Published in final edited form as:

Med Anthropol Q. 2015 June ; 29(2): 157–177. doi:10.1111/maq.12146.

Works of Illness and the Challenges of Social Risk and the Specter of Pain in the Lived Experience of TMD

Emery R. Eaves,

School of Anthropology and Department of Family and Community Medicine, University of Arizona

Mark Nichter,

School of Anthropology and Department of Family and Community Medicine and College of Public Health, University of Arizona

Cheryl Ritenbaugh,

Department of Family and Community Medicine and School of Anthropology, University of Arizona

Elizabeth Sutherland, and

National College of Natural Medicine

Samuel F. Dworkin

Department of Oral Medicine School of Dentistry and Department of Psychiatry and Behavioral Science, University of Washington

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.

Keywords

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.¹ 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 at present, meet such expectations. There is more involved than resolve, however, 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, as shown in the section on Participant Experiences).

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).

¹Other 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).

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% women) 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 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 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, 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 10 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.

The Work of Stoicism: “Just Dealing with Pain”

Our community-based sample was recruited for a clinical trial of TCM. Eligible participants had the 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 (DeVecchio 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. While 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 temporality 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.⁵ 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 also 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).

⁵. 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.

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.

Acknowledgments

The authors would like to thank Beth Yohalem-Ilsley for her interviews in Portland; project staff, practitioners, and dentists for their contributions; and our participants who willingly completed this series of interviews on a personal and difficult topic. Funding for this research was provided by a grant (U01-AT002570) from the National Center for Complementary and Alternative Medicine, National Institutes of Health.

References Cited

- Alexander, L. The Double Bind between Dialysis Patients and Their Practitioners. In: Eisenberg, L., Kleinman, A., editors. *The Relevance of Social Science for Medicine*. Boston: Reidel; 1981. p. 307-329.
- Antelius E. The Meaning of the Present: Hope and Foreclosure in Narrations about People with Severe Brain Damage. *Medical Anthropology Quarterly*. 2007; 21:324–342. [PubMed: 17937252]
- Bateson G, Jackson DD, Haley J, Weakland J. Toward a Theory of Schizophrenia. *Behavioral Science*. 1956; 1:251–264.
- Bral E, Shaughnessy MF, Eisenman R. Intimacy in People with Chronic Pain. *International Journal of Psychosocial Rehabilitation*. 2002; 6:51–60.
- Buchbinder M. Personhood Diagnostics: Personal Attributes and Clinical Explanations of Pain. *Medical Anthropology Quarterly*. 2011; 25:457–478. [PubMed: 22338290]
- Bulow PH. In Dialogue with Time: Identity and Illness in Narratives about Chronic Fatigue. *Narrative Inquiry*. 2003; 13:71–97.
- Bury M. Chronic Illness as Biographical Disruption. *Sociology of Health & Illness*. 1982; 4:167–182. [PubMed: 10260456]
- Bury M. The Sociology of Chronic Illness: A Review of Research and Prospects. *Sociology of Health & Illness*. 1991; 13:451–468.

