeply felt cultural conviction that individualized *will* can influence bodily processes” (p75). Anthropologists have also suggested that the placebo response is at least partially attributable to changes in the “meaning” a patient ascribes to their illness (Hahn and Kleinman 1983; Kaptchuk, et al. 2009; Kirmayer 2006; Moerman 2002; Tambiah 1977). Averill et al. point to the existence of culturally circumscribed “rules of hoping” that define those hopes considered appropriate, moral, and reasonable in particular contexts (Averill, et al. 1990; Averill and Sundararajan 2005).

In this analysis, we draw from the work of other researchers who have distinguished types of hope including: Lohne and Severinsson’s distinction between “big hopes” and “small hopes” (Lohne and Severinsson 2004); Leung et al. and Corbett et al.’s distinction between “particularized hope” versus “generalized hope” (Corbett, et al. 2007; Leung, et al. 2009); Wiles et al.’s distinction between “hope as want” and “hope as expectation” (Wiles, et al. 2008); Ratcliffe’s descriptions of “passive hope” and “active hope” (Ratcliffe 2011); and especially from Darren Webb’s concept of multiple “modes of hoping” (Webb 2007) to shed light on the role of hope in the reporting of expectations and evaluation of outcomes in a CAM trial. While these authors have distinguished hopes along different dimensions (e.g., small vs. big; general vs. specific) such judgments

regarding the sources or dimensions of participants' hopes are not the goal of this analysis. Instead we emphasize individual variation in the ability to hope as it relates to particular features of illness and the participants' orientation toward the future or past experiences with pain. All of these appear to influence the magnitude of a particular hope as it is felt in the lived experience of an individual.

In the following analysis of narratives from semi-structured open-ended interviews with 44 participants who were each interviewed up to five times over the course of a year, we explore reported expectations, hopes, and statements about increases or decreases in hope in relation to TCM treatment through a "modes of hoping" framework. We outline several "modes of hoping" that emerged from participants' narratives over the course of the study and explore the implications of conceptualizing hope as a dynamic and multi-faceted concept for future research on expectations and hopes in CAM.

## METHODOLOGY

### *Study context and sample selection:*

The present research consists of secondary analysis of qualitative interviews that were originally conducted as part of a multi-site (Tucson, AZ and Portland, OR) randomized phase 2 trial of whole system TCM for participants with TMD, most of whom had never had extended TCM treatment for any condition. The short-term (16 weeks) phase of the trial involved sequential randomization to TCM or an alternative time and attention-matched psychosocial self-care intervention (for trial design and exclusion criteria, see Ritenbaugh, et al. 2012). The long-term phase subsequently provided TCM to most

participants. The TCM protocol included individualized treatment with acupuncture, herbs, tuina, and lifestyle interventions (Mist, et al. 2008; Ritenbaugh, et al. 2008). Recruitment at both sites was done via community outreach and newspaper advertisements.

One hundred sixty-nine participants were enrolled in the overall trial; approximately half of them participated in qualitative interviews. Since we could not interview every participant, we created a 50% sample by inviting every second consenting participant to the qualitative interview component. Multiple interviews were completed over the course of each participant's experience with TCM because it is well known that ideas of illness, evaluation of experience, and other factors of interest change over time as participants adapt their understandings to new experiences (Hunt, et al. 1989; Young 1982).

Study participants were between 18 and 70 years, rated worst facial pain  $\geq 5$  on a 0-10 scale, had TMD diagnosis confirmed by standardized clinical exam [<http://www.rdc-tmdinternational.org/>] performed by trained dentists, and had one of 10 pre-specified Chinese medicine diagnoses. For baseline characteristics of this sample, see Table 1. The proportion of female participants reflects the proportion in the general population by most estimates (Dworkin 2011). TMD is the third most prevalent chronic pain condition and estimates of lifetime prevalence in the overall population range from 10 to 25 percent (Dworkin 2011; Glass, et al. 1993). By design, most participants eventually received TCM treatment, which included up to 20 treatments over one year. Qualitative participation consisted of up to five interviews planned to occur at key transitions and follow-ups, tailored to the various study trajectories. Ultimately, 44

participants completed at least three of the qualitative interviews and were included in this sample. The University of Arizona Human Subjects Protection Program and the Oregon College for Oriental Medicine Institutional Review Board approved all procedures, and all participants gave informed consent.

<b>Table 1. Baseline characteristics of TCM for TMD longitudinal qualitative sample (N=44)</b>		
<b>Age and gender</b>		<b>Mean (SD)</b>
Age in years		43.25 (13.35)
		<b>Percent</b>
Female gender		75
<b>Ethnic Categories</b>		
Hispanic or Latino		22.7
Not Hispanic or Latino		72.7
Unknown (individuals not reporting ethnicity)		4.5
<b>Racial Categories</b>		
White		77.3
Non-white		13.6
Unknown or not reported		9.1
<b>Education</b>	At least some High School	13.6
	Some College	34.1
	College	29.5
	Post Graduate	22.7
<b>Baseline pain characteristics</b>		<b>Mean (SD)</b>
Worst facial pain [0-10]		7.19 (1.68)
Average facial pain [0-10]		5.48 (2.13)
		<b>Percent</b>
How long ago did your facial pain begin?	<5 years	34.09
	5-10 years	29.55
	>10 years	36.36
<b>Other characteristics</b>		

Prior use of TCM for any other conditions	Never	40.91
	Once	11.36
	2-3 times	4.55
	4 or more times	34.09

*Data Collection:*

Baseline interviews were designed to cover 14 broad themes targeted at understanding participants' experiences and views as they entered the study and at specific points during and after treatment. The results presented in this paper are based on analysis of participant responses to open-ended questions surrounding expectations and hope. These questions were:

Baseline Interviews:

- 1) *What do you hope to get out of participating in this study? OR What would you consider to be a benefit from participating in this study?*
- 2) *What are your expectations for this study? About the self-care arm? Herbs? Acupuncture?*

Follow-Up Interviews:

- 1) *Did you experience "ups and downs" during the treatment? Times when you felt more or less relief? More or less hopeful?*
- 2) *Do you plan to continue this treatment after the study has ended? Why or why not? (Get at management strategy or cure)*
- 3) *Has the treatment you received matched your expectations? What were your expectations?*
  - a. *If not, how do you feel about going through all the study activities and feeling little change? Has it changed the way you feel about your pain?*

All interviews in Tucson were conducted by ERE, and interviews in Portland were completed by interviewers trained by MN. Regular conference calls were held to maintain consistency in approach and to solve problems as they arose.

*Data Analysis and Interpretation:*

Interviews were transcribed verbatim and coded by ERE using ATLAS.ti (<http://www.atlasti.com/index.html>). A draft coding scheme was created based on initial impressions from conducting and transcribing interviews and informed by relevant literature. The coding scheme was then revised as needed to include additional themes emergent from participant interviews. Regular meetings were held among ERE, MN, and CR to discuss coding and maintain consistency across transcripts. The analysis presented here focuses on statements related to expectations and hope, primarily drawn from responses to the questions above. After completing initial coding, we did additional sub-coding and matrix analyses. After considerable analysis, we selected a “modes of hoping” theoretical framework to assist us in explaining the themes that that emerged in participant narratives.

Participant quotations presented in the results are identified with a participant number and interview number (of five interviews) as follows:

I try not to have any expectations because I’m really not sure what to expect.  
(041, Interview 5)

Or in cases showing multiple quotes from a single participant, numbers precede text:

(029, Interview 2): My expectation is, if it doesn’t make it worse, I’m just looking forward to the experience...I don’t really necessarily have an expectation that it’s going to make it better.

## MAIN RESULTS & DISCUSSION

### *Expectations*

Many participants were reluctant to articulate expectations at baseline. Having expectations was perceived as a state in opposition to “remaining open to any outcome” and to being a willing research participant.

I’m really interested and want to try it, I mean um, I don’t have any particular expectations, I guess I’m, I’m not, not expecting any miracle outcomes but I’m open to whatever happens. (034, Interview 1)

I’m open to all of it. I mean I, I mean sure there’s part of me that says I want it all, I want to try it all, I want everything... You know, at some level. But yeah, I don’t have like, some crazy expectations I don’t think. (033, Interview 1)

Um, just from what I’ve been told in the research. I really don’t have any expectations. I’m just sort of going into this with, okay, let’s, let’s try it. Very open, very open minded. (012, Interview 1)

### *Shifting Stories of Expectations and Hope*

Originally, our goal was to report on baseline expectations and how they changed as the study progressed. However, during our analyses of participants’ reported expectations, we found that they nearly always talked about hope. We also found a lack of agreement between what participants told us they expected during the baseline interviews and what they described as having expected at baseline when reflecting back in later interviews.

The intertwining of these conflicting statements with references to hope led to our interest in hope, and to our analysis of multiple modes of hoping and their role in influencing narratives about expectations (Averill and Sundararajan 2005).

Often, participants who told us prior to treatment that they had no expectations about outcomes later told us of their disappointment with the treatment outcomes despite reporting to us that they received some pain relief.

(029, Interview 2): My expectation is, if it doesn't make it worse, I'm just looking forward to the experience...I don't really necessarily have an expectation that it's going to make it better.

(029, Interview 5): I mean my initial expectation was, I'm going to be cured. Right? So that was my thinking. I'm going to be cured. And then when I realized that that was not going to be the reality, then I didn't really have any expectations anymore.

(022, Interview 1): Having already tried a few things on my own and, and not saying that they've had like stellar results, I guess the cynic in me would say, I have hopes but I don't have expectations...(laughs) um, I guess my expectation is that I'm going to learn something new. And that's as high as I would rate it.

(022, Interview 5): I had some subtle expectations about the study that yeah, finally it'll be the thing that makes it all better...I don't think that's ever true for anything, and I'm just, and I know that on a deep level but you always still want it to be the thing that will make it wonderful...And I, and I think that's why we get out of bed in the morning. Because we still have hope.

Conversely, some who said they expected to be cured expressed pleased surprise at the level of pain relief they felt, albeit far from a complete cure.

(017, Interview 1): I hope [TMD is curable]. Sure. (laughs) If I didn't I wouldn't be here. *[ERE: And what do you hope to get out of participating in this study, or what would you consider to be a benefit?]* P: Pain-free...For sure. Some sort of pain management, long term, that I can take with me and use in the future.

(017, Interview 4): [The study treatment] reached [my expectations] and went above what I thought it would. I expected to go in there and get some minor relief and that be it...I was really impressed how much I benefited from the study.

While the longitudinal nature of such shifts is significant, conflicting stances on hope can often be seen in a single interview.

(030, Interview 4): I think it's made me realize um, that nothing's going to make these things go away... and I think that's fairly hard for me to deal with. And it's just the way it is, so like there's not a quick fix to things.

(030, Interview 4): I feel like the acupuncture's helping in ways beginning with me, you know, just going there, and when things were hard, having someone work on me... and then it felt better. I think that made me feel like I could just really hold onto that. It felt better and so I guess that made me feel really hopeful.

Originally, we wanted to relate these qualitative narratives to quantitative data on outcomes. However, we found that the complexity of participants' statements about their hopes and expectations precluded a simplistic comparison between these two disparate types of data. We then realized that these statements about expectations and hopes in the particular context of participants experiencing a novel alternative treatment as part of a research study had the potential to offer a much more nuanced understanding of hope and of how participants were reporting their expectations. Given the complexity of these narrative data, we chose to focus entirely on the qualitative data.

### *Modes of Hoping*

Lawrence Kirmayer (2006) suggests that healing involves not only "basic bodily processes of balancing, homeostatic regulation, and repair, but it is equally a matter of making sense of suffering and finding a way to continue" (599). In what follows, we outline five modes of hoping that were observed empirically in our data (Table 2) and discuss how they allowed participants in our study to maintain hope in the face of chronic pain. These modes of hoping are not intended to characterize all possible forms of hope, but rather to describe the modes of hoping that we observed among participants in this study and to show the existence of multiple modes of hope, which are likely to vary by context.

<b>Table 2. Modes of Hoping emerging from participant narratives in this study</b>	
Realistic Hope	<ul style="list-style-type: none"> <li>▪ Hope that would be considered reasonable or probable based on current medical knowledge</li> <li>▪ Would not be considered a “hope” by those who characterize hope as an emotion that does not include rationality<sup>2,15,26</sup></li> </ul>
Utopian Hope	<ul style="list-style-type: none"> <li>▪ Collectively oriented hope that group action can lead to a better future</li> <li>▪ Expressed here as hope that participation in a research study would contribute to greater overall knowledge of the condition</li> </ul>
Wishful Hope	<ul style="list-style-type: none"> <li>▪ Very high hopes that are currently within realm of possibility</li> <li>▪ Active form of hope, working to remain hopeful</li> </ul>
Technoscience Hope	<ul style="list-style-type: none"> <li>▪ Hope for unforeseeable scientific medical breakthroughs</li> </ul>
Transcendent Hope	<ul style="list-style-type: none"> <li>▪ General hopefulness, not directed to specific outcome or goal, may be related to religious faith</li> <li>▪ Hope that things will turn out well in the end, refusing to make any conditions on the future or to imagine a particular future</li> </ul>

### Realistic Hope

Realistic hope includes any hope that would be considered reasonable or probable based on current medical knowledge. This mode of hoping draws from several scholars conceptions of a realistic or probabilistic mode of hoping, primarily from Webb’s “estimative hope” (described as evidence-based hope) (Webb 2007), Lohne & Severinsson’s “small hope” (described as possible hope) (Lohne and Severinsson 2004), and Wiles et al.’s “hope-as-expectation” (described as the high end of a continuum of probability of a desired outcome) (Wiles, et al. 2008).

Realistic hopes expressed in our baseline interviews included statements about hoping for a small reduction in pain, a decreased need for versus a need for less pain medication, for finding new tools to manage pain, or for learning something new.

I'm hoping that I learn techniques to help, so that when I'm not in the study, I can keep doing them, I'm hoping. So that's what I hope. I hope that I can find some relief. (015, Interview 1)

[I hope] that maybe it will, not even necessarily get rid of it, but just help lessen it, just another tool or another, something else that will help lessen it a little bit more. (039, Interview 1)

### Utopian Hope

Utopian hope, as defined by Webb (2007), is hope that is collectively oriented, a hope that group action can lead to a better future. In the context of our study this hope appeared mostly in pragmatic statements about hoping that participation in a research study would contribute to overall knowledge about TMD and help others in the future.

