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Ways of Hoping: Navigating the paradox of hope and despair in chronic pain

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Abstract

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

Keywords

Hope; Chronic pain; Tacit knowing; Placebo

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COMPLIANCE WITH ETHICAL STANDARDS: Ethical Approval: All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. All procedures were approved by the University of Arizona Committee for the Protection of Human Subjects, and the Oregon College of Oriental Medicine Institutional Review Board. Informed consent: Informed consent was obtained from all individual participants included in the study.

INTRODUCTION

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

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

Placebo, latin for “I shall please” historically referred to an inert substance given to appease a patient, or to give them hope, in the absence of other treatment options (Moerman, 2002). Spontaneous healing in response to an inert substance is called the “placebo effect” in an individual and its average across a group is referred to as the “placebo response” (Thompson, et al., 2009). Despite being poorly understood, placebos serve as the baseline against which other treatments are measured—the “control” in a randomized controlled trial—because patients given placebos often improve as a result (Thompson, et al., 2009). Placebo responses are catalyzed by and pertain to a broad range of human experience, from changes in the meaning an individual ascribes to their illness (Kaptchuk, et al., 2009; Kirmayer, 2006; Moerman, 2002; Tambiah, 1977) to evolutionarily patterned and deeply embodied responses to conditioned action (such as the taking of a pill)(Thompson, et al., 2009; Hahn & Kleinman, 1983; Kirmayer, 2011). Although the placebo effect is often narrowly attributed to positive expectancy, it is far more complex and multidimensional (Kirmayer, 2011) and participants in healing rituals cannot be characterized as uniformly positive (Kaptchuk, et al., 2011). Moreover, while participants in healing rituals and participants undergoing novel treatments often report being generally hopeful, they are also realistic and aware of the possibility that the ritual or therapy may not “work” (Stone, et al., 2005; Kaptchuk, et al., 2011). The paradoxical nature of hoping enough to continue seeking treatment and live day-to-day with illness, yet not hoping so much as to risk despair when yet another treatment fails, complicates already tentative understandings of the placebo effect as individuals simultaneously describe being both hopeful and hopeless.

What is hope and why does it matter?

In the context of chronic pain or illness, hope has been characterized in multiple ways: as a process of making meaning (Antelius, 2007; Corbett, et al., 2007); as an existential state (Kaptchuk, et al., 2009); as a posture toward the world (Barnard, 1995); as a practice involving significant work (Mattingly, 2010); and importantly, as inherently paradoxical (Barnard, 1995; Chesla, 2005; Mattingly, 2010). Although hope has rarely been considered

in discussions of expectancy and the placebo response, we find that hope to is central to how people living with pain assess new experience over time and adjust their expectations to find meaning in individual treatment narratives.

Hope is fundamental to human existence. It is paradoxical in its duality, however, as its very existence implies the possibility of despair (Lynch, 1962). This dialectic between hope and despair is central to considerations of chronic illness management, as well as to studies of the relationship between expectations and the placebo effect (Corbett, et al., 2007; Ratcliffe, 2011). Hope influences expectation, but is a distinct and multifaceted cognitive, embodied, and broadly existential experience (Mattingly, 2010). In order to maintain hope when faced with a situation that appears hopeless, individuals must navigate multiple contradictions between reality and possibility, embrace cultural notions of what is deemed acceptable to hope for, and be attentive to the hopes and concerns of significant others (Averill and Sundararajan, 2005; Chesla, 2005; DelVecchio Good, et al., 1990; Sulmasy, et al., 2010; Brown, 2015).

The observation that negative information about an illness may dash hope and increase suffering has long been recognized as an ethical problem. Medical educators thus ask when a clinician should dispassionately inform a patient about hard “evidence-based” facts of their case, and when they should consult with family members to determine whether unfiltered information is likely to demoralize the patient, compromise their quality of life and negatively affect their prognosis (de Penthony O’Kelly, et al., 2011; Oliffe, et al., 2007; Pergert and Lützén, 2012) as well as minimize the placebo effect (Caspi and Hølexa, 2005).¹

Hope is deeply personal and difficult to describe (Barnard, 1995; Marcel, 1962). At the same time, hope is collectively produced, culturally interpreted, and linked to broader social and economic processes (Clarke, 2003; DelVecchio Good, et al., 1990; Novas, 2006).

