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"I Felt Like It Was God's Hands Putting the Needles In": A Qualitative Analysis of the Experience of Acupuncture for Chronic Pain in a Low-Income, Ethnically Diverse, and Medically Underserved Patient Population

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Abstract

Objectives: To examine the experience of patients from a low-income, ethnically diverse medically underserved population receiving acupuncture for chronic pain.

Design: Qualitative analysis using inductive thematic analysis of interviews with participants from an acupuncture trial.

Settings/Location: Four community health centers in the Bronx, New York.

Participants: Thirty-seven adults with chronic neck or back pain or osteoarthritis who participated in a previous acupuncture trial.

Interventions: Up to 14 weekly acupuncture treatments.

Outcome measures: Pain and quality of life were examined in the original trial; this study examines qualitative outcomes

Results: The themes grouped naturally into three domains of the acupuncture experience: the decision-making process, the treatment experience, and the effect of acupuncture on health. Regarding decision-making, important factors were a willingness to try something new even if you do not necessary "believe" in it or have specifically positive expectations; a sense that medications were not working for their pain, that they also caused significant adverse effects, and that natural strategies might be preferable; and a feeling of desperation. Cost and access were significant barriers to acupuncture treatment. Regarding the process of acupuncture, the open and personal communication with the acupuncturist was an important factor, as were the sense that the process of acupuncture related to a natural process of healing or correction within the body and that part of making acupuncture successful required being open to the power of the mind to generate a positive outcome. Regarding the effect of treatment, notable aspects were the deep sense of rest and relaxation participants reported during treatment as well as the benefit they experienced for conditions other than pain.

Conclusions: The themes that emerged in this ethnically diverse, low-income population were very similar to those that have emerged over the past decade of qualitative research on the acupuncture experience in other patient populations.

Introduction

CHRONIC PAIN IS AN EXTREMELY common problem that disrupts the lives of millions of people in the United States. Minority populations in particular experience greater

prevalence and worse outcomes of chronic pain. There is a positive association between pain and impairment of physical and psychological functioning, ¹⁻³ lost productivity, ⁴ and lower socioeconomic status. ⁵ Patient-level attributes contributing to undertreatment often involve variation in

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attitudes, beliefs, and concerns, such as medical mistrust, culturally different expressions of pain behavior, and culturally based opinions regarding the nature of illness and healing.^{6,7}

A great deal of evidence now supports the use of acupuncture therapy in the treatment of chronic pain conditions, particularly in osteoarthritis, ^{8,9} neck pain, ^{10,11} and low back pain. ^{12–14} Very few studies, however, have examined the impact of acupuncture for pain in a specifically low-income, ethnically diverse, medically underserved population, where the need for more effective pain treatment is perhaps most extreme. Thus, little is known regarding the effectiveness or the process of acupuncture delivery in this setting.

The authors' previous National Center for Complementary and Integrative Health-funded acupuncture trial, ADDOPT (Acupuncture to Decrease Disparities in Outcomes of Pain Treatment) did address this gap in the literature, demonstrating the acceptability and effectiveness of acupuncture treatment for chronic pain in the urban primary care health centers of an urban practice-based research network. This pragmatic effectiveness study completed data collection on a cohort of 227 patients in November 2011. 15,16 Back pain was the most common enrolled diagnosis (n=135; 59.5%), followed by osteoarthritis (n=37; 16.3%); many patients had multiple conditions (n=36, 15.9%). Participants were older (mean, 54.3 years); many had low income (40.6% had household incomes < \$20,000), and 59% were on Medicaid (the government-subsidized insurance available for lowincome patients in the United States). More than half were Hispanic (53.6%) and 27.1% were primarily Spanish speaking. About a third (39.1%) were disabled. Mean pain severity (Brief Pain Inventory) and physical health scores (Short-Form 12 instrument) changed significantly over time during the study, with 32.4% of patients experiencing a 30% or greater improvement in pain. This was the first published trial that we know of specifically focused on the effect of acupuncture for pain in low-income, ethnically diverse population.