That's why I'm here, mostly, is that you guys are trying to find answers. I feel that you are honestly looking to find out what might help. Which I think is wonderful because this is under the radar...you know I'm walkin' for diabetes and AIDS and I'm out there walking ten miles for any charity, but I never heard of TMD until I had it. You know? So I trust you guys, because you're doing research. Because you're honestly trying to find some answers. [*hope-utopian*] (005, Interview 1)

Optimally I hope to get, certainly, some relief of my pain. [*hope-realistic*] That would be great. But that's not why I'm participating in the study. I'm participating in the study because it's a scientific study to find out more about this disorder. So if there can be some treatment or cure for this, that's just wonderful. If not, that's not really why I'm here. What I would like to get out of it is to see you folks get something out of it. U of A College of Medicine and National Institutes of Health can maybe further along the science one little increment at a time. [*hope-utopian*] (015, Interview 1)

[I hope to] help you help somebody in the future. That's basically why I signed up. [*Hope-utopian*] (021, Interview 1)

### Wishful Hope

Wishful hope includes very high but possible hopes, anchored in the current world. This mode of hope is related to Wile's et al.'s "hope as a wish, want or desire" (described as conceptually distinct from "hope as an expectation") (Wiles, et al. 2008) and Lohne and Severinsson's "big hope" (described as possible hope, but higher than "small hope") (Lohne and Severinsson 2004). While scholars such as Marcel (1962) and Pruyser (Pruyser 1963; 1986) distinguish hope from wishing, Averill and Sundararajan (2005) argue that wishing is an important dimension of hope and Lynch (1962) characterizes the ability to wish as being "well on the way toward hope" (24).

We include wishful hope as a mode of hoping because participants admit that they hope for particular outcomes they think are unrealistic. Wishful hope, or the ability to imagine a better future, is particularly important in chronic pain, wherein sufferers often struggle with the ability to imagine life without pain (Jackson 2011). Wishful hope among participants in our study is expressed in statements such as hope for a cure, or related to hearsay about miraculous outcomes experienced by others.

In our participants' statements, wishful hopes were often paired with admissions that they are unrealistic, or of statements about one's realistic hope. They were also often couched in statements about hope being necessary for continuing to seek treatment and to cope with pain on a day-to-day basis.

I hope it's curable. It would be nice if everything was. [*hope-wishful*] You know? So if I have to manage it then I'll just manage it. [*hope-realistic*] Just like

anything else, any kind of real mental discomfort. (pause) I don't know what it's like not to have pain. (009, Interview 1)

I hope so [that TMD is curable].*[hope-wishful]* Sure. (laughs) If I didn't I wouldn't be here. *[ERE:And what do you hope to get out of participating in this study, or what would you consider to be a benefit?]* P: Pain-free... For sure. *[hope-wishful]* Some sort of pain management, long term, that I can take with me and use in the future. *[hope-realistic]* (017, Interview 1)

I really do [believe it could be cured]. *[hope-wishful]* 'Cause I think um, well if I didn't believe that it'd be a lot harder to try to deal with it...I also feel like, oh acupuncture has the magic ideas (giggles) you know, like there's some magic that's going to happen if I go get acupuncture. (032, Interview 1)

### Technoscience Hope

Technoscience hope, which relates to a faith in science, emerged from our participant narratives. This form of hope is based on faith in the inevitability of scientific or medical breakthroughs. We were struck by how many participants voiced hopes that were similar to wishful hopes, but that were dependent on unforeseen potential sources of treatment or cure. For Lynch, hope is “an arduous search for a future good of some kind that is realistically possible but not yet visible” (Lynch 1962). According to Scioli (2007) hope is profoundly related to faith, and faith is what sustains hope. Faith, however, need not be based in religion to sustain hope (Scioli 2007). In this case, we consider faith in science or medicine a mode of hoping, or perhaps as a way of sustaining hope, particularly when the lack of available treatment leaves few avenues for hope (Pruyser 1986).

The way, if, if medicine is changing at a fraction of the rate that computers are changing, we're gonna know so much about the human body in the upcoming ten, fifteen years, it's gonna be incredible. And I'm banking on that. *[hope-technoscience]* (042, Interview 4)

I was hoping some kind of maybe medication, or new combination of shark fin, or octopus hide, had some real massive rapid effect on cartilage formation or bone

healing or something like that will come along. Other than that, I don't know how to fix a broken joint. [*hope-technoscience*] (005, Interview 5)

There exist plenty of stories of “miraculous” cures from unexpected sources that allow patients room to retain hope for anything they want (Leung, et al. 2009). For these participants, technoscience hope was a way to remain hopeful regardless of whether one could realistically hope for relief from pain.

Because there's so much out there that we don't know, that can help...we can make our bodies healthy and new again. It's just a matter of finding what works...our cells you know, rebuild them, ourselves. So, who knows? You know? There's gotta be an answer out there somewhere we just haven't found it...you know I believe that with certain things that, the pain will go away, you know? [*hope-technoscience*] (009, Interview 1)

### Transcendent Hope

Merriam-Webster defines “transcendent” as a) “exceeding usual limits: surpassing”; b) “extending or lying beyond the limits of ordinary experience”; or c) in Kantian philosophy: being beyond the limits of all possible experience and knowledge (Merriam-Webster). As it relates to this study, transcendent hope is characterized as a general hopefulness that is not tied to a specific outcome or goal. In this mode of hoping, participants express a general attitude of hopefulness, but refuse to imagine or define the future they hope for. This mode of hoping is most aligned with Marcel's (1962) concept of hope, which is characterized by openness to the future. For Marcel, hope is not connected to any imagined future or goal (Barnard 1995; Marcel 1962; Webb 2007). Our concept of transcendent hope is inspired by Webb's “Patient Hope” (“directed toward an objective which defies any attempt to map it”; “a hope that everything will work out well in the end”) (Webb 2007) and Corbett et al.'s “generalized hope” (as opposed to

“particularized hope,” “generalized hope” is not directed toward a specific outcome) (Corbett, et al. 2007; Leung, et al. 2009). Hope that is drawn from religious faith includes transcendent hope and is often equated with being positive and hopeful for something better in the future (Averill and Sundararajan 2005; Sulmasy, et al. 2010).

Participant statements about finding more hope or feeling less hopeful reference this general feeling of hopefulness.

I’m still hopeful. *[hope-transcendent]* I mean I still, it’s something I reflect on. I can’t believe that I continue to have hope, you know, just that thing of, yeah sometimes you’re like, oh really? And then next day, oh yeah...you know (laughs) but I do. (033, Interview 5)

I mean I know. I’m asking for the moon here...It’s like, you know, there’s definitely hope. That’s what I’m looking for, a little hope that there’s something out there for me. *[hope-transcendent]* (040, Interview 1)

It’s a bright light, actually. You know? Knowing that there’s something out there that actually works. *[hope-transcendent]* The, by working at, you know walking in a dark tunnel for so long and you never see any light, you never think you will. But when you do (laughs) it’s the best thing ever! (013, Interview 5)

### *Implications of Modes of Hoping for CAM Research*

Hope, expectations, and patient-reported outcomes are contingent on individual experiences of treatment. We observed that the ability to remain hopeful for the future, regardless of whether participants felt they had experienced benefit, significantly impacted narrative evaluations of the treatment as well as willingness to continue with management strategies and other recommendations. The availability of multiple modes of hoping allowed participants to report a continued feeling of hopefulness even while also reporting decreases in hope.

The following quotes from a single post-treatment interview provide a clear example of multiple modes of hoping, as one mode of hope can be elevated while another is diminished. First, the participant describes feeling more in control of pain. Whereas before there were no options, now it is a choice not to seek treatment; simply knowing that the treatment is available becomes a source of hope (realistic) for management.

It's a choice I'm making not to get treatment as opposed to not being able to do anything about it. I know that I could go for acupuncture and it would help, as long as I continued to go, you know, as I said, two or three times a week. But finances and hours at work preclude that. (025, Interview 5)

On the other hand, this avenue for management of pain is not the long-term pain relief hoped for, and his more lofty hopes (transcendent, wishful) have lessened.

[TCM] was helping when I was doing it. When I stopped getting the acupuncture there were no long-term effects. It was only really helping the pain level come down when I went three times a week, or maybe twice a week. But when the study, that part of the study ended and I stopped going it didn't help—and, well I was hoping for long-term benefit but that didn't happen. (025, Interview 5)

In contrast to hopes related to changes in pain or function, the participant below describes the outcome of treatment as having impacted the hope itself, making the pain easier to bear. As we have stressed, hope is essential to living a meaningful life in the face of pain. The participant quoted below points to the idea that hopelessness, in and of itself, can be painful, perhaps more so than the physical pain.

The pain that I was feeling before this acupuncture started was complete suffering and fear. And as I started working through the layers of that, like an onion, I started realizing, and being able to pinpoint what has affected that, what caused it, and how to move forward. And that's through the advice of the acupuncturist... And so through the layers of moving through, and specifically, the pain before the acupuncture was completely different. *It was more deep-seated hopelessness.* [emphasis added] Whereas now it was just a physical—it was like bruising your knee. Just like healing a physical thing that you can actually see. (027, Interview 4)

## CONCLUSION

We presented five modes of hoping that appeared in narratives of participants living with TMD who received a CAM treatment: realistic hope, wishful hope, technoscience hope, utopian hope, and transcendent hope. Most of these modes of hoping have been previously observed in studies of other medical conditions (e.g., IBS (Kaptchuk, et al. 2009); low back pain (Corbett, et al. 2007); cancer (DelVecchio Good, et al. 1990); HIV/AIDS (Kylma 2005)) as well as in philosophical and cross-cultural reviews of hope (Averill and Sundararajan 2005; Webb 2007). We suspect that additional or different modes of hoping might be salient in other cultures and emerge in response to different illness scenarios.

Analysis of our longitudinal interviews revealed the limitations of assessing expectations at a single point in time, an issue also noted by Sherman et al. (2010). We further found that even at a single point in time, participants' expectations of treatment are multi-faceted and intricately bound both to multiple modes of hoping and to coping with pain. Moreover, Young (1982) has astutely observed that individuals' statements about their illness and treatment experience are often assemblages of different kinds of knowledge ranging from the subjective to the negotiated. Forms of knowledge and ways of framing experience are produced in context and continuously respond to contingencies as well as to the feedback of others. We would argue that forms of hope are experienced and co-produced in a similar manner.

Multiple interviews with study participants over the course of nine to twelve months revealed that participants continually updated their hopes and expectations based on new illness and pain related experiences. Significantly, multiple modes of hoping

enabled participants to incorporate and process new experiences and information in a manner that at once opened up possibilities for pain relief yet guarded against despair if such relief was not forthcoming.

In this paper, we have argued that expectations and hopes are usefully viewed as linked, yet distinct concepts. As such, what may appear to be a simple case of inaccurate recall between pre- and post-treatment may instead represent the interplay of multiple layers of hope, rationality, meaning, and culturally ascribed rules about what is appropriate to hope for.

Expectancy and sociocultural “meaning” are two major factors that have been proposed to explain the placebo effect (Thompson, et al. 2009). Placebo theorists have focused extensively on expectancy as well as on the meaning that individuals ascribe to their illness. However, they have paid relatively little attention to how hope mediates expectancy per se. Some of our study participants counterbalanced remaining hopeful with keeping their hope in check when it came to a novel treatment. They were willing to try one more thing in the hopes that eventually something might work for them, or somehow assist others, but they did not *expect* the treatment to work. Indeed, some were surprised when the treatment actually made them feel better, and in such cases hope preceded positive expectations.

Researchers need to take stock of how different types and combinations of hope affect expectancy and in so doing influence the magnitude of the placebo effect. They should also consider how multiple modes of hoping are interwoven in pain or illness narratives as a means of helping people cope not only with the present but also with the

future. To lose the possibility of any future relief from chronic pain may undermine individuals' abilities to create and maintain hope in the face of chronic pain or illness.

Csordas (1988) has suggested, and we concur, that “little understanding will result if research is directed toward definitive therapeutic outcome, rather than toward the ambiguities and partial successes (and failures) embedded in therapeutic process” (137). One of our goals in writing this paper has been to call attention to the ambiguities that arise in patients' narratives about treatment expectations and their hopes for pain relief, and to provide a framework for meaningful analysis of these ambiguities. Analyses of the roles played by coexisting modes of hoping in the lives of the afflicted are essential to the development of a more refined understanding of the placebo effect as a core element of all healing. In this clinical trial of TCM for TMD, hope emerged in study participants' discourses far more commonly than any reference to what they expected. Substituting hope for expectancy would have misrepresented the complexity of participants' experiences, and presenting hope as monolithic would have missed the range of thoughts and feelings they were attempting to convey at different points in time. How one hopes matters, as do transformations in hoping.

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## **APPENDIX C: Ways of Hoping: Navigating the paradox of hope and despair in chronic pain**

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### **ABSTRACT**

In this paper, we explore hope in the context of living with chronic pain. Individuals with chronic pain from temporomandibular disorder(s) (TMD) were interviewed four to five times over the course of their 18-month participation in a clinical trial investigating the effectiveness of Traditional Chinese Medicine. We sought to understand shifts in participants' descriptions of expectations and hopefulness, particularly with regard to the work involved in counterbalancing positive thinking with buffers against disappointment. We found hope to be a dynamic and multifaceted mindset as distinct from being a single entity to be measured. Drawing upon Polanyi's concept of tacit knowing, we explore how different *ways of hoping* emerge and index one another in participant narratives. We offer a working typology of hope and raise as an issue the manner in which the paradox of hope—hoping enough to carry on while keeping hopes in check to avoid the ever-present possibility of despair—complicates simplistic notions of the relationship between positive thinking and the placebo response.