- Bury M. Illness Narratives: Fact or Fiction? *Sociology of Health & Illness*. 2001; 23:263–285.
- Butler, J. *Giving an Account of Oneself*. New York: Fordham University Press; 2005.
- Castañeda H, Nichter M, Nichter M, Muramoto M. Enabling and Sustaining the Activities of Lay Health Influencers: Lessons from a Community-based Tobacco Cessation Intervention Study. *Health Promotion Practice*. 2010; 11:483–492. [PubMed: 18540006]
- Clark, K., Holquist, M. Mikhail Bakhtin. Cambridge, MA: Belknap Press of Harvard University Press; 1984.
- Connors MM. Risk Perception, Risk Taking and Risk Management among Intravenous Drug Users: Implications for AIDS Prevention. *Social Science & Medicine*. 1992; 34:591–601. [PubMed: 1574727]
- Corbin JM, Strauss AL. Managing Chronic Illness at Home: Three Lines of Work. *Qualitative Sociology*. 1985; 8:224–247.
- DelVecchio Good, M-J., Brodwin, PE., Good, BJ., Kleinman, A. Pain as Human Experience: An Anthropological Perspective. Berkeley: University of California Press; 1992.
- Dworkin, SF. Psychosocial Impact of Orofacial Pain: Integrating Research into Clinical Management. In: Turp, JC. Sommer, C., Hugger, A., editors. *The Puzzle of Orofacial Pain*. Basel, Switzerland: Karger; 2007. p. 187–208.
- Dworkin SF. Temporomandibular Disorder (TMD) Pain-Related Disability Found Related to Depression, Nonspecific Physical Symptoms, and Pain Duration at 3 International Sites. *Journal of Evidence Based Dental Practice*. 2011; 11:143–144. [PubMed: 21855814]
- Eaves, ER., Nichter, M., Ritenbaugh, C. “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; Chicago. 2013.
- Eaves ER, Ritenbaugh C, Nichter M, Hopkins AL, Sherman KJ. Modes of Hoping: Understanding Hope and Expectation in the Context of a Clinical Trial of Complementary and Alternative Medicine for Chronic Pain. *EXPLORE: The Journal of Science and Healing*. 2014; 10:225–232.
- Egermark I, Carlsson GE, Magnusson T. A 20-year Longitudinal Study of Subjective Symptoms of Temporomandibular Disorders from Childhood to Adulthood. *Acta Ontologica Scandinavica*. 2001; 59:40–48.
- Elder C, Ritenbaugh C, Aickin M, Hammerschlag R, Dworkin SF, Mist S, Harris R. Reductions in Pain Medication Use Associated with Traditional Chinese Medicine for Chronic Pain. *Permanente Journal*. 2012; 16:18–23. [PubMed: 23012594]
- Garro, LC. Chronic Illness and the Construction of Narratives. In: Good, M-JD. Brodwin, PE. Good, BJ., Kleinman, A., editors. *Pain as Human Experience: An Anthropological Perspective*. Berkeley: University of California Press; 1992. p. 100–137.
- Garro LC. Narrative Representations of Chronic Illness Experience: Cultural Models of Illness, Mind, and Body in Stories Concerning the Temporomandibular Joint (TMJ). *Social Science & Medicine*. 1994; 38:775–788. [PubMed: 8184329]
- Glass EG, McGlynn FD, Glaros AG, Melton K, Romans K. Prevalence of Temporomandibular Disorder Symptoms in a Major Metropolitan Area. *Cranio: The Journal of Craniomandibular Practice*. 1993; 11:217–220. [PubMed: 8242785]
- Goffman, E. *The Presentation of Self in Everyday Life*. New York: Doubleday; New York: Anchor Books; 1959.
- Good, BJ. A Body in Pain: The Making of a World of Chronic Pain. In: Good, M-JD. Brodwin, PE. Good, BJ., Kleinman, A., editors. *Pain as Human Experience: An Anthropological Perspective*. Berkeley: University of California Press; 1992. p. 29–48.
- Good BJ, DelVecchio Good MJ. In the Subjunctive Mode: Epilepsy Narratives in Turkey. *Social Science & Medicine*. 1991; 38:835–842.
- Hay MC. Suffering in a Productive World: Chronic Illness, Visibility, and the Space beyond Agency. *American Ethnologist*. 2010; 37:259–274.
- Hermans HJM. The Dialogical Self: Toward a Theory of Personal and Cultural Positioning. *Culture Psychology*. 2001; 7:243–281.
- Hermans HJM, Kempen H, VanLoon R. The Dialogical Self: Beyond Individualism and Rationalization. *American Psychologist*. 1992; 47:23–33.