Biomedical research institutions, pharmaceutical companies, and patient organizations are involved in a “political economy of hope” (DelVecchio Good, et al., 1990; Novas, 2006; Rose and Novas, 2005) wherein hope is both generative of and generated by market interests, research directions, and the possibility of breakthroughs in medical treatment (Novas, 2006; Rose and Novas, 2005; Sulmasy, et al., 2010). Hope itself is thus a source of biovalue for each of these stakeholders. For the afflicted and their families, hopefulness is a quality expected of good citizens (Novas, 2006; Rose and Novas, 2005; Sulmasy, et al., 2010) much like the “achieved status” of good health (Nichter and Thompson, 2006). Hope scales—metrics for measuring hope—produce “modes of self-management and codes of affective decorum” (Brown 2015:121).

¹Contemporary evidence-based medical culture in the U.S. intensely values truth-telling, full disclosure of prognosis, realism and adherence to “the facts” (Caspi and Hølexa, 2005; Oliffe et al. 2007; Pergert and Lützén 2012; DelVecchio Good et al. 1990). This has not always been the case. Indeed, it runs counter to the values espoused by clinicians in U.S. medical culture in the not too distant past (DelVecchio Good et al. 1990), where greater credence was paid to both the psychosocial state of the afflicted, and the wishes of family members responsible for a patients’ therapy management who may desire to provide a more peaceful and positive treatment environment where hope is sustained (Kagawa-Singer and Blackhall, 2001; Kodish and Post, 1995). The issue of disclosure and the weighing of autonomy versus non-maleficence is a particularly sensitive in end of life issues or in cultures where dashing the hopes of chronically and terminally ill individuals is considered immoral (de Penthony O’Kelly, et al. 2011; Gongal, et al. 2006; Harris, et al. 2003).

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

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

The Existential Paradox of Chronic Illness

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

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

“Dialectic relations between hope and despair, necessity and possibility, have been called the existential paradox of chronic illness (Barnard, 1995). Living the paradox means that those with chronic illness simultaneously confront their limitations and losses at the same time that they lean toward possibility, hope, and new openings. In trying to understand this paradox, it may be helpful to see its multiple oppositions, what this paradox is not. One opposite is surrender to one’s limitations and losses, what Kleinman (1988) calls *demoralization*, without the balancing thread of hope. Or, another opposite is hopefulness that denies the limitations and losses that are a part of chronic illness, what some would call *delusion*.” (Chesla 2005:373).

Mattingly (2010) similarly describes hope in existential terms as a “practice” as well as a paradox. Mattingly explains, “Paradoxically, hope is on intimate terms with despair. It asks for more than life promises. It is poised for despair.” (2010:3). In the context of chronic

illness, hope “emerges as a paradoxical temporal practice and as a strenuous moral project” (3). Mattingly’s informants describe hope as a moral call, bound up with what it means to be a “good person”. For the families in her study, “hope has represented a stance toward reality that requires careful cultivation” (Mattingly, 2010:4).

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

In the 1990s several medical anthropologists collected illness narratives from individuals with TMD attending residential pain clinics, pain treatment centers, and chronic illness support groups (see DelVecchio Good, et al., 1992). One of their observations was that when treatments failed, a sense of hopelessness emerged associated with the omnipresent existence of the ailment and its unpredictability (Garro, 1992; Good, 1992). In what follows, we provide examples of ways our trial participants avoided hopelessness by engaging in multiple ways of hoping. We describe these ways of hoping in terms of cognitive experience, spiritual experience, and embodied experience. These distinctions are by no means intended to draw strict boundaries between cognitive and embodied experience or among ways of hoping. They are merely intended to show hope in its multiple forms and multiple levels to illustrate hope as a complex and sometimes arduous experience. We draw from literature on multiple ways of knowing (Aickin, 2010; Geurts, 2002; Polanyi, 1962; Polanyi, 1969; VanMannen, 1977; Yorks and Kasl, 2006) to gain a clearer understanding of the elusive concept of hope and how it impacts and is impacted by evaluations of new information and experiences.²