To understand the experience of acupuncture treatment in patients from this population, a qualitative inquiry with a group of participants in the ADDOPT trial was conducted. The hope is that the findings will help inform the process of wider dissemination of acupuncture services into community-based and underserved settings.

Materials and Methods

The Albert Einstein College of Medicine institutional review board approved this qualitative study. Interviews were conducted during the 12-month period following the end of the trial; the amount of time between the end of the patients' acupuncture experience and the qualitative interview ranged from 6 to 18 months. The average time between completion of the acupuncture experience and the qualitative interview for the individual patients was approximately 11 months in each group. To ensure a sampling of the whole spectrum of acupuncture experience in this trial, two lists of 25 randomly selected patients from the parent trial to approach for qualitative interviews were generated: one from the patients who showed a significant improvement in pain during the trial and a second from the patients who did not. To do this, the pain response was dichotomized by using a 30% change in the Brief Pain Inventory as the cutoffgenerally considered a clinically meaningful response in pain studies—and labeling those above that point as having had a significant response. These individuals were contacted sequentially by telephone and invited to participate in an individual qualitative interview. The research coordinator conducted interviews in Spanish or English as preferred by the participant. Those agreeing to be interviewed provided informed consent before the interview began and were provided a \$50 stipend for participation. Interviews were audiotaped and then transcribed.

Based on the work of Astin¹⁷ and Paterson and Britten¹⁸ and other pertinent integrative medicine literature, ^{19,20} probe questions for the interviews were developed to elicit information from participants about their experience of acupuncture during the ADDOPT trial. Constructs such as the concept of self-healing and the healing power of nature, as well as the cultural congruence of complementary and alternative medicine (CAM) therapies and the importance of the patients' experience with CAM served as some of the starting points for the inquiry. Using this set of questions, an initial set of eight patients were interviewed. Three readers then read each of these interviews using a thematic analysis approach. On the basis of this preliminary analysis, several questions were added to the interview guide. This expanded interview guide was then used for the subsequent 29 interviews. Sample questions from the interview guide are provided in Table 1. Interviews were no longer conducted after reaching of the end of the two lists of 25 patients, at which point 20 of 25 responders and 17 of 25 nonresponders had been interviewed, resulting in a total sample of 37 patients. The authors were prepared to interview additional patients if necessary; however, the preliminary data analysis showed that saturation had been reached with this sample, with no new additional themes emerging from the interviews by the end of that analysis.

An inductive thematic analysis strategy, as developed by Braun,²¹ was used to examine and categorize the data and identify emergent concepts and themes. To develop a set of codes appropriate for the material, three independent readers read a sample of four interviews selected for maximum variation on rich content and independently identified themes. These readers then collaboratively identified the overlapping and unique coding categories and arrived at a tentative consensus set of codes. All three then applied the revised codes to a second sample of three interviews. The data were coded by using Dedoose software (Hermosa Beach, CA), a qualitative data analysis program. The coding of this second set of interviews was then examined for consistency between readers; the degree of consistency was found to be very high by using the Dedoose function to evaluate reliability across analysts.

All the interviews were then coded, with two of the three coders coding all interviews. This stage included a recoding of the original four interviews that had been used to generate the codes. Once the coding was completed, the immersion/crystallization approach²² was then used to look for emergent patterns in the data; these patterns were grouped into three domains of the acupuncture process. This approach, described by Miller and Crabtree, entails an iterative process in which the researchers first "immerse" themselves in the data by reading portions of it in detail. They then temporarily suspend this process to engage in a reflective analysis to identify and describe patterns that "crystallize" as a

TABLE 1. INTERVIEW GUIDE FOR ADDOPT QUALITATIVE ANALYSIS

What made you decide to join the pain study?

- Do you remember what your thoughts or ideas about acupuncture were going in to the study?
- Was there anything you were afraid of?
- What made you want to join the study?

