ILLNESS EXPERIENCE OF PEOPLE LIVING WITH CHRONIC PAIN
RESULTING FROM TEMPOROMANDIBULAR DISORDERS

by

Emery Rose Edwards

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EMERY ROSE EDWARDS

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This thesis discusses the illness experience of people living with chronic pain resulting from Temporomandibular disorders (TMD). The literature discusses various aspects of the experience of chronic pain, but there is little research reported specifically on the experience of living with TMD. Using analysis of sufferers’ narratives, I discuss common explanatory models and coping strategies. I then present aspects of the bodily experience of TMD as seen in people with comorbid illnesses. The personal or mental aspects of TMD are explored, particularly in terms of fear, anxiety, and hope for the future. Lastly, the broader impacts of TMD are explored through sufferers’ relationships with friends and family, and sufferers’ ability to function in social contexts. It is concluded that TMD impacts many areas of sufferers’ lives, and that the lived experience extends beyond diagnosis and treatment seeking to include the day to day management of TMD pain.
INTRODUCTION

This thesis is part of a larger project on the effects of a combination of treatments on the experience of pain, suffering, and coping among people with Temporomandibular Disorders (TMD). The data presented is based on a series of baseline interviews with study participants, and the goal is to present a description of the illness experience of these people at the time that they enter the research study. In order to fully understand the outcome of treatment on an individual’s experience of illness, it is crucial to understand the impact of this condition in the broader context of his or her life. In this thesis I provide an analysis of the multi-faceted experience of TMD that will add to the understanding of this illness as it impacts the broader person, including their bodies beyond the site of illness, their lives, and their interactions with others.

Acute pain is a common feature of human experience. It occurs in all cultures, ages and genders, and is possibly one of the few universal features of the human condition (Kleinman, Brodwin, Good, and Good 1992). Pain is often viewed as essential to being human, an elemental feature of existence that can be imbued with spiritual meaning. Although intertwined with bodily processes, pain is also socially and emotionally constructed (Honkasalo 2000). Pain is often thought to be essential for emotional development, and the ability to withstand pain is considered important as an index of character (Eccleston, Williams, and Rogers 1997). Acute pain is one of the main medical complaints in doctors’ offices in North America. It is also the focus of most of the literate medical traditions (Kleinman et al. 1992). Outwardly displaying pain
symptoms is culturally proscribed as a display of weakness, and the aversion to disclosing pain is shared even by those who suffer from pain indefinitely (Kugelmann 1999).

Unlike acute pain, chronic pain is persistent, and is related to pain signals in the central nervous system that keep firing for weeks or even years (NINDS 2001). Some forms of chronic pain are preceded by an initial mishap or an ongoing medical condition, but others have pain in the absence of any visible body damage. The most common forms of chronic pain are: low back pain; headache; cancer pain; arthritis pain; pain resulting from damage to the nerves (neurogenic pain); and psychogenic pain (NINDS 2001). Chronic pain has been one of the most common complaints in the Western medical system, and chronic pain patients have been found to use health services more frequently than the rest of the population (Barsky and Borus 1995; VonKorff, LeResche, and Dworkin 1993; VonKorff, Wagner, Dworkin, and Saunders 1991). The prevalence of chronic pain in the general population has been estimated to be as high as 45% (primarily low back pain and arthritis pain) (Croft, Rigby, Boswell, Schollum, and Silman 1993; Elliott, Smith, Penny, Smith, and Chambers 1999; Gureje, VonKorff, Simon, and Gater 1998).

This thesis is based on the experience of Temporomandibular Disorders (TMD) as a particular manifestation of chronic pain. As part of a larger project aimed at assessing the outcome of complementary and alternative medicine (CAM) treatment (specifically Traditional Chinese Medicine) on TMD, this analysis is intended to describe the pattern of illness of TMD sufferers as they enter a research study. Using an illness experience
approach, I will present narrative and observations that consider the everyday lives of people living with and in spite of pain (Baszanger 1989).

Using data from interviews with TMD sufferers, I discuss the illness experience of TMD sufferers in several areas. After reviewing previous literature on chronic pain and TMD, particularly in the social sciences, I will present a discussion of the ways in which sufferers understand the illness itself, or their explanatory models (EMs) (Kleinman 1978). I will then present some of the daily coping mechanisms that are employed by sufferers as well as the obstacles that arise in interactions between coping and pain. The bodily experience of TMD is explored using sufferers with multiple chronic pain complaints as examples of the way that TMD is felt as a systemic problem, not limited in its impact to the jaw or facial region. The individual or emotional aspects of TMD will be considered, particularly as they relate to sufferers’ visions of the future and anxiety about the possibility of increasing pain. Finally, the impact of TMD on the broader person will be discussed primarily in the areas of sufferers’ relationships with their families and friends. I will also discuss the impact of TMD on intimacy and intimate relationships as an important area of life that is affected by TMD pain.

The broader research goal of the study from which the interviews are drawn is to assess the outcome of treatments on sufferers’ patterns of pain, or “stuckness” (a term often used in describing Chinese Medicine treatment, see (Dessler 1996; Koithan, Verhoef, Bell, White, Mulkins, and Ritenbaugh 2007). The outcome will be partially assessed in terms of the possibility of facilitating movement in sufferers’ lives that allows them to cope more effectively with pain. In order to assess whether such movement has
occurred, it is necessary to understand the patterns in which sufferers are “stuck” as they enter the study. The relationship of this data to the broader study will be expanded in later sections, and the impact of the research study on participants’ willingness to share their experiences will also be discussed.

**Biomedical and Epidemiological Definitions of Temporomandibular Disorders**

The illness label, ‘Temporomandibular disorders’ (TMD), is not limited to a single disease, but is used as a collective term embracing a number of clinical problems that involve the masticulatory musculature, the Temporomandibular joints (TMJs), or both (deBont, Dijkgraaf, and Stegenga 1997; Magnusson, Egermark, and Carlsson 2005; Suvinen, Reade, Kemppainen, Kononen, and Dworkin 2005). Although the disorder represents multiple diseases and is thus difficult to diagnose, it represents a significant problem in the areas of dental medicine and public health (Ferrando, Adreu, Galdón, Durá, Poveda, and Bagán 2004).

Studies have shown that TMDs resemble chronic pain disorders in general, and they are often diagnosed in a similar manner (Suvinen et al. 2005). TMDs are a major cause of dental pain in the population, and are considered to be a subclassification of musculoskeletal disorders (Suvinen et al. 2005). They are widely accepted as degenerative and the major categories associated with TMDs are inflammatory and noninflammatory arthropathies (deBont, Dijkgraaf, and Stegenga 1997).

Cases of TMD are often identified through questionnaires that ask about stress, oral parafunctions, bruxism, and other individual variables. A clinical examination for
TMD typically investigates: measurements of range of movement of the mandible, presence of deflection during mouth opening, registration of TMD sounds, locking or luxation, pain on movement of the mandible, TMD or muscle pain on palpitation, number of teeth, number of occluding tooth pairs in maximal intercuspation, occlusal interferences, and the degree of occlusal wear (Magnusson, Egermark, and Carlsson 2005). The signs and symptoms of TMD fluctuate, often including headache, jaw pain, and loss of movement (Egermark, Carlsson, and Magnusson 2001; Suvinen et al. 2005). Although a pain assessment known as the RDC/TMD is becoming more widely used (Suvinen et al. 2005), because of the variation and the lack of definitive diagnostic devices, diagnosis of TMD is often limited to individual case history and physical examination (Baba, Tsukiyama, Yamazaki, and Clark 2001).

Generally, a patient will have two of the following to be classified as suffering from TMD: pain/discomfort in the jaw, mainly in the region of the TMJs and/or muscles of mastication; limitation of mandibular function and/or TMJ sounds (Suvinen et al. 2005). Inclusion criteria for an epidemiological study might consist of reports of pain in the face and jaw, Temporomandibular joints, or temples around once a week, and chronicity of pain for a specified minimum period of time such as three months (Wahlund, List, and Ohrbach 2005).

Although TMD does not cause death, as a chronic degenerative pain disorder it can be a source of major difficulty for sufferers. Most sufferers of TMD are likely to have multiple symptoms, as well as often having other somatic symptoms (such as other pain or somatic illness complaints) which are not associated with the disorder (Magnusson,
Egermark, and Carlsson 2005). Studies suggest that the prevalence of clinically significant TMD related jaw pain ranges from 5% to 13% in the general population (deBont, Dijkgraaf, and Stegenga 1997; Ferrando et al. 2004), however, it is estimated that as high as 70-93% of people in the general population experience TMD or at least some TMD symptoms at some point in their lives (Ferrando et al. 2004; Salvinelli, Casale, D'Ascanio, Rinaldi, and Paparo 2004; Suvinen et al. 2005). TMD often appears during childhood and there is substantial fluctuation of reported TMD symptoms and headache from childhood progressing into adulthood (Egermark, Carlsson, and Magnusson 2001). After age 35, the need for treatment in some patients is decreased—a decrease which has been suggested to be linked to lower stress levels later in life (Egermark, Carlsson, and Magnusson 2001; Magnusson, Egermark, and Carlsson 2005). Interestingly, in children, there was no reported difference in symptoms between males and females, but by age twenty differences had emerged (Magnusson, Egermark, and Carlsson 2005).

TMD is relatively common among adolescents, and the prevalence is estimated to be as high as 7% needing treatment (Wahlund, List, and Ohrbach 2005). Wahlund, List, and Ohrbach (2005) reported that adolescents who suffer from TMD symptoms report a higher degree of stress and more behavioral problems than healthy adolescents.

Although the signs and symptoms of TMD can be found in all age groups, and occur in both men and women, there is considerable female dominance in reported cases of TMD (deBont, Dijkgraaf, and Stegenga 1997; Egermark, Carlsson, and Magnusson 2001; Magnusson, Egermark, and Carlsson 2005; Suvinen et al. 2005). Women also
report significantly more frequent and more severe TMD symptoms than men, and men seem to recover from the symptoms after treatment to a greater extent than women (Egermark, Carlsson, and Magnusson 2001).

There are few hypothesis regarding the increased prevalence and severity of TMD in females. The gender differences that are observed in TMD sufferers cannot be explained on the basis of sex-linked behavior, such as treatment seeking (deBont, Dijkgraaf, and Stegenga 1997), and there is some controversy over possible explanations for the difference. Explanations range from increased pain sensitivity in females, to biological, hormonal, psychological, and social factors (Magnusson, Egermark, and Carlsson 2005; Suvinen et al. 2005). There are also few reasons suggested for the age variations observed among TMD sufferers. Some researchers have suggested that the decrease in need for treatment at older ages may be due to a decrease in stress in later life, however, this is contingent on the suggestion that TMD is related to stress (Magnusson, Egermark, and Carlsson 2005).

Although TMD may occur worldwide, studies of TMD have been conducted primarily on sufferers in the United States and Europe (deBont, Dijkgraaf, and Stegenga 1997; Magnusson, Egermark, and Carlsson 2005; Suvinen et al. 2005; VonKorff, LeResche, and Dworkin 1993; Wahlund, List, and Ohrbach 2005), as well as in Japan (Yun and Kim 2005).

Few risk factors have been definitively identified. Factors that may be related to TMD include jaw related factors and psychological factors. Some researchers have suggested that diurnal and/or nocturnal bruxism (tooth grinding) is a risk factor
(Egermark, Carlsson, and Magnusson 2001), and bruxism may also be a risk factor when combined with other oral parafunctions, jaw clicking, or with a deep bite or cross bite (Magnusson, Egermark, and Carlsson 2005). Another important risk factor in the development of TMD is facial trauma, either micro- or macro-trauma, and many cases were associated with facial injuries, or orthodontic experiences during adolescence (deBont, Dijkgraaf, and Stegenga 1997; Magnusson, Egermark, and Carlsson 2005; Yun and Kim 2005).

TMD has been associated with psychological factors such as stress, anxiety, differences in pain perception, depression, and overuse of health care facilities (Ferrando et al. 2004; Suvinen et al. 2005). Although the psychological factors have been investigated for causal relationships, a common belief is that these factors can predispose individuals to TMD, and that they can exacerbate the condition after symptoms have arisen (Egermark, Carlsson, and Magnusson 2001).

Oral parafunctions, bruxism, tooth-grinding and tooth-clenching are potential causes of TMD, however, it is unclear whether these are causes or functions of the disorder (deBont, Dijkgraaf, and Stegenga 1997; Egermark, Carlsson, and Magnusson 2001; Ferrando et al. 2004; Magnusson, Egermark, and Carlsson 2005). Other etiological factors that have been suggested are psychological variables, trauma, and other degenerative joint problems, however, the causal factors seem to differ with each case (Ferrando et al. 2004). There are many hypotheses related to psychological and psychosocial variables in the development of TMD. Some suggest that the disorder might
be related to stress-induced muscle spasms or clenching, or that stress-related muscle tension sets dysfunctional oral habits underway (Ferrando et al. 2004).

Some researchers hypothesize that TMD is a psychophysiological disorder of the central nervous system, and that TMD sufferers might be more sensitive to somatic stimuli than healthy individuals (Wahlund, List, and Ohrbach 2005). It appears that current perspectives on the etiology of TMD are multidimensional, and researchers appreciate that a combination of physical, psychological and social factors may contribute to the presence of this disorder (Suvinen et al. 2005).

In most cases, TMD can be managed non-surgically through techniques such as counseling and education, interocclusal appliances, control of factors such as clenching and bruxism, anti-inflammatory or pain medication, and jaw exercises (deBont, Dijkgraaf, and Stegenga 1997; Egermark, Carlsson, and Magnusson 2001). A large majority of the patients in these epidemiologic studies (as high as 83%) reported positive treatment outcomes after intervention (Egermark, Carlsson, and Magnusson 2001; Magnusson, Egermark, and Carlsson 2005). General treatments for chronic pain such as biofeedback, cognitive behavioral therapy, relaxation, and hypnosis have also been suggested as interventions for managing this condition (Ferrando et al. 2004).
LITERATURE REVIEW

A considerable amount of social science research has focused on the experience of chronic pain in Western cultures. Kleinman et al. (1992) explain that unlike acute pain, chronic pain is not ubiquitous, nor does it occur in all cultures. In the United States, however, chronic pain is becoming increasingly common, and is a frequent cause of disablement (Csordas and Clark 1992). The prevalence of chronic pain in the general population is not known, but estimates of chronic pain in some form range as high as 45% of the general population, and possibly higher in older populations (Elliott et al. 1999; Gureje et al. 1998). Elliot et al. (1999) reported a significant difference between reports of chronic pain in the general population and expressed need for treatment. Therefore, it is difficult to accurately assess the number of people who suffer from chronic pain without seeking medical treatment. As the reported prevalence of chronic pain increases, it is important to discuss the ways in which chronic pain is viewed and experienced.

For pain to be considered within normal parameters, and to fit into accepted social definitions, it must be temporary (Hilbert 1984). Pain cannot be diagnosed as chronic at its initial onset, and as it persists, the sick role that is assumed by the sufferer becomes delegitimated. Without the assurance that pain is normal, or the result of a legitimate illness, sufferers are often forced to alter the way they see themselves and their suffering (Garro 1992; Hilbert 1984). As pain persists, it becomes a reminder, present on all occasions, that things are not right and may never be right (Hilbert 1984). The lack of
certainty of ever improving leads an association of pain with inability to organize experience (ambiguity) and with management rather than cure (Baszanger 1989).

Jackson (2005) found that without an expected endpoint for illness, there is no culturally appropriate role for pain sufferers to fill. They exist in a state of liminality, similar to that outlined by Turner (1969). Jackson uses both Turner’s concept of liminality, and Douglas’ (1970) discussion of “matter out of place” to highlight the lack of cultural constructions available to chronic pain sufferers to make sense of their suffering. It is within this liminal state that chronic pain sufferers are expected to exist and find meaning in their illness.

The failure of cultural constructions to provide meaning for chronic pain sufferers has multiple implications for those who attempt to cope with pain and construct meaningful narratives. Chronic pain defies conventional meanings and escapes successful Western cultural construction (Hilbert 1984; Kleinman et al. 1992). As Hilbert (1984) explains,

When pain is chronic, one might expect the appropriate method of managing it to become chronic also. But when these methods become chronic, they cease to be appropriate. One cannot moan all the time; one cannot confide or expect deferential treatment all the time; one cannot quietly withdraw for the rest of one’s life; one cannot even conceal such an object of one’s attention all the time. Thus, culture fails once again to tell sufferers how to handle pain (370).

The failure of culture to provide meaningful ways of understanding chronic pain relates to Obeyesekere’s (1985) concept of the “work of culture.” As Obeyesekere describes, the work of culture is a process that allows painful motives and affects such as those occurring in depression or chronic pain to be transformed into publicly accepted symbols and meanings. If mourning is successful work, however, Obeyesekere points out
that melancholia is the failure of culture to provide appropriate symbols and meanings. In a similar way, chronic pain also presents an example of failure in the work of culture. Temporary or acute pain is accompanied by powerful meanings but its chronic occurrence leaves sufferers without cultural symbols and meanings on which to depend.

**Biomedicine and the Search for Pathology in Chronic Pain**

Aldrich and Eccleston (2000) report that pain is normally evaluated based on its duration, severity, and the part of the body in which it occurs. The idea that pain is “meaningless,” or not indexing a particular pathology, runs counter to the foundations of western medicine (Aldrich and Eccleston 2000). Chronic pain defies the central tenet of biomedical epistemology, that there can be objective knowledge independent of subjective experience (King 1999; Kleinman et al. 1992). This defiance causes conflict between doctors and patients, and indexes larger conflicts that exist within Western society.

Kleinman et al. (1992) suggest that chronic pain disorders are useful in studying the faultlines of society. They argue that even middle class, white Americans have not abandoned the use of somatic expression, and that chronic pain is often an outcome of the conversion of negative emotions into bodily idioms to communicate personal and interpersonal distress. Rhodes (1999) suggests that a more fluid understanding of pain in Western medicine could provide significantly more legitimacy to chronic pain sufferers.

Most of what is known about pain in the U.S. comes from the Western medical tradition. Biomedicine defines pain narrowly, as an indicator that something is in need of
repair (Aldrich and Eccleston 2000). This narrow definition effectively masks other ways of living with pain. The medical definition suppresses other understandings of pain and assures that an individual whose pain has no immediately apparent biochemical cause remains in a state of questionable legitimacy (Encandela 1993). Pain is not, in itself, considered pathological. It is positioned within biomedicine as a diagnostic tool (Aldrich and Eccleston 2000). In itself, pain is not viewed as a warranting significant medical attention (Jackson 2005; Reid, Ewan, and Lowy 1991). When chronic pain seems unconnected with any underlying pathology, not only its cause, but the fact that it exists at all is questioned. When pain fails to index a legitimate illness, it is often abdicated to the realm of psychosomatic, or even purely psychological illness (Baszanger 1989; Garro 1994).

Although most chronic pain sufferers reject the label of “stress” as the primary cause of their pain, they often list it as a contributor (Garro 1992). Kugelman (1999) argues that stress has become a “catch-all” definition, and that sufferers use the concept of stress to assign meaning to their pain without taking responsibility for it. Pollock (1988) found that many pain sufferers felt that they could not reduce the amount of stress in their lives, and that stress somehow forced the speeding of physiological processes of aging and degeneration. The concept of stress as it is loosely used in etiologies of chronic pain offers a method of linking pain to medicine without specifying a biological pathology. In other words, stress can be manifested in the body in the form of pain. The term “stress” as opposed to “Somatization” provides patients with an acceptable degree of legitimacy while relieving the burden of a specific diagnosis from the physician.
Medicine is never practiced independently of cultural values (King 1999). As King (1999) states, “Medicine constructs its object in a dialogue with culture; before treating sickness, it is necessary to decide who is sick and who is not, what behavior is abnormal and what is normal” (269). The line between who is sick and who is not determines what is considered to be legitimate illness and what is not.

**The Patients’ Search for a Legitimate Sick Role**

A major theme that has been discussed in social science research on chronic pain is the search for legitimacy. As outlined above, the lack of cultural constructions for understanding chronic pain and its defiance of medical categories leads to questions about its origin, and consequently, its legitimacy as an illness. Since individuals find it difficult to navigate the realm of assigning meaning to their pain, many spend a considerable amount of energy fighting to prove the legitimacy of their illness within a biomedical paradigm.

One of the great ironies of chronic pain is that sufferers are disappointed by what to most people is good news—that nothing is wrong with them—for such news seems to document their inability to experience their bodies correctly, adding to their suspicions that there must really be something wrong with them (Hilbert 1984:370).

Researchers have reported that chronic pain patients rely heavily on clinical diagnosis for legitimacy (Hilbert 1984; Lillrank 2003; Ong, Hooper, Dunn, and Kroft 2004; Rhodes et al. 1999). Pain sufferers spend considerable amounts of time and money seeing various practitioners in an attempt to find one who can offer them an adequate explanation for their pain (Garro 1992; Reid, Ewan, and Lowy 1991). In many cases,
when diagnoses are offered, they provide considerable relief. When treatment fails, however, the relief is replaced with loss of hope for a cure (Garro 1992; Good 1992a).

The question about whether chronic pain has physical origins goes far beyond whether it can be treated with biomedicine. Patients often feel the skepticism with which they are faced as an affront on their ability to experience their own bodies; as a suggestion that they are unable to handle stress or emotional difficulties; or as a suggestion that pain may be a product of their own minds, and as such, their own fault. The question of legitimacy and cause reaches into the realms of responsibility, strength, and moral worth of the sufferer (Ong et al. 2004). Patients are often compelled to seek multiple opinions, and when they continue to find that no diagnosis is available to them, they begin to question the knowledge of the practitioners, as well as the authority of the medical system itself. As Jackson (1992) eloquently states,

In a very important sense, the primary meaning connoted by ‘real’ pain is one of legitimacy—pain one is entitled to because one has in no way brought it upon oneself. Insofar as chronic pain serves an illegitimate function, it is in itself illegitimate (140)

A considerable portion of research on chronic pain has reported on pain sufferers search for legitimacy and credibility. Garro (1992) points out that questions of authenticity present an ontological challenge for sufferers since pain can never be proven or disproven, nor can pain be adequately explained or shared.

Without any option for making others understand the pain sensation, sufferers are confined to attempts to make their pain understood through the lens of legitimate pathology. Sufferers often attempt to establish the legitimacy of their condition through the use of expert terminology or clinical diagnosis to describe their ailments. Patients
struggle to present pain as real through their conviction that it does, in fact, have a physical origin (Eccleston, Williams, and Rogers 1997). Without a clinical diagnosis, physicians can only prescribe medications to alleviate pain. Without a verifiable physical ailment to support one’s claim to those medications, pain sufferers shift back and forth between the realm of legitimate sufferers in need of medication, to those regions inhabited by illegal drug addicts, liars and criminals (Jackson 2005). Pain patients struggle against their position in the realm of untreatable because if the cause of illness remains unknown, the burden of treatment is placed upon the patient, and they are seen as a lost cause (Eccleston, Williams, and Rogers 1997).

While patients do not perceive themselves as malingerers or as drug addicts, they are painfully aware of their fragile claim to an illness role in the eyes of the medical profession. For this reason, patients work hard to present themselves as credible patients in need of care. In the next section I will review some of the literature on the clinical encounter between chronic pain patients and biomedical practitioners.

*The Clinical Encounter*

There is a widespread belief in the medical profession that chronic pain sufferers without any legitimate physical complaint are malingerers wanting to claim care to which they are not entitled (Jackson 2005; Reid, Ewan, and Lowy 1991). The rise in chronic pain syndromes in Western contexts has been depicted in the literature as the increasing intolerance for any kind of pain (Barsky and Borus 1995). Barksy and Borus (1995) add that patients should be educated about the normative presence of bodily distress in
healthy people, and that symptom driven care is a negative outcome of people’s inability to handle normal pain. If pain treatments are unsuccessful and no physical origin can be identified, as mentioned above, patients are often referred to psychiatrists for alternative treatment (Baszanger 1989; Garro 1994).