RESEARCH CONTEXT

Participants

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

One hundred sixty-nine participants were enrolled in the trial. Of those enrolled, approximately every second participant (about half the sample) was approached prior to initial randomization and asked to complete a series of semi-structured, open-ended

²It is beyond the scope of this paper to map ways of hoping onto ways of knowing. We draw from this framework as a useful way to explore the range of cognitive to embodied experience subsumed under the term hope.

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

Data Collection

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

The following questions specifically elicited information about expectations and hope.

Baseline Interviews:

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

Follow-Up Interviews:

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

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

Data Analysis and Interpretation

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

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

REFLECTIONS ON HOPE AND EXPECTATIONS OVER TIME

Initially, we sought to explore participants’ expectations prior to trying TCM and, through longitudinal analysis, to determine whether initial expectations impacted the way they experienced treatment. We found, however, that expectations could not be disentangled from hopes in participants’ descriptions. Further, “hope” worked to moderate expectations, often in unexpected ways. Over the course of the study we recorded shifting narratives as participants assessed whether their expectations had been met and whether they felt “more hopeful” or “less hopeful” after participating in a novel alternative treatment. These narratives were often multivoiced as participants presented themselves as both more hopeful and less hopeful at the same time.

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

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

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

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

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

WAYS OF HOPING ON MULTIPLE LEVELS OF EXPERIENCE

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

Multiple ways of hoping are key features in the work of both *being* hopeful—a balancing act required for daily coping and seeking treatment—and *appearing* to be hopeful—living up to the often conflicting expectations of significant others and cultural ideals (see also Eaves et al. 2014b for a preliminary typology). For heuristic purposes, we have divided hope into overarching categories. First, hope is considered in terms of cognitive experience or ways of hoping that participants engage intellectually. Second, we describe hope as an embodied experience, sometimes more deeply felt than intellectually considered. Third, we consider hope as intertwined with experiences of faith. The categorization is not intended to distinguish between cognitive, embodied, or faith-centered experience, but rather, to emphasize that hope is practiced at all of these many levels of experience.

HOPE AS A COGNITIVE EXPERIENCE

Realistic Hope (or practical hope)

Realistic hope includes any hope for a reasonable or probable outcome in terms of normal or expected outcomes on the part of the broader medical community (cf. (Lohne and Severinsson, 2004; Webb, 2007; Wiles, et al., 2008)). In this sense, hoping for a small reduction in pain is a reasonable, or realistic hope. In most cases, participants considered

“reasonable” whatever they would not be hesitant to disclose to their health care practitioners.³

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

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

Utopian Hope

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

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

Wishful Hope

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

I really do [believe it could be cured]. ‘Cause I think um, well if I didn’t believe that it, it’d be a lot harder to try to deal with it... I also feel like, oh acupuncture has the magic ideas (giggles) you know, like there’s some magic that’s going to happen if I go get acupuncture. (Jessica, 30, Interview 1)⁴

³This mode of hoping is comparable to Webb’s (2007) “estimative hope” (described as evidence-based hope), Lohne and Severinsson’s (2004) “small hope” (described as possible hope), and Wiles et al.’s (2008) “hope-as-expectation” (described as the high end of a continuum of probability of a desired outcome).

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

Transcendent Hope (Or existential hope)

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

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

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

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

The pain that I was feeling before this acupuncture started was complete suffering and fear. And as I started working through the layers of that, like an onion, I started realizing, and being able to pinpoint what has affected that, what caused it, and how to move forward. And that’s through the advice of the acupuncturist... And so through the layers of moving through, and, and specifically, the pain before the acupuncture was completely different. *It was more deep-seated hopelessness.*

⁴We chose to include wishful hope due to its resemblance to widespread usage of the term hope in studies of expectation (Lynch, 1962; Leung 2009). Hope is often described as similar to expectations, but a wish or want, rather than a realistic projection. Among our participants, this form of hope was not widespread and was represented clearly in only a few participant statements. The relative absence of this form of hope supports the need for a more nuanced understanding of the experience of hope in chronic pain and illness.

