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

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Abstract

This article explores the role of hope in participants' assessments of their expectations, experiences and treatment outcomes. Data analysis focused on semi-structured, open-ended interviews with 44 participants, interviewed 3-5 times each over the course of a study evaluating Traditional Chinese Medicine (TCM) for Temporomandibular Disorders (TMD, a form of chronic orofacial pain). Transcripts were coded and analyzed using qualitative and ethnographic methods. A "Modes of Hoping"[1] framework informed our analysis. Five modes of hoping emerged from participant narratives: Realistic Hope; Wishful Hope; Utopian Hope; Technoscience Hope; and Transcendent Hope. Using this framework, hope is demonstrated as exerting a profound influence over how participants assess and report their expectations. This suggests that researchers interested in measuring expectations and understanding their role in treatment outcomes should consider hope as exercising a multifaceted and dynamic influence on participants' reporting of expectations and their experience and evaluation of treatment.

Keywords

Hope; Expectation; TCM; TMD; qualitative

INTRODUCTION

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

Although the potential role of hope in the placebo effect is not a new idea,[2,3] the literature on the role of expectancy in the placebo effect rarely mentions hope. The few studies referring to hope parenthetically note that it is often mentioned by patients when asked about their expectations, but is not easily defined or investigated.[4-6] Several researchers have pointed out that conceptualizing hope as a type of expectation is problematic and that increased conceptual clarity is needed.[7-9] The goal of the present analysis is to explore hope in the context of the lived experience of chronic pain. By investigating the role of hope in participants' considerations and reporting of expectations, we aim to contribute increased clarity to the concept of hope, and to its role in moderating the ways in which expectations are reported in the context of a complementary and alternative medicine (CAM) trial.

We draw from anthropology, psychology, philosophy and other disciplines for additional insights on the centrality of hope to patient narratives. As DelVecchio-Good et al.[10] have pointed out, in cancer diagnosis, ideas surrounding hope and modes of disclosure are influenced by a "deeply felt cultural conviction that individualized *will* can influence bodily processes" (p75). Anthropologists have also suggested that the placebo response is at least partially attributable to changes in the "meaning" a patient ascribes to their illness.[3,11-14] Averill et al. point to the existence of culturally circumscribed "rules of hoping" that define those hopes considered appropriate, moral, and reasonable in particular contexts. [15,16]

In this analysis, we draw from the work of other researchers who have distinguished types of hope including: Lohne and Severinsson's distinction between "big hopes" and "small hopes"; [17] Leung et al. and Corbett et al.'s distinction between "particularized hope" versus "generalized hope" [7,18]; Wiles et al.'s distinction between "hope as want" and "hope as expectation"; [9] Ratcliffe's descriptions of "passive hope" and "active hope"; [8] and especially from Darren Webb's concept of multiple "modes of hoping" [1] to shed light on the role of hope in the reporting of expectations and evaluation of outcomes in a CAM trial. While these authors have distinguished hopes along different dimensions (e.g., small vs. big; general vs. specific) such judgments regarding the sources or dimensions of participants'

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

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

METHODOLOGY

Study context and sample selection

The present research consists of secondary analysis of qualitative interviews that were originally conducted as part of a multi-site (Tucson, AZ and Portland, OR) randomized phase 2 trial of whole system TCM for participants with TMD, most of whom had never had extended TCM treatment for any condition. The short-term (16 weeks) phase of the trial involved sequential randomization to TCM or an alternative time and attention-matched psychosocial self-care intervention (for trial design and exclusion criteria, see Ritenbaugh et al.[19]). The long-term phase subsequently provided TCM to most participants. The TCM protocol included individualized treatment with acupuncture, herbs, tuina, and lifestyle interventions.[20,21] Recruitment at both sites was done via community outreach and newspaper advertisements.

One hundred sixty-nine participants were enrolled in the overall trial; approximately half of them participated in qualitative interviews. Since we could not interview every participant, we created a 50% sample by inviting every second consenting participant to the qualitative interview component. Multiple interviews were completed over the course of each participant's experience with TCM because it is well known that ideas of illness, evaluation of experience, and other factors of interest change over time as participants adapt their understandings to new experiences. [22,23]

Study 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. For baseline characteristics of this sample, see Table 1. The proportion of female participants reflects the proportion in the general population by most estimates.[24] TMD is the third most prevalent chronic pain condition and estimates of lifetime prevalence in the overall population range from 10 to 25 percent.[24,25] By design, most participants eventually received TCM treatment, which included up to 20 treatments over one year. Qualitative participation consisted of up to five interviews planned to occur at key transitions and follow-ups, tailored to the various study trajectories. Ultimately, 44 participants completed at least three of the qualitative interviews and were included in this

sample. The University of Arizona Human Subjects Protection Program and the Oregon College for Oriental Medicine Institutional Review Board approved all procedures, and all participants gave informed consent.