With such an attitude toward pain permeating physicians’ understanding, clearly the clinical encounter does not often go as either doctor or patient hopes. Kleinman et al. (1992) view the multiple sources of frustration in the medical encounter as a way to look at the power relationships that exist in biomedicine as a whole. Bates (1996) argues that the medical profession’s view of pain patients as malingerers is often a case of “blaming the victim.” She argues that it is equally as likely that biomedicine’s failure to treat chronic pain is a gap in available medical knowledge. While there are many shortcomings in the way that biomedicine approaches chronic pain, one of the most important is that while the patient experiences the pain as a whole, biomedicine breaks it into a series of dichotomies—mind versus body, physical versus mental—until the patient and practitioner are almost entirely unable to speak about or address the same issue (Epstein, Quill, and McWhinny 1999; Kleinman et al. 1992).

Doctor-patient relationships, like all institutional relationships, are colored by issues of power versus powerlessness (Encandela 1993). A major difficulty that arises in the understanding of pain between patient and physician is that pain, in itself, is often not considered an ailment, and is therefore viewed as outside the scope of what physicians are expected to treat. The medical profession has had limited success in the treatment of chronic pain. Due to this failure of treatment, patients and their families often state that
doctors are insensitive to their needs, and that they are disaffirming of the illness experience (Epstein, Quill, and McWhinny 1999; Kleinman et al. 1992). In the medical literature on chronic pain, it is clear that doctors admire patients who suffer with dignity, or in other words, quietly (Jackson 1992).

Often, patients feel as though they are required to present their pain in particular ways in order to make it seem real and urgent in the eyes of the practitioner (Barsky and Borus 1995). Kugelmann (1999) found that many people felt they were not believed when they presented pain symptoms to their doctors. At the same time they admitted that they did not often follow doctors’ advice or believe what their doctors told them about the causes of pain. This atmosphere of distrust leads to frustration on the part of both patients and physicians who are unable to make themselves heard and understood.

Despite the frustration with specialists and pain doctors that was commonly reported, researchers have found that patients often have positive opinions of their general practitioners (this observation is not general to all ethnic groups, and may not be true for other ethnic groups have less trust in physicians in general (Doescher, Saver, Franks, and Fiscella 2000). Particularly after a series of frustrating encounters with specialists, patients wanted their doctors to be able to listen and offer compassion and credibility to their experience as much as they wanted diagnosis or treatment (Kugelmann 1999; Lillrank 2003; Reid, Ewan, and Lowy 1991). It seems there is a conflict between patients and practitioners in their attempts to establish legitimacy. While doctors achieve legitimacy by offering effective treatments, often in the form of pharmaceutical medications, patients seek legitimacy for their experience of pain. Patients want doctors
to admit that there is a possibility that there is a real problem that they are unable to find, while practitioners maintain that if there is no visible pathology, there is no real physical problem.

While patients struggle to affirm that their illnesses are indeed real and have identifiable physical origins, physicians are unwilling to sacrifice their legitimacy by admitting that there could be a physical origin of pain that they are unable to locate. Patients become angry that physicians are unwilling to admit that they do not know what is wrong (Jackson 1992), and physicians become frustrated that patients return with the same complaints. In such an encounter, there is little hope of resolution without one or both parties losing some degree of the legitimacy that they strive for. Werner and Malterud (2005) suggest that when dealing with chronic pain patients, physicians have the option of turning the clinical interaction into an empowering experience. Through a change in their approach, they argue that physicians can turn the patients’ vulnerability into strength.

**Issues of Gender in the Clinical Encounter**

Stories of women with chronic pain are inevitably shaped by culture and gender. Chronic pain is often associated with somatization, and inevitably with syndromes such as *hysteria* (Greek for “wandering uterus”), that are commonly associated with women (Wool and Barsky 1994). Perhaps as a reaction to the portrayal of women as complainers, many women avoided sharing pain symptoms with others and express dislike at hearing others talk about pain (Werner, Isaksen, and Malterud 2004). While
they attempt to counter stereotypes in the public through stoicism, however, in order to be credible as patients, women are required to perform differently. Often facing skepticism, lack of comprehension or lack of interest in their suffering on the part of medical practitioners, many feel the need to “look sick” when they go into the doctor’s office (Lillrank 2003; Werner, Isaksen, and Malterud 2004). Werner, Isaksen and Malterud (2004) reported that women are required to negotiate a picture of themselves as sickly and weak in order to fit within a biomedical definition of illness.

While many patients expressed difficulty in achieving credibility in the medical encounter, women may face particular difficulty in conveying the nature of their pain. Women in general are supposed to express pain more freely than men, and they often encounter pain at earlier ages (Encandela 1993). Hoffman and Tarzian (2001) found that women were more likely to be under-treated for pain than men, and in some cases women were more likely to be prescribed sedatives and men more likely to receive pain medication for similar symptom presentations. How women present themselves to doctors, and how they view themselves may differ significantly, however, and in the study conducted by Werner, Isaksen, and Malterud (2004), many women viewed themselves as strong and ill. Their experience of chronic pain was not perceived as a form of weakness, and those women, like many pain sufferers, continued to live their lives with and in spite of illness (Baszanger 1989).

Good (1992b) presented the stories of two women who recreated the meaning of their illness through work. These women found refuge from pain by excelling in their careers, and thus challenged traditional associations between work and illness. Good
argues that these women use work as a realm of meaning which they are able to contrast with pain. She uses the women in her study to challenge ideas about the connections between work, stress, pain, and discourses of causation. In Good’s case studies, the women use work as “a haven from pain.” For these women, their careers allowed them to fulfill the roles of high-functioning and successful people despite the debilitating effects of pain in other areas of their lives.

**Ethnic Differences in the Reporting and Experience of Chronic Pain**

Many studies have reported “racial” or “ethnic” differences in reporting of chronic pain, although the prevalence of chronic pain in racial and ethnic minorities remains poorly understood (Green, Anderson, Baker, Campbell, Decker, Fillingim, Kaloukalani, Lasch, Myers, Tait, Todd, and Vallerand 2003). The majority of literature suggests that African Americans report more pain severity and increased disability due to pain (Edwards, Doleys, Fillingim, and Lowery 2001; Green et al. 2003; McCracken, Matthews, Tang, and Cuba 2001). These differences, however, do not take into account the fact that the voices of both women and minority populations are often unheard (Green 2007; Nicholson, Rooney, Vo, O'Laughlin, and Gordon 2006).

In a review of chronic pain literature, Green (2007) reported that minorities are less likely to have their pain assessed, which leads to an unequal burden of pain. That review also found that minorities were prescribed pain medications less often than whites, and had more difficulty filling prescriptions for opioid medications regardless of income (Green 2007). Edwards et al. (2005) reported that African Americans and
Hispanics were more likely to report praying and hoping as coping strategies which was associated with greater disability. The differences in reported pain severity and disability cannot be disaggregated from the effects of under-treatment, underreporting, or other differences in perception (Green et al. 2003).

The relationship of cultural affiliations and differences in perception and social support variables have not been well studied and these differences could have significant impacts on the reporting of pain symptoms (Bates, Edwards, and Anderson 1993; Greenwald 1991). More research is needed in order to understand the nature of ethnic variability in the experience of chronic pain.

**Stigma and Living with Pain**

Many researchers have reported that chronic pain sufferers face considerable stigma surrounding their condition. Jackson (2005) and Lillrank (2003) reported that most sufferers report that they feel stigmatized. The stigma that results from the non-visibility of pain or from incorrect behavior often becomes part of their identity. Sufferers often experience skepticism in the workplace about their conditions from coworkers and employers (Reid, Ewan, and Lowy 1991). People with chronic pain are often reluctant to talk about pain because talking about pain is construed by sufferers as whining or complaining. They are careful to avoid things which are socially proscribed such as initiating depressing discussion or lowering social spirits (Hilbert 1984; Werner and Malterud 2005).
Baszanger (1989) reported that pain sufferers are required to adapt their lives to the pain and that they live with and in spite of illness. Miles et al. (2005) found that sufferers work to maintain a normal life even while faced with constraint. The limitations imposed by pain, both activity constraints and identity constraints, were often more important than the pain per se. When talking about pain, Ong et al. (2004) reported, people often simultaneously present pain as part of their normal lifecourse and describe the disturbing impact it has on their daily living.

*The Private Experience of Pain: The Isolating Effect of Indescribable Suffering*

An important feature of chronic pain is the private nature of suffering that tends to isolate a person from their community. Part of the inherent ambiguity of chronic pain comes from the fact that it is invisible. Separating the outcomes of pain from the pain itself is difficult, if not impossible (Jackson 2005). The bodily experience of pain is inherently private and subjective and as such cannot be truly shared (Baszanger 1989; Johansson, Hamberg, Westman, and Lindgren 1999; Ong et al. 2004). Pain’s subjective nature often contributes to distrust in clinical and in family relationships (Kleinman et al. 1992). The difficulty of explaining pain also affects sufferers’ social identity (Baszanger 1989).

Kugelmann compared pain to homelessness, as it can often become a somewhat existential dilemma. In many instances, the pain sufferer does not feel as though they can live in their own body (Kugelmann 1999). Illness forces an awareness of the body as distinct from the self (Garro 1992). Good (1992a) reported that when the pain is intense,
it brings the sufferer further into their own body and away from interaction with the outer world, which serves to further the already isolating effect of the pain.

Pain sufferers often experience pain as an alien force or a foreign invasion that exists within the body and threatens the self (Aldrich and Eccleston 2000; Kleinman et al. 1992; Ong et al. 2004). Because of the disconnection that results from pain, Good (1992a) found that it was difficult for pain sufferers to order time in terms of when pain is felt with what circumstances. Werner et al. (2004) reported that chronic illness is often looked at as touching the sense of self or even causing loss of self.

Making Meaning in a Life of Pain

Pain itself is as much a social construction as it is a product of biochemistry or psychological states. Socialization and culture are inevitably involved in how people react to pain and display their reactions (Encandela 1993; Hoffman and Tarzian 2001). Researchers have shown that differing perceptions of pain and illness affect treatment seeking behavior (Bates and Rankin-Hill 1994; Borkan, Reis, Hermoni, and Biderman 1995). Additionally, Bates and Ranking-Hill (1994) found that the locus of control style of an individual, which was often influenced by his or her cultural background, affected the individual’s ability to adapt to pain and live a meaningful life.

Scheper-Hughes and Lock (1986) argue that it is impossible to rid powerful human experiences of metaphor. They point out that there are real links between anger, unhappiness, anxiety, resentment, and morbidity. Much chronic pain research has focused on the process of searching for meaning in the experience of chronic pain. Kugelmann
(1999) argues that pain is a way of being in the world, just as pleasure is a way of being in the world. In an article about complaining about chronic pain, he argues that “‘Painmaking,’ like lovemaking, is a cultural performance which, like its analogue, entails voicing those things that tear one’s world apart, and hoping to have one’s case heard” (Kugelmann 1999:1674).

Because people are often struggling both to find meaning, and to make their voices heard, the ways in which their narratives are constructed have been the focus of some chronic pain research. The persistence of pain despite treatment forces people to summon resources extrinsic to basic folklore to organize their experiences into something that has a meaningful role in their lives (Hilbert 1984). Garro (1994) reported that patients construct past experiences through narrative in a manner that is congruent with current understandings about pain and illness. This finding builds on her previous research, from which she explains that for chronic pain the story is continuous. Patients often incorporate new information into their current constructions, or sometimes revise the narrative in order to accommodate new interpretations (Garro 1992).

**Narratives of Causation**

Like Garro, Eccleston et al. (1997) reported that stories of causation are important for making sense of the experience of pain. If the search for clinical diagnosis fails, researchers have looked to narrative to reveal sufferers’ constructions of causation. Ong et al. (2004) point out that interviews are inherently social encounters. The narrative that results from an interview is a performance, and is not necessarily what one might say or
think in another context. For this reason, however, Ong et al. argue that narratives are a useful way to understand how pain patients construct themselves as believable narrators of their own pain experiences. These authors argue that it is precisely because narratives change in both in time and focus that talking about pain can be read in multiple layers (Ong et al. 2004).

Research on pain narratives within anthropology has often been focused on the ways in which narratives of pain and pain symptoms demonstrate some of the characteristics of a human language (Brodwin 1992; Kleinman et al. 1992). Pain symptoms often function like a language, particularly because they are resistant to description using words (Emad 2003). In many cases, anthropologists have shown that pain can become its own form of communication (Brodwin 1992).

Anthropologists such as Brodwin (1992) and Kleinman et al. (1992) have shown that pain symptoms are often difficult to explain through narrative. Through their stories, including the breaks in speech and difficulties in finding words, it becomes apparent that pain sufferers often use their pain symptoms as specific forms of communication. Brodwin (1992) suggested that families are important to consider in the discussion on chronic pain. He argues that pain symptoms can also be used as a form of communication between family members, and that to deny or elaborate medical symptoms could index closeness between family members. Block and Boyer (1984) found that by being overly accommodating to or ignoring symptoms, families could influence the presentation of illness behaviors. Turkat et al. (1984) reported that the actual development of pain symptoms may be influenced by the presence of pain models within the family.
Hypothesized Genetic Influences on Chronic Pain

There is a hypothesized link between the occurrence of chronic pain and genetic variables (Marbach and Levitt 1976; Zubieta, Heitzeg, Smith, Bueller, Xu, Xu, Koepppe, Stohler, and Goldman 2003). Recent findings related to changes in mRNA configuration support observational data showing a relationship between catechol-o-methyl transferase (COMT) polymorphisms and TMD (Diatchenko, Nackley, Bhalang, Sigurdsson, Belfer, Goldman, Xu, Shabalina, Shagin, Max, Makarov, and Maixner 2005). Those COMT functions may also be associated with somatization, depression, and personality features related to resiliency (Wichers, Aguilera, Kenis, Krabbendam, Myin-Germeys, Jacobs, Peeters, Derom, Vlietinck, Mengelers, Delespaual, and van Os 2007).

Diatchenko et al. (2006) have reported from recent study data that analysis of haplotypes accounted for variation in pain sensitivity better than any single nucleotide polymorphism (SNP). COMT, because of its direct action on availability of catecholemines, has been studied as a key regulatory enzyme in cognitive function, affective mood, and pain perception (Hosak 2007; Montagna 2007; Savitz, Solms, and Ramesar 2006). The mechanism affecting individual sensitivity to pain is not well defined. In addition, there is evidence that the beta adrenergic receptors (β2 and β3) may be involved in TMD pain (Diatchenko et al. 2006; Nackley, Tan, Fecho, Flood, Diatchenko, and Maixner 2007). The β2 adrenergic receptor gene may be related to the psychosocial features associated with chronic pain, particularly somatization (Diatchenko et al. 2006).
An additional genetic feature that may have a role in chronic pain is the neuropeptide Y (NPY), which has recently been shown to be a major modifier of pain (Michel 2004). The NPY also plays a role in reducing behavioral and neurophysiological signs of acute and chronic pain (Smith, Moran, Abdulla, Tumber, and Taylor 2007). More research is needed to determine the implications of the possibility of genetic variables associated with TMD and other forms of chronic pain.

*Pain Treatment Centers*

The number of patients referred to chronic pain treatment centers is increasing (Allcock, Elkan, and Williams 2007). There is little agreement on how best to treat chronic pain, and as a result, there is considerable diversity in the approaches of chronic pain treatment centers (Csordas and Clark 1992). Csordas and Clark (1992) report on various approaches that are used by pain centers in order to address many loosely defined pain disorders. These authors argue that despite widespread disagreement as to the definition of chronic pain syndromes and their treatment, the creation of standards for the accreditation of pain centers could be detrimental to the field.

Based on their interviews with directors and administrators from various pain centers, they conclude that without clearly defined pain syndromes or accepted treatments, the creation of standards would likely mean standardization. Csordas and Clark point out that in such a contested field, standardization would effectively limit the choices available to patients and would limit the diversity in practitioners. In addition,
standardization of chronic pain centers as medical facilities would ignore the fact that chronic pain may be a largely non-medical phenomenon (Csordas and Clark 1992).

While other researchers agree that there is considerable diversity among pain centers, many have commented that pain centers often approach chronic pain as psychogenic (Jackson 1992; McCracken and Eccleston 2003). A popular approach to the treatment of chronic pain is to change the way patients think about their pain, particularly by encouraging them to accept its chronicity (Allcock, Elkan, and Williams 2007; Esteve 2007; McCracken 2006; McCracken and Eccleston 2003). This approach is focused on challenging the cognitive causes of chronic pain by breaking down patients’ mental constructs about pain that are resistant to change (Ciccone and Grzesiak 1984; Jackson 1992; Jackson 1994).

Jackson (1992) and Csordas and Clark (1992) found that chronic pain centers advocate seeing the pain as the problem rather than as a symptom. Most centers are focused less on actually eradicating pain, and more on changing patients attitudes about pain, and returning them to functional, productive lives (Allcock, Elkan, and Williams 2007; Esteve 2007; Jackson 1992).

**Complementary and Alternative Medicine in the Treatment of Chronic Pain**

Complementary and Alternative Medicine (CAM) refers to the diverse medical and healthcare systems, therapies and products that are not considered part of biomedicine (NCCAM 2007; Tan, Craine, Bair, Garcia, Giordano, Jensen, McDonald, Patterson, Sherman, Williams, and Tsao 2007). As defined by the National Center for
Complementary and Alternative Medicine (NCCAM) there are four types of CAM: whole medical systems; mind-body medicine; biologically based practices; and energy medicine (NCCAM 2007).

The widespread use of CAM in the treatment of chronic pain is partially due to the lack of safe, effective treatments offered by biomedicine (Tan et al. 2007; Weiner and Ernst 2004). Despite the fact that most of these treatments are not covered by insurance (Weiner and Ernst 2004), the use of CAM therapies is widespread among people with disorders such as chronic pain, insomnia, anxiety, and depression (Cauffield 2000; Ernst 2004; Mamtani and Cimino 2002; Weiner and Ernst 2004). Many physicians, anthropologists, and other researchers have argued that integrating CAM practices into biomedicine could provide more holistic and effective health care (Micozzi 2002; Tan, Alvarez, and Jensen 2006).

Micozzi (2002) argued that traditional medical systems represent new interpretations of ancient healing practices in light of new beliefs about health. He pointed out that interest in CAM within the field of biomedicine is paralleled by a conceptual shift in the way we understand, explain, and interpret health in a broader context. Micozzi summarizes the approach of CAM practices by saying that “Ancient and indigenous medical systems think of the human body as having a kind of vital energy, the balance of which is critical for health and the flow of which can be manipulated to maintain and restore health” (Micozzi 2002:400).

While Micozzi has been criticized for portraying CAM practices – which consist of diverse healing systems from various cultures – as homogeneous (McGuire 2002;
Pizzorno 2002), other researchers confirmed the assertion that a central belief in CAM is that the body has the ability to heal itself (Pizzorno 2002). In general, CAM practices treat the whole person, they are patient-centered, and attempt to restore health and function rather than treating symptoms only when pathology arises (Pizzorno 2002). In addition, CAM is more apt at providing the empathy that patients often seek (Tan, Alvarez, and Jensen 2006), particularly for those who have chronic conditions without effective treatments.

Anthropologists have critiqued the integration of CAM into biomedicine for reasons such as the consumer-driven aspects of its acceptance (Baer 2002) and the practice of integrating only those aspects of healing systems which can be turned into commodities (Adler 2002).

Despite the methodological difficulties in measuring the outcomes of CAM (Kaptchuk 2002), a number of studies have reported on the efficacy of CAM treatments for chronic pain conditions (Ernst 2004; Myers, White, and Heft 2002; Weiner and Ernst 2004; White 2006). The fact that most CAM treatments are associated with fewer side effects than conventional therapies is an important factor in their use in the treatment of chronic conditions (White 2006). Several studies have reported that chiropractic health is effective in reducing musculoskeletal pain in short term studies (Nyiendo, Haas, Goldberg, and Sexton 2001; Weiner and Ernst 2004). Côté, Cassidy, and Carrol (2001) reported, however, that these findings are inconclusive due to the possibility that patients using chiropractic care have fewer comorbid conditions and are less limited in their activities than those consulting medical doctors. Several reviews have reported that a
number of studies show that acupuncture and Chinese medicine are effective in the management of chronic pain conditions (Thomas, MacPherson, Ratcliffe, Thorpe, Brazier, Campbell, Fitter, Roman, Walters, and Nicholl 2005; Weiner and Ernst 2004; White 2006). Reviews of the literature on the effectiveness of CAM therapies overall, however, are inconclusive and more research is needed to determine efficacy both in terms of measurable, and of “subjective” outcomes (Weiner and Ernst 2004).

**TMD as a Specific Form of Chronic Pain**

Within the social science literature on chronic pain, there are only a few studies that have reported specifically on the Temporomandibular disorders (TMD). Researchers have reported that TMDs are similar to other chronic pain disorders (Suvinen et al. 2005). Particularly TMD pain that is associated with muscular origins is reported to be associated with “emotional dysfunction” (Auerbach, Laskin, Frantsve, and Orr 2001). The majority of complaints related to TMD are due to associated pain (Dworkin 1995). Some researchers have found that pain associated with eating and chewing, which is common among sufferers of chronic TMD, is associated with reports of decreased quality of life and a negative impact on the sufferer’s mood (Kafas and Leeson 2006).

Like other pain sufferers, TMD sufferers commonly come to a diagnosis only after a taxing search for answers from multiple practitioners (Garro 1994; Lennon, Link, Marbach, and Dohrenwend 1989). Garro (1994) reported that no participants in her study reported having seen only a single practitioner, and that numerous medical visits often lead to financial difficulty because TMD is not covered by most insurance. TMD is not
typically recognized as a legitimate illness by the medical profession, and patients are often caught between dentists and doctors who refer them back and forth (Ostermann, Dowdy, Lindemann, Turp, and Swales 1999).

Lennon et al. (1989) found that TMD sufferers, like other chronic pain sufferers, report that they feel stigmatized due to the ambiguity of their condition. Unlike psychologically based etiologies for chronic pain, however, the association of TMD with clenching and grinding was not difficult for patients to accept. People are able to attribute their illness to something concrete such as a car accident or overuse (Garro 1994), which makes legitimacy of the pain itself somewhat less of an issue. Despite this rather concrete seeming diagnosis, treatment is largely ineffective, and some treatments, such as surgeries, create more problems than they address (Garro 1994; Ostermann et al. 1999).

There has not been much research done on the sufferers’ views of TMD and its impacts on their lives. Although in many ways TMD is similar to the experience of other forms of chronic pain, the unique aspects of the experience of TMD remain poorly understood. More research is needed to understand the specific outcomes of TMD on individual experiences, particularly as a form of pain that affects a high percentage of people at many stages of life. In addition, more research is needed to determine whether the experience of TMD has changed as a result of increased awareness or understanding in the fifteen or more years since the majority of research was completed.
Previous Methods used in the Anthropology of Chronic Pain

Previous studies of the experience of chronic pain in anthropology, the most well known of which are found in the volume edited by Good, Brodwin, Good, and Kleinman (Good, Brodwin, Good, and Kleinman 1992), have been based almost entirely on lengthy, semi- or unstructured interviews with a few informants. One section of this volume was based on ethnography conducted in a chronic pain treatment center (Jackson 1992).