[emphasis added] Whereas now it was just a physical- it was like bruising your knee. Just like healing a physical thing that you can actually see. (Lisa, 30, Interview 4)

HOPE AS AN EXPERIENCE OF FAITH

Hope as Religious Faith

Faith is closely aligned with hope both cognitively and emotionally. In the Christian tradition, “faith is the substance of things hoped for” (Hebrews 11:1, as cited in Sulmasy, et al., 2010). To hope is equated with having faith (Sulmasy, et al., 2010). In Judaism hope and faith are linked and among believers, to lose faith is equivalent to giving up or turning one’s back on God (despair) (Lamm, 1995).

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

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

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

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

Hope as Faith in Bioscience or Biomedicine

Faith as a way of hoping is not limited to religious faith. Sulmasy et al. (2010) found that faith was a common theme in participants’ narratives about hope in living with cancer. Among their participants, however, faith in science and medicine was more common than religious-based faith. We found a similar trend among participants, although often expressed in terms of loss of faith or difficulty keeping faith in medical science.

It’s kind of hard after 20 years to have any faith that [pain] can really be made to go away. But, there’s a part of me that feels like we’re gonna be able to do something with the pain that allows us to take chronic conditions and, at least, change how they’re perceived and felt. I think we’re gonna make major breakthroughs in pain

control in the next few years because there're so damn many of us baby-boomers hurting. And there's more and more women doctors looking at things. And there's more and more of us that have been affected by these things, who are in the medical industry. So, I believe there're a number of factors that are gonna lead to good breakthroughs. And, I want to think they'll be in my functional lifetime. (Evelyn, 47, Interview 1)

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

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

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

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

Among participants in this study, we noted comments directed toward faith in alternative medical paradigms. Unlike cancer or other high-profile (and high market potential) terminal illnesses, chronic pain is positioned in the medical establishment as an elusive, intractable, and troubling illness category, sometimes even characterized as lacking a biophysical component (Crowley-Matoka and True, 2012; Good, et al., 1992; Jackson, 2005; Jackson, 2011). While some study participants continued to hope for medical breakthroughs, many had long since given up on biomedical treatments. Some of these participants were now turning toward alternative medical paradigms rather than religion as a way to regain or maintain hope.

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

HOPE AS EMBODIED EXPERIENCE

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

Many researchers have discussed a pervasive cultural belief in the power of hope, positive thinking, or individual *will* to change the course of illness (Cassel, 1982; Clarke, 2003; DelVecchio Good, et al., 1990; Herth, 1992; Scheper-Hughes and Lock, 1987; Sulmasy, et

al., 2010). This *faith in hope* is often intertwined with deeply felt personal convictions that the body has the ability to heal itself.

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

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

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

The way people intuitively grasp what they perceive through bodily sensation and imagination is complex (Yorks and Kasl, 2006). Sensing, or "bodily ways of gathering information in the world" are basic to how we perceive and experience the world (Geurts, 2002). Ratcliffe (2011) argues that in cases of loss of hope or hopelessness, there is a hope that remains. This visceral sense of hope, in his view, is neither an intentional state nor a non-intentional bodily feeling, but rather "is a 'pre-intentional' orientation or 'existential feeling'" (600). Faith in the body's ability to heal can counterbalance despair that one's body has somehow let them down, and feed hope that a treatment may be out there that can trigger the body's natural healing capacity. Some participants who had turned to CAM treatments held out this possibility.