- Hilbert RA. The Acultural Dimensions of Chronic Pain: Flawed Reality Construction and the Problem of Meaning. *Social Problems*. 1984; 31:365–378.
- Holquist, M. *Dialogism: Bakhtin and His World*. London: Routledge; 1990.
- Honkasalo ML. Chronic Pain as a Posture towards the World. *Scandinavian Journal of Psychology*. 2001; 41:197–208.
- Hunt L, Valenzuela M, Pugh J. Porque Me Toca a Mi: Mexican American Diabetes Patients' Causal Stories and Their Relationship to Treatment Behaviors. *Social Science & Medicine*. 1998; 46:959–969. [PubMed: 9579748]
- Ingram D, Hutchinson SA. Double Binds and the Reproductive and Mothering Experiences of HIV-positive Women. *Qualitative Health Research*. 2000; 10:117–132. [PubMed: 10724748]
- Jackson JE. Stigma, Liminality, and Chronic Pain: Mind–Body Borderlands. *American Ethnologist*. 2005; 32:332–353.
- Jain SL. Living in Prognosis: Toward an Elegiac Politics. *Representations*. 2007; 98:77–92.
- Kavanagh AM, Broom DH. Embodied Risk: My Body, Myself? *Social Science and Medicine*. 1998; 46:437–444. [PubMed: 9460824]
- Krefting L. Double-bind and Disability: The Case of Traumatic Head Injury. *Social Science & Medicine*. 1990; 30:859–865. [PubMed: 2315751]
- Labov, W. *The Social Stratification of English in New York City*. Cambridge: Cambridge University Press; 1972.
- Labov, W. *The Language of Life and Death: The Transformation of Experience in Oral Narrative*. Cambridge: Cambridge University Press; 2013.
- Lennon MC, Link BG, Marbach JL, Dohrenwend BP. The Stigma of Chronic Facial Pain and Its Impact on Social Relationships. *Social Problems*. 1989; 36:117–134.
- Lillrank A. Back Pain and the Resolution of Diagnostic Uncertainty in Illness Narratives. *Social Science & Medicine*. 2003; 57:1045–1054. [PubMed: 12878104]
- Lupton, D., editor. *Risk and Sociocultural Theory: New Directions and Perspectives*. Cambridge: Cambridge University Press; 1999.
- Magnusson T, Egermark I, Carlsson GE. A Prospective Investigation over Two Decades on Signs and Symptoms of Temporomandibular Disorders and Associated Variables. A Final Summary. *Acta Ontologica Scandinavica*. 2005; 63:99–109.
- Miczio N. Beyond the “Fetishism of Words”: Considerations on the Use of the Interview to Gather Chronic Illness Narratives. *Qualitative Health Research*. 2003; 13:469–490. [PubMed: 12703411]
- Muehlenhard CL, McCoy ML. Double Standard/Double Bind. *Psychology of Women Quarterly*. 1991; 15:447–461.
- Muhr, T. *ATLAS.ti Qualitative Data Analysis Program*. Berlin: ATLAS.ti Scientific Software Development GmbH; 2011.
- Nichter M. Illness Semantics and International Health: The Weak Lungs/TB Complex in the Philippines. *Social Science & Medicine*. 1994; 38:649–663. [PubMed: 8171344]
- Nichter, M. The Social Relations of Therapy Management. In: Nichter, M., Lock, M., editors. *New Horizons in Medical Anthropology*. London: Routledge; 2002. p. 81–110.
- Nichter, M. Harm Reduction: A Core Concern for Medical Anthropology. In: Harthorn, BH., Oaks, L., editors. *Risk, Culture, and Health Inequality*. Westport, CT: Praeger; 2003. p. 13–33.
- Nichter, M. Understanding the Patient's Experience of Illness: From the Production of Knowledge to the Works of Illness. Birmingham: Oakstone Medical Publishing; 2005.
- Nichter M. Idioms of Distress Revisited. *Culture, Medicine & Psychiatry*. 2010; 34:401–416.
- Ostermann AC, Dowdy JD, Lindemann S, Türp JC, Swales JM. Patterns in Self-reported Illness Experiences: Letters to a TMJ Support Group. *Language and Communication*. 1999; 19:127–147.
- Reid J, Ewan C, Lowy E. Pilgrimage of Pain: The Illness Experiences of Women with Repetition Strain Injury and the Search for Credibility. *Social Science & Medicine*. 1991; 32:601–612. [PubMed: 2017728]
- Ritenbaugh C, Hammerschlag R, Dworkin SF, Aickin MG, Mist S, Elder CR, Harris RE. Comparative Effectiveness of Traditional Chinese Medicine and Psychosocial Care in the Treatment of