Data Collection

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

Baseline Interviews

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

Follow-Up Interviews

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

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

Data Analysis and Interpretation

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

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

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

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

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

MAIN RESULTS & DISCUSSION

Expectations

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

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

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

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

Shifting Stories of Expectations and Hope

Originally, our goal was to report on baseline expectations and how they changed as the study progressed. However, during our analyses of participants' reported expectations, we found that they nearly always talked about hope. We also found a lack of agreement between what participants told us they expected during the baseline interviews and what they described as having expected at baseline when reflecting back in later interviews. The intertwining of these conflicting statements with references to hope led to our interest in hope, and to our analysis of multiple modes of hoping and their role in influencing narratives about expectations.[15]

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

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

> (029, Interview 5): I mean my initial expectation was, I'm going to be cured. Right? So that was my thinking. I'm going to be cured. And then when I realized that that was not going to be the reality, then I didn't really have any expectations anymore.
>
> (022, Interview 1): Having already tried a few things on my own and, and not saying that they've had like stellar results, I guess the cynic in me would say, I have hopes but I don't have expectations…(laughs) um, I guess my expectation is that I'm going to learn something new. And that's as high as I would rate it.
>
> (022, Interview 5): I had some subtle expectations about the study that yeah, finally it'll be the thing that makes it all better…I don't think that's ever true for anything, and I'm just, and I know that on a deep level but you always still want it to be the thing that will make it wonderful…And I, and I think that's why we get out of bed in the morning. Because we still have hope.

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

> (017, Interview 1): I hope [TMD is curable]. Sure. (laughs) If I didn't I wouldn't be here. [ERE: And what do you hope to get out of participating in this study, or what would you consider to be a benefit?] P: Pain-free…For sure. Some sort of pain management, long term, that I can take with me and use in the future.
>
> (017, Interview 4): [The study treatment] reached [my expectations] and went above what I thought it would. I expected to go in there and get some minor relief and that be it…I was really impressed how much I benefited from the study.

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

> (030, Interview 4): I think it's made me realize um, that nothing's going to make these things go away… and I think that's fairly hard for me to deal with. And it's just the way it is, so like there's not a quick fix to things.
>
> (030, Interview 4): I feel like the acupuncture's helping in ways beginning with me, you know, just going there, and when things were hard, having someone work on me… and then it felt better. I think that made me feel like I could just really hold onto that. It felt better and so I guess that made me feel really hopeful.

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

Modes of Hoping

Lawrence Kirmayer [12] suggests that healing involves not only "basic bodily processes of balancing, homeostatic regulation, and repair, but it is equally a matter of making sense of suffering and finding a way to continue." (p599) In what follows, we outline five modes of hoping that were observed empirically in our data (Table 2) and discuss how they allowed participants in our study to maintain hope in the face of chronic pain. These modes of hoping are not intended to characterize all possible forms of hope, but rather to describe the modes of hoping that we observed among participants in this study and to show the existence of multiple modes of hope, which are likely to vary by context.

Realistic Hope—Realistic hope includes any hope that would be considered reasonable or probable based on current medical knowledge. This mode of hoping draws from several scholars conceptions of a realistic or probabilistic mode of hoping, primarily from Webb's "estimative hope" (described as evidence-based hope), [1] Lohne & Severinsson's "small hope" (described as possible hope), [17] and Wiles et al.'s "hope-as-expectation" (described as the high end of a continuum of probability of a desired outcome). [9]

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

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

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

Utopian Hope—Utopian hope, as defined by Webb, [1] is hope that is collectively oriented, a hope that group action can lead to a better future. In the context of our study this hope appeared mostly in pragmatic statements about hoping that participation in a research study would contribute to overall knowledge about TMD and help others in the future.

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

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

> can maybe further along the science one little increment at a time. *[hope-utopian]* (015, Interview 1)
>
> [I hope to] help you help somebody in the future. That's basically why I signed up. [*Hope-utopian]* (021, Interview 1)

Wishful Hope—Wishful hope includes very high but possible hopes, anchored in the current world. This mode of hope is related to Wile's et al.'s "hope as a wish, want or desire" (described as conceptually distinct from "hope as an expectation") [9] and Lohne and Severinsson's "big hope" (described as possible hope, but higher than "small hope").[17] While scholars such as Marcel[26] and Pruyser [2,27] distinguish hope from wishing, Averill [15] argues that wishing is an important dimension of hope and Lynch[28] characterizes the ability to wish as being "well on the way toward hope" (pg 24).