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

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

THE WORK OF HOPE IN THE CONTEXT OF CHRONIC PAIN

Maintaining hoping when one is experiencing chronic pain requires vigilance not only requires against impending despair, but also against biographical disruption that may ensue if pain undermines one's sense of self and identity (Bury, 1982; Eaves, et al., 2014a). Below, we consider how people living with pain engage in the work of hope. Areas of work include managing the paradox of hope as well as working to *appear* hopeful in the presence of significant others regardless of what one feels at any given moment.

The Work of Having Hope

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

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

Chesla (2005), describes “small moments of suffering” in daily life with chronic illness that can lead to either hope or despair. Individuals living with chronic pain work to maintain a “safe” space between the vulnerability of overly-inflated hopes and the vulnerability of losing hope. Beth explains in the following statement that she feels safe from the vulnerability of having high hopes by remaining somewhat pessimistic. In this sense, pessimism is a protective strategy, avoiding the much more daunting possibility of despair.

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

In life with chronic pain or illness, finding hope is part of appropriately working toward mastery over one's condition (Rose and Novas, 2005).⁵ Individuals living with chronic pain

⁵In contemporary Western culture, hope has become a moral imperative (Rose and Novas, 2005). Ignorance, resignation, and hopelessness in the face of the future are deprecated. In cases where there is little hope for resolution in a realistic sense, individuals are encouraged to pin their hopes on the promise of new technology and medical advances (Brekke and Simes, 2011).

must therefore work to live up to the expectation of being hopeful while avoiding hope that denies the everyday reality of living with chronic pain (Chesla, 2005).

The Work of Describing Hope

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

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

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

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

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

WORKING THROUGH THE PARADOX OF HOPING IN EVERYDAY PAIN

In daily life and in broader experience, our informants faced the continuous experience of pain. Hope, in this context, presents a paradox and requires constant and onerous work. Some modicum of hope is necessary for carrying on with daily living (Cassel, 1982; Good and Good, 1991; Kaptchuk, et al., 2009; Kylma, 2005). At the same time, hope represents a daunting source of vulnerability (Ratcliffe, 2011; Simpson, 2004). Those living with chronic TMD pain work to keep their hopes at a level resistant to being dashed from either side

(hopes too high present the risk of disappointment, whereas hopes too low make it difficult to cope in daily living). Much research on hope has focused on individuals facing death or coming to grips with terminal illness who grapple with a similar paradox (e.g. Barnard, 1995; Chesla, 2005). Similar to Mattingly's (2010) informants, our study participants were keenly aware of this paradox and of the need to manage hope. Here are two examples:

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

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

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

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

Implications of Ways of Hoping for the Placebo Effect

Hope itself has been referred to as a "magical pill" able to produce an effect similar to that of the placebo (Averill and Sundararajan, 2005). Engendering hope is central to arguments concerning the role of the therapeutic relationship in enhancing the placebo effect (Moerman and Jonas, 2002). Health care providers are thus expected not only to treat illness, but to assist patients in cultivating reasonable or appropriate hopes (Corbett, et al., 2007; DelVecchio Good, et al., 1990; Sulmasy, et al., 2010) while at the same time informing them of prognosis and the risks and benefits of treatment options (de Penthony O'Kelly, et al., 2011; Oliffe, et al., 2007; Pergert and Lützn, 2012).⁶ The afflicted are faced with the paradox of needing to remain hopeful enough to maximize their chances of positive outcome

⁶Hope presents a paradox for the afflicted and clinicians alike. For the afflicted, hope is needed, but too much hope risks disappointment to the point of despair. For the conventional medicine practitioner, "truth-telling" (and full disclosure of the facts, costs and benefits, etc.) is deemed the ethical thing to do by the standards of evidence-based medicine, which favors rational decision-making. Yet in practice clinicians often face an ethical dilemma when trying to balance truth with inspiring hope (de Penthony O'Kelly, et al., 2011; Oliffe, et al., 2007; Pergert and Lützn, 2012). This dilemma will only grow with increasing evidence that hope is a powerful healing mechanism (Clarke, 2003; Herth, 1992; Nikolaichuk, et al., 1999; Snyder, et al., 1991) and ethical arguments identifying hope as an existential aspect of the individual that must be treated with respect and sensitivity (Kodish and Post, 1995). CAM practitioners appear to be particularly sensitive to the hope dilemma and to the impact of their words and actions on the patient's healing response (Caspi and Hoxha, 2005; Schafer, et al., 2012). The paradox for clinicians is therefore to consider the patient's right to be informed while at the same time to avoid undermining both the placebo response (the body's natural ability to heal) and the emotional necessity of continuing to hope.