The private and subjective nature of pain (Baszanger 1989) makes it inherently difficult if not entirely impossible to do observational research on the experience of chronic pain. Many pain sufferers, due to the stigma that is associated with their conditions, do not outwardly express the pain they experience. Due to its invisible and private nature, narrative analysis based on lengthy interviews, is the typical method used in anthropological and other qualitative studies of chronic pain (Good et al. 1992; Honkasalo 2000; Ong et al. 2004).
METHODOLOGY

The interviews on which this analysis are based were collected as part of a larger study aimed at assessment of the outcome for participants diagnosed with TMD after training in pain self-management (based on the protocol created by S. Dworkin and E. Truelove) and treatment with Traditional Chinese Medicine (TCM). The study, “Traditional Chinese Medicine for Temporomandibular Joint Dysfunction: A Multi-Site Whole Systems Trial,” recruited 85 participants from each site (Tucson, AZ and Portland, OR) and provided them with various combinations of self-care management training and treatment with TCM, including acupuncture and herbs. All participant names have been changed for protection of their privacy.

As mentioned above there are few effective treatments for managing chronic pain (NINDS 2001), and increasingly, sufferers’ are seeking care from complementary and alternative (CAM) healing modalities (Cauffield 2000; Tan et al. 2007). Many researchers have called for research focused on the efficacy of CAM in the treatment of chronic pain (Côté, Cassidy, and Carrol 2001; Kaptchuk 2002; Weiner and Ernst 2004). The Traditional Chinese Medicine component of this study is intended to provide more insight into the outcomes of Chinese Medicine treatment for TMD.

CAM therapies are described as more “intuitive,” “individualized,” “empowering,” and “holistic” (Barrett et al. 2004:255). In addition, while allopathic medicine generally focuses on pathologies and symptoms, CAM modalities are generally more oriented toward treating the underlying causes of ill health, and maintaining wellness rather than combating illness (Barrett, Marchand, Scheder, Appelbaum, Plane,
The participants in this study, based on the inclusion criteria, were those TMD sufferers who had not previously found an effective treatment for pain. The qualitative component of the study, on which this analysis is based, was designed with the intention of measuring the more subjective outcomes of Traditional Chinese Medicine treatment. Using in-depth interviews, the qualitative component is more suited to determine whether the treatment had affected participants in ways that would not be visible through quantitative survey questions. Outcomes commonly missed by quantitative studies include whether the patients felt “empowered” or able to achieve the mental and physical balance required to restore his or her own health (which is one of the primary goals of many CAM treatments) (Verhoef, Lewith, Ritenbaugh, Boon, Fleishman, and Leis 2005). Additionally, the interview questions sought to assess whether patients had gained functionality in their lives, had paid more attention to their health in other ways, or had changed the way they thought about living with pain.

Study participants were recruited through community-based recruitment strategies such as distribution of posters, newspaper advertisements, and outreach to and recruitment through dentists’ offices. A typical poster or advertisement stated that the study was looking for people who suffered from moderate to severe jaw and facial pain, and that treatments might include a combination of training in pain self-management and Traditional Chinese Medicine. Approximately half of the participants were selected randomly from each site and asked to participate in qualitative interviews. The interviews
were designed with questions targeted at understanding participants’ experiences and views as they entered the study, and at specific points during and after treatment.

**Inclusion and Exclusion Criteria for Study Participants**

Criteria for eligibility in the study required that participants: be between the ages of 18 and 70 years; have a diagnosis of TMD; report pain levels (headache or facial) of 5 or higher; have one of the TCM diagnoses included in the treatment protocol; and be willing to complete a symptom history and symptom questionnaire.

Exclusion criteria included: being unable to follow the study protocol; a history of serious psychiatric conditions; a history of surgical implants for treatment of TMD; bleeding abnormalities; conditions whose medications preclude the use of Chinese herbs; other life threatening conditions; infections in facial area; inability to read and understand study questions; use of full dentures; or pregnancy at any point during the study. In addition, patients in need of more aggressive treatment for severe joint/disc displacement were not included.¹

**Analysis of Baseline Interviews: Relevance to the Research Study**

The analysis presented here is based one baseline interview with each participant, and explores their past and current experience with TMD pain and treatment seeking, as well as their expectations for treatment on entrance into a research study. The non-biomedical treatment protocol used in the study warrants investigation of outcomes that

¹ Exclusion criteria listed as described in final protocol description for the study by Dr. Cheryl K. Ritenbaugh, PI.
are not easy to assess through the use of reported pain levels or other numerical outcome measures. One of the goals of this thesis is to more fully understand the participants’ patterns of living with TMD pain, which will be useful in later assessment of the outcomes on all areas of sufferers’ lives and their understandings and experience of TMD.

**Description of Interviews Used**

In all, 47 interviews were completed and transcribed: 27 interviews with participants in Tucson and 20 interviews with participants in Portland form the basis of this analysis. Interview length ranges from less than 25 minutes to more than one hour. Most interviews were conducted in an office that was used for the project, and they were introduced as a way to understand people’s experience as they entered the study. There were approximately 47 interview questions asking for aspects of experience including: sleep, relationships, work, stress, family life, self-care activities, experiences with both biomedical and alternative health care practitioners, and expectations about the study. The full interview introduction and questionnaire is included in the appendix.

The 27 Tucson interviewees included 6 men and 21 women, and the 20 Portland interviewees included 3 men and 17 women. I conducted all interviews in Tucson, and interviews in Portland were completed by trained interviewers working on the project. Participants ranged in age from 18 to 69. The average age of participants in the sample was 39, and the median age was 36. All names of participants in this thesis are pseudonyms to protect the privacy of participants.
The majority of participants were Anglo-American middle class and held steady, professional jobs (as teachers, health care professionals, administrative personnel, or customer service representatives) in addition to having families or long-term relationships. The onset of TMD pain had occurred recently for some and for others as early as adolescence. The use of over-the-counter analgesic medications was common among participants, and a few were using prescription pain medications or sleep medications. The use of prescription pain medications however, was not widespread among participants.

Although most participants I interviewed were working, the lack of adequate health insurance coverage for treatment of TMD was a motivating factor to participate in the study. Because of the small number of men (n=9) included in the sample, I am unable to comment on gender differences. It is important to note however, that based on the interviews conducted, there appeared to be few, if any differences between men and women.

**Analysis of Interview Transcripts**

All interviews were transcribed verbatim and coded manually for basic themes. After initial analysis they were recoded for more specific ideas based on identified themes. Initial codes were concepts loosely based on the interview questions such as sleep, coping, feeling pain, worse pain, and families or relationships. Later codes included expanded versions of the original codes, as well as additional codes for themes
that were identified during the initial coding process such as stress and emotions, medications and coping difficulties, hope, anxiety, intimacy, and the future.

While in the midst of analyzing the initial set of 47 interviews used in this thesis, I was able to continue conducting interviews with TMD sufferers. Although I completed most of the interviews used in this analysis before June, 2007, I continued to conduct interviews until October, 2007 and I completed more than 45 interviews overall (which do not include the interviews that were completed in by interviewers in Portland). The majority of interviews used had already been transcribed, and additional interviews were selected and transcribed for their usefulness as case studies or the insightfulness of the participants. As themes emerged, I was able to continue to ask questions and probe further into these themes in interviews. While I did not ask additional questions, I was able to ask for more thorough descriptions of what people meant by their comments that spoke to specific themes in which I was interested. This iterative process of identifying salient themes and then discussing the issues in greater depth with new informants allows me to feel confident about my findings.

The Interview Process

As I will discuss further in the following section, one of the primary factors that exacerbates TMD pain is awareness of the pain itself. The primary coping strategy for many TMD sufferers was to ignore the existence of pain whenever possible. To be able to forget the pain, or push it so far into the background that it was no longer bothersome was the most common way to deal with its constant sensation. The interview process was
often affected by the fact that for many sufferers, talking about the pain caused the pain to come into the foreground of their consciousness, making it seem more severe.

Often, participants would grimace during interviews and say that talking about pain was making it worse. While it was clear that for many people, having someone to share their experience in a non-judgmental setting was a welcome experience, the pain that it caused often led to a situation in which people seemed torn between sharing their stories and theories about TMD while working to maintain their disassociated stance toward the feeling of pain. People were careful to construct their narratives in a way that allowed them to share the aspects of dealing with TMD that were important to them. It often seemed as though they were coming to an edge, and were simply unwilling to delve completely into the description of and awareness of pain. While there may have been information that was not shared as a result, the fact that people were guarded in the way they talked about pain is significant of the way in which pain is forced to the background in order to cope with its omnipresence.

Often sufferers had constructed narratives that were meaningful to their experience, and that could be easily shared, but when I asked more personal questions about families and self awareness, it became more difficult to avoid the awareness not only of pain, but of the ways in which it impacted the sufferer’s life. Not only was the pain pushed to the background of experience, but also the impact that pain has on daily life is carefully minimized. When I asked them explicitly to describe this impact, however, I often felt as though I was in some way affecting the level of pain that was experienced that day, as well as the level of awareness about the negative outcome of
pain on the person’s daily activities. These issues of awareness will be discussed further in the following sections, but as it relates to the interview process, the fact that I was adding to current pain levels may have reduced my willingness to probe for information about sensitive issues, and likely impacted the quality of the interview.

In addition to the increased severity that is associated with talking about pain, describing pain to another person, particularly an unknown interviewer, often seemed quite difficult for people. The body language used to convey the severity of pain and the facial expressions that accompanied informants’ discussion of these difficult topics cannot be easily described. It should be noted that interviewing a person who is visibly in pain, who is sitting in an uncomfortable chair, and who is attempting to describe a pain that is increasing with the very process of thinking carefully about it is a unique experience.

Theoretical Tools Used

Illness narratives are a useful way for people to explain and contextualize their selves and lives (Reissman 2003). Narrative situations allow people to create meaning or coherence out of lived experience, and challenge them to make sense out of enigmatic and frustrating situations (Ochs and Capps 1996). Using narrative, people are able to situate their selves in terms of past, present and future experiences. According to Ochs and Capps (1996), the function of narrative is to allow sufferers of chronic illness to generate a multiplicity of partial selves. They point out that selves are inseparable from
narrative, an argument that is grounded in the phenomenological notion that experience is what provides entities with meaning.

Using Bakhtin’s “heteroglossia,” or the idea that people are exposed to multiple cultural situations which they internalize in different ways, Strauss (1993) argues that since people are constructed by social messages which are never consistent, people are never consistent either. In her analysis of a retired factory worker, Strauss displays the process by which an individual can display multiple, seemingly contradictory voices within the course of an interview. Following Kondo (1990), Strauss pointed out that subjects have multiple identities which become the site for potentially conflicting meanings. Because interviews are one of the few places where a person would ever be faced with the need to juggle inconsistent beliefs, narrative is an important way to situate people in the context of their experiences, memories and feelings (Strauss 1993).

Multivocality does not imply that there are a multitude of characters within a unified objective world, but that there is a polyphony of voices, or a plurality of perspectives and worlds (Hermans, Kempen, and VanLoon 1992). According to Hermans, Kempen, and VanLoon (1992) “the dialogical self” allows an individual to live in a multiplicity of worlds. The ability to construct multiple selves allows individuals to negotiate how they want to be known, and to reveal not an essential self, but a preferred one (Reissman 2003).

As Good and Good (1991) argue, narrative can uniquely position reality as being open to mystery, potency and change. In their analysis of epilepsy, they found that in chronic illness, sufferers maintain ambiguity, or a “subjunctive reality.” Narrative is a
way for sufferers from chronic illness to “subjunctivize” reality, which leaves alternate possibilities for the future available. Because people living with chronic illness are uncertain about the meaning of events that have already occurred, and even more uncertain about the future, narratives can portray the future as uncertain, and effectively allow people to retain hope for the future (Good and Good 1991).

Throop (2002), using Dilthey’s “descriptive psychology,” argues that the anthropology of consciousness should focus on experiences like pain that are ambiguous and require informants to struggle to articulate and verbalize their sensations, perceptions and feelings. By examining those experiences that are resistant to cultural patterning, Throop suggests, we can better understand pre-objective modes of experience (Throop 2002).

**Limitations of the Data**

The analysis presented is based entirely on interview data. It does not include interviews with participants’ family members, friends, or other members of their social networks, nor does it include observation of how the pain affects daily activities. My observations and comments are based entirely on sufferer’s perceptions of TMD pain and its impact on their lives.

Pain is a subjective and personal experience that is inherently difficult to put into words and communicate to others. The difficult nature of describing pain could be viewed a shortcoming of using narrative analysis with this type of illness. Narratives about illness and events surrounding it however, are a useful way to understand sufferers’
experience of pain and how they attempt to make sense of it (Garro 1994; Good and Good 1991; Ochs and Capps 1996; Reissman 2003). For this analysis the severity of pain that a person reported may actually be secondary to impact of pain as they describe it. Therefore, narrative analysis is a logical way to understand TMD and how people cope and make meaning in other areas of life as a result of living with pain.

The possibility of generalization about the experience of TMD sufferers is limited. The use of reported pain level as a criterion for eligibility in the study limits the sample to people who have been unsuccessful in coping with pain, or who have not sought treatment for pain for other reasons. The qualitative interviews, however, were randomly selected from among the study participants.

Since the experience of chronic pain associated with TMD is also likely to be limited to those sufferers who have not found effective treatment for pain, the exclusion criteria for the study are actually limiting participation to those participants for whom TMD is truly a form of chronic pain. This analysis is focused on TMD as chronic pain. Therefore, although I am not presenting a random sample of TMD sufferers, the participants included are likely to be representative of the population of TMD sufferers for whom the pain is a chronic condition.
EXPLANATORY MODELS AND COPING STRATEGIES

Sufferers’ Explanations of Illness Causation

In interviews, participants were asked to discuss their understanding of TMD as a disorder in terms of its cause, progression, and outcome. Most informants had a considerable understanding of the causes of the disorder, but knew less about illness progression and outcome. Sufferers’ understandings of TMD were varied, although many were loosely based on what physicians have explained or what people have read or heard. Many people said that the original cause of their TMD pain was a traumatic incident such as a car accident. Others said that their jaws were not correctly formed, or that there was a genetic reason that their jaws did not fit together properly.

Having jaws that were out of alignment, or perhaps that had simply been overused were common explanations for why the pain became chronic. While most people began their explanations with structural or physical causes of illness, most discussed “stress” as an important exacerbating factor. Unlike other chronic pain disorders, participants seemed to have little difficulty describing the physical reasons for pain. Additionally, causes were often related to the fact that for most people, the pain worsens with stress.

The pain from TMD according to sufferers is often associated with deterioration of the cartilage in the jaw as a result of various factors including deformity, arthritis, overuse, trauma, and clenching or grinding the teeth. Many had seen the deterioration in x-rays, or had been told by physicians that they suffered from deformed bones, misalignment, osteoarthritis, or bone loss. The relationship between physiological causes
of pain and stress is somewhat difficult to reconcile. Many sufferers seemed to shift from a structural, physical or genetic cause of TMD to an unstructured, loosely conceived description of how stress can exacerbate a physical problem.

In the following examples, it seems the sufferers describe stress or emotional trauma as the root cause of their illness, while at the same time describing their pain as being caused by something profoundly physiological.

[The pain] kind of comes and goes though, um, it’s um, I guess a heavier workload than I’m used to and so normally things might not get to me but when it’s crunch time, I can tell that my stress level sort of goes up, or things that would bother me-not bother me normally kind of get to me. And that’s when my TMJ flares up too. There’s a real direct correlation…with the stress… it’s really my stress and how I’m dealing with it … Um, but during the course of the, that TMJ treatment, you know, they do the x-rays and everything and, and my, I do have osteoarthritis in, I guess in the right hand side so it’s just kind of bone on bone so, it’s pretty, it’s pretty bad but, there’s really not much they can do. (Georgia, 36)

Georgia sees a clear link between times when her jaw pain flares and the level of stress that she is dealing with. She points out not only that she is aware of the link between pain and stress, but also that she notices that the pain is affected by the way she deals with stress. Despite her description of the pain as being a product of how she deals with stress, she goes on to explain the origin of her pain as osteoarthritis in the right side of her jaw.

Like Georgia, Patty described her pain as a physical problem, but then explained that she was increasingly connecting the pain to emotional difficulties.

Um, my understanding is, it is a jaw problem, but the, I also know like underneath somewhere too that it’s a stress thing. You know, that it’s a, um, what do you call it? Like a stress disorder… Um, before, I just thought it was the physicalness of my jaw, you know, displacement from having braces, whatever, but um, now I’m, I’m coming to see more that it’s, you know, it’s something emotional I guess… It’s just a, um, it feels like you bone, jaw bone is rubbing back and forth. You know, bone on bone
and, and most of the time I, if someone asks me I just have them feel my jaw… And sometimes I think the people on the other can hear it clicking when I talk, you know, if I’m having a real rough day. I can hear it… It’s, you know, crunching and, and bone against bone and, constant uh, like muscle ache or, that’s probably enough, like I don’t know, it’s hard to explain. (Patty, 47)

It appears that many TMD sufferers are caught between a desire to convey the truly physiological, serious and incurable nature of their pain, while at the same time they are acutely aware of its connection with stress caused by difficult life situations or events.

Some people connected their jaw pain to holding in emotions, or not speaking when they want to. Instead of speaking and sharing their emotions, particularly sadness or anger, sufferers explained that they tend to clench their teeth, which causes TMD pain.

Yeah. Just, not my, like not the actual situations, but just having to um, one curb what, what I say, you know, like someone demeaning you but not being able to say anything. (Patty, 47)

Definitely, stress… Umm, [short pause] and I, a broad term for it, yeah. There are, like, more specific things, like, if I’m in a situation where I feel like I can’t say what I mean to say, I notice my jaw, my jaw starts to tighten and clench. (Josie, 29)

I don’t know, things that I’m not throwing out there and like, externalizing if that makes sense, like maybe whatever upsetting thing, or like stressful things that I am actually like holding onto seem to be more related to the TMD. (Sandra, 29)

Much of the literature on chronic pain in general discusses sufferers’ reluctance to admit that there may be a psychological origin of their pain (Eccleston, Williams, and Rogers 1997; Garro 1992; Jackson 1992). While not all of the TMD sufferers I spoke with connected their pain to stress, the majority were openly aware of and willing to discuss the impact of stress and emotions on their experience of pain.

Stress in this situation, as mentioned in the literature review, is used as a catch-all to describe emotions or adverse events in life that are manifested as physical pain or
tension (Kugelmann 1999). Stress appears to be a safe way to acknowledge a psychosomatic component without minimizing the structural nature of the jaw pain. In addition, while it is likely that these sufferers were careful to describe the physical origin of their pain in order to maintain legitimacy, they may have been more willing to discuss other, less biomedically based origins of pain as a means of expressing hope about the possibility of treatment with Chinese Medicine.

**The Search for Diagnosis and Treatment**

Earlier studies of Temporomandibular disorders reported that sufferers often searched for diagnosis for an unknown source of pain (Garro 1994; Lennon et al. 1989; Ostermann et al. 1999). TMD was not well-known, and sufferers reported seeing various practitioners and spending considerable amounts of time and energy searching for diagnosis. As Linda Garro states about narratives from TMD sufferers in 1994,

> The narratives relate how, over time, persons come to accept TMJ as an appropriate label for their illness. But before this occurs, individuals are often immersed in a protracted and taxing search for diagnosis, with conflicting interpretations for their illness, including suggestions or intimations that their illness is psychologically, and not physically, based. The search for effective treatment is no less difficult and is often inconclusive or results in therapeutic strategies which provide only partial alleviation. (Garro 1994: 776)

What I found in these interviews, more than ten years after much of the anthropological research on TMD was collected, was somewhat different. As I have mentioned previously, sufferers often spoke insightfully about the psychological component of TMD. In addition, it was not uncommon for people to state that they were diagnosed with TMD based on clicking sounds in their jaw long before they began to
experience pain. Being diagnosed before the onset of pain impacted treatment seeking, since many people were told there was nothing that could be done. Unlike Garro (1994) I spoke to several people who had seen only one practitioner, or who were self-diagnosed with TMD prior to entrance in the study and had never sought treatment.

I don’t really know, um, I think uh, it- it was just someone talking about, “well that that’s the way TMJ is- or uh, TMJ, TMD is, is that it’s um, that your jaws pop.” And um, I think I, probably the first time I, I first figured out that I had it was when I yawned and it, oh go- you know when you yawn and it, all the sudden it hurts? Um, so then I wondered what that was and that’s probably when I figured it out. (Margaret, 63)

I don’t know, I can’t remember exactly how I made the connection [that it was TMD]. But uh, it seemed to me it was just the fact that my bite was off, and, and it was just uh, uh you know, kind of an ongoing irritation and it was painful and, so I think I, I just started. I don’t remember how I connected it to TMJ. I think I, it, somebody told me that might be what it was, I don’t remember… Um, no I haven’t tried anything else [other than a specialist, which did not help]… I just haven’t taken the initiative. I haven’t heard of any good treatment I guess, I you know have done a little research on it and it seems like there’s really no, no good treatment… it’s just a matter of dedicating the time to it. You know, I don’t want to spend a lot of time on something that has no real prospect of being that useful. (Keith, 61)

For others, when asked when they were first diagnosed with TMD, instead of telling the story of a taxing search for diagnosis, they could not remember how they came to find out they had TMD.

Well, I can’t really remember [the diagnosis], but I mean I’ve always had the cracking in my jaw, and been uncomfortable, and a dentist, when I was fifteen wanted me to get braces to fix the problem….I did not. I started out in a retainer, and then I just didn’t have proper, adequate health insurance and pretty much that’s the story… My mother definitely has [TMD] and she’s gone to a doctor much more… for it than I have. (Katia, 37)

It is important to note that Katia states that her mother did see several doctors for TMD. The fact that many sufferers in this study were familiar with the symptoms and
lack of treatment for TMD before they experienced it led them to avoid the search for
diagnosis and treatment, and to be resigned to living with pain.

I’ve always known [I had TMD], because I’ve always had a click, and you know I
used to be able to make it click and always made, you know loud noises and
everything, but it never bothered me. And then, the last year or two it started
bothering more, and then I noticed I wasn’t doing a lot of stuff, just without realizing
it. Not chewing gum, not eating hard vegetables, that kind of stuff. And then it got a
lot more painful. And I realized, oh, that must be why I’m doing that. (Susan, 38)

While as I demonstrated above, many participants felt as though their physicians
were disinterested in offering treatment for TMD, few reported feeling as though they
were not believed. Many people had received a diagnosis of TMD from their primary
care physician, and some had been offered various types of muscle relaxing medications
or narcotic pain medications. Garro (1994) reported that many TMD sufferers felt
vulnerable to being categorized as suffering from a problem of the mind rather than of the
body.

What I found, however, was that many people accepted TMD as an illness with a
visible physical component. Some had seen X-rays of their bone degeneration, or had
been told they had osteoarthritis in their jaw that was related to TMD. Unlike previous
studies of TMD, I found that people were willing to discuss the psychological
components of TMD not because they were willing to let go of a physical component, but
precisely because they did not feel as though the legitimacy of the physical source of
their pain was in question.

It is possible that this difference in my findings is due to the proliferation of
knowledge about TMD both in the public and in the medical and dental professions. As
TMD has become more widely known, sufferers are more often given diagnoses of TMD
based on the clicking in their jaw, even before they begin to experience pain. This difference in knowledge about TMD might be associated with a significant difference in the experience of TMD pain, as well as the way in which sufferers cope with pain and attempt to seek treatment.

Perhaps more importantly, the recruitment for this study included posters and other public invitations to participate. For this reason, it is possible that unlike studies that recruit participants from practitioners or chronic pain centers, the sample includes a population of TMD sufferers who live more stoically with pain. The offer of free alternative care may have appealed to sufferers who would not otherwise have been found seeking treatment in medical facilities. The sample also includes people who were diagnosed with TMD before they began to experience pain, and accepted that there was no treatment available. Many people were involved in their own strategies for managing pain, or attempted to live with pain by simply ignoring its presence.