### **KEYWORDS**

Hope, Chronic pain, Tacit knowing, Placebo

### **INTRODUCTION**

“Without differentiation of its subtypes, the term hope can become reified as a biological entity or a magical pill, an entity presumed to have direct causal relations to health and disease.” (Averill and Sundararajan 2005)

Over the course of conducting a clinical trial testing the effectiveness of Traditional Chinese Medicine for Temporomandibular Disorders (TMD), we were struck by the different ways participants spoke about hope. Multiple waves of interviews with 44 participants over the eighteen-month duration of their participation in the five-year study revealed that participants maintained several distinct, and often coexisting concepts of hope, and that the prominence of particular concepts shifted over time. Our aims in this paper are: first, to call attention to the paradoxical nature of hope—hoping enough to carry on while keeping hopes in check to avoid the ever-present possibility of despair—when contemplating new treatment; second, to identify different ways hope is thought about and experienced by those contemplating new treatment for chronic pain; and third, to consider the work of hope in light of this paradox and to call attention to the importance of this coping process in considerations of the placebo effect.

Placebo, latin for “I shall please” historically referred to an inert substance given to appease a patient, or to give them hope, in the absence of other treatment options (Moerman 2002). Spontaneous healing in response to an inert substance is called the “placebo effect” in an individual and its average across a group is referred to as the “placebo response” (Thompson et al. 2009). Despite being poorly understood, placebos serve as the baseline against which other treatments are measured—the “control” in a randomized controlled trial—because patients given placebos often improve as a result (Thompson et al. 2009; Myers 2010; Craffert 2012). Placebo responses are catalyzed by and pertain to a broad range of human experience, from changes in the meaning an individual ascribes to their illness (Kaptchuk, et al., 2009; Kirmayer, 2006; Moerman, 2002; Tambiah, 1977) to evolutionarily patterned and deeply embodied responses to

conditioned action (such as the taking of a pill)(Thompson et al. 2009; Hahn & Kleinman 1983; Kirmayer 2011). Although the placebo effect is often narrowly attributed to positive expectancy, it is far more complex and multidimensional (Kirmayer, 2011) and participants in healing rituals cannot be characterized as uniformly positive (Kaptchuck et al. 2011). Moreover, while participants in healing rituals and participants undergoing novel treatments often report being generally hopeful, they are also realistic and aware of the possibility that the ritual or therapy may not “work” (Stone, et al., 2005; Kaptchuck et al. 2011). The paradoxical nature of hoping enough to continue with treatment seeking and daily living, yet not hoping so much as to risk despair when yet another treatment fails, complicates already tentative understandings of the placebo effect as individuals simultaneously describe being both hopeful and hopeless.

*What is hope and why does it matter?*

In the context of chronic pain or illness, hope has been characterized in multiple ways: as a process of making meaning (Antelius, 2007; Corbett, et al., 2007); as an existential state (Kaptchuk, et al., 2009); as a posture toward the world (Barnard, 1995); as a practice involving significant work (Mattingly, 2010); and importantly, as inherently paradoxical (Barnard, 1995; Chesla, 2005; Mattingly, 2010). Although hope has rarely been considered in discussions of the relationship between expectancy and the placebo response, we find hope to be central to expectations, meaning-making, and assessment of new experience over time and as individual treatment narratives unfold.

Hope is fundamental to human existence. It is paradoxical in its duality, however, as its very existence implies the possibility of despair (Lynch, 1962). This dialectic

between hope and despair is central to considerations of chronic illness management, as well as to studies of the relationship between expectations and the placebo effect (Corbett, et al., 2007; Ratcliffe, 2011). Hope influences expectation, but is a distinctive multifaceted cognitive, embodied, and broadly existential experience (Mattingly, 2010). In order to maintain hope when faced with a situation that appears hopeless, individuals must navigate multiple contradictions between reality and possibility, embrace cultural notions of what is deemed acceptable to hope for, and be attentive to the hopes and concerns of significant others (Averill and Sundararajan, 2005; Chesla, 2005; DelVecchio Good, et al., 1990; Sulmasy, et al., 2010; Brown, 2015).

The observation that negative information about an illness may dash hope and increase suffering has long been recognized as an ethical problem leading medical educators to ask when a clinician should dispassionately inform a patient about hard “evidence-based” facts of their case, and when they should consult with family members to determine whether unfiltered information is likely to demoralize the patient, compromise their quality of life and negatively affect their prognosis (de Pentheny O’Kelly, et al., 2011; Oliffe, et al., 2007; Pergert and Lützén, 2012) as well as minimize the placebo effect (Caspi and Hølexa, 2005).<sup>9</sup>

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<sup>9</sup> Contemporary evidence-based medical culture in the U.S. intensely values truth-telling, full disclosure of prognosis, realism and adherence to “the facts” (Caspi and Hølexa, 2005; Oliffe et al. 2007; Pergert and Lützén 2012; DelVecchio Good et al. 1990). This has not always been the case. Indeed, it runs counter to the values espoused by clinicians in U.S. medical culture in the not too distant past (DelVecchio Good et al. 1990), where greater credence was paid to both the psychosocial state of the afflicted, and the wishes of family members responsible for a patients’ therapy management who may desire to provide a more peaceful and positive treatment environment where hope is sustained (Kagawa-Singer and Blackhall, 2001; Kodish and Post, 1995). The issue of disclosure and the weighing of autonomy versus non-maleficence is a particularly sensitive in end

Hope is deeply personal and difficult to describe (Barnard, 1995; Marcel, 1962). At the same time, hope is collectively produced, culturally interpreted, and linked to broader social and economic processes (Clarke, 2003; DelVecchio Good, et al., 1990; Novas, 2006). Biomedical research institutions, pharmaceutical companies, and patient organizations are involved in a “political economy of hope” (DelVecchio Good, et al., 1990; Novas, 2006; Rose and Novas, 2005) wherein hope is both generative of and generated by market interests, research directions, and the possibility of breakthroughs in medical treatment (Novas, 2006; Rose and Novas, 2005; Sulmasy, et al., 2010). Thus, hope itself is a source of biovalue for each of these stakeholders. For the afflicted and their families, hopefulness is a quality expected of good citizens (Novas, 2006; Rose and Novas, 2005; Sulmasy, et al., 2010) much like the “achieved status” of good health (Nichter and Thompson, 2006). Hope scales—metrics for measuring hope—produce “modes of self-management and codes of affective decorum” (Brown 2015:121).

Marcel (1962) described hope as a “mystery” and argued that rationalizing or placing it into categories flattened or distorted our understanding of it. Like Marcel, Polanyi observed that, “Every time we concentrate our attention on the particulars of a comprehensive entity, our sense of its coherent existence is temporarily weakened; and every time we move in the opposite direction towards a fuller awareness of the whole, the particulars then become submerged in the whole” (Polanyi, 1969:460). Drawing upon Polanyi we approach multiple ways of hoping as forms of tacit knowledge. Hope is something that we know “subsidiarily in terms of something else” (Polanyi, 1962:600).

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of life issues or in cultures where dashing the hopes of chronically and terminally ill individuals is considered immoral (de Pentheny O’Kelly, et al. 2011; Gongal, et al. 2006; Harris, et al. 2003).

While this observation would appear, at first blush, to run counter to the task of categorizing multiple forms of hope, Polanyi also recognized that “every dismemberment of a whole adds more to its understanding than is lost through the concurrent weakening of its comprehensive features” (Polanyi 1969:460). We concur and proceed with our categorization of ways of hoping acknowledging our limited ability to describe hope as a complex human state of think/feel (Wikan, 1990). We proceed by first calling attention to hope and the existential paradox posed by chronic disease, identify types of hope that emerge in treatment narratives, and address how different types of hope alone and in combination are drawn upon in what we describe as the “work of hope”. We draw attention to the feedback loop between hope and the experience of novel medical treatments, more specifically how hope influences the experience of the treatments one receives, and how the experience of treatment in turn influences hope.

### *The Existential Paradox of Chronic Illness*

Barnard (1995) described an “existential paradox of living with chronic illness” wherein people living with chronic illness live on a boundary between hope and despair, finitude and transcendence. To hope, Barnard explains, “means to project oneself beyond one’s present definition of reality, but with no guarantees against disappointment” (48). On the other hand, despair can be a defense against the risk of disappointment inherent in allowing oneself to hope (Barnard 1995).

Chesla (2005) further develops Barnard’s concept of the paradox of hope by making clear what the paradox is not.

“Dialectic relations between hope and despair, necessity and possibility, have been called the existential paradox of chronic illness (Barnard, 1995). Living the

paradox means that those with chronic illness simultaneously confront their limitations and losses at the same time that they lean toward possibility, hope, and new openings. In trying to understand this paradox, it may be helpful to see its multiple oppositions, what this paradox is not. One opposite is surrender to one's limitations and losses, what Kleinman (1988) calls *demoralization*, without the balancing thread of hope. Or, another opposite is hopefulness that denies the limitations and losses that are a part of chronic illness, what some would call *delusion*." (Chesla 2005:373).

Mattingly (2010) similarly describes hope in existential terms as a "practice" as well as a paradox. Mattingly explains, "Paradoxically, hope is on intimate terms with despair. It asks for more than life promises. It is poised for despair." (2010:3). In the context of chronic illness, hope "emerges as a paradoxical temporal practice and as a strenuous moral project" (3). Mattingly's informants describe hope as a moral call, bound up with what it means to be a "good person". For the families in her study, "hope has represented a stance toward reality that requires careful cultivation" (Mattingly, 2010:4).

Among chronic pain sufferers offered new treatment, the paradox boils down to the struggle to simultaneously maintain hopes high enough to embrace (or at least not to undermine) any potential effects of the treatment, while at the same time avoiding hoping for too much and risking disappointment if not despair (Barnard, 1995; Mattingly, 2010). We will argue that it is through employing multiple *Ways of Hoping* that individuals actively navigate this paradox, and attempt to live up to culturally valued notions about sustaining hopefulness, while also being "realistic" (Averill and Sundararajan, 2005; DelVecchio Good, et al., 1990; Sulmasy, et al., 2010).

In the 1990s several medical anthropologists collected illness narratives from individuals with TMD attending residential pain clinics, pain treatment centers, and chronic illness support groups. One of their observations was that when treatments failed,

a sense of hopelessness emerged associated with the omnipresent existence of the ailment and its unpredictability (Garro, 1992; Good, 1992). In what follows, we provide examples of ways our trial participants avoided hopelessness by engaging multiple ways of hoping. We describe the ways of hoping in terms of cognitive experience, spiritual experience, and embodied experience. These distinctions are by no means intended to draw strict boundaries between cognitive and embodied experience or among ways of hoping. They are merely intended to show hope in its multiple forms and multiple levels to illustrate hope as a complex and sometimes arduous experience. We draw from literature on multiple ways of knowing (Aickin, 2010; Geurts, 2002; Polanyi, 1962; Polanyi, 1969; VanMannen, 1977; Yorks and Kasl, 2006) to gain a clearer understanding of the elusive concept of hope and how it impacts and is impacted by evaluations of new information and experiences.<sup>10</sup>

## RESEARCH CONTEXT

### *Participants*

The semi-structured, open-ended interviews on which this analysis is based were conducted as part of a dual-site (Tucson AZ, Portland OR) randomized phase 2 trial of Traditional Chinese Medicine (TCM) for Temporomandibular Disorder (TMD) (For the full description of the overall study and sample characteristics, see Ritenbaugh, et al. (2012)). Recruitment was through community outreach and newspaper advertisements that described a study evaluating TCM for jaw and facial pain.

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<sup>10</sup> It is beyond the scope of this paper to map ways of hoping onto ways of knowing. We draw from this framework as a useful way to explore the range of cognitive to embodied experience subsumed under the term hope.

One hundred sixty-nine participants were enrolled in the trial. Of those enrolled, approximately every second participant (about half the sample) was approached prior to initial randomization and asked to complete a series of semi-structured, open-ended interviews over the course of their treatment. To adequately represent men's voices in our sample, men were over-sampled in the qualitative study due to low overall enrollment in the study. Although not all participants completed all follow-up interviews, no participants declined to participate in a pre-treatment qualitative interview. Participants were between 18 and 70 years, rated worst facial pain  $\geq 5$  on a 0-10 scale, had TMD diagnosis confirmed by standardized clinical exam [<http://www.rdc-tmdinternational.org/>] performed by trained dentists, and had one of 10 pre-specified Chinese medicine diagnoses. By design, most participants ultimately entered the TCM treatment arm. Once in the TCM arm, participants could receive up to 20 treatments over one year. Qualitative sub-study participation consisted of a series of up to five interviews planned to occur: 1) prior to beginning any study activities; 2) prior to beginning TCM treatment; 3) after two to three months of experience in treatment; 4) at the end of treatment; and 5) two to three months after treatment was completed. Ultimately, 44 participants completed at least three of the follow-up interviews and were included in this sample (See Table 1 for detailed interview numbers). All procedures were approved by the University of Arizona Committee for the Protection of Human Subjects, and the Oregon College of Oriental Medicine Institutional Review Board, and all individuals participated under informed consent.

*Data Collection:*

Baseline interviews were designed to cover 14 broad themes targeted at understanding participants' experiences and views as they entered the study, and at specific points during and after treatment. The results presented in this paper are based primarily on participant responses to open-ended questions surrounding expectations and hope.

The following questions specifically elicited information about expectations and hope.

Baseline Interviews:

- 3) *What do you hope to get out of participating in this study? OR What would you consider to be a benefit from participating in this study?*
- 4) *What are your expectations for this study? About the self-care arm? Herbs? Acupuncture?*

Follow-Up Interviews:

- 4) *Did you experience "ups and downs" during the treatment? Times when you felt more or less relief? More or less hopeful?*
- 5) *Do you plan to continue this treatment after the study has ended? Why or why not? (Get at management strategy or cure)*
- 6) *Has the treatment you received matched your expectations? What were your expectations?*
  - a. *If not, how do you feel about going through all the study activities and feeling little change? Has it changed the way you feel about your pain?*

All interviews in Tucson were conducted by the first author, and interviews in Portland were completed by two interviewers trained by MN. Regular conference calls were held to maintain consistency in approach and solve problems as they arose.