We include wishful hope as a mode of hoping because participants admit that they hope for particular outcomes they think are unrealistic. Wishful hope, or the ability to imagine a better future, is particularly important in chronic pain, wherein sufferers often struggle with the ability to imagine life without pain. [29] Wishful hope among participants in our study is expressed in statements such as hope for a cure, or related to hearsay about miraculous outcomes experienced by others.

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

> I hope it's curable. It would be nice if everything was. *[hope-wishful]* You know? So if I have to manage it then I'll just manage it. *[hope-realistic]* Just like anything else, any kind of real mental discomfort. (pause) I don't know what it's like not to have pain. (009, Interview 1)
>
> I hope so [that TMD is curable].*[hope-wishful]* Sure. (laughs) If I didn't I wouldn't be here. [ERE:And what do you hope to get out of participating in this study, or what would you consider to be a benefit?] P: Pain-free… For sure. *[hope-wishful]* Some sort of pain management, long term, that I can take with me and use in the future. *[hope-realistic]* (017, Interview 1)
>
> I really do [believe it could be cured]. *[hope-wishful]* 'Cause I think um, well if I didn't believe that it'd be a lot harder to try to deal with it…I also feel like, oh acupuncture has the magic ideas (giggles) you know, like there's some magic that's going to happen if I go get acupuncture. (032, Interview 1)

Technoscience Hope—Technoscience hope, which relates to a faith in science, emerged from our participant narratives. This form of hope is based on faith in the inevitability of scientific or medical breakthroughs. We were struck by how many participants voiced hopes that were similar to wishful hopes, but that were dependent on unforeseen potential sources of treatment or cure. For Lynch, hope is "an arduous search for a future good of some kind that is realistically possible but not yet visible" [28] (pg23). According to Scioli et al.[30] hope is

profoundly related to faith, and faith is what sustains hope. Faith, however, need not be based in religion to sustain hope. [30] In this case, we consider faith in science or medicine a mode of hoping, or perhaps as a way of sustaining hope, particularly when the lack of available treatment leaves few avenues for hope. [27]

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

> I was hoping some kind of maybe medication, or new combination of shark fin, or octopus hide, had some real massive rapid effect on cartilage formation or bone healing or something like that will come along. Other than that, I don't know how to fix a broken joint. *[hope-technoscience]* (005, Interview 5)

There exist plenty of stories of "miraculous" cures from unexpected sources that allow patients room to retain hope for anything they want. [7] For these participants, technoscience hope was a way to remain hopeful regardless of whether one could realistically hope for relief from pain.

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

Transcendent Hope—Merriam-Webster defines "transcendent" as a) "exceeding usual limits: surpassing"; b) "extending or lying beyond the limits of ordinary experience"; or c) in Kantian philosophy: being beyond the limits of all possible experience and knowledge.[31] As it relates to this study, transcendent hope is characterized as a general hopefulness that is not tied to a specific outcome or goal. In this mode of hoping, participants express a general attitude of hopefulness, but refuse to imagine or define the future they hope for. This mode of hoping is most aligned with Marcel's[26] concept of hope, which is characterized by openness to the future. For Marcel, hope is not connected to any imagined future or goal.[1,26,32] Our concept of transcendent hope is inspired by Webb's "Patient Hope" ("directed toward an objective which defies any attempt to map it"; "a hope that everything will work out well in the end") [1] and Corbett et al.'s "generalized hope" (as opposed to "particularized hope," "generalized hope" is not directed toward a specific outcome).[7,18] Hope that is drawn from religious faith includes transcendent hope and is often equated with being positive and hopeful for something better in the future.[15,33]

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

> I'm still hopeful.*[hope-transcendent]* I mean I still, it's something I reflect on. I can't believe that I continue to have hope, you know, just that thing of, yeah

> sometimes you're like, oh really? And then next day, oh yeah…you know (laughs) but I do. (033, Interview 5)

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

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

Implications of Modes of Hoping for CAM Research

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

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

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

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

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

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

> The pain that I was feeling before this acupuncture started was complete suffering and fear. And as I started working through the layers of that, like an onion, I started

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

CONCLUSION

We presented five modes of hoping that appeared in narratives of participants living with TMD who received a CAM treatment: realistic hope, wishful hope, technoscience hope, utopian hope, and transcendent hope. Most of these modes of hoping have been previously observed in studies of other medical conditions (e.g., IBS[13]; low back pain[18]; cancer[10]; HIV/AIDS[34]) as well as in philosophical and cross-cultural reviews of hope.[1,15] We suspect that additional or different modes of hoping might be salient in other cultures and emerge in response to different illness scenarios.