**Coping Strategies and Difficulties**

No matter how excruciating the pain is, if you know it’s going to go away, you can probably put up with it. But, you don’t, this, you, you know this one’s not going to go away. It may become less, but it’s not goin’ away. And it’s coming back tomorrow. (Steven, 54)

Coping strategies that can be consciously explained by sufferers are not highly variable. As Hilbert (1984) stated, however, coping is something that chronic pain sufferers engage in continuously whether they wish to or not. Strategies for dealing with pain include avoiding chewy or hard foods, not chewing gum, massaging the jaw area, using ice or heat, herbal teas, Transcutaneous Electrical Nerve Stimulator (TENS) units,
physical therapy type exercises, and various pain medications. Although many people use these strategies regularly, most people said that they provided only minimal if any relief. Additionally, although professional massages or chiropractic treatments had provided short-term relief for many participants, the expense of those appointments was too much for most people to afford continuously without promise of long-term beneficial outcomes.

This analysis, as previously stated, is not based on a random sample of TMD sufferers. The people interviewed represent a small percentage of TMD sufferers for whom common techniques for treating or reducing pain proved insufficient. Therefore, although there are many therapies available for coping with TMD, with these sufferers, what was more commonly discussed when I asked people what they did to reduce pain were some of the coping techniques they had tried but failed. People often said they were simply not motivated to do exercises or other techniques on a daily basis, but also that there were obstacles such as allergies and medication interactions that prevented them from using common pain relief strategies such as over-the-counter pain medications, aromatherapies, or herbal teas.

One difficulty expressed by informants, particularly those whose pain was related to stress, was that physical exercise, usually an effective way to relieve tension and stress, was hard for them. Many TMD sufferers explained that although exercise may be beneficial for their overall sense of well-being and stress management, it is often a time when they clench their teeth or have to strain their bodies in other ways. Thus, exercise is viewed as something that can both cause and relieve pain, which leads to a dilemma. The following short case study provides an example of a young man who is profoundly
affected by his chosen method of exercise – skateboarding – in terms of his ability to relax and let go of stress, while at the same time being fearful of the long term effect on his TMD pain and the overall health of his body.

Case Study: JR

Well I’m a skateboarder also, so, I’ve hurt myself many times. And I don’t know, it all caught up with me, all at once just, everywhere… Skating is the only thing I can figure out really that makes me feel real good. Just like my head not hurt, but then when I’m done skating it’s even worse really.

JR is twenty years old. He has been skateboarding for years, and has a surprisingly nuanced view of the sport. JR recently completed his first semester in college, and he plans to major in fine art. Although he completed the semester, he found it difficult to concentrate and go to class on many occasions because he wakes up every day with an intense headache associated with TMD. Although he wonders if other elements might have contributed to his experience of TMD, JR explained that the primary reason for his daily experience of pain is the fact that he pushed his body too hard in his desire to become a skateboarder. For years, he explained, he fell often and performed various jumps and hops onto concrete surfaces.

I started when I was like twelve… super-skinny, didn’t uh, didn’t work out, but I loved to skate so I’d just keep hitting the cement, breaking bones… but uh, yeah, I don’t know. I c- if I would’ve, if I could- all go back in time, back in time now I just wish I would’ve just, physically trained myself better.

Despite his high level of daily pain, JR continues to skateboard regularly. He is no longer as reckless as he used to be, and although he continues to think that skateboarding adds to his pain, he also views it as an important part of his daily activity.
Nothing else makes me as happy as skateboarding does. I don’t know, the feeling you get, just flying through the air.

The time of day that JR feels free from pain is only the time when he is skating. Normally, the pain in his head and jaw is so intense that he finds it difficult to be outside during the day. While he is skating, however, he is not aware of pain, and feels entirely pain-free. He compared the feeling he gets during this activity to something like meditation.

I probably have about like four hours a day of feeling pretty good. I guess it depends on what I’m doing. If I’m skating though, as long as I’m skating I’ll be feeling good… When you’re skating, the way you’re thinking is just, I don’t know, you can just clear your mind, focus, and you, I don’t know. I think it’s a good way to like, deal with things… I don’t know what it is about skateboarding, but it can take away my pains and give me more.

While many people expressed similar dilemmas in terms of exercising or other activities and pain, few were as clear cut as what JR experienced. Particularly now that he suffers from intense TMD and other bodily pain and sees it as the result of skateboarding, he finds it difficult to reconcile the sheer enjoyment and freedom from pain that he experiences while skateboarding with the increased pain afterward.

**Awareness of Pain**

For many of these TMD sufferers, meditation was an effective method of relaxation and dealing with stress in other areas of life, but it did little to help with TMD pain.

Meditation doesn’t really help [with TMD pain] as much as it does for everything else in my life. It sort-of alters the stresses, pains, everything, it just doesn’t help this. (Sophie, 31)
For some, the increased awareness of pain that occurred during meditation actually added to its severity, and was a reason to discontinue meditation practice.

I have not been meditating much at all lately, and so that’s, like when it, if I would, it would help a lot but it also makes me aware of how painful it is. … everywhere else I would just go like deep into my body but in here I just like, would, I just could never get any deeper sensation of it so I’d kind of skip it. And then it started to come and it was the most severe pain ever, like I don’t know if I just like, it is pain that I’m so used to that I just don’t even think its pain. But um, and [I] acknowledged the pain and I finally like felt it and kind of, I don’t know, had, it was a weird thing but it made me realize how much pain there is and where it connected from. (Kyra, 30)

Because pain is often felt most clearly when sufferers are most aware of its presence, one of the most important strategies for coping is simply to ignore the sensation of pain. Many people are unable to differentiate times when they feel pain from times when they became more aware of it.

I mean, I don’t know if [stretching is] actually helping physically, or if it’s more of a mental distraction, like the fact that I’m thinking about it… I notice the most [pain]… when I’m doing something that’s like, like laying down. You know, like when I’m laying down at night to go to bed and I’m, or when I wake up cause, you know, it’s the most obvious thing because I’m not doing something else. But if I’m currently engaged in… some sort of activity, even just like eating breakfast or taking a shower, you know, it’s like, I think about it less so it bothers me less. (Allan, 29)

The idea that awareness of pain is what seems to make it the most difficult to deal with makes many of the coping strategies mentioned seem somewhat counter-productive. If the sufferer is required to concentrate on their pain in order to use a coping technique, the relief that is provided must be greater than the increase in pain that is caused simply by focusing on it. For many of these sufferers, common coping strategies such as jaw exercises, relaxation techniques, applying heat or ice, massaging the muscles, and over-the-counter pain medications provided minimal if any relief. Therefore, not using those
techniques regularly and avoiding exercise or meditation may be seen as ways to avoid focusing energy on the pain.

Medications as a Coping Strategy

Some people who suffer from severe TMD pain are prescribed muscle relaxants, analgesics, or narcotic pain medications. Others simply use over-the-counter analgesics to relieve pain, or choose not to use medications at all. Unlike taking a pill to relieve pain from an acute disorder, taking a pill for pain that is constant, every day is not so simple. Sufferers are constantly deciding how much pain they are willing to tolerate, and whether the side effects or long term outcomes of taking pain medications too often are outweighed by temporary relief that is provided.

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)

I used to at one point like five years ago. I used to take three, three ibuprofren at a time. I wouldn’t think twice about it… But not now… I can’t, you know, I’m too worried about the, it affecting my liver and stuff… I um, I’m trying, I’m trying real hard not to take any of that, you know, because I’ve taken it so much all my- you know, all along the, you know, it’s bad for your liver, it’s ba for your kidneys and, you know, I’m starting to worry about that, so I try to, I try to tough it through. And then sometime- but then sometimes I get so, um, I don’t want to say worked up but, you know, it’s a conundrum, do I take it and feel better or, you know, should I try to make it through the pain? (Patty, 47)

Some people attempted to balance the pain with the effects by taking only enough medication to bring the pain down to a level where it can be tolerated.

I’m okay with, like, taking the edge off, is what it feels like, and, I don’t like taking a lot of pills. (Josie, 29)
Others are concerned with the effect of taking pain medications too often because it impairs their ability to function normally. With a chronic illness, taking medications for pain can mean that one is willing to deal with long term side effects or even to give up their social role entirely. Not taking pain medications allows sufferers to choose not to let their pain control their lives. Moreover, knowing that the pain will return as soon as the medication wears off provides incentive for sufferers to learn to ignore the pain without assistance from pharmaceuticals.

Um, I usually take a little bit, cause I try not to take pain medicine if I don’t have to. I don’t like being up on pills cause I gotta take care of my little girl… So I don’t like to be out of it, I wanna be awake if she’s doing something. And I have to be careful with side effects and reactions with my antidepressant too. So that limits me… Cause it, the pain’s always going to be there, it don’t matter how many pain pills you take it’s still gonna be there. That’s the reason why I don’t take ‘em either cause it’s not gonna help. (Chloe, 31)

Another difficulty that commonly arises in coping with TMD is the financial aspect of seeking treatment. The treatment of TMD generally falls into the category of dental problems, and is an issue that is not often addressed within the medical profession (Garro 1994). Because it has to do with the teeth and jaw, TMD is not often covered by medical insurance. Unfortunately for TMD sufferers, there is no effective dental treatment, which means that dental insurance does not often provide treatment compensation either. Sufferers are often referred back and forth until they are finally referred to a specialist and expected to pay out of pocket for expensive treatments that may or may not reduce the pain (Ostermann et al. 1999). Often, people have seen alternative practitioners for treatment. Many find temporary relief, but are unable to continue due to the high cost of paying for treatment.
Umm, I’ve done some acupuncture. And, hot packs, and I’ve used, a couple years ago, a massage therapist who worked inside my mouth. And that was really helpful. But, they’re all, the practitioners are expensive to maintain so. (Josie, 29)

I think it’s pretty horrible personally that they don’t cover it on any type of insurance. None that I know of anyway. Cause I know um, when I first realized it was a problem I was having, I started to do research on the uh, types of insurance and as far as I could see there was none that covered TMJ. It’s pretty sad considering the amount of people in the world that have it. (April, 25)

The use of medications and other long-term strategies for coping with TMD leads to a heightened awareness of the impact on other areas of the body. Because of the long-term nature of the pain, and the common idea that the TMD is the result of an underlying problem, the experience of TMD extends beyond sensations of pain in the head and jaw. In the following section, the bodily experience of TMD will be examined through case studies of people who suffer from multiple illnesses. Because of the private and subjective nature of pain, the experience of multiple chronic illnesses is a way to understand the whole body experience of TMD.
Not all sufferers from TMD have other chronic illnesses, but the effect of TMD is felt on the whole body. The pain or discomfort caused by TMD affects the whole person in various ways that are difficult for sufferers to express, and that make coping with pain exponentially more difficult. This section is focused on the experience of TMD as it occurs in tandem with other chronic illnesses. It is not intended to represent the population of TMD sufferers as being illness-prone or unhealthy. The case studies and discussion presented in the section highlight the impact of TMD on the whole body. The way people describe the interaction between various chronic pain disorders or other chronic illness sheds light on the way TMD is felt as more than jaw pain, and provides a clearer picture of the nature of TMD and its effect on the individual.

In the following case studies of women who suffer from multiple forms of pain and illness, their narratives about the interaction between those illnesses and other parts of the body and other areas of life are poignant examples of TMD’s effect on broader experience. In addition, their narratives highlight the difficulty of dealing with daily pain, and at the same time, the way that sufferers see TMD as something that can be overcome and handled. TMD is often not the most painful thing that is experienced, but the constant nature of the discomfort means that TMD can make other illnesses, stresses, or anxiety almost unbearable. While not all TMD sufferers have multiple chronic illnesses, TMD is a compounding factor in many areas of difficult life experience.
In addition to the elevated level of stress, TMD adds to an overall feeling of the body being overworked, drained, or out of order. The following case studies demonstrate many of these observations. As Amalia demonstrates, TMD is often felt as something that runs against the body’s “current,” as something that goes against the flow, and in many ways serves to counteract other forms of self care. Adding to the discussion of difficulties in coping, comorbidities demonstrate the interactions between TMD pain and the possibility of healing occurring in other areas.

Case Study: Amalia

When it’s so many, so many different things, so many different kinds of pain, that I get. Like, I get cramps, which is like, cramp and dull pain. Sometimes I get really sharp, sharp pain. It’s, it’s like somebody’s stabbing you sometimes. And sometimes the pain is, just pressure, tons of pressure, and then sometimes it’s like, like a bad toothache. And uh stiffness, there’s a lot of stiffness, a lot. And the joints, the joints hurt all over the joints. Little ones, big ones, everywhere. And the same way with the head and the face.

Amalia is sixty years old, and suffers from a variety of chronic health problems including TMD, Fibromyalgia, a fallen bladder that requires repeated surgeries, chronic pharmaceutical allergies, and anxiety. She was born in Puerto Rico, and despite having lived in the United States for over forty years, Amalia speaks with a thick Puerto Rican accent. She is a small woman who laughs and smiles a lot despite the obvious pain it causes her.

For Amalia, like many sufferers of multiple chronic pain disorders with whom I spoke, pain was part of her life even at a young age. The first experience of untreatable pain came with puberty in Puerto Rico, when Amalia’s menstrual cycle brought intense
pain. At that point, her family was unable to afford medical care, but she was able to find relief from pain through the use of traditional teas made by women in her community.

I used to get really bad periods. My menstrual cycle was painful, very painful. All the neighbors knew when I had it because they could hear me screaming [laughs]. But we were poor you know, nobody could do nothing and, when that happened my mother was at work and, my father, I don’t know, he was blind and he was old, and so one of my nieces… would go out and fix me a hot tea, for, she used to go in her yard and spread some, bark from certain tree, and then she put them in a pot with some onions, and then sugar, and I drank that and I felt better.

At age nineteen, Amalia left Puerto Rico to work in the United States. She has been married twice and has five grown children. Giving birth to so many children, she said, may have contributed to her body’s current state. The problems with her bladder began during a difficult labor, and having so many children has contributed to her overall feeling of being overworked.

I think if I hadn’t worked so hard, you know, abusing the body, I probably would uh, be in better health. Especially with the children too, I’m, I have five kids… So maybe if I had uh, maybe two [laughs] my body wouldn’t be so, if I’d not worked so hard my body would’ve been in better condition.

In addition to the overall feeling of being overworked, Amalia explained that her bladder fell, and needed to be lifted through surgery after so many births. She has had the surgery performed three times, and at the time of the interview she said that it felt like it needed to be done again. Each time the surgery was performed it lasted only about five years, she explained, and was “ruined” by lifting something that she should not have been lifting.

I push myself too hard too. Like that’s why I ruined my surgery, because I was alone and I wanted to move my bed [laughs]… because how else, you know I need things done, you know, and there’s, when you live alone you don’t got nobody to help, so.
Amalia continues to work despite the intense pain that is often associated with it because of her desire to remain independent. She is able to work only ten hours per week, and often even that becomes almost unbearable. Amalia is aware of the lasting effects of hard work on the body, and she is careful to avoid repetitive motions.

The onset of Fibromyalgia for Amalia occurred more than fifteen years ago while she was employed at a factory in South Tucson. Her job required that she work long hours doing the same activity repeatedly all day while standing on a concrete floor.

I worked on the assembly line so you had to use your hands, real real fast and use the body, you know like, this machine just keeps moving around and you have to, you know, your body’s in constant move…long, long hours doing the same thing, the body doing the same movement over and, over and over. Plus we, we worked with a lot of solvents and stuff. So that didn’t help any.

Amalia began to have problems with her back and shoulders during that time, and eventually quit her job to find something less painful. After quitting the job she was involved in a car accident that exacerbated the pain she was experiencing, and may have been a contributor to the later onset of TMD pain. The initial onset of TMD symptoms, she explained, is difficult to determine.

I have sinus problems too, so I don’t know, I don’t know if everything that, you know, I was kind of confused I, all I knew is that I had pain… And so I blamed it all on Fibromyalgia. But some of it might be from, you know, the TMJ, where I complained to the doctor about it and he goes, “oh, that’s just a little TMJ.” …So I never did anything about it. I mean uh, I mean I just kept thinking it’s the Fibromyalgia. Because the rest of my body hurts, so why not up there?

Although TMD is common in people with Fibromyalgia (Balasubramaniam, de Leeuw, Zhu, Nickerson, Okeson, and Carlson 2007), Amalia attributed her jaw pain to the car accident, as well as to chewing sugar cane and opening bottles with her teeth as a
teenager in Puerto Rico. The pain in her jaw is an added stress in her life, and there are important interactions between her various health problems.

Exercise helps Amalia relieve tension. It also helps her jaw to relax and provides some relief from TMD pain. The possibility of her bladder falling due to strain, however, currently prevents her from doing much exercise. The inability to exercise and relieve jaw tension becomes even more of a problem when the experience of pain in other parts of her body causes her jaw to clench and tighten even further.

Well, well, the jaw tightens sometimes due to the pain. When the pain gets real bad, it’s hard for me to relax my jaw, so that, and the like, a lot of it is, involves the whole head, and the throat gets tight. The neck, the shoulders and the back, that’s mostly what hurts all the time.

Chronic allergies to medication, which developed after a negative reaction to a cholesterol medication, steer Amalia away from taking pain medications or muscle relaxants. The constant experience of pain and the threat of being unable to work also contribute to stress, which exacerbates many of these conditions.

In addition to pain during the day, Amalia has difficulty sleeping. Sitting or lying down for long periods of time causes pain, and sleeping, which is generally seen as a time to relax, can be a source of pain.

I just have to um, like if I’m sitting down and something starts to hurt, and then I just, like with my neck when I sleep, I sleep with a towel rolled up in the back of my neck, and the front, depending on how I fall asleep, like the last early in the morning like, cause I wake up all through the night, cause I have to roll over all the time. I can’t stay in one position, ‘cause the pain, it’s so horrible … So, sometimes if I wake up on the wrong side of my, fell asleep with the neck, or the head kinked, or whatever, I wake up in horrible pain.
As mentioned previously, awareness of pain is often the most powerful exacerbating factor. Amalia explains that when she is “relaxed” is often the time when she becomes aware of pain.

So when I’m busy I’m not thinking about it. ..So, cause my mind is on other things, so I can forget it a little. But when, in the morning when the body is relaxed and, I don’t know, it must be the way that I fall asleep, or the body falls asleep, whether it’s on the side on the right, on the back or, the neck is back or the neck gets down or whatever (chuckling). That uh, that’s why I think it’s so bad in the morning. Cause the, the body stayed in that position too long. Or in the wrong position, to cause the pain.

Pain is a major part of Amalia’s existence. Her body is in the forefront of her consciousness, and the experience of pain is pervasive in all areas of her life.

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 you know.

Case Study: Beth

I wonder too if, you know, if I hadn’t had such an extreme pain when I was a teenager, how I would feel about [TMD] if it just, you know, kind of came on and that was the only thing. I would probably be a little more um, you know, upset about it. But, you know, in the bigger picture it just… it’s not, the TMJ and the jaw pain is not, it’s a part of my life, but it’s not like this thing that’s getting in the way of, of me like really living my life.

Beth is thirty years old. She lives in Portland, Oregon and has suffered from multiple forms of chronic pain for most of her life. Her ailments include TMD, Fibromyalgia, severe pelvic pain, and insomnia. With a master’s degree in environmental law, Beth wanted to work on water policy issues, but has had difficulty finding permanent employment. Her options for employment are limited by a difficult job market, as well as her inability to work more than thirty hours a week due to her health.
Beth’s experience of pain began as early as kindergarten, when she experienced “classical migraines” about once per year until she reached adolescence. “That was a big, big transition, um, and it didn’t go smoothly.” Upon reaching puberty, the migraines ceased and were replaced with severe pelvic pain.

Um, when I was fifteen I started having really severe pelvic pain, and um, missed six months of school and saw thirty doctors and went through all these tests and surgeries and, um, and was part of an FDA study to get this um, nerve stimulator approved and, I mean the- there’s just been a lot of uh, a lot of uh, chronic health issues. Um, TMJ’s just kind of been only a part of that. So, so I kind of feel like, you know, since I was fifteen, you know, that’s kind of when the shit hit the fan, and it’s, it’s just kind of been an ongoing thing since then.

Despite visits to multiple doctors and trying various forms of treatment, Beth’s pelvic pain persisted. Upon returning to high school after being away for a semester, she was frustrated when people were unable to see that she was in pain. She was often chided for having a handicapped parking permit, and felt as though people were insensitive to the incapacitating pain she was experiencing.

Beth spent the next eight years enduring severe pain and seeing multiple specialists. When she was eighteen years old, a doctor determined that the source of her pain was her bladder and implanted a nerve stimulation device to assist with the pain.

And so, what they did is they put a nerve stimulator onto my sacral nerves and it had a little battery and that was underneath my skin and it powered this nerve stimulation to, to stimulate the nerves that go to the bladder. And it was, amazingly helpful for me. Um, and so I had that put in when I was eighteen.

At age twenty-three, Doctors put Beth into medical menopause, which she continued with for three years before deciding to discontinue the ineffective treatment.

When I was twenty-three, um, I had just graduated from college and I had also, one of the things that they did to try to make my pelvic pain less of an issue was they put me into medically induced menopause. And they did that for three years. And um, when I
was twenty-three I was like, “Okay, you know, it’s been three years,” like you’re, the doctors were telling me, um, “we’re working on it. We’ll come up with a cure for you.” And it’s like how much longer do I have to be in menopause, you know, like “forget this.”

After discontinuing the medical menopause, Beth sought treatment from alternative practitioners such as a Naturopathic doctor and an acupuncturist. She also began doing yoga, seeing a counselor, and trying to focus on maintaining her own health. A major breakthrough for Beth in understanding her own experience of pain came when she was able to become independent from nerve stimulation on her bladder.

When I was twenty-two [the nerve-stimulator implant] started to malfunction, and my pelvic pain came back so quickly…And so I had it revised. They, you know, went in and fixed it…And um, that helped with the pelvic pain again, but, but after I started doing all these alternative things and exercising and yoga, I got kind of curious to see what would happen if I could turn it off. ‘Cause I was feeling so much better in other ways, so, I thought, “well I can turn it off, and then if it’s, my pain comes back I’ll just turn it back on again.” You know, so I turned it off and a month passed and then three months passed and then a year had passed and it had been off that whole time, you know, so that to me was like, that was amazing, you know, I was really dependant upon this, this implant to, to um, keep me going basically. And um, I didn’t need it anymore. And I had it removed.

At the time of the interview, pelvic pain was no longer a dominating feature in Beth’s life. Only during menstrual periods, which continue to be unpredictable, does she deal with pelvic pain currently. During the time that she was searching for a biomedical cure for her pelvic pain, however, Beth became aware of the existence of Fibromyalgia and was convinced through her own research that she also suffered from that disorder. Although the first practitioner she consulted about Fibromyalgia was not willing to discuss that as an explanation, Beth persisted in getting a Fibromyalgia diagnosis.

With the Fibromyalgia actually that, that was something that, more found me. Like I um, I was on a, a list serve support group for women with pelvic pains and women on there were talking about Fibromyalgia and, and so I just started doing a bunch of
research on it, and you know, was reading the symptoms and I was like “oh my god!” you know, like “that’s me, and that’s me and that’s me and.”… And then started reading a lot of books about it and, and um, you know, and went to the doctor and was like, “this is what I, you know, this is what I think I have. Like these are the symptoms that I have.” And you know, “what do you think?” and he was like, “No.”… So I went to go see a Fibromyalgia specialist and I was like, “I think I might have it, you know, I want to get a diagnosis from someone who actually knows about it.” And um, you know, there’s eighteen pressure points and I had seventeen of the eighteen.