*Data Analysis and Interpretation:*

Interviews were transcribed verbatim and were analyzed using a phenomenological approach attentive to the interview context, the subjective and shifting nature of individual experience, and the possibility of multiple voices or conflicting selves arising in interviews (Tanggaard, 2009). Initial interview transcripts were hand-coded and considered by the authors for emergent themes. These themes were then compared with relevant literature to create a codebook for coding in ATLAS.ti (Muhr, 2011). Attempting to map initial expectations onto later expectations and “outcomes” or participants satisfaction, we explored the possibility of trajectories in hopes or expectations, or relationships between high or low levels of hope with satisfaction. In these iterations of analysis, which included a secondary re-coding of statements broadly related to hopes or expectations for more intricate themes, the present focus on multiple ways of hoping emerged.

We were attentive to multivocality as well as performative aspects of our informant’s illness narratives (Goffman, 1959; Labov, 2013; Strauss, 1997; Tanggaard, 2009). It was commonplace to encounter different “voices” representing various aspects of informants’ lives and stances toward their illness in the same interview. Although we asked informants about their expectations and hopes from therapy at baseline and in later interviews, these questions were located at the end of interview guides and were not a central point of questioning. The centrality of statements indexing different ways of thinking about hope emerged unsolicited in discussions of many areas of life.

#### *REFLECTIONS ON HOPE AND EXPECTATIONS OVER TIME*

Initially, we sought to explore participants' expectations prior to trying TCM and, through longitudinal analysis, to determine whether initial expectations impacted the way they experienced treatment. We found, however, that expectations could not be disentangled from hopes in participants' descriptions. Further, "hope" worked to moderate expectations, often in unexpected ways. Over the course of the study we recorded shifting narratives as participants assessed whether their expectations had been met and whether they felt "more hopeful" or "less hopeful" after participating in a novel alternative treatment. These narratives were often multivoiced with participants neither presenting themselves as more or less hopeful; they were both at the same time.

Intuitively, we expected to find participants who were surprised by positive treatment outcomes reporting increased hope, and those who were not happy with treatment reporting less. We found no such pattern, however, and were faced with a conundrum of how to make sense of varied response and expressions of surprise or disappointment that seemed unrelated to either initial expectations or the reported "outcome" of TCM treatment in terms of pain relief. Further, as has been reported in other studies of expectations, participants were often forthcoming with expressing hopes, but reluctant to voice expectations (Eaves, et al., 2014b; Kaptchuk, et al., 2009; Stone, et al., 2005). Helen, below, explained that her expectations were low but she had hopes before starting treatment.

Having already tried a few things on my own and, and not saying that they've had like stellar results, I guess the cynic in me would say, I have hopes but I don't have expectations... (laughs) um, I guess my expectation is that I'm going to learn something new. And that's as high as I would rate it. (Helen, 57, Interview 1)

After treatment, Helen reflected on her initial hopes, explaining that there is always some hope “on a deep level” that a new treatment will be “the thing that makes it all better”.

I had some subtle expectations about the study that yeah, finally it'll be the thing that makes it all better... I don't think that's ever true for anything, and I'm just, and I know that on a deep level but you always still want it to be the thing that will make it wonderful... And I, and I think that's why we get out of bed in the morning. Because we still have hope. (Helen, 57, Interview 5)

Notably, the changes described by participants like Helen not only index changes in expectations over time, but also changes in the framing of one's assessment of initial expectations in light of new experience. In part, this reassessment and exercise of reflexivity may have been prompted by our interviews, but it is our sense that many respondents experienced shifts in expectation that effected and were moderated by the way they experienced hope.

#### WAYS OF HOPING ON MULTIPLE LEVELS OF EXPERIENCE

What follows is a typology of ways of hoping gleaned from participant narratives. After identifying these distinct ways of experiencing hope we will turn to a consideration of how different ways of hoping were used concurrently in the “work of hoping”. Our intent is not to provide an exhaustive list of ways of hoping, but to draw attention to the co-occurrence of ways of hoping as a means to address what may appear to be discontinuities in explanations of hope, but turn out to be part of a complex coping process.

Multiple ways of hoping are key features in the work of both *being* hopeful—a balancing act required for daily coping and seeking treatment—and *appearing* to be hopeful—living up to the often conflicting expectations of significant others and cultural

ideals (see also Eaves et al. 2014 for a preliminary typology). For heuristic purposes, we have divided hope into overarching categories. First, hope is considered in terms of cognitive experience or ways of hoping that participants are intellectually engaged with. Second, we describe hope as an embodied experience, sometimes more deeply felt than intellectually considered. Third, we consider hope as it intertwines with experiences of faith. The categorization is not intended to distinguish between cognitive, embodied, or faith-centered experience, but rather, to emphasize that hope is practiced at many levels of experience.

#### *HOPE AS A COGNITIVE EXPERIENCE*

##### *Realistic Hope (or practical hope)*

Realistic hope includes any hope that is for a reasonable or probable outcome in terms of normal or expected outcomes on the part of the broader medical community (cf. (Lohne and Severinsson, 2004; Webb, 2007; Wiles, et al., 2008)). In this sense, hoping for a small reduction in pain is a reasonable, or realistic hope. In most cases, participants considered “reasonable” whatever they would not be hesitant to disclose to their health care practitioners.<sup>11</sup>

Being realistic is a way of hoping that allows individuals to live up to cultural ideals of realism and adherence to evidence while still maintaining openness toward the possibility of positive change.

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<sup>11</sup> This mode of hoping is comparable to Webb’s (2007) “estimative hope” (described as evidence-based hope), Lohne and Severinsson’s (2004) “small hope” (described as possible hope), and Wiles et al.’s (2008) “hope-as-expectation” (described as the high end of a continuum of probability of a desired outcome).

For myself, I really hope to um, lessen the pain, but get, get better tools of dealing with it, physically, um, and you know, just uh, more able I guess to um, reduce my own stress. You know, or- or know what would help more. You know, whether that's, you know, an herbal thing or, you know, a physical thing, um, and you know, it's certainly not like I'm going to be depressed if there's no change or whatever, but I- you know, I'm hopeful that there is going to be, and that, I'm going to get better at dealing with it. (Sarah, 42, Interview 1)

### *Utopian Hope*

Webb (2007) describes utopian hope as collectively oriented, a hope that group action can lead to a better future. This way of hoping is outwardly focused and does not require individuals to factor their own prognosis or practical considerations into their hope. In our study this hope appeared as a pragmatic hope that being part of research will help others in the future by contributing to overall knowledge about TMD. This type of altruism is often found in study participants (McCann, et al., 2010).

I'm really excited about the study happening. I'm excited about it for myself and I'm excited that it's being done because I feel like it's important that things like [research studies] start being- you know, I hate that it has to be proved to those people that don't believe in it. But then it can start being, becoming more available for people that have health insurance that never normally would cover something alternative or these ideas, and just the more they're being talked about the more people will believe in them. You know, more and get helped. (Kyra, 30, Interview 1)

### *Wishful Hope*

Wishful hope includes hopes that are very high and not necessarily “realistic” (hope for cure, stories of miracle outcome experienced by others, very high hopes) (cf. (Lohne and Severinsson, 2004; Wiles, et al., 2008). Wishful hopes were rarely expressed in participants' narratives without simultaneous descriptions of realistic hope. Participants further avoided appearing unrealistic by explaining that hope is necessary for continuing to seek treatment and to cope with pain on a day-to-day basis.

I really do [believe it could be cured]. 'Cause I think um, well if I didn't believe that it, it'd be a lot harder to try to deal with it... I also feel like, oh acupuncture

has the magic ideas (giggles) you know, like there's some magic that's going to happen if I go get acupuncture. (Jessica, 30, Interview 1)<sup>12</sup>

Positive “illusions” have been described as a way to maintain hope in the face of dire circumstances (Barnard, 1995; Taylor, 1983; Taylor and Brown, 1988). Wishful hope as a way of hoping may allow individuals to develop, nurture, and ultimately be restored by illusions (Taylor, 1983) while adapting to the contingencies of daily living by adjusting other hopes.

### *Transcendent Hope (Or existential hope)*

Transcendent hope encompasses three types of hope described by other social scientists. The first is Webb’s characterization of “Patient Hope”, which is “directed toward an objective which defies any attempt to map it”; “a hope that everything will work out well in the end” (Webb, 2007:69). Webb draws from Marcel (1962), who argues that hope is open-ended and does not make conditions on the future. Transcendent hope also encompasses “generalized hope” (Corbett, et al., 2007; Leung, et al., 2009) and “universal hope” (Hammer, et al., 2009). Like “generalized hope”, Transcendent hope is not directed toward a specific outcome. In this case, it may not be concerned with the pain itself, but rather on the possibility of a good life in general. When hope that is connected with time and object is threatened, hope for general good provides a defense against despair or “giving up”.

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<sup>12</sup> We chose to include wishful hope due to its resemblance to widespread usage of the term hope in studies of expectation (Lynch, 1962; Leung 2009). Hope is often described as similar to expectations, but a wish or want, rather than a realistic projection. Among our participants, this form of hope was not widespread and was represented clearly in only a few participant statements. The relative absence of this form of hope supports the need for a more nuanced understanding of the experience of hope in chronic pain and illness.

As it relates to our participants, transcendent hope describes a stance of general hopefulness not tied to a specific outcome or goal. This way of hoping is expressed as a general attitude of hopefulness, but refusal to imagine or define the future.

[I'm looking for] Answers, um, not, you know, if not a cure today, I recognize that this is research. So I'm looking for tools to help me either manage it, or make it go away. And I know I'm n- I'm asking for a lot. But if I'm able to find tools to help me manage it, or help it subside to such a degree that it's not such a part of my life. So, I mean I know. I'm asking for the moon here... It's like, you know, there's definitely hope. That's what I'm looking for, a little hope that there's something out there for me. (Eleanor, 42, Interview 1)

Conversely, the absence of transcendent hope may be experienced as deeply felt hopelessness. Whereas a lack of hope for a specific outcome may not impact participants' overall outlook, a lack of hope for any good in the future is more difficult to overcome. Lisa's statement below articulates that such hopelessness, in and of itself, can be painful, perhaps more so than the physical pain.

The pain that I was feeling before this acupuncture started, was complete suffering and fear. And as I started working through the layers of that, like an onion, I started realizing, and being able to pinpoint what has affected that, what caused it, and how to move forward. And that's through the advice of the acupuncturist... And so through the layers of moving through, and, and specifically, the pain before the acupuncture was completely different. *It was more deep-seated hopelessness.* [emphasis added] Whereas now it was just a physical- it was like bruising your knee. Just like healing a physical thing that you can actually see. (Lisa, 30, Interview 4)

## *HOPE AS AN EXPERIENCE OF FAITH*

### *Hope as Religious Faith:*

Faith is closely aligned with hope both cognitively and emotionally. In the Christian tradition, "faith is the substance of things hoped for" (Hebrews 11:1, as cited in Sulmasy, et al., 2010). To hope is equated with having faith (Sulmasy, et al., 2010). In Judaism

hope and faith are linked and among believers, to lose faith is equivalent to giving up or turning one's back on God (despair) (Lamm, 1995).

Religious-based faith is one important way for individuals to find hope, and may be particularly important for those who lack other ways of finding hope through work or family support (Hall, 1994). Among our study participants, religious faith was a way of taking care of oneself, a way of being uplifted, and a way to feel as though one is part of something larger and “not alone”.

I go to church. I am a believer in Christ. I can take care of myself spiritually I, you know, knowing that I have salvation through God, you know, in God. I, that uplifts me, in that I have salvation for eternity. (Larry, 52, Interview 1)

As Amalia explains below, faith is part of working with the mind and soul, often overlooked in considerations of pain's physical impact. Finding hope, in this case, is not explicitly mentioned. Amalia does explain, however, that through spiritual practice she has found peace and feels she can “handle anything”. We consider this feeling of peace of way of being hopeful in daily experience.

I went to this little chapel and started taking classes in spiritual healing... I went to the chapel, every Sunday and learned how to work with the mind and the spirit and just, the soul. So that's what brought me the happiness, so that stays with me, a very important part of my life, that I stay connected to the source. Which some people call God, and other call it all kinds of different names... and I notice that, it works, it really works. ... It brings you a lot of peace. It makes you feel like, you know, you can handle anything, because you're not alone. (Amalia, 63, Interview 1)

#### *Hope as Faith in Bioscience or Biomedicine:*

Faith as a way of hoping is not limited to religious faith. Sulmasy et al. (2010) found that faith was a common theme in participants' narratives about hope in living with cancer. Among their participants, however, faith in science and medicine was more

common than religious-based faith. We found a similar trend among participants, although often expressed in terms of loss of faith or difficulty keeping faith in medical science.

It's kind of hard after 20 years to have any faith that [pain] can really be made to go away. But, there's, there's a part of me that feels like we're gonna be able to do something with the pain that allows us to take chronic conditions and, at least, change how they're, they're perceived and felt. I think we're gonna make major breakthroughs in pain control in the next few years because there're so damn many of us baby-boomers hurting. And there's more and more women doctors looking at things. And there's more and more of us that have been affected by these things, who are in the medical industry. So, I believe there're a number of factors that are gonna lead to good breakthroughs. And, I want to think they'll be in my functional lifetime. (Evelyn, 47, Interview 1)

Amalia compared her faith in doctors' ability to heal to faith in God. In seeking alternative treatment, however, she admits that this faith has waned.

I was kind of trusting [of doctors]. That they know what they're doing you know. So that was, I was very much trust of doctors. Whatever they say, you know, was it. Because, (short pause) I don't know, because they were the doctors, you know how that goes. They're almost like god (laughs) to us, to a lot of us you know. If they can make you feel better. (Amalia, 63, Interview 1)

Faith in bioscience and biomedicine is not necessarily based on current knowledge or technology. Individuals living with illness for which there is little possibility of cure often put their faith in technological or scientific breakthroughs (Brekke and Sirnes, 2011).

The way, if, if medicine is changing at a fraction of the rate that computers are changing, we're gonna know so much about the human body in the upcoming ten, fifteen years, it's gonna be incredible. And I'm banking on that. (Taylor, 53, Interview 4)

Among participants in this study, we noted comments directed toward faith in alternative medical paradigms. Unlike cancer or other high-profile (and high market potential) terminal illnesses, chronic pain is positioned in the medical establishment as an elusive, intractable, and troubling illness category, sometimes even characterized as

lacking a biophysical component (Crowley-Matoka and True, 2012; Good, et al., 1992; Jackson, 2005; Jackson, 2011). While some study participants continued to hope for medical breakthroughs, many had long since given up on biomedical treatments. Some of these participants were now turning toward alternative medical paradigms rather than religion as a way to regain or maintain hope.