Analysis of our longitudinal interviews revealed the limitations of assessing expectations at a single point in time, an issue also noted by Sherman et al.[35] We further found that even at a single point in time, participants' expectations of treatment are multi-faceted and intricately bound both to multiple modes of hoping and to coping with pain. Moreover, Young [22] has astutely observed that individuals' statements about their illness and treatment experience are often assemblages of different kinds of knowledge ranging from the subjective to the negotiated. Forms of knowledge and ways of framing experience are produced in context and continuously respond to contingencies as well as to the feedback of others. We would argue that forms of hope are experienced and co-produced in a similar manner.

Multiple interviews with study participants over the course of nine to twelve months revealed that participants continually updated their hopes and expectations based on new illness and pain related experiences. Significantly, multiple modes of hoping enabled participants to incorporate and process new experiences and information in a manner that at once opened up possibilities for pain relief yet guarded against despair if such relief was not forthcoming.

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

Expectancy and sociocultural "meaning" are two major factors that have been proposed to explain the placebo effect.[36] Placebo theorists have focused extensively on expectancy as well as on the meaning that individuals ascribe to their illness. However, they have paid relatively little attention to how hope mediates expectancy per se. Some of our study participants counterbalanced remaining hopeful with keeping their hope in check when it came to a novel treatment. They were willing to try one more thing in the hopes that

eventually something might work for them, or somehow assist others, but they did not *expect* the treatment to work. Indeed, some were surprised when the treatment actually made them feel better, and in such cases hope preceded positive expectations.

Researchers need to take stock of how different types and combinations of hope affect expectancy and in so doing influence the magnitude of the placebo effect. They should also consider how multiple modes of hoping are interwoven in pain or illness narratives as a means of helping people cope not only with the present but also with the future. To lose the possibility of any future relief from chronic pain may undermine individuals' abilities to create and maintain hope in the face of chronic pain or illness.

Csordas [37] has suggested, and we concur, that "little understanding will result if research is directed toward definitive therapeutic outcome, rather than toward the ambiguities and partial successes (and failures) embedded in therapeutic process" (p137). One of our goals in writing this paper has been to call attention to the ambiguities that arise in patients' narratives about treatment expectations and their hopes for pain relief, and to provide a framework for meaningful analysis of these ambiguities. Analyses of the roles played by coexisting modes of hoping in the lives of the afflicted are essential to the development of a more refined understanding of the placebo effect as a core element of all healing. In this clinical trial of TCM for TMD, hope emerged in study participants' discourses far more commonly than any reference to what they expected. Substituting hope for expectancy would have misrepresented the complexity of participants' experiences, and presenting hope as monolithic would have missed the range of thoughts and feelings they were attempting to convey at different points in time. How one hopes matters, as do transformations in hoping.

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Table 1

Baseline characteristics of TCM for TMD longitudinal qualitative sample (N=44)

Age and gender		**Mean (SD)**
Age in years		43.25 (13.35)
		Percent
Female gender		75
Ethnic Categories		
Hispanic or Latino		22.7
Not Hispanic or Latino		72.7
Unknown (individuals not reporting ethnicity)		4.5
Racial Categories		
White		77.3
Non-white		13.6
Unknown or not reported		9.1
Education	At least some High School	13.6
	Some College	34.1
	College	29.5
	Post Graduate	22.7
Baseline pain characteristics		**Mean (SD)**
Worst facial pain [0-10]		7.19 (1.68)
Average facial pain [0-10]		5.48 (2.13)
		Percent
How long ago did your facial pain begin?	<5 years	34.09
	5-10 years	29.55
	>10 years	36.36
Other characteristics		
	Never	40.91
Prior use of TCM for any other conditions	Once	11.36
	2-3 times	4.55
	4 or more times	34.09

Table 2

Modes of Hoping emerging from participant narratives in this study

Realistic Hope	■	Hope that would be considered reasonable or probable based on current medical knowledge
	■	Would not be considered a “hope” by those who characterize hope as an emotion that does not include rationality[2,15,26]
Utopian Hope	■	Collectively oriented hope that group action can lead to a better future
	■	Expressed here as hope that participation in a research study would contribute to greater overall knowledge of the condition
Wishful Hope	■	Very high hopes that are currently within realm of possibility
	■	Active form of hope, working to remain hopeful
Technoscience Hope	■	Hope for unforeseeable scientific medical breakthroughs
Transcendent Hope	■	General hopefulness, not directed to specific outcome or goal, may be related to religious faith
	■	Hope that things will turn out well in the end, refusing to make any conditions on the future or to imagine a particular future