Fibromyalgia continues to be a source of pain for Beth. She also suffers from TMD pain, although both disorders, she explained, are relatively manageable compared to the pelvic pain that she experienced in her youth. For Beth, as I have mentioned, TMD is not the main source of discomfort in her life, nor does she view it as particularly salient in terms of her experience of chronic pain. Beth has difficulty disaggregating the onset of TMD pain from other experiences of chronic pain that were occurring during the same time period.

I don’t really remember, um, (pause) I- I- you know there are so many other like, doctors and diagnoses that I was focused on around that time so I don’t really remember how that happened but I, you know, went to my dentist and I was getting my teeth cleaned and then, and then I had a jaw brace so I- I’m not really, I don’t, I don’t really recall, what, what led to all that… Um, I feel like the pelvic pain was so overwhelming that it kind of overshadowed the rest of the pain that I was having, and I thought that I was having, you know, headaches and, I thought I was clenching my jaw cause I was in so much pelvic pain and I thought, you know, all of the, I thought I was having insomnia because I was having so much pelvic pain. And once I was able to make the pelvic pain be less of a, you know, a force in my life, I still had all these other symptoms, and was like, “wait a minute” you know, “I think that this is what this is. There’s something else going on here than just having pelvic pain.”

As Beth gained awareness about her medical conditions and their effects on her body, she became less concerned with official diagnoses, and more conscious of the interactions between different health issues on her body and on her well-being.
I’m going to find my answers in Yoga instead. Kind of like sitting with my body and listening to it, and um, it doesn’t really matter what someone in a white coat calls it, it’s what I call it and my experience of it.

Despite the conviction that Beth displays in finding her own ways of dealing with her health issues, she continues to struggle with those that are more resistant to change. Beth also feels as though there is an underlying problem causing her pain and illness that she has yet to address. She also continues to have issues with her hormones, perhaps due to an imbalance from early in her life, and possibly also related to the fact that she was in Menopause for three years.

Even in the last two years, even though it’s been very turbulent, um, and it continues, it’s like it’s an ongoing process… I’m not sure what it’s going to look like but, somewhere inside of me I believe that [it can be healed]. And there are other parts of me that don’t [think so]. You know, just you know, I’ve been clenching my jaw for fifteen years, am I going to be able to stop? You know, my other, my other big thing is, is you know, hormones and having a period. Having a regular period, like, I’ve been through all this stuff. I was in menopause for three years, like, can I ever have a normal period? I don’t know. I keep trying to, and it’s just like, it’s not working so…

Another area in which Beth struggles with overcoming the effects of pain on her life is in her sleep patterns. She suffers from insomnia and a lack of energy as a result that is both caused by and contributes to her pain cycle.

I guess the main place it shows up when I’m, when I’m really stressed out is through lack of sleep. I get insomnia and I’m just up worrying.

Beth began sleeping with a biteguard when she was seventeen years old. The few times that she has allowed herself to fall asleep without it and she said, “I’ve learned not to do that because it’s, it’s excruciating if I, if I don’t put it in.” Although Beth often clenches her teeth during the day, the clenching is more severe during the night particularly when it is exacerbated by stress.
Despite her success in overcoming chronic pain, co-morbidity and persistence of pain have profound effects on Beth’s outlook on the possibility of finding and cure or leading a life free from pain. She struggles against an unknown underlying problem that impacts her health in a variety of ways, and in turn, affects many areas of her life. While her experience of severe pain early in life seems to put her current ailments into a broader perspective, Beth seems caught within a web of ongoing causal interactions between pain, stress, and uncertainty that affect each other through multiple pathways and form a cycle that is extremely difficult to break away from.

I kind of am, like in the rapid, rapid right now and I can like put my head above water on occasion and breathe and like, see how great the river is and, the rest of the time I’m just getting like, pummeled by the rapid so. Um, and I, you know, I see the, the lack of stability with jobs all just kind of tying into that. It’s all this like, you know, very linked web of, of things, and I’m, I’m just trying to, to keep breathing and find some amount of grounding while all of that’s going on.

Beth’s description of feeling as though she is in a rapid relates to the idea that TMD is something that goes against the flow of the body or the flow of daily living. The ways in which these sufferers speak about the flow is not necessarily similar to flow as described in some healing modalities, but is associated with the idea that there is a natural rhythm within the body, or a natural progression of life that TMD sufferers feel unable to attain. TMD is felt as a presence in the background, something that should not be given attention, but that cannot be entirely ignored. In many instances, activities that are otherwise helpful are things that aggravate TMD, and those things that are useful in managing TMD pain hinder sufferers’ ability to participate in other activities or enjoy other parts of their lives.
As illustrated by these women, TMD sufferers display considerable resilience and adaptation to pain. As something that they are accustomed to living with, TMD is not always in the forefront of their experience. I found this to be common, regardless of whether they suffered from multiple illnesses. Other important issues in life generally took precedence over the pain caused by TMD. An important feature of TMD pain, however, was its constant presence, the fact that it was always there in the background. By itself, in the present, TMD was not a major part of life. It could be “handled” or ignored. The crucial part of the ability to handle TMD pain without complaint, however, was that it took energy. Constant pain required constant effort to handle or ignore.

Um, and it’s just, you know, it- [TMD] affects how much stress I can deal with I guess, which, so and I have, usually have to uh, there’s a lot that I’m exposed to at work that I have to handle and so I think at some point in the day it limits my ability to deal effectively with that. Um,… sometimes when it’s very distracting or intense, um, yeah. I mean it just distracts my ability to focus and concentrate… I mean I think I’m able to, to handle it fairly well and so it doesn’t, you know, obviously affect outside anyway, how much I’m doing. (Keith, 61)

The energy spent on dealing with TMD every day was thus not available to cope with issues that arose unexpectedly. Sufferers often expressed a feeling of vulnerability resulting from their lack of energy reserved for handling additional stress.

An area in which it becomes apparent that TMD takes a backseat to other issues in sufferers’ lives is in doctor-patient interaction. As I have pointed out, although sufferers’ see TMD as connected to other health issues, this interconnectedness is not addressed in the medical encounter. When seeking care for other health issues, particularly those that are difficult to diagnose, TMD is not often mentioned. Sometimes
sufferers themselves do not see TMD as an important issue relative to their other health problems. Other times they choose not to share their TMD out of fear that the doctor’s confidence in their assessment of the severity of the other issue will be compromised. The feeling that having TMD negatively impacts the patient’s credibility in terms of their ability to interpret bodily symptoms becomes apparent in the following section.

**Doctor-Patient Interaction in the Context of Multiple Illnesses**

I like my regular doctor. Um, but I tried to tell him about that I thought I had um, sleep apnea cause my twin has it, and I didn’t know if uh, I was starting to think that maybe the headaches were, were not really from my [TMD], that were- that maybe I had the sleep apnea because I wake up in the morning and, and my eyeballs feel like they’re bulging out, you know, I just have a bad headache and, …And he just kind of pshawed it, like it was, you know. So I didn’t even mention the [TMD] to him. I didn’t even mention it to him, cause I figured, you know, he- if he thinks sleep apnea where people stop breathing at night is something to just, ppff, at, then he’s, for sure he’s gonna, you know, … he’s gonna um, what do you call it? Demean me for having [TMD] and not, you know, so I just didn’t even mention it to him. (Patty, 47)

Chronic pain researchers have commented on physicians’ perception of TMD and on chronic pain in general as not warranting significant medical attention (Jackson 2005; Reid, Ewan, and Lowy 1991). In the context of other illness, the view that TMD is not a serious illness becomes more apparent. Particularly when TMD is viewed as a side effect of medications for other illnesses, sufferers did not think their doctors viewed TMD as a serious condition.

I wouldn’t say she shrugs it off but it, you know in relation to the other problems, you know she wouldn’t consider it the high priority…You know, not that she belittles it, she recognizes it, but she recognizes it’s more from the…the romatase inhibitor that I take, and that makes all my joints sore. And it’s just kind of exacerbated. (Susan, 38)
Not only physicians, but also patients often seem to view TMD as secondary to what they consider to be serious illness. Like Beth, many sufferers from multiple illnesses seemed to view TMD as less pressing than other health issues.

You know, it’s embarrassing to say, but I’ve been to see her, like, for about my joints and for a physical and there was concern [chuckle] about my blood-sugar levels because my eyesight was getting worse. So, I don’t know if we even talked that much about the [TMD]. (Rebecca, 43)

For many of the TMD sufferers that I interviewed, other illnesses or issues took precedence over TMD pain. Because there is no well-known and effective cure, and the pain is often seen as a product of stress, TMD is often in the background of bodily experience. While there are many other ways of understanding pain, comorbidities shed light on the way that TMD is felt on other areas of the body and thus impacts life beyond jaw pain. As Beth pointed out, the TMD pain itself is not overwhelming for many sufferers. What comorbidities illustrate, however, is that TMD pain is a constant feature in the background that has a significant, if indirect effect many areas of sufferers’ lives.
LIFE IN THE PRESENT: THE NATURE OF HOPE, FEAR, AND ANXIETY IN THE FACE OF CHRONIC PAIN

No matter how excruciating the pain is, if you know it’s going to go away, you can probably put up with it. But, … you know this one’s not going to go away. It may become less, but it’s not goin’ away. And it’s coming back tomorrow. (Steven, 54)

The internal experience of TMD, aside from the physical sensation of pain, is associated with important outcomes in terms of sufferers’ orientation toward the present and the future. The ways in which people are able to find meaning in living with pain and the ability to retain a sense of hope require a considerable amount of work on the part of the sufferer. Uncertainty about the future of a chronic condition, and fluctuation in severity of symptoms produce circumstances in which the work of illness may or may not be manageable, which limits the ability to plan effectively (Thorne 1993). In order to avoid losing hope, sufferers work hard to maintain control over their activities in a continuous attempt to arrange their daily lives in a way that minimizes pain (Garro 1994). Things that can be arranged to avoid pain, however, have little impact on the perceived progression of the disease, and the possibility that the pain will continue to worsen with time, becoming more than sufferers can handle, is a constant source of anxiety.

The following is a discussion of the work that is done by TMD sufferers to avoid pain triggers, to maintain control over their illness, and to mitigate the effects of pain on their daily activities. Chronic illness requires sufferers to devote a considerable amount of energy to managing their energy and maintaining their current health status (Thorne 1993). This has been called the work of illness, which is an important part of coming to
terms with chronicity and managing the condition (Corbin and Strauss 1988; Thorne 1993). The way that sufferers retain hope for the future by thinking about life only in terms of what else one might have to give up is an important part of this discussion.

When I asked people what things they did on a daily basis that caused pain, I was often met with confusion, and people were rarely able to describe a normal daily pattern of pain. Pain is unpredictable, they explained, and when pain flared there was little they could do to stop it. Only on some occasions were they able to assess what had triggered the pain even after it had subsided.

There were pain triggers that each person listed and I expected them to be able associate those things with the experience of pain. What I found, however, was that those pain triggers listed were not typically the causes of pain on a daily basis, nor were they the causes of “flare-ups” which I will discuss below. What became clear was that the things that continue to cause pain are unknown or unavoidable, and the things that are known to cause pain are not practiced on a daily basis and if possible, are avoided entirely. One thing that often came up as a trigger was chewy or crunchy foods. Simple, I thought, there should be increased pain at mealtimes. My initial reaction was quickly countered when I asked if eating led to increased pain and heard answers like, “Well it would if I ate something crunchy, but I don’t. I eat soft foods.” (Darla, 49)

I was surprised to find that for most of the people I spoke with, the extent of the impact of TMD on their lives was on what they were or were not able to eat. People rarely admitted that TMD pain had any impact whatsoever on their future plans. Looking further into the narratives of these TMD sufferers, however, it became clear that the
impact of TMD pain on their lives was significant. I struggled to reconcile how people could see pain as having so little effect on their daily activities and on their plans for the future, but talk about pain as a major part of their lives.

In the following sections I will describe the limitations that TMD pain places on people, and the things that are avoided. I will then discuss the perceived impact of pain on people’s lives, as well as the impact that is perhaps not consciously understood, but is nevertheless clear from the narratives about life with pain. I will demonstrate that despite the minimal impact of pain on people’s activities, its unpredictable nature leads to profound consequences in terms of how people are able to participate in normal activities, and how they think about the future. I will discuss the possibility that when people say that TMD pain does not affect their future plans, while this statement is not untrue, it may be that people view their future plans as unaffected because they are focused on maintaining pain at its current level. The future is planned only in terms of what might happen if pain worsens. Plans for the future are limited to speculations about what else might have to be cut out of sufferers’ lives. Actual goals for the future were seldom if ever offered, and if I probed for goals or speculations about the future, sufferers quickly returned the conversation to their day to day lives.

I will use sufferers’ narratives to support my argument that TMD pain impacts the process of planning activities not by changing the plans, but by limiting the possibility of planning at all. Other researchers have found that chronic pain makes the future seem uncertain, and makes planning difficult for sufferers (Richardson, Bie Nio, and Sim 2006). Through the narrative and analysis in this section, I will support Jean Jackson’s
assertion that pain sufferers exist in a liminal state (Jackson 2005), and I will further discuss the implication of living in such a liminal state on how people are able to cope with, and create meaning in the face of chronic TMD pain.

Merleau-Ponty’s phenomenological analysis requires understanding of the body as a source of experience, not as an object (Honkasalo 2000). Although Merleau-Ponty’s analysis has been criticized for shortcomings (Csordas 1993), his ideas about what is “lost” by sufferers of chronic illness are useful. According to Merleau-Ponty,

What is in us which refuses mutilation and disablement is an I committed to certain physical and inter-human work, who continues to tend towards his world despite handicaps and amputations… The refusal of this deficiency is only obverse of our inherence in a world, the implicit negation of what runs counter to the natural momentum which throws us out into our tasks, our cares, our situation, our familiar horizon.” (see Honkasalo 2000:205).

While Merleau-Ponty was writing about phantom limb pain, his observations can be meaningfully applied to TMD. Merleau-Ponty suggests that humans are inclined toward certain tasks and activities, and that they will continue to attempt to live as normal despite whatever disabilities they face. The stoicism displayed by many TMD sufferers is an example of this refusal to acknowledge anything that might get in the way of one’s activities, or the possibility that it could affect one’s perception of the future.

**An “Irritating Uncomfortableness”: Dealing with Pain in Daily Life**

There are a few things that come up repeatedly when TMD sufferers are asked what kind of effect pain has on their daily lives. Chewing and yawning are commonly mentioned when talking about pain in this context.
Well, it’s just kind of there, and you know, it’s something that I’m noticing, uh you
know, trying to avoid, I don’t chew gum very much, and um, I uh, always a little
leery when I yawn. So those are the main things. (Margaret, 63)

Other than those, which are minimized in terms of their actual impact on daily life,
people were careful not to present TMD pain as something that limits their daily activity.
The word “just” often precedes statements about coping with pain, as though it is easy to
“just deal with” chronic pain.

I just kind of cope with it… I really can’t really say it’s affected [my life] a whole lot.
I just keep going about what I need to do. (Deborah, 59)

I just deal with it and go about my daily, do what I gotta do. Don’t have time for pain.
(Chloe, 31)

Um, [TMD has affected my life] not as much as you’d imagine, I just uh, deal with it,
I guess. Um, I can practice just trying to ignore it. Um, I don’t enjoy it, but if I’m in
pain I try to kinda not complain about it and just I get through it. (John, 33)

I still go to work and I still eat, you know, I still do the same things I do. It just, it just
hurts. (Mark, 25)

Even people for whom the pain is intolerable after only a few days without
wearing a mouthguard, the impact of pain is expressed as being minimal.

I’ve forgotten my retainers on vacation and I’ve had to have them like, fed-exed to
me so I can only go like a day, maybe two. Um, and uh, you know I’ll get like the
headaches and stuff if I, if I get really if an acute, you know something flares up. But
um, typically it’s, it’s just kinda there. (Lauren, 42)

While many people I spoke to did spend a considerable amount of energy
searching for treatment, I was surprised with how often people spoke of TMD pain as
something that they would not spend time addressing because its impact on their lives is
not debilitating.

And I and it’s never, it’s not inhibiting like a range of motion, like if I had something
with my arm and I couldn’t move it or turn my head. I’d get acupuncture, and spend a
lot of money to try to do that, but for this it’s like well I, you know. I just kinda live with it. (Lauren, 42)

I haven’t gone anywhere. I just, know I have it and that’s that. (chuckles) It’s like one of those things, if you have it you have it, if you don’t you don’t, and you just live with it. (Danielle, 34)

In addition to feeling as though it is not debilitating, many people believe that since the pain is always going to be there, it is not worth paying attention to. It seems chronic pain sufferers feel as though thinking about something that cannot be resolved is a waste of their already limited energy.

Um, well I try not to think about it at all, and, but it’s like I’ll just all the sudden realize it, like oh it’s aching, it’s really bothering me today. But I try not to, obviously not let that rule your life or infringe upon [my life], I don’t want any kind of, um, you know with the exception of the eating and um, pretty much the eating, I try and, I do everything I possibly can. (Susan, 38)

Trying to stay positive or to handle the pain is not a choice that people make, rather, it is necessary for functioning. As Amalia points out, since thinking about or dwelling on the pain tends to make it worse, doing so would be somewhat counter-productive. In addition, the inability, or perceived inability to change it means that people become somewhat resigned to the daily experience of pain. The experience of pain regardless of activity means that instead of staying home or staying in bed, carrying on with life as normal appears as reasonable as any other option.

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. I could make it worse just by dwelling on it or, or crying about and spend all my life in bed or, which I couldn’t anyway (chuckling) cause the bed is an enemy. It might cause the pain you know? (Amalia, 61)

I think I got used to it more or less. I mean, if you can’t change something you have to live with it. (Sarah, 69)
In struggling to convey the importance of pain while maintaining that it does not overwhelm daily activities, sufferers often experience difficulty explaining their thoughts and sound rather conflicted. Crucial to understanding the impact of pain beyond daily experience is the element of time. As April explains, over time, a pain that is relatively minor can become a major source of irritation.

I wouldn’t say it’s like a pain where I feel like I’m going to die, but it’s a, over time it’s a pain that makes you want to feel like you’re dead, or close to it. You know like over time it can be, um, kind of like a, a thorn in your side. It’s more of an irritating problem to me than anything else… Um, I think, to me, uh pain, if it’s short and sweet, then it’s not so bad. Uh the, pain lasting for long amounts of time, again is just more of an irritating uncomfortableness. (April, 25)

Time is also crucial to consider in relation to TMD pain because of the widespread belief that the pain will worsen with age. Therefore, many people experience anxiety about how they will deal with pain in the future if it gets progressively worse. As I have mentioned, when sufferers did talk about what effect pain might have on the future, they did not actually talk about their future plans, but about things that they might have to cut out in the future in order to continue to avoid pain.

Fear is a big part of this… there’s a fear developing that if this pain continues, what else am I going to have to give up? I have to quit playing harmonica or at least as much as I do. Um, I love playing it and I’m very good at it. Now, you know I’m learning to play another instrument but I’m never going to be as good on accordion or anything else as I am on that. Uh, had to stop uh, the idea of going hiking to the, up saddle mountain or something is just not going to happen, I can’t do it cause the jarring etcetera would just cause too… and, what happens if I get in trouble? I don’t have the physical I I- don- I, I don’t have the physical strength to uh, um use my arms like I used to cause it’s gonna hurt too much. Uh, so I have to stop doing these different activities. So there’s a real fear developing about what’s down the road. Other than just what people have of getting older, you know. (Steven, 54)

In addition, episodes of severe pain, or “flare-ups” have a major impact on sufferers’ lives and activities. The following discussion is focused on the unpredictable
and debilitating occurrence of acute episodes of pain, which often include pain affecting more than just the jaw or face.

“Flare-ups”: When the Pain becomes Debilitating

On a worse day, usually I have been having flare-ups for 2 or 3 days or the weather has been changing…Or, there’s some unusual stress going on…That’s the [short pause], that’s the car alarm feeling is how I think of it when that happens. You know, it’s just, you can’t think about it, you can’t look anywhere or do anything without hearing it or dealing with it, you know. (Darla, 49)

While as I have said, the pain of TMD is not normally debilitating, most TMD sufferers spoke of “Flare-ups” or times when their pain became much more intense than normal.

Episodes of increased pain are unpredictable. When pain flares, it can trigger migraines, neck pain, and a series of other things that often lead sufferers to stop their daily routines and retreat to dark, quiet places. Little can be done to reduce the pain once it reaches this level.

Normally what happens is that it’s the same as ever, and then I’ll bite down on something and all the sudden I’ll get this shooting pain. It’ll go up my jaw through my ear into my head, and I’m like, oh no, it’s gonna be one of those days. (Susan, 38)

Sometimes I just put up with it, and hope, you know, I can handle it or it’ll go away or whatever. (Amalia, 61)

With the constant fear that pain could worsen at any moment, sufferers are unable to plan their lives to account for pain, but neither are they able to forget it. For this reason, pain sufferers experience anxiety about the pain even when it is not present. In order to retain a sense of control, and mitigate the effects of anxiety, sufferers work to rearrange their lives in order to minimize pain triggers as much as possible.
Minimizing Pain: What Can be Avoided

There are a number of activities that are known to cause pain, but what was mentioned the most were things like eating and sleeping. People spoke about the effect of TMD on their lives in these terms. On the surface it seemed as though the extent of TMD’s effect on people was the need to change their habits in order to avoid aggravating pain.

Um [TMD has affected my life] (short pause), just in a pain sense, uh, and then there’s, you know (short pause), um, the use of mouthpieces or splints um, change in the diet, what you eat so you don’t aggravate it to cause pain. Um, some habits, you know you change some habits, so you don’t irritate or aggravate (clears throat) the pain you already have or bring it on. (Lily, 40)

When it comes to doing things that cause pain on a daily basis, the fact is, if something is known to cause pain and is not necessary for well-being, they don’t do it. It was difficult for people to tell me what things they did during the day that caused the pain to increase, because if they became aware that something was negatively affecting their jaw, that activity would be discontinued, and other activities would be arranged to compensate.

Oh, it [is aggravated by] any kind of chewing. I don’t eat raw carrots, um, definitely not gum. Caramels, anything tough that requires a lot of chewing motion, um, in fact you know those little tootsie roll things?…Nothing like that. I don’t eat any of that. Um, I don’t eat anything that requires my mouth to be open. Like a big thick hamburger, anything that, uh requires like a wide opening. (Susan, 38)

Eating, I can’t eat, I go out to eat I get fish. And I love fish but, fish and mashed potatoes it’s just soft food. Pasta. I haven’t had a steak, not that I was a big meat eater but I haven’t had a steak in three, or no two and a half years. I haven’t had a sandwich in two and a half years. I mean like, a Subway, um, everything has to be overcooked and, just basically soft (pause). (David, 53)
On days when pain is bad, some sufferers express lack of desire to eat at all because of the pain it causes. Despite not wanting to eat, sufferers say that their lives are normal. The major difference is that many people view their lives as unusually stressful. When asked what life with TMD is like, Chloe answered that it is “Normal. Stressful. Painful. Achy. Don’t want to get out of bed some mornings. Don’t want to eat. I want all my teeth out of my head.”

The practice of rearranging activities to avoid causing pain goes beyond the simple sensation of pain in the moment. Life for TMD sufferers is arranged according to ideas of overworking, and careful attention to the boundaries of one’s body, and in particular, the body’s energy.

*Case Study: Kyra*

Kyra is thirty years old and has suffered from major depression for more than fifteen years of her life. At the time of the interview, she was working as a nanny and independently studying holistic medicine. She does not currently experience depression, but the recurrence of both depression and pain at many times in her life have led to her unique understanding of pain and depression as part of her body’s response to overworking. In addition to her TMD, Kyra has been in a series of accidents involving being hit by a car on her bicycle. She suffers from additional chronic pain resulting from those accidents, and is perhaps more affected by pain than other TMD sufferers. While the severity of her pain sets her apart from others in terms of how much it affects her activities, Kyra’s ideas about energy and overusing her body were echoed by people with
varying levels of pain. She provides an excellent example of the interaction between energy level and chronic pain, and living with depression has led her to many insightful conclusions about life with pain.