I really believe in Chinese medicine. I've used it all over the world for many years. I've gone to Chinese medicine doctors, and I know that they are— but it's a much more precise kind of medicine practice and descriptive, sorry, prescriptive. In other words, the herbs are always combined for exactly what the person needs. So I had a kind of faith in them. (Louise, 53, Interview 4)

### *HOPE AS EMBODIED EXPERIENCE*

Faith in Hope Itself: faith in the body's ability to heal

Many researchers have discussed a pervasive cultural belief in the power of hope, positive thinking, or individual *will* to change the course of illness (Cassel, 1982; Clarke, 2003; DelVecchio Good, et al., 1990; Herth, 1992; Scheper-Hughes and Lock, 1987; Sulmasy, et al., 2010). This *faith in hope* is often intertwined with deeply felt personal convictions that the body has the ability to heal itself.

Because there's so much out there that we don't know, that can help... because we can make our bodies healthy and new again. It's just a matter of finding what works. Because our cells you know, rebuild them- ourselves... we shouldn't *be* old because our cells renew our, every, I forgot how often it happens... the whole body, all the cells renew themselves every certain time. And they say if we're able to rebuild our cells like that, then there's no reason for us to grow old. She said the reason we grow old is because we're programmed to, that we're gonna grow old. We're programmed to grow old and die, so that's why she says we grow old and die, but not if you tell yourself, you are young, you'll stay young. So, who knows? You know? There's gotta be an answer out there somewhere we just haven't found it. So that's why I'm always willing to learn about new things. And I believe in it, you know I believe that with certain things that, the pain will go away, you know? (Amalia, 61, Interview 1)

Such a conviction is strengthened by individuals' awareness of the existence of the widely reported yet little understood placebo response (Kaptchuk, et al., 2009; Moerman, 2002). Media coverage of the placebo effect, spontaneous healing, and the power of positive thinking engenders hope in the lives of individuals living with pain and chronic illness. Brian, for example, explains a belief in the power of positive thinking as capable of curing even the most "mysterious diseases".

I think anything's curable... I mean, yeah, people have cancer and there's just no way you know? Which is like cancer's one of the biggest things that we don't understand, or you know it's one of the most mysterious diseases, it's huge. I mean it kills millions and millions of people a year and it's like, some people will just have it and then it just goes away, for some reason, and maybe it's mental you know? I mean, someone decides they don't want it and, or maybe they actively changed it, their lifestyles and that, maybe that affects it too. (Brian, 28, Interview 1)

The way people intuitively grasp what they perceive through bodily sensation and imagination is complex (Yorks and Kasl, 2006). Sensing, or "bodily ways of gathering information in the world" are basic to the way we perceive and experience the world (Geurts, 2002). Ratcliffe (2011) argues that in cases of loss of hope or hopelessness, there is a hope that remains. This visceral sense of hope, in his view, is neither an intentional state nor a non-intentional bodily feeling, but rather is a 'pre-intentional' orientation or 'existential feeling'. Faith in the body's ability to heal can counterbalance despair that one's body has somehow let them down, and feed hope that a treatment may be out there that can trigger the body's natural healing capacity. Some participants who had turned to CAM treatments held out this possibility.

People really want to believe in the myth of the permanently fit body. You know, instead of the temporarily able body that we actually have... But my housemate got sick one time with something that her MD doctors couldn't identify and she went to a holistic practitioner who gave her some drops in bottles and I swear to god three days later she was up out of bed. And she had been sick for a month and

a half. So, I kind of had a fantasy that maybe I would go drink this dirt and a week later I'd be back at work or something (Taylor, 53, Interview 3)

## THE WORK OF HOPE IN THE CONTEXT OF CHRONIC PAIN

Maintaining hoping when one is experiencing chronic pain not only requires sufferers to be vigilant against impending despair, but also against biographical disruption that may ensue when pain undermines one's sense of self and identity (Bury, 1982; Eaves, et al., 2014a). We turn to a consideration of some of the many works of hope engaged in by those experiencing chronic pain including management of the paradox of hope and the work of *appearing* hopeful in the presence of significant others regardless of what one feels at any given moment.

### *The Work of Having Hope*

Having expectations, whether high or low, was considered a source of vulnerability. High expectations made one vulnerable to disappointment if those expectations were not met. On the other hand, having low expectations was regarded as negatively impacting the outcome of treatment. Dennis, below, explicitly refers to multiple sides of himself—a “hopeful side” and a “cynical side”—which allow him to remain open despite his acknowledgement of the paradoxical nature of hope.

My cynical side or my hopeful side? Um, (pause) I'm trying to remain, honestly I'm trying to remain open. I'm trying not to have expectations. I'm trying to let the interaction do whatever it's supposed to do. Um, if I expect that it's, I'm going to be cured and it's not, I'll be unhappy. And if I expect that nothing will happen, and I go into it thinking that nothing's going to happen, nothing probably will happen. So I'm trying to remain pretty open to whatever, you know, whatever comes along. (Dennis, 32, Interview 1)

Chesla (2005), describes “small moments of suffering” in daily life with chronic illness that can lead to either hope or despair. Individuals living with chronic pain work to maintain a “safe” space between the vulnerability of overly-inflated hopes and the

vulnerability of loss of hope. Beth explains in the following statement that she feels safe from the vulnerability of having high hopes by remaining somewhat pessimistic. In this sense, pessimism is a protective strategy, avoiding the much more daunting possibility of despair.

I guess there are, I just have days where I feel like completely pessimistic about everything. Um, and taking those into account it's hard for me to say, yes I have a lot of hope for the future... I think that's one of the ways that I keep myself down. You know? Keep myself in this very small place. Um, and for some reason, that's where I feel safe. You know? So, if I'm down on myself then, then I'm staying *in my place*. You know? Um, and I don't want to stay in that place anymore, but stepping out of it, too, feels *really* scary. (Beth, 30, Interview 4)

In life with chronic pain or illness, finding hope is part of appropriately working toward mastery over one's condition (Rose and Novas, 2005).<sup>13</sup> Individuals living with chronic pain must therefore work to live up to the expectation of being hopeful while avoiding hope that denies the everyday reality of living with chronic pain (Chesla, 2005).

### *The Work of Describing Hope*

In interviews, participants worked to convey their hopes for treatment while taking care not to appear unrealistic or uninformed. They avoided statements they felt could jeopardize the possibility of benefit from the TCM treatment, but also kept their enthusiasm in check. Humor was a common way for participants to express high hopes while avoiding vulnerability. Subtle uses of humor often index more serious underlying ideas or emotions (Bletzer, et al., 2011; Crowley-Matoka and True, 2012). In Angelica's

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<sup>13</sup> In contemporary Western culture, hope has become a moral imperative (Rose and Novas, 2005). Ignorance, resignation, and hopelessness in the face of the future are deprecated. In cases where there is little hope for resolution in a realistic sense, individuals are encouraged to pin their hopes on the promise of new technology and medical advances (Brekke and Sirnes, 2011).

statement below, she laughs at herself as she admits that the possibility offered by a novel treatment allows some hope to surface.

I'm really, I ha- I guess I, kind of have higher expectations on the Chinese medicine side, just, just from common knowledge of what everybody know, they're healthy people (chuckles). You know, for the most part, and ac- that everybody swears acupuncture does wonders so, I guess I have a little higher expectations on that, that side of it. But I really, honestly don't know what to expect from it. Just, I can only hope that it does what I would like it to do, and ideally teach me to manage it with the least amount of medications, that's my best explanation. (Angelica, 37, Interview 1)

A chuckle or laugh following a statement of very high hopes allows the participant to appear as though they are not seriously harboring such hopes, which are often called “false hope” and discouraged by nurses and other caregivers (Crites and Kodish, 2013; Simpson, 2004; Brown, 2015).

I was just hopeful to the end, you know? Hoping a miracle would happen. Even [a TMD specialist] was telling me, you know, there's no cure [chuckling]. I hope someday there will be a cure. Just for like all diseases we hope there will be cure for cancer, all our problems. (Lin, 71, Interview 5)

Chronic pain sufferers in this study were, for the most part, aware that there is no cure for their condition. Catering to the hopes and expectations of significant others, like describing hope to medical practitioners or researchers, requires a delicate balancing act. On one hand, sufferers are expected to continue to seek treatment and to display appropriate desire to become well, despite the difficulty they experience in trying to live a “sick role” (Glenton, 2003). On the other hand, sufferers are expected to be realistic, to live in spite of pain, and to avoid burdening others or becoming a drain on family resources.

## WORKING THROUGH THE PARADOX OF HOPING IN EVERYDAY PAIN

In daily life as well as in broader experience, our informants faced the continuous experience of pain. Hope, in this context, presents a paradox and requires constant and

onerous work. Some modicum of hope is necessary for carrying on with daily living (Cassel, 1982; Good and Good, 1991; Kaptchuk, et al., 2009; Kylma, 2005). At the same time, hope represents a daunting source of vulnerability (Ratcliffe, 2011; Simpson, 2004). Those living with chronic TMD pain work to keep their hopes at a level resistant to being dashed from either side (hopes too high present the risk of disappointment, whereas hopes too low make it difficult to cope in daily living). Much research on hope has focused on individuals facing death or coming to grips with terminal illness who grapple with a similar paradox (e.g. Barnard, 1995; Chesla, 2005). Similar to Mattingly's (2010) informants, our study participants were keenly aware of this paradox and of the need to manage hope. Here are two examples:

I don't really have any expectations. If something goes well I'll be delighted. Um, I still hold back on, basically I feel like I've got a structural issue, so any of these things, you know, might be able to provide me relief, but it's not going to fix the real problem. So, um, for me it was just like if I can get some relief, that would be great and I- but I didn't want to, you know, I don't have any expectations that I'll get tremendous relief cause then if I don't I don't want to be disappointed. (Stephanie, 36, Interview 1)

It doesn't seem like after all this amount of time that it could be cured. But I'm hopeful. But I'm not, I mean it's, yeah a miracle can happen but, um, I'm hopeful. That's why I'm here. If I thought there was nothing else to do, I wouldn't try anything so. (Evelyn, 47, Interview 1)

As Good and Good (1991) point out, maintaining a sense of hope often requires thinking about an illness “in the subjunctive (what if) mode.” Some semblance of possibility must be maintained in order for participants to continue to seek treatment (Good and Good, 1991; Kaptchuk, et al., 2009; Kaptchuk, 2011; Kirmayer, 2006).

I kind of, it's one of those things that I want it to be curable so even if somebody says it's not I'm kind of like looking long term, yeah, I think it's curable. It's one of those things, you gotta think it's curable because nobody wants to live without hope you know what I mean? Even if it's not, tell me that it is anyway. Make me think it's curable. (John, 33, Interview 1)

*Implications of Ways of Hoping for the Placebo Effect*

Hope itself has been referred to as a “magical pill” able to produce an effect similar to that of the placebo (Averill and Sundararajan, 2005). Engendering hope is central to arguments concerning the role of the therapeutic relationship in enhancing the placebo effect (Moerman and Jonas, 2002). Health care providers are thus expected not only to treat illness, but to assist patients in cultivating reasonable or appropriate hopes (Corbett, et al., 2007; DelVecchio Good, et al., 1990; Sulmasy, et al., 2010) while at the same time informing them of prognosis and the risks and benefits of treatment options (de Pentheny O’Kelly, et al., 2011; Oliffe, et al., 2007; Pergert and Lützén, 2012).<sup>14</sup> The afflicted are faced with the paradox of needing to remain hopeful enough to maximize their chances of positive outcome from a new treatment yet not setting themselves up for despair by hoping for too much. This need to balance ways of hoping may well have an impact on the placebo effect at different points in a treatment trajectory as perceptions shift and life contexts change.

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<sup>14</sup> Hope presents a paradox for the afflicted and clinicians alike. For the afflicted, hope is needed, but too much hope risks disappointment to the point of despair. For the conventional medicine practitioner, “truth-telling” (and full disclosure of the facts, costs and benefits, etc.) is deemed the ethical thing to do by the standards of evidence-based medicine, which favors rational decision-making. Yet in practice clinicians often face an ethical dilemma when trying to balance truth with inspiring hope (de Pentheny O’Kelly, et al., 2011; Oliffe, et al., 2007; Pergert and Lützén, 2012). This dilemma will only grow with increasing evidence that hope is a powerful healing mechanism (Clarke, 2003; Herth, 1992; Nekolaichuk, et al., 1999; Snyder, et al., 1991) and ethical arguments identifying hope as an existential aspect of the individual that must be treated with respect and sensitivity (Kodish and Post, 1995). CAM practitioners appear to be particularly sensitive to the hope dilemma and to the impact of their words and actions on the patient’s healing response (Caspi and Hoxha, 2005; Schafer, et al., 2012). The paradox for clinicians is therefore to consider the patient’s right to be informed while at the same time to avoid undermining both the placebo response (the body’s natural ability to heal) and the emotional necessity of continuing to hope.

Unlike expectation, which typically describes rational, logical projections about what will occur, hope describes a range of cognitive, emotional, spiritual, meaning-centered, and embodied experiences. Whereas expectation may be amenable to bounding, to consideration in terms of a single experience, hope, in its many forms, requires that time horizons remain open (Good, 1994). As such, hope needs to be viewed in context and as a dynamic state of being. While some forms of hope may be elevated briefly given the possibility of a new treatment, other forms may compensate and counterbalance. Mattingly (2010) has rightly pointed out that finding or maintaining hope is a central feature in the lives of chronically ill patients and their families. Finding or maintaining hope relates not just to one's immediate experience and the demonstration of the effect of a treatment, but to one's life overall. Similar to the paradoxical (compensatory) response by the body, sometimes responding in the opposite direction to a conditioned stimulus (Thompson, Ritenbaugh, and Nichter 2009), hope may impact placebo responses in complex ways.