from a new treatment yet not setting themselves up for despair by hoping for too much. This need to balance ways of hoping may well have an impact on the placebo effect at different points in a treatment trajectory as perceptions shift and life contexts change.

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

CONCLUSION

The ability to imagine a better future or to remain open to alternate possibilities, even if it necessitates some reliance on illusion or imagination, is crucial to maintaining hope when one is experiencing chronic pain (Barnard, 1995; Chesla, 2005; Kirmayer, 2006; Taylor and Brown, 1988). At the same time, one must buffer against unrealistic expectations that can end in disappointment and further exacerbate pain. Barnard asks, "What happens when distorted views of reality *are* disproved by experience? If positive illusions are adaptive in the face of threat, what happens to one's adaptation when the illusions that sustain it must yield to the ways things 'really are'?" (Barnard 1995:44). We would answer that multiple *ways of hoping* enable sufferers to adapt to contingencies and experiences such that they can remain hopeful and open to the possibility of aid on the horizon.

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

The phrase “ways of knowing” has been used to describe the acquisition and application of knowledge, understanding, and embodied experience (Aickin, 2010; Geurts, 2002; Polanyi, 1962; Polanyi, 1969; VanMannen, 1977; Yorks and Kasl, 2006). *Ways of hoping* similarly describes the work of reconciling practical knowledge, prior experience, and phenomenological perception in one’s experience. Geurts (2002) draws attention to a gap between cognitive models of perception and phenomenological levels of sensation, existence, and bodily experience. Related to Polanyi’s (1962) description of “things we know but cannot tell,” Geurts (2002) cites Desjarlais’ (1992) description of bodily knowing as “a lasting mood or disposition patterned within the working of the body” (Desjarlais 1992:150, as cited in Geurts 2002:5). While expectation is thought to be related to reason, hope is often characterized as an emotion or feeling, albeit active and creative (Averill and Sundararajan, 2005; Lynch, 1962; Pruyser, 1986). In this paper we have argued that hope is a process of feelings, thoughts, and embodied dispositions that are looped and affect each other in context and in response to feedback. Hope is not a denial of reality, but is part of continuous re-evaluation of reality in light of other possibilities (Pruyser, 1963).

A concept such as hope is difficult for an individual to characterize at any point in time, particularly given that much of our understanding is built on things we cannot know objectively, but rather know as “lived reality” (Clarke, 2003). As Polanyi points out, “Every time we make sense of the world, we rely on our tacit knowledge of impacts that the world makes on our body and the responses of our body to these impacts” (Polanyi 1962:605). As such, ethnographic inquiry needs to be attentive to sensations associated with embodied memories, as well as to reasoning, if we are to better understand feelings of fear and vulnerability, or conversely, of well-being and protection (Nichter, 2008). Future ethnographic accounts of hope should consider sensorial, embodied, cognitive, and emotional aspects of hope, as well as cultural norms and expectations associated with religious or spiritual values, social and gender norms, and interpersonal dynamics associated with managing strong emotions. We would re-iterate that division of hope into categories is not intended to imply that there are separate components when in fact we are dealing with an integrated whole. We have used these categories as tools to explore multiple ways of hoping as a complex experience of tacit knowing and varied states of think/feel (Wikan, 1990). A greater appreciation of the work of hoping and the roles played by different ways of hoping in context will offer depth to our understanding of both the placebo effect and the process of coping with chronic pain and illness in everyday experience.

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Table 1

Total Interview Numbers

# of interviews per participant	# of Participants	Total # of Interviews
4 Interviews	6	24
5 Interviews	38	190
Total	44	214