Kyra carefully listed things that she is able to do without harming her body. She pities those around her who are unable to do anything because of their pain or illness, and thinks it is important to push herself.

There’s certain things I, like I wouldn’t go on a long bike ride, it would just hurt too much, like if I rode forty miles or something. There’s just no way I can do it whatsoever, but, I’ll, you know, go walk ten miles, or garden all day long and do these things… Part of me does feel like maybe you need to try to just like push it a little bit, because movement helps ease a lot, you know, swimming like helps me a lot. But I also think I really just don’t want to be like, “oh I’m in pain I just have to lay on the couch” because it’s not what I want to do. You know, but it has changed, like I am really nervous. Like this summer I want to go like hiking for like five days and I know I probably can’t handle it at all but I just don’t want to believe that at all. My knee would probably give out right away, you know, like certain things with my body.

Kyra is aware of a variety of things that her body cannot handle at this point in her life, but says that what causes her anxiety is not what she is unable to do now, but the possibility that pain will increase in the future.

You know, when it’s the worst it hurts and it’s bothering me, but it’s not like a horrible amount of pain… I don’t know I mean it’s like, on a day to day basis it’s, like I feel it all the time, and it’s more irritating in, like right now it feels, it just bothers me, and my, this whole like something in here just feels really bad. The twitching drives me insane, but it’s more of what it means. I’m like, what is going to happen? Like, how much pain am I going to be in in five years? What’s happening to my face? Am I going to have a stroke? … Like I want to believe that it can stop and that something’s pinched or, you know, I just don’t know what to do so, it’s more of like this constant kind of anxiety about what’s going on with it and why is it hurting a lot more. [emphasis added]

The feeling of anxiety that Kyra mentions is a crucial aspect of TMD’s impact on the lives of many sufferers. The feeling of uncertainty, of not knowing what might result
from such pain, is a common source of anxiety for people who suffer from TMD. For Kyra and others, even when pain is absent, or at a low level, the possibility of its return causes people to live with pain at all times. After suffering from pain and depression for a long period of time, Kyra is grateful for her high spirits, but unable to escape from the fear that with an unexpected event her pain and depression could return without warning.

Now I’m just like every day, I’m just so incredibly happy that I am okay, like I just feel so well, and so that feels great but then it scares me because I’m like maybe [the pain and depression] just enters.

Anxiety about the return of pain leads Kyra to weigh her options carefully in terms of what she may have to give up in order to maintain her current energy level.

It [affects my vision of the future] a lot. Like I definitely question, have- not, like I feel like I shouldn’t have children now. I feel like it’s going to start hurting a lot more and it’s already really hard when I’m with younger children to like, deal with it. My hip will just start hurting so bad like if I’m carrying around a six month old like, I just feel so, the- the pain something that exhausts me, and I just feel too tired like, my energy just can’t last for like, that. I question going to school, I just feel like I probably can’t handle it, like, just the pain will get too much and I’ll just be really exhausted and, you know, it makes me think what kind of profession I want to go into, and just everything. I mean what kind of work I- you know I- harvested seaweed for a little bit and I loved doing it but like my knees would always give out and then I couldn’t do it anymore because like, I just, there’s certain things that I can’t do and I used to be very, so much stronger. So I feel like yeah my future very much is I’m trying to direct it in a way that my body and like energy level can handle.

Unlike many people, Kyra does admit that TMD affects her plans for the future. Despite this, however, her narrative about conserving energy is illustrative of how pain shapes the way she conceptualizes the future in negative terms. She feels as though her energy simply cannot handle things like caring for children or going back to school. Notably, however, she speaks of only what she is unable to do, and does not present alternative possibilities for the future. It seems the attempt to conserve energy itself it
what she expects to do in the future. Kyra views her lack of energy as the result of things she put herself through in the past, which directly relates to avoiding things that abuse her body now.

I feel like, from the things I put myself through that were just really traumatic and hard for me for a while, I feel like kind of- the other day I was lying in bed and I just like, I re- I had never really understood in those terms but I felt like I’d used up all my energy of my whole life already. Like, I just felt like I had exerted it all, and now I’m just left like, just kind of running on nothing. I’m just like trying to keep going and hardly let anyone know that, cause I’m not eighty years old I’m thirty years old you know.

The belief that one has a certain amount of energy to expend in their lifetime leads Kyra to find little hope for improvement in the future. Like many chronic pain sufferers, she views her energy level and pain level as things that can be carefully maintained, but not improved. I found that many TMD sufferers shared the idea that the body has a finite amount of energy, or that the body starts out free from pain and any abuse causes it to deviate from the original state of health. Many struggle to maintain the position they are in, and have little hope of returning to that original state of health.

Umm, and then I just pushed it over the edge when I, and once it was injured I’ve made it manageable but never made it go all the way back to what it was before. (Catherine, 36)

Kyra’s sense that her pain resulted from lack of awareness when she was young is not limited to her body. Her idea that the body has a limited energy supply not only causes anxiety about her own health, but about the health of others as well.

Like, I live with, the woman I live with is twenty and sometimes I want to like, I try not to give her advice or be like this, you know, wise old grandma or something but I, I just really, sometimes I’m like, I feel towards her, I’m like “she needs to be careful what she’s doing.” because it affects you physically so much more than you can ever be aware of when you’re twenty. Like the emotional choices that you make and
there’s no regaining that, like, at all. And I just feel like I’ve worn myself down completely.

The idea that the body has limited health or energy that can be maintained or depleted has been documented by other researchers as well. Herzlich (1974) found that people viewed health as a reserve that could something that one is born with or builds up during their childhood. The reserve of health could be built up or broken down. Similarly, Kyra views her energy as something that must be carefully conserved, and her health as something that has been significantly depleted by events and actions in her lifetime.

**Conflict of Selves: The Practical Self and the Hopeful Self**

When asked if TMD is curable, many participants quickly responded that they did not think it was curable. They almost always added, however, that they would like to maintain some hope for improvement and that they would be open to a cure if one was offered. Particularly as they entered a treatment study, the TMD sufferers I interviewed were careful to remain hopeful, but were conflicted about allowing themselves that hope when their practical selves told them pain would be a persistent part of their experience.

My cynical side or um, my hopeful side? … Um, if I expect that it’s going to be cured and it’s not, then I’ll be unhappy. And if I expect that nothing will happen… nothing probably will happen. So I’m trying to remain open to whatever, you know, whatever comes along. (Dennis, 32)

Umm, in my wildest dreams, umm, [I want] a lower pain level. Umm, in my practical dreams, [all I can hope for is] more help dealing with pain. (Darla, 49)

Although most people told me they would like to believe that their pain could be eradicated, most said that they felt as though hope was more like a fantasy to them that an actual expectation for treatment.
I think it’s something I’ll probably always have to deal with. Although, I have an open mind and I would like to think that it would be something I could possibly, um, eradicate from my life (chuckles). (April, 25)

Um, really no [I don’t think it’s curable], I’m hoping so because I don’t want to be tied to those retainers forever… But uh, I would prefer that not to be the case. So I’m hoping that there can, you know some way other than surgery, you know. (Lauren, 42)

Manageable. Manageable, not curable. If it’s something that uh, if it’s something that’s a wear and tear say, or say it is- it’s a stress or strain, then how? I don’t see how it could be curable but it just, I could see how it would be manageable yeah. But if I’m told it’s curable, I’ll try and, I’ll believe anything about it. (Sophie, 31)

It seems that while people who suffer from TMD want to think their illness is curable, they are unable to imagine their lives without pain.

Well on very rare, really rare occasions, I find myself, I’ll go, ‘oh man, it’s not so bad,’ …But that doesn’t happen very often. It just surprises me (laughs). And I don’t know what it feels like not to be in pain. That would be wonderful, feeling, not to be in pain…I hope it’s curable. It would be nice if everything was. You know? So, so if I have to manage it then I’ll just manage it, you know? Just like anything else, any kind of real mental discomfort. (pause) I don’t know what it’s like not to have pain. (Amalia, 61)

The inability to conceptualize life without pain is crucial to understanding the experience of chronic pain. If one is unable to imagine life without the presence of pain, they inevitably expect its return and are plagued by it even when the pain itself is entirely absent. Incurable pain will undoubtedly return, and even for those with minor pain, the fear that it will become debilitating is pervasive.

**Not Planning Life: Living in the Present with Pain**

Some psychological research has suggested that the memory of pain is dependant on the narrator’s current level of pain (Bryant 1993; Eich, Reeves, Jaeger, and Graff-
Radford 1985). Pain sufferers have difficulty explaining their past pain in terms of its relationship to time (Good 1992b). These observations were supported by an attempt to use a graph during the interview to get sufferers to describe their pain in terms of a daily pattern. I asked what things people did during the day, and at what times. Few participants were able to conceptualize their average day in terms of things that cause pain at particular times. Sufferers explained that at times when they were not consciously aware of pain, they were unable to determine whether they were feeling pain and unaware of it, or whether the pain had not been present. The inability to plan the day out in terms of what activities will be associated with pain threatens sufferers’ sense of control over their lives, and makes them reluctant to make plans (also reported by Garro 1994). Maintaining control was an important feature in retaining hope for the future and coping with pain in the present.

Case Study: Sophie

I tend to wear my glasses outside of my ear because I don’t, when it’s touching or on my jaw I’m scared. I live in a lot of fear of the pain of the TMD. A lot of fear of that. I don’t eat much, like chewing, steak-wise, uh, or meat. Uh-huh. So I just won’t chew... Um, so, I deal. Usually I just stay put. Motion, everything seems to trigger it, anything. Talking, noises, light. Mostly movement of the jaw. Yawning, although I haven’t yawned in, it seems like ages. Years.

Sophie is 31 years old and is a full-time student at the local community college. She is more affected by TMD pain than most of the sufferers I interviewed and described the effect of TMD on her life as “horrible.” Her narrative provides several clear examples of the ways in which people attempt to adapt their lives to the possibility of triggering pain, but are unable to avoid flare-ups, which become a constant source of anxiety.
Sophie is careful to avoid anything that she knows will trigger pain.

I avoid food, or talking too much, excessively. I don’t talk on the phone long. I don’t talk on it with, I don’t listen on the phone with this ear. I try to avoid, I don’t sleep on this side of my face. There’s a lot of things. I’ll just avoid a lot of things, you know, so it doesn’t trigger that.

Despite her efforts to avoid pain triggers, Sophie is unable to predict what her pain level will be at any time of the day.

Some days I wake up with pain level one, from zero to one, just like a nagging reminder to take the medicine, and to waking up the next day with a seven or an eight. Back down the next day to zero. Don’t know.

In an attempt to “… control [the pain] and lasso it, harness it… settle it.” Sophie tries to organize her life in a way that allows her to maintain control at all times.

I try to get enough sleep every night. I try to uh, at least. Um, and when stresses happen I just, I know I need to cut things… I’ve learned to cut things, before they build up to a point where I can’t handle them. And actually… things have never got to the point where I can’t handle them anymore. I think that’s a big part of everything. I’ve never been out of control.

When asked whether Sophie maintained control out of fear, she answered, “I’m scared of that, yeah. It’s a fear. Just as much as the pain in my face, I don’t want it to happen.” The issue of control was mentioned several times during the interview. Sophie was careful to explain the ways in which she avoids pain, which she compared to having a mental breakdown or going crazy.

I’ve learned to recognize the warning signs and deal with them before it becomes so escalated that I can’t bring it down. It’s like emotions, it’s like dealing with something very emotional, before you, before I start to cry from it, I’ll adjust and, try to work on it before. Try to adjust it and deal with it before it becomes like, I don’t know, having to hospitalize yourself or having a mental breakdown or something, you know. You can’t let yourself get like that. So, if it starts to hurt I will stop eating, I will stop chewing. I will put, I will do everything in steps… if it happens, you know suddenly stop drinking, I mean drinking, stop chewing, stop talking. Uh, basically keep my mouth shut. And uh, stay away from big vibrations and I’ll be fine.
During the time period when her pain was the worst ever, Sophie was an inpatient at the hospital. She had been having dizzy and falling spells, which she connected to the TMD pain.

That was the worst. And the pain was horrible, it felt like… it was just a nightmare. All around mental and physical. Um, the closest thing I’d call myself to crazy was right then.

Sophie fears that her TMD symptoms will worsen with time, and she avoids information about it. She was diagnosed after a car accident by an emergency room doctor, and feared even then that at some point it would become a problem for her. Every since then she has been “careful careful.” Despite her focus on avoiding pain and its debilitating effect on her life, however, Sophie denies that TMD has affected her future plans.

No. Not my future but uh, my here and now when it hurts, the here and now when it hurts yeah. I don’t find any pleasure in anything when it’s hurting… I can focus on nothing but that.

Like many sufferers I interviewed, she denies the effect on her future, and quickly shifts to talking about the present. This existence in the present, or the “here and now” was the extent of the impact of pain that she was willing to discuss.

While many sufferers do not view TMD as having a significant impact on their lives, one area of experience in which it has an effect is on sufferers’ ability to sleep deeply. While many people do not suffer from insomnia, the primary causes of TMD, clenching and grinding the teeth, most commonly occur during sleep. The knowledge that one’s actions while sleeping have a negative outcome on their illness is a source of anxiety for sufferers, and manifests in a variety of ways.
Sleep and TMD

Not being able to sleep, it kind of drives me crazy. Cause it’s like, I have a hard enough time sleeping, because I think I have a slight case of um, insomnia. So, for me to try and sleep with this problem on top of that creates even more of a problem. (April, 25)

There are obvious connections between chronic pain and sleep, as pain limits sufferers’ ability to sleep comfortably. The interaction between TMD and sleep reaches beyond the pain it causes, however, and is of fundamental importance to understanding the experience of TMD pain. In this section, the relationship between insomnia, sleep and TMD is explored as a fundamental aspect of the experience of TMD, as well as a compounding factor.

While many TMD sufferers do experience insomnia, this is not the only way that sleep is important to the experience of TMD. Some people told me that while they sleep soundly through the night, the sleep is not restful, and the worst pain for many sufferers is experienced just after waking up in the morning.

I go to work at four in the morning, so I’m up by quarter to three. And, I don’t usually go to bed until like nine or nine-thirty. So right there I don’t get hardly enough sleep as it is really. And um, I just, I feel like I have not slept all night, and not, it’s not that I like have insomnia or, or toss and turn or whatever. I sleep like a zombie all night long. I mean, you know, just comatose... But when I wake up I feel like, I just feel like I have not, you know, I haven’t gone to bed... It’s so tiring. I mean I could stand in the shower and fall asleep. … And then when I get home, I try to keep myself busy and stuff but sometimes I’m just so tired, you know, I just take a nap and, I’m trying to get where I can be on the go and, and exercise and do something you know, helpful for me. But I’m so damn tired all the time that I can’t. you know. (Patty, 47)

The lack of energy caused by not getting enough sleep makes other activities more difficult. Clenching during sleep is common among TMD sufferers, and for most,
even the use of a mouthguard does not significantly decrease the likelihood of clenching while asleep.

Lately, I’ve been sleeping pretty good. ... So, you know, it just, it just varies. I guess whatever’s happening in my life... Sometimes. I’ll wake up because I clench my teeth. I wear a mouthpiece, but still, it’ll wake me up... If I’m not, I feel if I’m not sleeping real sound or whatever, you know. Uh, I don’t know if it’s because I’m clenching my teeth that I wake up or you know, uh, or the other. You know what I’m saying? I don’t know if that’s what’s waking me up or if I wake up and then realize that my TMD is bothering me. (Deborah, 59)

Clenching while asleep is a source of anxiety for many TMD sufferers. Because it occurs unconsciously while sleeping, the possibility of avoiding it is minimal. The desire to limit activities that cause pain however, places sufferers in a position where it is often difficult to relax even while sleeping.

I’ll try, you know not to sleep, in a way where I’m pressing on the chin or, or, you know where I feel like something’s going to annoy the jaw. (Lily, 40)

Sufferers often wake up during the night and realize that they have been clenching or grinding their teeth. As I previously mentioned, one of the biggest factors in reducing the pain of TMD that I heard was “awareness.” As long as people were aware of what they did with their jaws, they could manage pain. While it is somewhat possible to mitigate the effects of other activities that cause pain, awareness is not an option while sleeping. At times, the awareness of pain and clenching during sleep extends into sufferers dreams. Restlessness while sleeping is manifested not only as tightness in the morning or insomnia, but also in the form of nightmares that contain powerful images of the feeling of TMD in terms of its effect on the whole person.

Sometimes I’ll wake up at night and I’m clenching. Um, and sometimes too I’ll have, I’ll go through periods where I have a lot of nightmares, and that there’s a correlation between that and when I’m clenching too so, I think the dreams affect it, or vice
versa, I don’t know…when my stress level is higher, you know, the dreams and then the TMJ, um, but sometimes they will come out of nowhere too and I can’t really figure out why I’m having them so. (Georgia, 36)

I have um, in the past had terrible dreams related to clenching my teeth. And I don’t think that I, I haven’t had those dreams in a while, I think that I actually trained myself to relax my jaw in my sleep because it wo- it started happening very frequently that I’d have dreams that um, I couldn’t open my mouth or that I was like, my teeth were stuck together. Just, um, and they were kind of panicky dreams too, it was not just “oh I can’t open my mouth.” But, I couldn’t open my mouth and it made me feel like panicking because of it. (Sandra, 29)

Case Study: Dennis

Dennis is 32 years old. He works as a firefighter and an EMT, and lives with his wife and two young children. At the time of the interview, Dennis and his wife were expecting a third child within two months. As a firefighter for the past ten years, Dennis has been doing 24 hour shifts during which he is expected to rise unexpectedly and possibly risk his life to remove others from danger. While he was always a restless sleeper, this job has compounded a tense, restless feeling during sleep that has a negative effect on his sleep patterns. He also discovered recently that he grinds his teeth, and that the grinding is the primary source of his jaw pain and associated migraines.

In addition to the impact of his job, Dennis explained that his sleep is also affected by a traumatic experience of watching his son as he was run over and dragged by a car. At the time, Dennis believed that he had watched his son die. Despite the fact that his son is fully recovered with only superficial scarring, he often wakes with intense fear that his son is dead, and that the belief that he survived the event was a dream. He fears that believing his son is alive is his way of coping with the event. In the middle of the
night Dennis often looks in his son’s room to verify that he is in fact alive and asleep in his room.

Dennis does not describe his pain as particularly debilitating. When asked whether pain affects his future plans, he answered that it had not affected them yet.

Not yet. I worry sometimes … if I don’t get it corrected, or if I don’t at least, you know, find a way just to maintain this level, I might, I don’t want to be one of those people who have just so much dental pain that, you know, they can’t function… I don’t want to rely on Vicodin and Hydrocodone to, to have a day to day, you know, day to day life.

Dennis’s mother, father, and some of his siblings also suffer from TMD, and he sees a hereditary component to its occurrence. His description of TMD as hereditary, however, is not clearly related to his description of TMD as something that “just has to do with the way some people handle stress, you know as a physical manifestation of it.”

The ability to handle stress, as other people mentioned, is a significant component in managing TMD pain. Dennis explained that although he tends to clench his teeth during some activities, he is often able to control this tendency during the day.

I seem to catch it pretty quick when I’m awake. So I wouldn’t say, I wouldn’t think that much of the pain increases while I’m awake. I seem to catch it pretty quick.

Not only does Dennis have difficulty falling asleep, he also feels as though he is tense while sleeping. In the morning, Dennis often wakes with pain from clenching and grinding during the night which he relates to the way in which tension manifests in his sleep.

Being pain-free is not necessarily an ideal state for people as far as Dennis is concerned. He views pain as something that builds character. This pain, however, which stems from stress, is more difficult to tolerate. In addition, Dennis is frustrated by the
fact that the pain is caused by something that he does while sleeping, and is thus not able to control.

I think the pain is not necessarily a bad thing… [but] it wouldn’t be bad if, if this pain or future debilitating jaw pain was not there, you know, I could find other ways to hurt myself, that I can deal with better. Stress, … stress oriented, I don’t- I don’t like suffering from stress-oriented pain, you know? I think I do a pretty good job of, of uh, being analytical or, or trying to find different, different things that, that uh, stress me out or, stress triggers. I try to find ways to deal with them and it’s frustrating that this happens when I sleep. And I can’t, like I can’t find, and I can’t find something I can do to, so it doesn’t hurt when, in the morning, you know?

Dennis does not view his pain as particularly severe, but he has an image of someone whose pain is completely debilitating, who is unable to function, and he fears that he is in danger of becoming “one of those people.”

Although I do have a certain amount of pain now, it’s not unbearable… I can’t say I’m one of those people who it’s made their life miserable… I definitely don’t, I mean if I knew it was going to be like this for the rest of my life, I’d be okay. I don’t want to get to the point where, where it’s, you know, I wear my teeth down to the nerves and I’m dealing with a high level of pain every day.

**Pain as Grounding: Positive Aspects of Life in the Present**

The way that chronic pain compels sufferers to live one day at a time is meaningful for some. The following case study is an example of a woman who views her pain as a positive way that her body lets her know when she needs to take life less seriously. The pain forces her to pay attention to her body in the present and allow herself time to relax instead of pushing herself toward an ultimately unimportant goal. Physical pain, for her, is a grounding factor. It allows to care for herself in the present, and to appreciate times when she is not in pain.
Case Study: Georgia

Georgia is 36 years old and works for a behavioral health agency. At the time of the interview, she had recently moved and changed jobs. She described her new job as significantly more stressful than her previous job, which caused her TMD to flare up. Although Georgia suffers from severe pain associated with TMD, she is careful not to see herself as a victim.

It’s kind of like an external message to me that I need to take care of myself. So I try to look at it as a blessing in a lot of ways because I think I can kind of have a tendency to sort of plow through things and, maybe not take care of myself as well as I should. So, to me when it flares up I always kind of have to take a step back and think, “Okay, what do I need to do to really be more loving towards myself right now?” Um, I try to look at it in a positive way because otherwise, if I give it too much energy, um, I’m afraid that it’ll make it worse or it just sort of perpetuates it so, um, I don’t know how else to word that. I try not to be a victim of it, sort of, it’s there sort of to give me a guidepost, but I don’t give it the energy or, as an excuse…

Georgia recognizes a direct correlation between times when she feels stress and the intensity of her TMD pain. She views the pain as being there for a reason, to remind her to do more self-care. As mentioned earlier, there is a common idea that TMD is the result of resisting, or of not “going with the flow.”

To me it’s sort of that it’s me resisting, you know, like you think just physically that you’re, you know, clenching and holding back, um, so it tells me sort of I need to go with the flow more and let go rather than resist because when I’m sort of going against the current instead of with the flow, and trusting that things are happening as they’re supposed to be happening, that it’s causing me physical pain so I just need to change the way that I’m thinking about things and when I get back to that that does seem to help it quite a bit but it’s really hard to, lesson for me to learn for whatever reason. I guess I have control issues but, um, it’s uh, I look at it, as much as I can as a gift. This is a way my body’s telling me I need to change certain things.

While this sentiment was not often so clearly articulated by the TMD sufferers I interviewed, there were many people who viewed TMD as the result of not paying
attention to their bodies and dealing with stress appropriately. Although the onset of TMD was often triggered by an accident or trauma, its chronicity was viewed as representative of the ways that people allowed their self care practices lapse for various reasons. For Georgia it was a reminder to, as she said, “not take anything so seriously that I’m causing permanent damage… nothing’s, you know, worth, worth that really. You know, what could be that dire?”