## CONCLUSION

The ability to imagine a better future or to remain open to alternate possibilities, even if it necessitates some reliance on illusion or imagination, is crucial to maintaining hope when one is experiencing chronic pain (Barnard, 1995; Chesla, 2005; Kirmayer, 2006; Taylor and Brown, 1988). At the same time, one must buffer against unrealistic expectations that can end in disappointment and further exacerbate pain. Barnard asks, "What happens when distorted views of reality *are* disproved by experience? If positive illusions are adaptive in the face of threat, what happens to one's adaptation when the

illusions that sustain it must yield to the ways things ‘really are?’” (Barnard 1995:44).

We would answer that multiple *ways of hoping* enable sufferers to adapt to contingencies and experiences such that they can continue to remain hopeful and open to the possibility of aid on the horizon.

Hope is significant in the lives of individuals with chronic pain or illness in multiple ways. Statements about hopes and expectations are performed to serve several purposes. Expressing high hopes or downplaying one’s hopes can reassure family members or significant others that one is maintaining an appropriate level of hopefulness (Chesla, 2005; Sulmasy, et al., 2010). In a culture in which hope and optimism are positively valued and expected, expressions of appropriate hopes may also express adherence to cultural expectations of hopefulness and striving for one’s best possible future (Adams, et al., 2009; DeVecchio Good, et al., 1990; Rose and Novas, 2005). Expressions of hopefulness may further serve as personal reminders of the importance of maintaining hope, remaining positive, and embracing the magical power of words (Tambiah, 1968). Hope is also associated with embodied ways of knowing, memories of past treatment experiences, and quite possibly with evolutionarily patterned responses to adverse circumstances (Hahn and Kleinman, 1983; Thompson, et al., 2009).

The phrase “ways of knowing” has been used to describe the acquisition and application of knowledge, understanding, and embodied experience (Aickin, 2010; Geurts, 2002; Polanyi, 1962; Polanyi, 1969; VanMannen, 1977; Yorks and Kasl, 2006). Ways of hoping similarly describes the work of reconciling practical knowledge, prior experience, and phenomenological perception in one’s experience. Geurts (2002) draws attention to a gap between cognitive models of perception and phenomenological levels

of sensation, existence, and bodily experience. Related to Polanyi's (1962) description of "things we know but cannot tell," Geurts (2002) cites Desjarlais' (1992) description of bodily knowing as "a lasting mood or disposition patterned within the working of the body" (Desjarlais 1992:150, as cited in Geurts 2002:5). While expectation is thought to be related to reason, hope is more often characterized as an emotion or feeling, albeit active and creative (Averill and Sundararajan, 2005; Lynch, 1962; Pruyser, 1986). In this paper we have argued that hope is a process of feelings, thoughts, and embodied dispositions that are looped and affect each other in context and in response to feedback. Hope is not a denial of reality, but is part of continuous re-evaluation of reality in light of other possibilities (Pruyser, 1963).

A concept such as hope is difficult for an individual to characterize at any point in time, particularly given that much of our understanding is built on things we cannot know objectively, but rather know as "lived reality" (Clarke, 2003). As Polanyi points out, "Every time we make sense of the world, we rely on our tacit knowledge of impacts that the world makes on our body and the responses of our body to these impacts" (Polanyi 1962:605). As such, ethnographic inquiry needs to be attentive to sensations associated with embodied memories, as well as to reasoning, if we are to better understand feelings of fear and vulnerability, or conversely, of well-being and protection (Nichter, 2008). Future ethnographic accounts of hope should consider sensorial, embodied, cognitive, and emotional aspects of hope, as well as cultural norms and expectations associated with religious or spiritual values, social and gender norms, and interpersonal dynamics associated with the management of strong emotions. We would re-iterate that division of hope into categories is not intended to imply that there are separate components when in

fact we are dealing with an integrated whole. We have used these categories as tools to explore multiple ways of hoping as a complex experience of tacit knowing and varied states of think/feel (Wikan, 1990). A greater appreciation of the work of hoping and the roles played by different ways of hoping in context will offer depth to our understanding of both the placebo effect and the process of coping with chronic pain and illness in everyday experience.

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**APPENDIX D: “Just Advil”: Harm reduction and identity construction in the consumption of Over-The-Counter medication for chronic pain**

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**ABSTRACT**

Direct-to-consumer marketing has sparked ongoing debate concerning whether ads empower consumers to be agents of their own care or shift greater control to the pharmaceutical industry. In particular, over-the-counter (OTC) medications are portrayed as simple solutions, enabling consumers to seek relief while also living up to the demands of social life. Rather than join the longstanding debate between consumer agency and social control, I consider how those living with chronic pain engage in avoiding stigma as best they can by self-medicating with over-the-counter (OTC) pain medications. Through analysis of interviews with pain sufferers themselves, as well as of OTC pain medication advertising, I discuss trade-offs between physical harm reduction and reducing potential harm to one’s identity in terms of harm justification as consumers work to describe their use as minimal, responsible, and justified by the severity of their pain. OTC medication advertising, while ostensibly ambiguous and targeting all forms of pain, effectively supports the self-projects of chronic pain sufferers, allowing them to reconcile conflicting demands for pain relief while being stoic and maintaining a positive moral identity. Describing medications as “just over-the-counter” or “not real pain medication” is ideological harm reduction, allowing participants to distinguish themselves from “those people who like taking pain medication.” Justifying one’s use of OTC medication as minimal and “normal,” regardless of actual intake, distances the

consumer from association with the addictive potential of prescription pain medications and aligns the pain sufferer with a culturally sanctioned identity as stoic bearer of pain.

#### KEYWORDS

Chronic pain; Pharmaceutical Advertising; Over-the-Counter Medication; Harm Reduction; Stigma

#### *Introduction*

*“Americans are constantly asking themselves if they are doing the right things in order to be the good people they want to be, and they answer those questions with reference to how they ‘choose’ to manage their drugs” (Dumit & Greenslit 2006:130).*

Medication consumption in the United States is part of individual and social identity construction and is involved in the performance of who we “really are” (Nichter and Thompson 2006; Baudrillard 1998; Rose 1998). Medications are socially embedded and carry meanings about those who choose to use them and those who choose not to (Cohen et al. 2001). Pills can likewise impact relationships with others and conceptions of oneself as an agent and as a moral individual (Vuckovic and Nichter 1997; Helman 1981). Decisions about which drugs to use and in which combinations, as well as positioning oneself “for” or “against” drugs in general are bound up with considerations of risk, moral identity, and control (Dumit and Greenslit 2006).

From an anthropological perspective, goods are consumed as visual and tangible means of communicating social values (Douglas and Isherwood 1979; Bourdieu 1984; McCracken 1990; Miller 1995). Not only consuming, but also the decision not to consume, are morally imbued actions through which consumers construct and contest notions of self and social relationships (Baudrillard 1998 [1970; McCracken 1990). Consumer demand is not produced by individual needs or whims, but rather, is part of a socially shared symbolic code (Douglas and Isherwood 1979; Appadurai 1988; Friedman

2007; Bourdieu 1984). Kirmayer (2002) has described the role of pharmaceutical advertising in promotion of a “global monoculture of happiness” (316) and in support of cultural expectations of maintaining a pain-free and productive self (c.f. Ecks 2005). Taking medications as a form of symbolic communication assists sufferers with achieving idealized selves and thus becomes part of fulfilling the social role of a good citizen (Ecks 2005). Advertisers, keenly aware of the symbolic communication involved in consumption, actively tailor messages to maximize symbolic appeal and align with and support the self-projects of their target audiences (Greenslit 2005; McCreanor et al. 2005; Wattanasuwan 2005). In contrast to the focus on self-diagnosis and advocacy for one’s treatment through medical practitioners in Rx advertising (Ebeling 2011; Applbaum 2009), over-the-counter (OTC) meds are marketed directly to consumers who may go out and buy them as they please.

Illnesses such as depression (Lakoff 2004; Applbaum 2006; Ihara 2012; Martin 2006a), Erectile Dysfunction (Asberg et al. 2009), and Pre-Menstrual Dysphoric Disorder (Smirnova 2012) are defined, promoted, and effectively “sold” by pharmaceutical companies (Martin 2006a; Healy 2006; Kirmayer 2002). Chronic pain, on the other hand, presents a unique context in which medicalization remains incomplete. Despite availability of opiates and analgesics, their medical necessity and legitimacy (and the legitimacy of those requesting them) is questioned by many physicians (Crowley-Matoka and True 2012). Unlike other pharmaceutical medications that can serve to legitimate illness (Helman 1981; Barksy 1983), pain medication often confers suspicion onto patients rather than legitimacy. Biomedical literature on pain medication has recently focused on a so-called “opioid epidemic” since regulations were relaxed in the late 1990s

(Franklin 2014; Turk et al. 2008; Manchikanti et al. 2012, 2014). Research is targeted at identifying those patients “at-risk” for developing “aberrant behaviors” such as drug abuse (Turk et al. 2008; Manchikanti et al. 2012, 2014; Sullivan 2010; Nuchols et al. 2014; Chou et al. 2015). The potential for addiction, a concern heightened by the existence of a street market for such medications, puts the use of opioids for any purpose into question as a legitimate or even moral act.

Whereas in other illness contexts “non-compliance” with prescriptions is considered a problem, those patients who refuse prescriptions for pain medication are congratulated for fulfilling cultural ideals of stoicism and toughness (Crowley-Matoka and True 2012; Hay 2010). As Goffman (1959) points out, consumption activities are deeply personal and those items not in line with one’s idealized self are often forgone or consumed in secret. Any person being prescribed opioids is immediately categorized a potential drug abuser but the daily experience of pain makes avoidance of pain medications altogether an unlikely solution (Rouse 2009). OTC medications, offering a means for consumption of medications while still performing one’s idealized self, therefore becomes an important means of maintaining identity for chronic pain sufferers

Vuckovic and Nichter (1997) describe conflicting views of medications as consumers see them as potentially harmful but at the same time expect “fast relief”. Martin (2006b) likewise finds that despite views of medications as harmful, consumers are often able to justify continued use. Harm reduction, according to Nichter (2003), refers to actions taken to minimize the harm associated with risky behaviors with which one continues to engage. Harm reduction involves expressions of agency as well as manipulation of one’s surroundings that lead to an enhanced sense of control. Using harm

reduction as a framework, I explore the advertising of OTC meds and how messages are re-interpreted by a specific group of consumers, those living with chronic pain. This is not an argument for consumer agency, as considerable research has shown the insidious gendered and racialized power involved in consumers' adaptations of pharmaceutical advertisements in their definitions of self (Applebaum 2009; Rose 1998; Ebeling 2011). Rather, this is an exploration of how those living with a particularly contested condition engage in self-medication and draw from or contest advertising messages in their attempts to live up to particular cultural ideals.

In what follows, I draw from interviews with individuals with chronic pain to consider their views regarding medication and their descriptions of decisions to use or avoid pain medication. The unanticipated emergence of OTC medications as a key aspect of participants' performance of self in the interview context is then considered in light of the advertising messages encountered by consumers. OTC medication advertising, while ostensibly ambiguous and targeting all forms of pain, effectively supports the self-projects of chronic pain sufferers and assists them in reconciling conflicting desires to relieve pain while at the same time maintaining a positive moral identity. Recognizing that descriptions of behavior are not necessarily aligned with actual behavior, participants' descriptions of medication use are explored not to determine actual intake, but in terms of the role of these medications in the construction of an idealized self-concept (Ecks 2005).

### **Research study participants and methods.**

TMD, colloquially called “TMJ,” is the third most common chronic pain disorder in the United States, impacting 10 to 25% of the general population, with higher rates reported for women than men (Dworkin 2011; Glass et al. 1993). The primary symptoms of TMD, including chronic pain affecting the face’s muscles and Temporomandibular joint (TMJ), negatively affect everyday activities, social relationships, and the emotional states of sufferers. TMD is frequently associated with depression and other health problems (Dworkin 2007; Slade et al. 2013).

I conducted semi-structured qualitative interviews between 2006 and 2011 as the qualitative component of a dual-site (Tucson AZ, Portland OR) randomized phase 2 trial. The trial offered up to 20 Traditional Chinese Medicine (TCM) visits over the course of one year to individuals with chronic pain from Temporomandibular Disorders (TMD).<sup>15</sup> Entrance criteria required that participants report average pain levels of 5 or higher on a 0 to 10 scale.<sup>16</sup> Approximately every other participant who entered the trial was asked to participate in a qualitative interview component consisting of a series of up to five interviews planned to occur: 1) prior to beginning any study activities; 2) prior to beginning TCM treatment; 3) after two to three months of experience in treatment; 4) at the end of treatment; and 5) two to three months after treatment was completed. Because of the small number of men in the study we asked all men who entered to participate in

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<sup>15</sup> Participants were between the ages of 18 and 70 years old and mostly Caucasian. Most held steady jobs and lived with families or significant others. For a more detailed description of the overall study and sample characteristics, see Ritenbaugh, et al. (2012). Participants for the study were recruited through community outreach and newspaper advertisements that described a study evaluating TCM for jaw and facial pain.

<sup>16</sup> The Likert pain scale used in this study asked participants to rate their pain on a scale of 0 to 10, where 0 is no pain and 10 is pain as bad as can be. The same scale is commonly used in pain assessment for treatment purposes.

qualitative interviews. Ninety-five people participated in baseline interviews. Of those, 44 participants completed at least three of the follow-up interviews in addition to the initial baseline interview (271 total interviews). All procedures were approved by the University of Arizona and Oregon College of Oriental Medicine institutional review boards and all participants provided informed consent.

Questions specifically addressing medication use were raised in both the qualitative and quantitative components of the study. Participant's responses to questions about specific drug use were part of quantitative data collection and are not considered here.<sup>17</sup> Qualitative interviews explored explanatory model (EM), illness history, treatment history, beliefs about illness and healing, family and social support, experience of stereotypes, expectations and hopes for treatment, and pain tolerance. Questions specific to medication use queried about how participants used medications, whether during or in anticipation of pain flares as well as other aspects of how and why participants chose to use or not use particular medications.