- Temporomandibular Disorders—Associated Chronic Facial Pain. *The Journal of Pain*. 2012; 13:1075–1089. [PubMed: 23059454]
- Schlesinger L. Chronic Pain: A Qualitative Study of Women Who Live with Pain. *The Journal of Sex Research*. 1996; 33:249–256.
- Simpson C. When Hope Makes Us Vulnerable: A Discussion of Patient–Healthcare Provider Interactions in the Context of Hope. *Bioethics*. 2004; 18:428–447. [PubMed: 15462025]
- Slade GD, Fillingim RB, Sanders AE, Bair E, Greenspan JD, Ohrbach R, Dubner R, Diatchenko L, Smith SB, Knott C, Maixner W. Summary of Findings from the OPPERA Prospective Cohort Study of Incidence of First-onset Temporomandibular Disorder: Implications and Future Directions. *The Journal of Pain*. 2013; 14:T116–T124. [PubMed: 24275219]
- Smith AA. Intimacy and Family Relationships of Women with Chronic Pain. *Pain Management Nursing*. 2003; 4:134–142. [PubMed: 14566711]
- Smith B, Sparkes AC. Contrasting Perspectives on Narrating Selves and Identities: An Invitation to Dialogue. *Qualitative Research*. 2008; 8:5–35.
- Strauss C. Partly Fragmented, Partly Integrated: An Anthropological Examination of “Post-modern Fragmented Subjects”. *Cultural Anthropology*. 1997; 12:362–404.
- Tanggaard L. The Research Interview as a Dialogical Context for the Production of Social Life and Personal Narratives. *Qualitative Inquiry*. 2009; 15:1498–1515.
- Tulloch, J., Lupton, D. *Risk and Everyday Life*. London: Sage; 2003.
- Werner, Anne, Isaksen, Lise Widding, Malterud, Kirsti. “I Am Not the Kind of Woman Who Complains of Everything”: Illness Stories of Self and Shame in Women with Chronic Pain. *Social Science & Medicine*. 2004; 59:1035–1045. [PubMed: 15186903]
- Wilce JM. The Kalimah in the Kaleidophone: Ranges of Multivocality in Bangladeshi Muslim’s Discourses. *Ethos*. 1998; 26:229–257.
- Williams S. Chronic Illness as Biographical Disruption or Biographical Disruption as Chronic Illness? Reflections on a Core Concept. *Sociology of Health & Illness*. 2000; 22:40–67.

Table 1

Interactions between stoicism and vigilance across 3 lines of work

	Work of Stoicism	Work of Vigilance
	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	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 In professional and public situations: Eating and talking normally; smiling to avoid appearing anti-social With significant others: managing others’ emotions; not burdening others with pain; participating in family activities; maintaining intimate relationships Sleeping enough to avoid being irritable and to be productive	Working to avoid situations likely to result in pain flare-ups; eliminating activities known to cause/increase pain Avoiding crunchy/chewy foods; not talking too much/too long; not smiling or laughing too much; avoiding intimate activities involving mouth Hyper-vigilance against clenching/grinding during sleep
Illness Work	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 Avoiding being “someone who likes taking pain medication” ² by avoiding prescription pain meds (or if taking them, emphasizing severity of pain)	Reliance on mouthguard; working to describe pain severity to family members or physicians when necessary Taking large doses of OTC meds to manage pain (working to construct them as not pain medication ³); not taking pain meds to retain bodily awareness and ability to monitor pain
Autobiographical Work	Working to create stoic moral identity; avoiding stigma by not drawing attention to pain Keeping up hope for improvement; ⁴ expressing hopefulness and positive attitude to significant others; denial that TMD impacts future plans Working to accept pain and to care for the self and the body on one’s own; requires knowledge about the condition	Working to stay focused on the present; maintaining “at risk role” always attentive to pain Keeping hopes in check, not hoping for too much as a form of vigilance against possibility of despair Avoiding prognosis; working to keep hopes up by avoiding too much negative information or accepting that pain is “chronic”

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

². See Eaves et al. 2013.

³. Eaves et al. 2013.

⁴. 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.