**Hope for the Future**

While hope is often viewed as a way to relate the present to the future, it serves a different function in “incurable” illness. In an illness in which there is little hope for recovery, some researchers have found that a present orientation can become a meaning making strategy for sufferers (Antelius 2007). As Eric Cassell (1982) pointed out, everyone has a perceived future. Suffering, he argued, is ultimately linked to the possibility of losing that future. “Hope dwells in this dimension of existence, and great suffering attends the loss of hope” (Cassell 1982:16).

Unable to arrange life completely in order to avoid the worsening of pain over time, many TMD sufferers find it extremely difficult and stressful to attempt to envision their futures. The arrangement of life in the present to avoid pain necessitates avoiding stress as much as possible. Avoiding stress then, for many, means not thinking about the future and what the outcome of pain might be.

I don’t know because at my age now, I’m, I just want to enjoy the rest of my life. I don’t have no, no goals where I have to, I don’t, I don’t want any stress, any more stress so, so I just want to take it easy and enjoy life, rather than stress myself out
making deadlines or… I have enough just, everyday life and dealing with the pain to, to plan for the future about what I want to do when I grow up [laughs]. (Amalia, 61)

I, you know, I haven’t really been thinking much about my future. Just because it’s been so, over the last two years it’s just been so much of like, month to month, day to day, you know… I don’t feel like I know particularly where I’m going… I don’t feel like I know where I’m headed. (Beth, 30)

Changing one’s perception of the future to include the experience of chronic pain would mean admitting that one is resigned to its permanence. While many people stated that they did not think their pain could be cured, actually rearranging future plans for pain would be to risk losing hope for a cure. On the other hand, retaining one’s original goals for the future is also risky, because sufferers are aware that the pain will likely be part of their continued experience.

Not discussing the future allows sufferers to be realistic in their expectations while not sacrificing the element of hope that is crucial for daily coping, as well as for overcoming the emotional elements of the disease. According to Honkasalo (2000), pain alters the direction of intentionality, forcing it to look backward. Sufferers often look into their past for reasons for pain, and look less at the future due to uncertainty as to what might occur. In this way, she argues, sufferers can maintain openness despite loss. As Good and Good (1991) point out, people living with the uncertainty of chronic illness leave alternate possibilities available by “subjunctivizing” reality. Through the subjunctive elements of their narratives, sufferers are able to retain the possibility of healing, even if miracles are necessary (Good and Good 1991).
SOCIAL AND INTIMATE RELATIONSHIPS:
BEYOND THE INNER STRUGGLE

While there has been research in the area of chronic pain and families, most has been concerned with the impact of chronic pain on the functioning of the family unit (Friedemann 1995; Ranjan 2006; Turk, Flor, and Rudy 1987). Studies have been widely varied in their findings, and report that one of the major impacts on family function is the result of the loss of productivity of the pain sufferer which requires the other family members to compensate by doing more. In addition, most of these studies are focused on pain disorders that impact the ability to perform normal household functions, and consequently affect marital satisfaction (Ahem, Adams, and Follick 1985). In the following chapter, I discuss the impacts of TMD on family and other relationships as perceived by the pain sufferers.

Because of the unique nature of jaw and facial pain as opposed to other forms of chronic pain, my focus will be distinct from other studies that have discussed the impact of pain in other parts of the body on family relations. Although I discuss similar topical areas to the existing literature, the way these areas are affected by TMD differs from other chronic pain disorders.

While there has been research on the dynamic nature of the relationship between families and chronic pain (Ranjan 2006; Richardson, Ong, and Sim 2007; Smith and Friedemann 1999; Turk, Flor, and Rudy 1987), most are focused on widespread pain, low back pain, or chronic pain as a subcategory of chronic illness in general (Ahem, Adams,
and Follick 1985; Monga, Tan, Ostermann, Monga, and Grabois 1998; Smith and Friedemann 1999). The majority of reports are focused on pain sufferers relationships with their spouses and the impact of family members on symptom presentation (Block and Boyer 1984; Turk, Flor, and Rudy 1987). Much of the previous literature is relevant to the participants in my research, but the unique nature of TMD adds a dimension to the impact on family relationships that has not been widely considered.

Using a case study to illustrate my findings, I discuss the perceived impact of TMD on sufferers’ families, friendships, and intimate relationships. There are two significant differences between widespread chronic pain or low back pain, and jaw or facial pain. The first is that TMD pain is concentrated in the face, neck and head. It does not affect one’s ability to walk or perform normal household activities in the same way that other pain symptoms might. While TMD pain can be debilitating at times, for most of the sufferers that I interviewed the pain is tolerable even at high levels, and does not affect normal daily routines. However, activities such as talking, laughing, kissing, smiling, and eating can be profoundly affected by TMD pain in ways other chronic pain sufferers may not experience.

The following is an attempt to understand some of the perceived effects of TMD on relationships and families based on the narratives of TMD sufferers. As an illustrative case study I will describe the life and relationships of a woman with a severe case of TMD. Angelica’s story highlights many of the important aspects of how a pain sufferer perceives the impact of TMD on relationships. I will add narrative from other participants.
to support my analysis of Angelica’s story, and my conclusions about such impacts on relationships.

I chose Angelica as a case study for this topic because of the severity of the pain she experiences and the fact that she lives with her mother due to her inability to work. Despite the pain it causes her, Angelica enjoys talking, and she is considerably more open than many chronic pain sufferers. I also chose Angelica because of the ways in which her narrative is constructed. She shifts among a few distinct voices that provide her with particular ways of making meaning in her illness (see Strauss 1993). At times she is crying for help, overcome by pain and debilitated by the medication that she in unable to function without. Other times she is a survivor, pursuing a college degree despite difficulty. An important voice that Angelica often uses is that of a caregiver to her mother. Through these multiple voices, Angelica is able to convey the severity of her pain and its impact on her life while maintaining an important role for herself. Although Angelica’s pain is more disabling than many TMD sufferers, her narrative reveals a carefully constructed role which conveys the severity of her illness while allowing her to retain some sense of dignity and self worth in her position as a caregiver to her mother.

Angelica’s Life Before TMD

Angelica is 37 years old. She suffers from severe TMD pain, and lives with her mother in a retirement community. She was married at age nineteen to a man that she describes as controlling, “a traditional Sicilian,” and gave birth to her son after dropping out of high school. Angelica did not return to school until her son was an adolescent.
Before deciding to stop working, Angelica worked as an administrative executive, which provided her with excellent health benefits, and considerable satisfaction in her career. She returned to school online to complete a degree in business administration in order to advance in her field. Never having graduated from high school, she explained, graduating from college is important to her sense of self worth (at the time of the interview she continued to pursue her degree).

Prior to the onset of TMD symptoms, Angelica described herself as normal.

Oh yeah, just like what I guess what a normal person would be. I could turn my head, laugh, smile, be intimate. I had no problems at all, you know, none. I … was living a very good life before this really hit me.

**Transition to Admitting Inability to Cope with Pain**

Angelica began experiencing severe pain from TMD in 2004, approximately three years before I interviewed her. She had experienced minor pain previously, but when it “really really started hitting [her] hard,” she explained, the pain affected her both physically and mentally. As the pain worsened, she described herself as getting “wacko.” Angelica began taking medications for pain, depression, and anxiety. In addition to the pain, she was dealing with the after effects of a divorce. Angelica’s fifteen year-old son learned of her inability to cope with pain and depression when he was required to help her locate her medications during an anxiety attack. This episode led to a breakdown in Angelica’s relationship with her son.

And then one night I just, I had a really bad panic attack, or anxiety attack and, I had to have him help me find my medications and that’s when he found out. And then it was shortly after that (crying) that he decided he wanted to go live with his father. And that just killed me. And that just made my depression and everything all that much worse.
Prior to her son’s decision to live with his father, Angelica explains that her life was going well. She continued to work and function normally in social situations. After that incident, however, she went “over the edge” and was unable to cope with depression. I started getting suicidal after that and I would go out on disability from work just because I’d be so depressed I couldn’t function. I couldn’t function in daily life so, dealing with the pain and depression just made [the inability to function] worse.

Angelica’s use of medications and her instability during that time period continued to create a rift in her relationship with her son. Her son’s lack of understanding about her condition contributed to feelings of failure in her ability to fulfill her maternal role, because “mothers don’t do those kind of things or… experience those kind of feelings.” After her son moved, Angelica continued to pursue her college degree, but found it difficult to complete the classes when she was in pain. Instead of failing classes, she would often withdraw, causing her to remain in school in school long after she had planned to graduate.

As the pain worsened, Angelica was frustrated by her inability to find adequate treatment despite having excellent medical and dental insurance. This frustration with the medical system is common among TMD sufferers (Garro 1992; Good 1992a; Reid, Ewan, and Lowy 1991). In essence, Veronica was given a mouthguard to sleep with and a series of narcotic medications, none of which provided the relief that she needed. “The pain was becoming unbearable” and as the pain worsened with time, even cortisone shots in her jaw provided only minimal relief.

The more I talk, laugh, smile, you know the things that we take for granted in everyday life, are very difficult for me… There are [times] when I yawn or laugh or smile where I literally have to hold, hold [my jaw], to keep it in.
As symptoms continued without improvement, Angelica increased her use of pain medications. Although she hates being on so many medications, she feels unable to live without the relief that they provide. As she continues, it becomes apparent that the pain has become the major difficulty in her life, and the depression and anxiety that she struggles against are portrayed as direct results of the pain itself, and not of other life circumstances.

I’m on some se- what I consider some pretty serious nar- narcotics. You know, and I hate them… But if I didn’t have them, I would probably kill myself from the pain… not so much from the depression that it causes or the anxiety, but the pain.

After searching for medical relief through a cure for her illness and finding only pain medication, Angelica “got tired of the fight” and decided to leave her job. She moved across the country to live with her sister. After a series of disagreements with her sister, however, Angelica decided to move in with her mother who, she explained, is in need of a caregiver. She is currently living with her mother, and her narrative is constructed to reveal an intricately crafted story about care and disability. The story allows her to regain legitimacy in her role that has been lost in the struggle with chronic pain.

**Communication and Family Support**

Angelica’s mother is in her early seventies and until recently, she has lived alone in a retirement community. Although Angelica moved because of her inability to work, and left her sister’s home because of disagreements, the reason she gives for moving in with her mother is her mother’s need for a caregiver, and not her own.
Previously, Angelica had little contact with her family. She explained that in the past her mother had “burned” her more often than her sisters in “family drama type situations.” Currently, however, Angelica feels as though she is her mother’s favorite child. She is the only one of her siblings that was able to give birth to a child, which she connects with her mother’s affinity for her. She explains that she has helped her mother more than her sisters have and vice versa. In her narrative, Angelica shifts from descriptions of the intensity of her pain and her difficulty coping with it, to stories of her mother’s forgetfulness and the reasons that she is in need of care.

One night I forgot to take my medications at night, so when I woke up the next morning my mom’s like, “what’s wrong?” and I’m like (shuddering) “I- think- I- forgot to take my pills” cause I was shaking so bad, and I don’t ever want my mom to see me at my worst because I’m there to take care of her. You know, and she’s so, to me, feeble and fragile, that I wouldn’t want her to see me at my worst, because I know what it would do to her… and that’s you know, those are the reasons why I take care of her, so she remembers, mom, turn off the burner, mom take that off the toaster. You know, and help her so she doesn’t fall, you know, if she falls I’m there. (emphasis in original)

In Angelica’s current situation, she feels as though her support system is excellent. In the past she lacked any emotional support for her pain or depression, since her son was too young to be able to support her and her ex-husband did not believe in depression or therapy. Her mother, in contrast, has also suffered from TMD and is very supportive. Angelica relies on her mother’s understanding of her pain in various ways. Despite financial aid difficulties, her mother encourages her to continue in school. She is supportive of Angelica’s decision to stop working, although the two of them now live on a small social security income. Angelica also relies on her mother for communication of pain symptoms with other family members.
I have a very good support system with my mom, and that, that to me, (pause, begins to cry) it makes so much of a difference when you have somebody who understands, and who can support you with everything...if I’m very quiet, like if we’re at grandma’s for dinner or something and everybody’s around and I’m very quiet, my mom will say “well she- she’s hurting.”

In contrast to the support Angelica receives from her mother, she has difficulty conveying the intensity of her pain symptoms to her sisters. Resorting to gruesome descriptions of torture is the method she uses to convince her sisters that she is actually in pain, and not simply trying to avoid them.

I had to sit my sister down one day, because she always kept [saying] “oh, you’re avoiding me, you don’t pick up the phone na-na na-na.” And I said, “you know, you just don’t get it.” I said “give me a, a scr- a drill, different sized drill bits, give me an ice pick and a mallet,” I said “give me these tools and let me have about ten minutes of working on you in different ways, and that will only be an inkling of what I feel for pain. And then you will understand why I don’t like to talk.” So, that kind of made a big difference and then she got better about instant messaging (chuckles) after that. Yeah. And she doesn’t get on my case if I don’t pick up the phone or anything.

Despite her use of such descriptions, Angelica feels unable to gain her son’s understanding, and many of her friends are unwilling to be in contact through instant messaging, which has led to deterioration of those relationships. She presently has no social life to speak of, although she hopes to find a church community that will offer some social support from peers. Although she was socially active previously, the inability to talk and laugh has had a profound impact on both family and other relationships for Angelica. In the following section, I will discuss the impact of pain caused by laughter, smiling, and talking on Angelica and on others who described the important ways in which laughter and talking were once part of their lives that is now sorely missed.
Laughter and Talking as Sources of Pain

Although TMD is often not debilitating in the same way as many chronic pain disorders, the inability to talk and laugh without pain is felt as extremely limiting for many sufferers. As Angelica explains, talking and laughing are essential to success in many professions, and the inability to carry on normal conversations can mean the inability to work at all.

I did work a couple temp jobs when I first got here. And it was really tough because they were… administrative jobs so talking all day on the phone and greeting people so on, and so forth. And then the end of the day, I just… didn’t want to say a word. Once I walked out of that office that was it. Okay I’m done.

Angelica fears that if the pain continues, she will be unable to return to her career, and she will have wasted a considerable amount of money and time pursuing a college degree that she can’t use.

I’m thirty-seven years old, I should be out and enjoying life and have a career, and it scares me a lot that if I don’t (crying) find a way to manage it, that I’m go- doing all this school work for nothing. Because what’s the point in having this kind of degree to do what I want to do in my life if I can’t talk? If I can’t talk to people and smile and, you know, give off that impression that yes, I’m happy to be here not, not in excruciating pain, you know, that I’m only smiling to your face but I turn around and then, I’m crying because of the pain.

For many of the TMD sufferers that I interviewed, the pain associated with talking and laughing fundamentally affects their outlook on life and their desire to participate in social situations. This is often perceived as more difficult still for those who, like Angelica, were once very personable or social. While many TMD sufferers choose not to let pain limit their social interaction, they temper the enjoyment of being around people with the knowledge that they will pay for their enjoyment later in the form of increased pain.
I’ve been to over five hundred concerts in my life and, you know, I miss that- I miss that part of my life. My son’s a musician, my ex-husband was a musician, so I really miss that social outlet, and I don’t know anybody here, and even if I, I don’t really have a problem going by myself, cause I used to do it in Orlando, but I have issues because I can’t scream and enjoy and be happy and thrilled, you know, feel that energy. It’s just not the same when you’re sitting there in pain and knowing that it’s going to hurt if you do that.

**Payment in the Form of Pain**

Other informants expressed concerns that were similar to those expressed by Angelica. David, a fifty-four year old man speaking through a heavy Boston accent, admits that the anticipation of pain makes it difficult to feel excited about interacting with his family.

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. Literally I don’t talk as much as I used to talk. I’m much quieter, um, (Short pause). Smiling is [painful] but laughing is a *killer*. My goodness. 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 [with increased pain] later… but you know, you gotta make that payment. (David, 53)

For Darla, a 50-year old woman, going out and participating in social situations takes energy. When she goes out, her friends are excited to see her and unaware of the pain their hugs and pats on the back cause her.

I don’t have a whole lot of social contact because I don’t often feel up to it. Umm, but I do have a social circle of acquaintances from before the accident and a, and a social organization that I’m involved in, umm, that has parties a lot. And so, I go to some of those, when I feel up to smiling and, you know, getting my back pounded. ‘Cause no matter what I do, somebody’s gonna walk up and give me a bear hug and I’m just gonna, you know, and I’m just gonna, you know. [demonstrates how she winces in pain when someone hugs her] So, sometimes I’ve had to come home early from things. (Darla, 53)
Even polite conversations with strangers in the street can be painful. The pain, however, does not stop Angelica from talking to her neighbors, which she views as common courtesy.

I walk the puppies during the day because I live with my mother in a senior community so, and you can’t be rude to the older people and, so I have to smile and talk to them about the puppies and stuff…you know, so of course I, I’m very cordial, to them. You know, and they don’t know [about the pain] and they don’t need to know. I know they have their own ailments, which they tell me their life stories anyway [chuckles] but I sit there and listen and smile and laugh with them, you know, out of respect and common courtesy, and then later, I’ll just, you know, go home and not say anything.

As Angelica mentions, sharing pain with others involves a decision-making process that often considers the context of the interaction as well as the age and medical situation of the other person.

*Sharing Pain Experiences*

Choosing with whom and when to share pain is contingent on a variety of factors. The age of an individual, their gender, the problems they experience, and the degree of relatedness to the sufferer all impact a relationship’s amount of TMD discussion. It seems that being too young makes someone seem unable to handle and be understanding about problems, while being old is often associated with medical complaints. Participants choose to share pain symptoms with those who they deem to be old enough to handle the “burden” but relatively free from their own serious medical or emotional ailments.

When I do need to talk I just call my two girlfriends that I see all the time and talk to them, or my daughters (short pause) if I have to. I try not to burden them too much. But they’re older, they understand, they’re not getting any younger at forty-one (laughs). They’re getting gray hairs (laughing). (Amalia, 61)
I don’t really try to talk to my brother or my sister about stuff like, that’s troublesome, or anything cause I mean they’ve already got enough stress going on in their lives and they’re too young to even be dealing with my problems, so I don’t really put that on them. And I don’t really talk to my mom so much anymore about my problems just because I know she’s in a lot of pain most of the time and she’s got her own problems so, I don’t really want to put that on her so… It’s, again I just don’t go to them all the time because I really don’t want to put my stresses on them. Um, my boyfriend and my roommate, I don’t mind so much (laughs), they’re around the same age group.

(April, 25)

For David, talking about problems seems inappropriate because he feels as though it is “dragging everybody down.” He keeps his pain and problems to himself as much as possible in order to avoid burdening his wife and thirteen year old daughter, leaving him without anyone from whom to seek emotional support. The lack of energy that he experiences as a result of TMD affects his relationship with his wife, and despite his effort not to discuss the pain with her, she is aware of it. Conflict arises when David attempts to hide his pain and be flexible, while his wife wishes to express support by not doing things that cause pain in front of him, or eating foods that he is unable to eat.

My uh, my wife kind of knows, but it’s just, she’ll talk to me, or if I’m excited about something then we’ll talk. Like, “oh that sounds great yeah.” I’m like, and that’s the problem I just don’t have this energy. The energy level is just gone. Like that spark I just, how to be happy about things…Mm, at times but you know [it affects our relationship], cause it’s frustrating for the other person. It’s like someone has a disease, and it’s like, they’re sick and you want to go, (snapping fingers) go do something and the other person, and you- you- you know it, but sometimes, you get tired of someone being sick. (David, 54)

David feels guilt at being unable to recover from his illness. He is painfully aware of the frustration that family members feel at an illness that cannot be cured. His inability to be the “joker” that he used to be limits his interaction with his family. In addition, the soft food diet that he follows in order to minimize pain limits the possibility of going to restaurants that his family enjoys. The combination of these factors, and of his lack of
energy, leads David to feel like a burden on his family. As a result, David attempts to compensate by minimizing his pain. His attempt to compensate leads to conflict when his wife feels guilt for her inability to remedy the situation, and also attempts to overcompensate.

You know, so I feel that kind of guilt, knowing that I feel like I’m, I don’t want to drag, dragging them down too. And they, they’re over, they overcompensate. “Well we don’t have to go, what can you eat tonight? What do you think you could eat?” 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. We can’t do that. We’ll have to go where, like who has fish? Who has good fish?” 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,” or, Mexican food, I used to love you know, Mexican, the nachos, and with salsa you wait for your meal to come. So she doesn’t want to go to Mexican food because they will have salsa that, I mean the chips there. And I can’t eat that so I say “well you go ahead eat, I don’t care.” You know, and it’s like, but we get into these crazy arguments like that. (David, 54)

As David’s narrative illustrates, the social nature of eating meals is a source of difficulty for many people who experience pain when eating all but very soft foods. Even for those whom pain has little impact on other areas of their lives, eating is a source of pain, and therefore often causes anxiety in social situations. Often, in order to avoid offending well-meaning friends or family members, TMD sufferers eat what is prepared for them, knowing that the chewing is likely to cause the pain to flare-up later or the next day. In both eating and talking sufferers often mask their pain in order to appear normal and avoid burdening others.

Unlike other chronic pain disorders, TMD does not affect the whole body. For this reason, many sufferers are able to continue with normal daily activities despite sensations of pain. Ironically, however, the non-widespread nature of the pain seems to
make it more difficult to explain in social situations, and thus to justify the limitations that it imposes. Because it is so localized, it seems less important than pain in other parts of the body. The lived reality however, is extremely debilitating as TMD sufferers cannot engage in the simplest of human activities including talking, smiling, laughing, and eating with friends and family. In the following sections, I discuss some aspects of chronic pain, and TMD pain in particular, that have important impacts on sufferers’ intimate relationships.

**Impact of Temporomandibular Disorders on Intimate Relationships**

The inherent invisibility of pain has a profound implication for intimate relationships (Schlesinger 1996). Researchers have found that widespread chronic pain has a negative impact on intimate relationships due to a variety of factors (Bral, Shaughnessy, and Eisenman 2002; Schlesinger 1996; Smith 2003). Women who suffer from widespread chronic pain are faced with a dilemma when sex is painful, and when their partners are reluctant to hurt them. Sexuality is one of the most fundamental forms of shared intimacy in relationships (Jensen and Schover 1988). Pain is also associated with a decrease in sexual desire, which can impact intimate relationships (Bral, Shaughnessy, and Eisenman 2002; Schlesinger 1996). Often, Schlesinger reports, even if the partner is understanding, the pain sufferer is bothered by the outcome of the pain on sexual intimacy (1996). The diminished possibility for sexual intimacy that often results from chronic pain has the potential to profoundly impact both partners’ quality of life.
(Bral, Shaughnessy, and Eisenman 2002); (Roberto 2001). There has been little research, however, on the intimate lives of people with chronic pain resulting from TMD.

TMD is distinct from other chronic pain disorders because of the concentrated nature of pain in one body part that is necessarily part of sexually intimate relationships, the mouth. In my interviews I found that many women mentioned the impact of jaw pain on their intimate relationships. Kissing, which many considered to be a crucial component of intimacy with a partner, was often painful for women with TMD.

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. And, that I gotta explain. So, there are times when an explanation just, you know, isn’t quite enough. But, that’s what you gotta go with…. but 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?” You know? (Darla, 50)

Darla’s gesture of blowing into her hand, as though telling her partner that it was painful to kiss her was construed as a hint that her partner had bad breath is an important example. Unlike other aspects of social interaction, it is difficult for sufferers to convince partners that lessened sexual desire results from the pain, not from other problems in the relationship, or with the partners themselves. Darla states that although there is considerable research on TMD, the impact on relationships is seldom mentioned.