I completed all interviews in Tucson and many of the follow-up interviews with participants in Portland (via telephone). Two other interviewers conducted in-person interviews in Portland. I transcribed interviews verbatim with some assistance from another transcriber. Interviews were transcribed verbatim and coded using ATLAS.ti (Muhr 2011) with a single broadly defined code encompassing any mention of medication use. In an initial round of coding I used a single broad code for all statements regarding medication use. After initial in-depth coding of all transcripts, I re-coded

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<sup>17</sup> For more information about specific medication use in the overall study, see Elder et al. (2012).

medication related quotations in greater detail to identify important themes in medication use. OTC medication use was not a specific focus of the interview guide, but emerged from this second level of analysis as a theme of importance to participants, particularly in their descriptions of self in relation to medication use.

### **OTC medication advertising methods and analysis.**

In section two of the paper, I focus on the advertising taglines and imagery used by the three main OTC pain medication manufacturers. Advil, Tylenol, and Aleve are marketed for relief of general pain and were most commonly mentioned by brand name by participants. I searched online advertisements (ads), printed fliers and magazines for ads marketing each of the three drugs. Television commercials and company web pages (Advil.com, Tylenol.com, and Aleve.com) are also considered. I used marketing search engines such as Moat.com, Google Images, and YouTube in addition to print magazines, television and fliers to obtain a wide range of advertising taglines.<sup>18</sup>

I coded advertising taglines and imagery to identify key themes and common marketing strategies as well as to ascertain what messages our participants might be receiving about the implications of using OTC pain medication. Of particular interest in the ads were mentions of “normal,” getting back to normal, taking action, and other identity related terminology. Because of the power relations and self-mastery messages often contained in pharmaceutical advertising (Applebaum 2009, Ebeling 2011) and the identity and morality talk that was attached to descriptions of OTC medication use among

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<sup>18</sup> Although historical ads for these medications are also informative, only those used in the last 5 years are included in this analysis.

participants, I consider whether the messages they receive from advertising relate to explanations about use or avoidance of such medications.<sup>19</sup>

### **Chronic pain sufferers' descriptions of Over-the-counter medication use**

Although people with severe TMD pain are often prescribed narcotic pain medications, at study baseline, 1/3 of participants in the study ever used narcotics but only 10% were using them regularly. While many used over-the-counter analgesics, most chose not to use prescription medications at all or to use them sparingly, regardless of pain severity, and in spite of having been prescribed them (Elder et al. 2012; Eaves et al. In Press).

Informants cited several reasons for wanting to avoid all forms of pain medication, including (a) wanting to maintain awareness of pain to monitor symptoms and avoid further damage; (b) saving medication for when they really needed it; (c) perception of medications as being less effective if taken often; (d) concern that pain medications impair ability to function normally; and (e) concern about addiction, one more problem to add to their list. Knowing pain would return as soon as medication wore off led participants to regard pain medication as a poor coping strategy. The opportunity cost of temporary relief provided by prescription medications was simply too high. Participants chose instead to use OTC pain medications, even though they often expressed reluctance even to engage in those, to mitigate some of the opportunity costs while still gaining some level of relief.

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<sup>19</sup> Although related issues such as sleep and depression impact individuals with chronic pain, we excluded ads for? Or, questions about participants' use of? Medications not specifically intended for pain relief.

Not taking any pain medication on a regular basis was important for participants. Also important is that despite all the above reasons participants gave for *not* taking medication, when probed about OTC pain medications, participants often described consistent use. When asked directly whether they were taking pain medication, the majority of participants simply said “no.” When probed, however, it became clear the use of OTC medication had not been considered in their response. Although many participants were still reluctant to take them, participants clearly differentiated between OTC analgesics and pain meds.

*“I’m not one of those people who likes taking pain medication”*: constructing legitimate cultural identities, living up to cultural ideals

Participants described taking medication as something “other” people in pain enjoyed. The “other”—the pain medication user—enjoyed medication, lacked the high pain tolerance and ability to “just handle it”, and was unable to live up to cultural ideals of toughness and stoicism (Hay 2012; Eaves et al. In Press). The phrases “not one of those people” or “not that kind of person” were common in participants’ statements. For example, Dennis, a father of three who worked long hours in a traditionally male-dominated service profession, described being reluctant to take pain medication despite severe TMD pain. Taking pain medicine, he explained, was not part of his identity.

I’m concerned about an entire culture being addicted to, you know, Pfizer. So I have political reasons that I’m concerned with medicine but, on a personal level I’m, I’m not the kind of person that’s going to, I know this is the classic answer, but I’m not the kind of person to be addicted to pain medicine. (Dennis, 32)

Being “one of those people” who likes taking pain medications carries multiple levels of stigma. Participants are well aware of the stigma and negative feelings directed

toward people with chronic pain. They do not, however, categorize themselves as part of this group (Eaves et al. 2014).

The construction of a stigmatized other through which to define oneself as a "normal" and "stoic" person living in spite of pain was a central theme in these participant narratives about the use or decision not to use pain medication. Key to this construction was the stance that OTC medication was not "real" pain medication and therefore not harmful. Deanne, a 56-year-old woman who described living with intense pain and headaches associated with TMD, explained at first that she would not take medicine unless she was in a "life or death situation." She then explained that she did not consider OTC medication to be pain medication. When probed about the use of OTC medication, her admission that she "might have took one of those or two" sounds as though the act of taking medication is very rare. Note, however, that she does not clarify whether she means one or two a year or one or two a week. This ambiguity was common in participants' narratives when describing their use.

I don't take medication. I never take any medicine unless, you know, I really, it's like a kind of life or death kind of thing ... I take a lot of herbs... I never take pain medication.

I: Never? Okay. Even with the, stuff like Excedrin?

P: Codeine with Aspirin I think I might have took one of those or two, yeah, but that's not pain medication. I think it's an aspirin, I don't think of it as Excedrin for tension headache as being pain medication. (Deanne, 56)

As Deanne's explanation reiterates, Americans often view pharmaceutical medications with considerable ambiguity (Martin 2006b). Martin finds that although medications are viewed as potentially harmful, the harms are often overlooked to justify continued use. In this study, participants commonly described concerns about the harmfulness of prescription pain medications. Pain medications, particularly due to

blurred boundaries between licit and illicit use (Quintero and Nichter 2011), were described in terms of their potential harm not only to the body, but also to the identity of the individual. For example, Sarah, a woman whose profession demanded hard physical labor noted that she was frustrated by her inability to do work at the level she would like, described the “other” as “people that just get all stuck on painkillers.” Despite difficulty and stress about her work and severe pain, she chose to avoid the “horrible route” of taking pain medications.

And at this point, if I'm in pain, I'll take like an Aspirin or two. Um, but I don't, I you know it's like, if I start doing that I'm going to do it every day, and I don't want to do that. I'm not the kind of person who wants to take pain pills every freakin day. You know, I just, I'd rather um, get through it or find other ways... I'm not down with most pain killers is all I can say. They just don't, they don't really work for me enough to, for whatever offset I think they're causing... I already take a ton of pills I feel like. Just vitamins and, and herbal supplements and so, it'd have to be the right thing for me to want to take it regularly. But I'm, I'm open to, you know, I don't know. I just pict- I've seen people that just get all stuck on pain killers and that's just, a horrible route. So um, I think I just try to deal with it as best I can. (Sarah, 42)

As in other studies, participants often described prescription medications as potentially harmful (Nichter and Vuckovic 1994; Martin 2006b). On the other hand, the use of OTC medications was justified through descriptions of harmlessness and through the use of phrases such as “pretty mundane” and “not addictive”.

#### *Disordered temporality and the difficulty of assessing harm in the present*

Good (1994) argues that chronic pain leads to a shift in “the embodied experience of the lifeworld” (118). The world of the pain sufferer is thus “unmade” such that he or she can focus on little but the present, little outside of the pain itself. Among these participants, there was profound reluctance to speculate about the future, or how pain

might factor into one's assessment of it (Eaves et al. In Press; Eaves et al. 2014).

Assessing long-term harm presents an ongoing challenge in the context of such a constricted temporal state.

Multiple levels of decision-making involved with taking either prescription or OTC medication are complicated by the difficulty of assessing linear time in the context of pain (Good 1994; Garro 1994). Often participants described trying to ignore the pain and save medication for when they "really need it" as circumstances such as work or family obligation demand.

I worry that if I take pain medication too much it loses its effectiveness. And that might not be true but, that's from some people I've known and different experiences. I also tend to want to be able to, mind over matter sometimes, which isn't necessarily the best way to, but then, it's kind of like, for me taking Adv-Ibuprofen is a last resort kind of thing. Cause if I have general pain every day, why- why wouldn't I take it every day then, so I take it when I really need it I guess. (April, 28)

In contrast to literature reporting that medical practitioners serve as gatekeepers, attempting to withhold medications from patients who seek it, many participants described being given medications instead of the attention they desired. Buchbinder et al. (In Press) likewise report that pain sufferers are often reluctant to request pain medication from practitioners.

Chronic pain sufferers, particularly women, often report reluctance to talk about their pain for fear of being perceived as whiners or complainers (Werner, Isaksen, and Malterud 2004). There are strong prohibitions in U.S. culture against complaining or dampening the mood in social situations (Hilbert 1984). Participants in this study often expressed reluctance to talk about pain, not wanting to "burden" others with their problems or allow pain to interfere with social and family life (Eaves et al. 2014). Many

chose not to talk about pain even with their primary care physicians at all.<sup>20</sup> Many participants chose to manage their own medication intake in the form of OTC medications and avoid the risk of being labeled a “chronic pain patient” just to be offered prescription medications they didn’t want anyway.

I'm not sure what the recommended dose is anymore. I think it's probably two or something, and just today I took four. I'll take four of them at once. I'll take what I can take without them making me feel funny or something. I may make it through the day with just those four. And then if it's a normal day it's going to be four in the afternoon. [I: Have you ever had to take any more, sort of heavy-duty medication?] No. No. Yeah, that's one of the reasons I didn't want to tell the doctor is that they give you the heavy duty stuff and then it makes you feel funny. (Lloyd, 54)

At times when complaints were brought to medical practitioners, medication recommendations were often ignored or adapted to fit individual bodily understandings and past experience. How much medication to take depended on context, body size, and perceived severity or abnormality of pain. Cindy, offering an example of the centrality of medication decisions in identity construction, describes herself as a “3 Advil woman” at times of elevated pain.

I take what's on the bottle unless I've got a really bad headache, and then I'm a 3 Advil woman, instead of 2. (Cindy, 36 1\_01131)

Dose decisions were often adapted from, or justified by prior prescription recommendations as well as from practical experience (Dew et al. 2014). Sufferers described being aware of prescription doses of Ibuprofen and Acetaminophen and used that knowledge to justify exceeding recommended doses. On the other hand, Carol offers

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<sup>20</sup> TMD is a condition understood by the participants to be more within the purview of dentists than physicians, which could be one reason for not describing pain to primary care physicians.

an example of the many strategies sufferers used to convince themselves they were not taking too much medication.

[On a bad day] I'll take Advil Migraine, and I'll. I'll take, I take one at a time, hope, hoping that'll catch it but, usually I would take, you know, three by the end. [Later I will take more] If I haven't taken what I think is too much. Cause the migraine Advil say two a day and I know that you can take a little more than that, but I try not to cause then I'm in a cycle that I have to take a pill every three hours or something, and I don't want to do that. (Carol, 61)

Carol also points out a common concern when taking pain medications was about getting into a cycle or habit. Despite this, the present experience of pain often overshadowed such concerns, and participants reported taking OTC pain medications regularly. Byron Good (1994) asserts that everyday life goals are subverted by the presence of constant pain. The difficulty of mitigating future harm stemmed not from lack of knowledge about potential harms, but from the difficulty of dissociating oneself from the experience of pain in the present (Good 1994; Scarry 1985; Garro 1992; Jackson 1992, 1995), leading participants to report feeling at odds with themselves.

My predisposition is not to take medicine. So, I'm always at odds with myself in terms of, you know, just wanting it to go away and not wanting to take medicine. (Fran, 46)

Unlike patients in recovery from surgery or other sources of acute pain, chronic pain sufferers are faced with the decision of whether or not to take pain medication on a daily basis. In the context of chronic pain, every day presents the sufferer with the same decision: the pain or the potential harms of the medication?

A lot of times I just have to think about by what I want to do for that day (chuckles). How much I want to put up with, I mean the Aleve, the side effects of the Aleve or just the pain of the TMJ. (Gloria, 49)

Although side effects were often mentioned as Gloria does above, participants rarely explained what the side effects were. Because different brands of OTC medications

contain different pharmaceutical components and we did not query specifically about brand usage, it is unclear how much participants were paying attention to brand or particular side effects. Often, side effects seemed to be used as a gloss for all potential harm, whether to the body or to the identity, of taking a medication regularly over an indefinite period of time.

### *Harm reduction in the presence of conflicting harms*

While for many harmful behaviors there is a clear need to reduce harm associated with them, pain sufferers are faced with a dilemma. Although the potential harm of taking OTC medications too often over long periods was referred to by most participants, the harm is unclear and ambiguous. At the same time, pain is experienced as a signal of continuous harm inflicted on the body (Jackson 2011). Although the harmfulness of OTC medications may be known, the pain itself presents a harm that often takes precedence over other issues. Often, participants expressed a desire to maintain awareness and monitor pain. Increased pain, for those participants, signaled harm to be avoided and in this sense, not taking prescription pain medications is a form of harm reduction.

I don't like to take pain killers unless I have to... basically it's just numbing it and ignoring it as opposed to like oh there's something wrong, I should do something about this. (Brian, 28)

Although participants expressed awareness of the potential harmfulness of OTC medications, their descriptions focused on justifying the medication use they engaged in along with strategies for reducing harm. Participants worked to justify their medication use, regardless of actual intake, as “the minimum” as they weighed their options on a daily basis. Many informants attempted to take the minimum amount of medication to

ratchet pain down to a barely tolerable level. Josie, in tears when she described the severity of her pain and its impact on her life overall, took a more pragmatic approach in her description of taking medication.

I'm okay with, taking the edge off, is what it feels like, and, I don't like taking a lot of pills. (Josie, 29)

Aware, however, that the severity and persistence of pain often prevents rational consideration of harm, participants check themselves in a number of ways. They described attempts to take as few pills as possible, although this involved strategies like taking one pill at a time every hour. Such strategies allowed participants to feel as though they were taking the “minimum” despite ingesting substantial amounts of OTC medications.