Nobody ever talks about the impact on relationships. And, especially with sexual contact and stuff. I mean, nobody ever says anything about intimate activities that you have to modify. How you do them, if you do them, when you do them and how to deal with it if you can’t do them. Umm, nobody talks about the social aspects like smiling and stuff. And how hard it is to, you know, be pleasant when, I mean, I’ve had friends tell me that I should smile more often. And, what I couldn’t get across to them was I’m not trying to be glum-faced. It’s just having a big grin on my face doesn’t feel good. (Darla, 50)
Not only does the pain force her to modify sexual activities, it also affects her ability to be pleasant in social and intimate situations. Despite their attempts to mask pain, sufferers find that they communicate it through non-verbal facial and bodily expressions. For Angelica, the impact of jaw pain on sexual relationships causes her to feel anxious about the possibility of beginning a new relationship and being unable to participate in sexual activities that she considers fundamental to her role as a woman in an intimate partnership.

I haven’t been intimate with anybody in a while, and the last relationship I had was pretty abusive but prior to that, I was a very, and not promiscuous, but when I was with somebody, very intimate. And not, sexually, kissing and oral, was, I was good at it. And now, I just can’t do it. Oral sex is out of the question, there’s no ifs ands or buts about that. And kissing, um, I’m, I’m afraid that if I do (begins to cry) meet somebody (pause) it’s going to be very hard because, kissing would be very uncomfortable, and it is a very intimate thing and, an important part of any relationship. And I’m afraid that if that person finds out that I can’t do it, can’t do either, that they won’t want to be with me. I mean I feel bad enough that I can’t give anybody a child, and then to lose [short pause] that sense of being able to perform womanly duties, I can’t say womanly duties, let me rephrase it, intimate things, that once they find that out, that’s it, I’m gone, you know? Those are just fears that I have. Not so much, I’m hoping that that person would be considerate enough that not being able to perform oral sex, but kissing is like a whole nother thing, so I, I do have concerns about that.

Fear of sexual inadequacy due to pain is a common topic, as also mentioned in other study findings (Schlesinger 1996). There has been little mention, however, of women’s perception of the impact of sexual intimacy on the origin of their pain. One woman who participated in an interview about her TMD, asked not to be recorded in this section of the interview, and stated that she felt that oral sexual activities during her youth had contributed to her development of TMD. Another listed having sex as one of the important ways that she takes care of herself emotionally, and the inability to do so is
detrimental to her well-being. More research is needed on the specific impact of TMD on sexual intimacy, and the ways in which people relate sexual activity to pain.

*The Social Dimension of TMD Pain*

As I have demonstrated, the experience of jaw and facial pain has a unique impact on sufferers’ social, family, and intimate relationships. Laughing, talking, eating, smiling, and kissing—fundamental features of human interaction—are profoundly impacted by TMD. The inability to participate in such activities is viewed as severely limiting to those who live with TMD pain.

As Angelica states, the inability to talk and laugh can be as debilitating as losing a limb in terms of being able to work, particularly for those who are required to interact with people.

I want to be able to finish school and get a job, and I know that any job I get requires, just proper communication, smiling, being courteous, talking. I miss that, I miss people, I’m a people person, you know, that’s why I chose human resources. You know, and I know I can go any direction once I get my degree with the business and the HR, I could go anywhere with it. I just have to be able to, you know, talk, and smile and laugh without it being excruciating to where I can’t function at work.

In addition to not being able to talk and interact normally, the impact on intimate relationships is profoundly felt as a limitation. As mentioned previously, chronic pain is an inherently private experience (Baszanger 1989; Johansson et al. 1999; Ong et al. 2004). For those who are unable to share their pain with others, the fact that TMD affects intimacy compounds the isolating effect because sexuality is not openly discussed. In attempting to explain the impact of TMD in one’s life, the private nature of such an impact makes sharing the experience of pain even more difficult for many sufferers.
Unlike the impact of widespread chronic pain or low back pain, jaw pain’s impact is less apparent, and perhaps even more personal to sufferers. Sufferers often minimize the pain they experience in order to avoid burdening family members with something that cannot be remedied, and thus internalize their illness experience. In addition to trying to hide pain in social contexts, sufferers are unable to maintain their social role as “joker” or “people person,” and are unable to explain the reason for such changes in their style of interaction without bringing attention to their pain and disability. Laughter is a fundamental part of social interaction as an index of solidarity, affection, or appreciation (Herron 2006).

TMD sufferers are disabled in a way that other chronic pain sufferers often continue to function. The loss of ability to communicate normally affects social functioning very differently than the inability to vacuum or to lift heavy objects. While other forms of chronic pain invariably have profound impacts on sufferers close and intimate relationships, I have attempted to demonstrate the unique nature of the impacts of pain on TMD sufferers. Often, instead of facing skepticism about their condition from co-workers (Reid, Ewan, and Lowy 1991) or from physicians who view their complaints as attempts to avoid work (Jackson 2005; Reid, Ewan, and Lowy 1991), TMD sufferers face skepticism from their friends, partners, and family members. The inability to work or complete household chores affects relationships differently than does the inability to kiss a partner or laugh at a friend’s jokes. I found that many people who suffer from jaw pain expressed difficulty in convincing their family members and partners that the change in their relationships resulted from pain, and not from other personal issues. TMD sufferers
struggled to convince partners and family members that their lack of interest in intimate and friendly interaction was due to pain and not due to the partner’s bad breath, or boredom interacting with a sister or friend.

More research is needed in this area, and on how the partners, family members and friends of TMD sufferers perceive the impacts of this disorder on their relationships. The profoundly personal nature of the impact of jaw pain in sufferers’ lives warrants a closer look in order to understand how such limitations are experienced on a daily basis.
CONCLUSION

The narratives of those who live with chronic pain do not reveal the absolute truth of what it means to live with illness or suffer from pain (Ochs and Capps 1996). As embodied trauma or experience however, pain presents a form of embodiment and an informative way to understand human participation in the world (Csordas 1993). The words of sufferers provide insight into the more authentic feelings, beliefs and actions associated with chronic pain (Ochs and Capps 1996). The conflicting elements that exist in the details of sufferers’ narratives, particularly as seen through detailed case studies, reveal inconsistencies and complexities of the experience of illness (Reissman 2003).

Explanations of TMD according to my informants were varied, but most included a relationship between structural or physical factors such as misaligned jaws, trauma, or clenching the teeth, and difficulty coping with stress. I found that for many people, confidence that their pain had a true physical basis allowed them to speculate about the psychological or emotional contributors. Stress was a safe way for people to acknowledge a psychosomatic component of illness without threatening the legitimacy of their bodily experience. It is important to note that as people entered a research study in which they were offered the possibility of treatment with Chinese Medicine, they may have been more willing to discuss aspects of pain they perceived as more accessible for treatment with CAM therapies.

Unlike previous studies of TMD, many of the sufferers in this study had not sought treatment from multiple practitioners, particularly because they were often
diagnosed with TMD prior to experiencing pain. The fact that many sufferers in this study were familiar with the symptoms and aware of the lack of treatment for TMD before they experienced it led them to avoid the search for diagnosis and treatment, and to be resigned to living with pain.

The difference in my findings suggest that although chronic pain sufferers have been characterized as overusing health care resources and having multiple somatic complaints (Barsky and Borus 1995; VonKorff, LeResche, and Dworkin 1993; VonKorff et al. 1991), there may be many people living with chronic pain who do not seek care. This thesis demonstrates the functional and stoic nature of many who live with TMD, and highlights the many ways in which people live with TMD pain that do not revolve around the search for diagnosis or treatment.

One of the most important strategies for coping with pain was learning to ignore its presence. As long as sufferers were not focused on it, they could generally handle the pain without medication. Even meditating, which was helpful for relaxation in other areas of sufferers lives, required too much awareness of pain and was sometimes avoided altogether.

Common strategies for coping with pain (ice, heat, jaw exercises, and relaxation techniques including meditation) that provided minimal relief were rarely worth the increased focus on pain they required. Other difficulties in coping with pain included the interaction between exercise as a stress reliever and as something that strains the body and increases pain. Thus, TMD sufferers are left with relatively few strategies for managing pain.
Although a few sufferers used prescription pain medications, this was not widespread. Many sufferers were involved in a complex decision-making process every time they wanted to take an Ibuprofen or other over-the-counter pain reliever. Knowing that the relief it provided was only temporary and had no curative potential encouraged people to learn to “handle” pain without the use of medications. With every pill, the short term and often minimal relief from pain was weighed against the long-term outcomes of medications on other parts of the body, as well as on sufferers’ ability to function.

More broadly, the fact that many people felt as though their TMD pain was a symptom of a larger problem led to heightened awareness of the health of their bodies. The complex relationship between TMD and other parts of the body discouraged sufferers from putting substances into the body that might add to an overall feeling of being out of balance or not in optimal health.

There is an important financial component involved in the decision to seek care for TMD pain. Particularly for those sufferers who, as I have mentioned, were aware of the lack of an effective treatment for TMD, the expense of seeking treatment was a major consideration. TMD as an illness is located somewhere between dental and medical care, and for this reason it is not often covered by either type of insurance (Ostermann et al. 1999). Lack of insurance coverage, therefore, often prevents even those people with adequate medical coverage for their other ailments from seeking treatment for TMD.

TMD sufferers, as illustrated by case studies of women living with comorbidities, displayed a considerable amount of resilience in their adaptation to pain. The experience of other illnesses in addition to TMD highlights the interconnectedness between TMD
and the rest of the body as it is felt by sufferers. Although TMD pain was not always severe or debilitating, it was time consuming and required a considerable amount of energy for sufferers’ to handle on a daily basis. The energy that it takes to cope with constant TMD pain ultimately leaves less energy available for coping with unexpected stresses or difficulties.

Case studies of informants with multiple chronic pain disorders shed light on the way TMD sufferers understand energy in the body. Similar to the lack of energy left over to handle stress, the body’s experience of pain was viewed as leaving it with less energy to heal itself and maintain balance. The idea of a reserve of health (Herzlich 1974) is useful in understanding TMD sufferers’ views of energy and of maintaining their health through careful management of activities. Many TMD sufferers viewed their pain as the result of depleted energy caused by not caring for their bodies earlier in life. The feeling of having used all of one’s available energy, and thus having little left to cope with daily life is an important theme in the narratives of TMD sufferers.

Multiple illnesses demonstrate the difficulties that arise in coping with TMD pain. In the discussion of comorbidities, sufferers’ narratives reveal the ways in which living with, or coping with TMD is often in conflict with other activities, even those that are done to maintain health and well-being.

Although TMD sufferers viewed TMD as being related to other health issues, its interconnectedness with the rest of the body was not addressed in interactions with medical practitioners. Many sufferers felt as though their doctors did not see TMD as an important health concern, and even themselves often viewed other health issues as more
pressing. They were less willing to discuss TMD with their physicians when seeking treatment for other ailments out of fear that it would compromise the doctor’s confidence in their assessment of the severity of other pain. Despite the acknowledgement of other ailments in the clinical encounter, TMD often exists in the background of sufferers’ experience and has a significant, if indirect, impact in many areas of their lives.

In addition to its perceived impact on the body, I found that TMD has important impacts on emotional and psychological worlds. Finding meaning and retaining hope in the face of uncertainty associated with chronic pain required constant work on the part of sufferers. The work of illness is an important part of coming to terms with chronicity and managing pain (Corbin and Strauss 1988; Thorne 1993). Sufferers are involved in constant work to maintain control of their illness, especially by avoiding pain triggers and mitigating the effects of pain on their daily activities. Maintaining control over the pain, and participating in the work of illness is a way for sufferers to retain a sense of agency in living with unpredictable pain. While sufferers are careful to minimize pain as much as possible, the inability to maintain control at all times or to predict the onset of flare-ups leads to a considerable amount of anxiety.

Retaining control of one’s life is difficult if not impossible in the face of chronic pain, but many sufferers were involved in careful strategies to maintain control over their pain at all times. The experience of anxiety surrounding the pain stemmed from the possibility of losing control and becoming unable to handle pain. Sleep is an area in which the impossibility of maintaining control becomes clear. The work of illness that is performed at all times of the day is difficult to maintain during sleep but sufferers often
attempt to be aware of their positions and activities even while sleeping. The fear that TMD pain will be triggered during sleep often limits the possibility of sleeping deeply or restfully which exacerbates stress and anxiety and adds to the feeling of already limited energy that is associated with TMD.

It seems that TMD impacts the process of planning for the future not by changing an individual’s plans, but by limiting the possibility of planning for the future at all. Sufferers live in a profoundly present-oriented, or perhaps what can be called a liminal state (Jackson 2005). Living in the present can be a meaning-making strategy for sufferers (Antelius 2007) and it is important for understanding how sufferers maintain hope for the future. As Eric Cassell (1982) pointed out, suffering is ultimately linked to loss of identity or of a perceived future. Living in the present allows sufferers to have realistic expectations without sacrificing the element of hope that allows them to cope with pain, and to overcome the emotional elements of TMD. By “subjunctivizing” reality, sufferers leave alternate possibilities for the future available (Good and Good 1991) and stay open despite what is lost as a result of pain (Honkasalo 2000).

Choosing when and with whom to share pain is an important decision-making process. Sufferers avoid “burdening” others, especially their children, with their ailments. They are acutely aware of the possibility that their pain will negatively impact the mood of others, and often choose not to disclose the fact that they are in pain even if it means they left without emotional support. Sufferers are careful to maintain their normal social relationships as much as possible, which often includes talking, laughing, or eating things that will cause pain later. Sufferers are often aware that they will “pay” for their actions
later in the form of pain, but in some situations that are willing to “make that payment” (David, 54).

There were important differences between TMD and other forms of chronic pain in terms of its impact on social relationships. Because TMD pain is so localized, it seems less important than pain in other areas of the body. The lived reality, however, of being unable to eat, laugh, or carry on a normal conversation makes it extremely debilitating in terms of its impact on social and family relationships. Talking and laughing are essential to normal social functioning, as well as to success in many professions. The impact of pain in the face and jaw has unique outcomes on the intimate relationships of TMD sufferers as well. Pain resulting from kissing, hugging, or other intimate activities impacts sufferers’ sexual desire and thus impacts their intimate relationships overall.

Using a case study and other narrative selections to illustrate the outcomes of pain on relationships, I illustrated the ways in which people construct their “selves” in different contexts. Like Strauss, (1993), I was struck by the different and seemingly conflicting selves that were constructed by individuals when talking about their lives with pain. The stoic individual who “handled” pain without complaint was countered by the person in intense pain, crying out for help and not receiving it. In another instance, a pain sufferer could assume the role of selfless caregiver, dedicated to maintaining their familial role in spite of pain. Particularly at times when trying to find meaning or convey the broader implications of TMD on daily life, an inwardly reflective, meditative self emerged and provided insight and clarity into pain as a connection between mind and
body. In this voice, sufferers were able to explain how pain was in part a manifestation of difficulty dealing with stress and emotions.

These profoundly different voices, however, were not those of different individuals, but were commonly found in each narrative. The stoic person and the person who is totally overcome with severe pain are not different people, but are constructions of selves for presentation in different contexts. In the context of an interview, unlike other contexts, these strikingly different narratives can be seen as different voices of an individual in pain (Strauss 1993), and not so much as differences in the experience of pain between sufferers.

The theoretical platforms used in this thesis, particularly the discussions of multivocality and narrative analysis were helpful in understanding the narratives of TMD sufferers. The profound differences between the pain sufferers’ internal or bodily sensations and the selves they presented in various contexts were made clear using the theories of Bakhtin, particularly as described by Strauss (1993) and Hermans, Kempen and Van Loon (1992). The reasons that sufferers carefully coped with pain in the present were also illuminated by Cassell’s (1982) work on the nature of the self and its relationship to hope, and Good and Good (1991) in their discussion of the construction of subjunctive realities. These theoretical tools were necessary and useful for interpretation of the data due to the fact that my findings were distinct in some important ways from previous work on TMD in anthropology.

Narrative theories were useful in understanding the way people explained and contextualized their selves and their lives (Reissman 2003). The multiple selves that
emerged in sufferers narratives were made coherent using the work of Bahktin (1981) Ochs and Capps (1996) and Strauss (1993). Strauss’ discussion of Bahktin’s multivocality was instrumental in understanding the inconsistencies that arose in sufferers voices as they explained the impact of TMD in their lives from multiple and often conflicting selves. Strauss’ work was also helpful in understanding the way people spoke of the severe and life-altering effects of pain while at the same time they had normal lives, jobs, and families.

As a new researcher, conducting interviews with chronic pain patients has been a valuable experience. The iterative process of analyzing data while continuing to conduct interviews added to my understanding of how best to ask questions and elicit meaningful responses and allowed me to more fully understand the data as well as why people chose to say what they did. More research is needed to understand the experiences of people who live with chronic pain, particularly those who do not perpetually seek treatment. The ways in which people create meaning in their lives with pain in contrast to seeking legitimacy from the health care system remains poorly understood, and medical anthropology can add valuable layers of understanding to the experience of this illness.
APPENDIX A: INTERVIEW QUESTIONNAIRE

QUESTIONNAIRE #14: Qualitative Interview - Baseline Interview Probes

1. Let me begin by getting a sense of what your life is like—I am going to follow up on some of these questions later as well

   a. Who do you live with at present?

   b. Any pets?

   c. What kind of work do you do? (If you are not working, how do you spend your day?)

   d. Do you enjoy your work (or if not work, the way you spend your days: probe for major activities)?

   e. Do you find your work very stressful (if don’t work: is the way you spend most days stressful—probe for what is stressful if not working): on a scale of 1-10 how stressful is your work (the way you spend your day) right now?

   f. What about other stressors in the rest of your life, on a scale of 1-10, how stressful is it?... Is there any major stressor you want to tell me about?

2. How long have you had TMD?

3. How did you first find out you had it? (e.g. -did a practitioner tell you, did you suspect before hand, did a friend suggest you had it?)

4. Open-ended to build rapport, probe for symptoms

   a. How has TMD affected your life? How has it affected your future plans (ie get at not only present losses, but future planning and loss)

5. Is there a general daily pattern (rhythm) to your pain that characterizes most days?
6. Think about an average weekday when pain is moderate.

a. Help me understand what that day is like for you in terms of work and domestic tasks

b. Are there different levels of pain associated with different times of day?

c. Is there pain associated with different tasks you are responsible for doing?

d. How do you cope with pain at these different times of day?

7. What time of the day is pain management most problematic for you? How come

8. Think about a day when your pain was particularly bad. How did you cope with this pain at different times of the day?

9. What OTHER kinds of things have you tried to reduce the pain of TMD? (PROMPTS: HOME CARE, Practitioners) (IF NAME PRACTITIONERS, SAY THAT WE’LL COME BACK TO PRACTITIONERS)

a. Of these other things you tried, what was helpful (include practitioners, and practices)?

b. What have you tried that was not helpful?

10. Does the pain you experience from TMD fluctuate widely from day to day? Describe.

11. What is your understanding of TMD?

a. What do you think causes TMD?

b. What may have caused your TMD? Probe: Why do you think it became a chronic problem for you

(If the participant indicates that there was some type of trauma, ask:

Was this a single event or did it happen more than once?)
How long ago was it? (Then stop, wait, if necessary. When ready, ask, Is it okay to go on to the next question?)

c. Where have you gone to find about TMD? (prompts: internet, health care practitioner, reading, others with the disorder)

d. Based on your experience, what factors exacerbate your TMD?

12. Is your TMD curable? (Do you expect to have to manage it for the rest of your life?)

13. Have you ever tried to explain it to someone else who has not experienced it? If yes, How was the experience

14. How did you (or would you) explain your TMD to someone who does not have the disorder?

15. Is there a stereotype out there in the public about what TMD is and who gets it

16. How would you describe yourself in terms of your tolerance for pain in general? When you’re in pain, do you let other people know?

17. Where do you feel stress in your body (besides your jaw)?

18. Was this different before you had TMD?

19. When was the last time you felt really good, pain free? What was going on?

20. When was the TMD the worst it’s ever been? What was going on?

21. What kinds of experiences with biomedical health care providers did you have in relation to TMD in the past?

1) Good experiences

2) Bad experiences

3) Frustrating experiences
22. Do you have a doctor you consider your doctor at present. If yes how long have you been seeing him/her?

Next: How would you describe your most recent experiences with this practitioner re: TMD (If patient says she/he didn’t bring it up, end here. If does bring it up, probe:

a. do you think he/she understands the pain you are in,

b. do they listen to what you are saying,

c. are you comfortable talking to them about your life and problems,

d. how did you feel when you left the office, or when you look back now?

e. did he/she recommend something helpful?

f. Was anything else suggested that you didn’t try? If so, why didn’t you try it?)

23. Are there any therapies for TMD that you have always wanted to try? Follow up

a. Have you used these therapies for anything else?

b. Do you know anyone who has used these therapies?

c. Why have you not tried these therapies?

24. Have you tried any alternative therapies for other, not TMD, health problems? How long did you use it? Was it helpful?

25. Is there anything that you want to know about a therapy (a new therapy, or an alternative therapy?) before you try it?

26. Is there anything you want to know about a practitioner before you’ll consult him/her?

27. Imagine a practitioner you would like to go to for your TMD. Please describe the qualities of that practitioner: What would they be like and how would you want to be
treated (This is trying to get at the character and style of a practitioner, not necessarily the type of therapy they practice).

28. How would you describe yourself in terms of your sensitivity to medication in general:

   a. Are you the type of person who needs the maximum dose to get relief of symptoms, or are you very sensitive to medications leading you to take lesser doses of medications whenever possible? (this includes OTC medications, herbs, etc—it is about body sensitivity to medicines)

   b. How about pain medication? (Prompt: pain threshold)

      1) If you take a pain medication of any kind, do you generally take the amount specified on the bottle—the maximum or minimum does recommended?

      2) How about when you take medicines like Advil or other analgesics? OTC medications?)

29. Tell me about what medications you have taken for your TMD

   a. In the past?

   b. Currently?

30. How do you take your TMD pain medications? (PROMPTS: only when in severe pain, routinely, to avoid pain)

31. Are you concerned about taking pain medications too often? If so, what are you concerned about:

   a. Addiction?

   b. Tolerance and inability to control pain?

   c. Interferes with life?

   d. Other
32. Now I want to ask you a few more questions about your family and folks who are close to you

a. Who are your 1st degree relatives (PROMPTS: spouse, siblings, children, parents)

b. Has anyone in your family or anyone close to you had any significant health problems?

c. Does anyone in your family or anyone close to you have any stress-related illnesses?

d. Has anyone in your immediate family or close friends tried any alternative medicine/healing (defined as non allopathic treatment) for any health problem?

e. What have they (ever) tried?

f. What have they continued using?

33. Do you tell people that you interact with routinely that you have TMD?

34. Do you know any people with TMD?

35. Have you shared your experience with them? IF YES expand

36. Who do you talk to about life problems? PROBE: may not be support system

37. What is your social support system like?

38. Can people around you tell when TMD is really getting to you?

39. How do people who are close to you, those in your support system, respond when your TMD is really getting to you?

40. How do other people you have to interact with respond to you when your TMD is really getting to you? (PROBES: do you interact differently when in pain?)

41. How has TMD affected your future plans (ie get at not only present losses, but future planning and loss)?
42. *Tell me what your life is presently like with TMD*

43. *Tell me about your sleep patterns, PROBES: delay in falling asleep, interrupted sleep, early waking, sleeping medications)*

   a. *How does TMD affect your sleep?*

   b. *Tell me how any partners sleep affects you.*

   c. *Tell me how your sleep affects your TMD.*

44. *What kinds of things do you do to take care of yourself?*

   a. *Physically?*

   b. *Socially?*

   c. *Emotionally?*

   d. *Spiritually?*

   e. *And if you can’t do it/them what happens?*

45. *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?*

46. *What are your expectations for this study? About the self-care arm? Herbs? Acupuncture?*

47. *Is there anything else you want to tell me, or any other questions you would like to ask me?*
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