I don't need the maximum dose. Definitely not. I need, I just want the minimum, cause I have not taken a lot of medicine, Because of my resistance to wanting to invite that stuff in, and so I would choose to start out with a low dose, and if I- if the need shows itself, then I'll move up. But I have a good, um, (short pause) how do you say? It works fine, just at the minimum, I don't, take like AB Ibuprofen 800s at the first sign of a cramp, you know (laughs). But I wouldn't even always take the minimum dose. Let's say I had a pill that I was um, I remember I would- she would give me a hydrocodone, and when it was really and I knew I would take a whole pill, but at times when I knew it was bad but it could have been worse, I would take the half pill so I- I am kind of, I police myself. (Lisa, 30)

Lisa describes “policing” herself in regard to medication use. Her comment, indicative of the constant self-surveillance many participants described, again points to a sense of being at odds with oneself. A need to police one's own behavior suggests a distrust of oneself. The difficulty assessing harm appears again here, as sufferers put strategies in place for those times when the pain becomes their focus and potential harm is shoved to the background.

Potential harms associated with OTC pain medications often seem ambiguous and open to interpretation. Although most sufferers referred to awareness of risks associated with use of these medications including liver damage or stomach problems, the risks were tied to words like “overuse” or “misuse” of the medications. Participants, as described above, were careful to justify their use, regardless of dosage or frequency, as *not* overuse or misuse. Due to ambiguity surrounding chronic pain itself, defining “overuse” or “misuse” is slippery and potential harms can be easily explained away.

### **Messages encountered in over-the-counter pain medication advertising**

In the following section, I consider the marketing of three common OTC analgesic pain relievers. I include analysis of OTC pain medication advertising to contextualize the narratives of chronic pain sufferers and to consider how these messages seem to support the self-projects as well as overcome desires to avoid medication expressed by participants.

To gain an understanding of advertising messages encountered by consumers, I collected 63 different advertising taglines used in marketing OTC pain medication online, in magazines, and on television (29 Advil, 24 Tylenol, and 10 Aleve). Print ads with no taglines are also considered. These ads contained images of severe pain such as a mountain biker landing on his face, a boxer taking a punch, or even a crown of thorns on a simple white background. While some ads portray injury and thus clearly target acute pain, most are ambiguous. The image of a crown of thorns on a white background, for example, evokes an underlying cultural morality of stoic suffering at the same time the ads purports to offer relief. Major recurrent themes in taglines and images that I will

discuss in turn below include: taking action and responsibility for oneself; overcoming limitations; fulfilling social roles and obligations; being strong, tough, and stoic; the offer of professional legitimacy without professional oversight; the promise of technological innovation; and finding one's true self or getting back to "normal" through the use of medication.

Advertisements focus on taking action and taking responsibility for oneself. Taglines such as, "*Take Action. Take Advil*" (*Advil*) imply that not treating pain could be construed as a form of laziness, lack of responsibility, or carelessness. Taking action and gaining control over one's illness are part of self-governing and being a good citizen (Ecks 2004, 2005). Health is increasingly viewed as a moral obligation or a personal achievement to work towards (Clarke et al. 2003; Scheper-Hughes and Lock 1987). Tylenol is sold with the tagline, "get relief responsibly." In these ads, Tylenol intentionally draws attention to potential risks associated with taking multiple drugs containing acetaminophen, the active ingredient in Tylenol. At the same time, this tagline could be interpreted as implying that consumers should use Tylenol rather than more dangerous painkillers such as opiates. Tylenol implores consumers to take responsibility for their own safety and well-being while also seeking relief. Aleve similarly markets with the claim that with their product, fewer pills are needed to obtain lasting pain relief. Consumers are asked, "If you could take fewer pills, why wouldn't you?" The descriptions above of attempts to take the "minimum," policing oneself, and managing medication intake on a daily basis align with these ads as chronic pain sufferers take on messages of self-responsibility for monitoring harm.

Using images of athletes and outdoor enthusiasts, on the other hand, OTC ads portray images of happiness and stamina among those not limited by pain, as seen for example in Advil's image of a tennis player in the background of a court covered with hundreds of practice balls, coupled with the tagline "*No pain. No limit*" (Advil). The majority of OTC pain medication ads considered here feature images of individuals who are happy, outdoorsy and participating in active lifestyles (cf. Singer et al. 2013). Pain is portrayed as the limiting factor in leading the happy, healthy lifestyle that individuals wish to pursue. According to Ecks (2005), pharmaceutical marketing portrays anti-depressants as "bringing the patient back into society." Such drugs are only accepted insofar as they provide a path toward "true happiness" through social reintegration (Ecks 2005). Ads for OTC meds convey similar messages of happiness and fulfillment of social obligation. In the "global monoculture of happiness," individuals must be pain-free, completely comfortable, and ready to consume the latest goods and fashions (Kirmayer 2002, Ecks 2005). Removing limits imposed by pain circles back to finding one's true self, in this case by overcoming the isolation imposed by illness (Dumit 2006).

Messages of personal responsibility alongside messages of achieving true happiness through pain relief play on pain sufferers' feeling of being "at odds" with oneself. Sufferers are expected to take as little medication as possible while also not being limited by pain. In a similar vein, both Advil and Tylenol ads feature messages of fulfilling social obligations with the help of their products. Participants in our study stoically described wanting to "just handle" pain. Ads drawing on images and slogans of speed and toughness seem to support this ideal, while others seem to berate sufferers for selfishly allowing themselves to be limited by pain. For example in one ad for Advil, a

mother is pictured playing with her children alongside the words, “I take Advil because my kids deserve a mom without a headache.”

Family life is a crucial arena in the formation of moral identities (Finch 1989). OTC pain medications target such moral identities, featuring taglines such as “for everything we do, you do so much more” (Tylenol) or “we eased your back pain, you made it the best playdate ever” (Tylenol). Coupled with images of active parents enjoying time with their happy children, OTC marketing positions the deservingness of others as impetus to overcome bodily limitations and be pain-free.

In her study of young mothers’ use of OTC medications, Vuckovic (1999) reports that a culture of “time famine” leads young mothers to medicate themselves and their children in an effort to avoid missing work. Vuckovic found that OTC medications were used as a way to hide symptoms and discipline bodies to comply with lifestyle demands. Tylenol and other OTC pain medication manufacturers target these audiences, knowing that the demands placed on parents, especially mothers, lead to regular use of their products. In these ads, Tylenol appeals to the moral identity constructions involved in parenthood, emotively appealing to the desire to live up to family expectations.

Ads do not expressly suggest that pain sufferers should be tough; however, the emphasis on toughness and stoicism in U.S. culture (Hay 2010), evidenced by the many participants who describe being able to “just deal with” chronic pain, is reinforced by many of the advertising taglines collected. Using taglines such as “as fast as it is strong” alongside images of celebrities and athletes, Advil is portrayed as part of achieving the U.S. cultural ideals embodied by athletes, celebrities, and public servants such as fire fighters.

Using taglines such as, “*The brand hospitals use most*” (Tylenol), advertisers also called upon the authority of doctors, hospitals, or health care professionals in recommending their products. Taglines like “you can’t get a stronger pain reliever without a prescription” (Tylenol) and “advanced medicine for pain” (Tylenol) reify biomedical authority, suggest that OTC pain relievers offer that same strength and legitimacy, without the need for professional oversight. Prescription strength without the stigma of being a prescription pain medication user appeals to participants’ work of saving credibility and preserving identity. Ads featuring images of pills speeding across the screen, leaving trails of what could be chemicals or magic, emphasize the promise of modern technological innovation sought by many consumers. Even for chronic pain sufferers who describe acceptance of the long-term nature of their pain, promises of technological advancement and getting back to “normal” may be appealing. The words “everyday” and “Join movement” (Aleve) portray the use of OTC pain medications as the everyday action of normal people. Further, OTC ads featuring taglines such as, “Thousands of people are switching to Advil from Tylenol every day” (Advil) resonate with pain sufferers’ desires to avoid being labeled “chronic pain patient” or worse, “drug addict.” Even Santa Claus is depicted as an OTC medication user (Aleve).

From a medical anthropological perspective, however, “normal” is a problematic concept (Lock and Nguyen 2010; Hacking 1990). Particularly in health care contexts, “normal” and “pathological” are increasingly defined in relation to available medical treatment (Kaufman et al. 2004). The role of medications in defining what behaviors are considered normal or abnormal involves pharmaceutical companies in governance and social control (Conrad 2005). Ideas of “normal” are also contested, however, by social

movements advocating for the valuation of individual difference (e.g. Taussig, Rapp, and Heath 2005; Klawiter 2008). As Dumit and Greenslit (2006) point out, pharmaceutical advertisers are aware of the need to market their drugs in a way that aligns them with social ideals and consumer identities. As Ebeling (2011) points out, pharmaceutical marketing has considerable power to exploit the uncertainty surrounding contested conditions. The ability of drug marketers to pathologize and render “ab-normal” any deviations from expected versions of masculinity (Asberg et al. 2009), eternal youth and beauty (Smirnova 2012), and responsibility for self-diagnosis (Ebeling 2011), for example, have been well-documented. In the words, “*Get back to normal, whatever your normal is*” (Tylenol), the supremacy of being “normal” is communicated simultaneously with ideas of acceptance and individual expression. OTC pain medication marketers suggest that living in pain is not one’s normal state and consumers should therefore be involved in treating it.

Applebaum (2009) argues that over-emphasis on consumer agency masks the exercise of power in pharmaceutical advertising. In exercising agency, consumers are involved in the reproduction of pharmaceutical ideologies that have influenced the very definitions of normal and pathological they purport to remedy (Ebeling 2011; Healy 2006; Ihara 2012). Finding one’s true self through medication is a common and problematic sentiment in pharmaceutical advertising (Kirmayer 2002; Singer et al. 2013). Using the tagline, “*So I can be myself again, sooner,*” Tylenol speaks to the concerns expressed by many sufferers that pain medications threaten identity. OTC ad campaigns seem carefully aligned with the concerns of sufferers in suggesting that by using

relatively harmless albeit powerful OTC medications, consumers can simultaneously be stoic and regain their sense of a true self by quickly relieving pain.

### **Conclusion**

Like other consumption activities, taking OTC pain meds is a form of symbolic communication. Through the use of OTC instead of prescription medication, sufferers contest images of chronic pain sufferers of prescription drug addicts and suggestions that reduced tolerance for pain is what drives increases in chronic pain (Barksy and Borus 1999; Barksy 1983). Sufferers in this study worked to distance themselves from negative stereotypes by consuming OTC pain medications as idioms of self-care. Not only consumption of certain items, but also resistance to consuming others, conveys messages (Baudrillard 1998 [1970]).

Through analysis of OTC pain medication advertising, I have shown how trade-offs between physical harm reduction and reducing potential harm to one's identity and sense of self produce narratives of harm justification as consumers work to describe their use as minimal and responsible. Describing medications as "just over-the-counter" or "not real pain medication" signify forms of harm reduction. They are uttered with the intention of minimizing stigma and distancing the individual from association with the addictive potential of prescription pain medications. *Harm justification* is therefore harm reduction, but in an altered sense. Navigating discourses of "authentic" versus "inauthentic" suffering (Ecks 2005), participants reduce harm to their identities through description of medication use as "minimal" in light of their experience of intense and ongoing pain.

Direct-to-consumer advertising has been the subject of a debate concerning whether such ads are educational to consumers or serve to shift greater control to the pharmaceutical industry (Vuckovic and Nichter 1997; Applbaum 2006; Healy 2006). In advertising, OTC drugs are often portrayed as simple solutions to problems (Tsao 1997). Consumers likewise equate OTC with “safe” and see widespread availability as an indicator of harmlessness (Nichter and Thompson 2006). Viewing OTC meds as harmless commodities is problematic, however, given that the Federal Trade Commission (FTC) does not require the same risk disclosures in OTC ads as for prescription medications (Ling, Berndt, and Kyle 2002). In this article I have considered OTC pain medication advertising as it relates chronic pain sufferers’ narratives to explore how people living with chronic pain draw from and adapt these messages in their identity constructions. Drawing from de Certeau (1984) Dew et al. (2014) argue that consumers are not passively shaped by dominant discourses, but rather actively engage with them in their production of a hybridized self-medical practice. Future research should consider the extent to which OTC medication advertising supports notions of harmlessness and social acceptability of their products and the extent to which those living with chronic pain may be ingesting these medications without full awareness of potential risks or even of their actual intake.

There are several potential limitations to this data. First, TMD is a condition normally addressed by Dentists rather than primary care physicians. Reluctance to talk to PCPs about pain may therefore be related to the ambiguity of the condition itself. As Buchbinder et al (In Press) point out, however, reluctance to ask for pain medication can be observed in other pain conditions as well and is therefore likely to be at least partially

attributable to fear of stigma. Second, many participants refer to “Advil” by brand-name. Because interview guides did not specifically cover brand-loyalty as an issue, we cannot comment on whether Advil is a blanket term to refer to the product (like, for example “Kleenex”) or whether participants specifically seek the brand-name as opposed to generic Ibuprofen. Further, we did not observe actual intake of OTC medication and can therefore comment only on the self-constructions involved in participants’ descriptions of their use.

In sum, participants worked to position themselves as “normal” and handling pain as any normal person would. Messages of normality, simplicity, and ease conveyed by OTC advertisements offer a sense of belonging in the everyday world that is often illusive to pain sufferers. OTC medications allowed sufferers to construct their pain as within the realm of what “normal” people experience in everyday life. Advertising messages play on cultural discourses to assist sufferers in reconciling inner conflicts between being stoic and “suffering with dignity” (Jackson 1994; Hilbert 1984) versus finding relief from constant pain. Drug marketing is thus implicated in perpetuating ideals of normality and deservingness but may also offer consumers with chronic pain the idioms of self-responsibility, self-care, and responsible citizenship they seek. Future research should explore conceptions of OTC medications as harmless substitutes for prescription medication and the ways consumers draw from OTC advertising to support their constructions of self and moral identity through consumption.

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