Tell me about the history of your past experiences with pain

- When did you first develop the pain?
- What impact has pain had on your life up to now?
- Who has helped you cope with the pain in the past?
- What treatments have worked well for you in the past?
- What aspects of your life have made it more difficult to deal with your pain in the past?
- What aspect of your pain did you feel you most needed help with?
- Does your pain "teach" you anything? What does it teach you?

Tell me about your past experiences of CAM/unconventional treatment approaches

- Had you ever had acupuncture before the study?
- What was that like?
- What other types of therapies have you tried for your pain? Have they been helpful? In what ways have they been helpful?
- Do other people in your life use CAM? What were your views of CAM like before starting this study? How effective did you think CAM was in general? How do you think those effects really work?
- If you did see a CAM practitioner in the past, what was your relationship with that person like?
- How do you see acupuncture as different from your regular pain care?
- Have any other types of therapies been helpful in other aspects of your life?

Tell me about your experience during the study

- What do you think is happening in your body when you get acupuncture? What do you think it does?
- What if anything was different about the acupuncture experience from other health care experiences you have had?
- How did you feel about the acupuncturist?
- Did you learn anything from the process of getting acupuncture treatment? What did you learn?
- Did the acupuncturist treat any medical issues other than your pain? What was that like?
- Did the acupuncturist get to know you as a person?
- During the course of the acupuncture treatment, did anything change about how you feel about things? Did anything change in how you think about or relate to your pain?

ADDOPT, Acupuncture to Decrease Disparities in Outcomes of Pain Treatment; CAM, complementary and alternative medicine.

result of this immersion. These two processes are then repeated until all the data have been examined and the meaningful patterns and themes extracted and described Once these themes were described, the interviews were reread to identify any disconfirming data.

Results

The themes grouped naturally into three domains of the acupuncture experience: the decision-making process, the treatment experience, and the effect of acupuncture on health. Interestingly, no specific patterns or themes were unique to the pain responders or non-responders. In the following section, quotes are identified by study number, followed by sex, age in years, and status as responder (R) or non-responder (NR).

Deciding to try acupuncture: "Sometimes you realize you just got to go for it, you've got to jump"

Several themes emerged from the interviews regarding how and why patients had decided to try acupuncture. First was a sense of "might as well try it." Patients often expressed a sense that it is necessary to be willing to try something new, even if you do not necessary "believe" in it or have specifically positive expectations, to be able to get better. For many, this was part of the decision to try acupuncture.

- I learned pretty much that I need to open my mind to different things on the way of trying to make my life a little bit better because it was never like my first priority to try to get acupuncture. [W030/F/34/NR]
- If you're going to be close-minded and lock yourself into—into a box ... you're never going to cure yourself because everybody has to—at least one time in their life—has to experiment with something else better than just routine. [F043/F/62/NR]
- I said ... everybody's body is different, nobody is the same. What happens to one person doesn't necessarily happen to the other person ... I said I'll try it, I'll try anything. [C056/F/63/R]

A second major factor in the decision to try acupuncture was the feeling that medications were not working for their pain and that they also caused significant adverse effects.

- I don't like to get into the medication thing. You take the medication one day, residual the next day, then you got to take another medication that day for the residual ... so you're in a damn cycle, a downward cycle. [P020/F/66/NR]
- The pain management, like they just basically like to give you a lot of medication ... I can't function taking that medicine. It really like makes you drowsy and sleepy and you be in another zone. I have to be able to function. [P028/F/57/NR]

For many participants, this led to a sense of desperation, of being willing to try anything, as a motivation.

- I was so desperate I just wanted to go. I didn't think about anything how it was going to work or what it felt like or anything. [P007/F/77/R]
- I was pretty much at my wit's end. I tried different things ... With the pain that I go through, pretty much anything I will try. [W030/F/34/NR]

Many patients felt that natural treatments would be preferable to using medication for their pain.

- I would pick this over pain medication any day ... I just wanted something healthier and holistic and natural for me. [P020/F/66/NR]
- If people would try natural medicine instead of prescription drugs, I believe that a lot of other drugs will

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not be needed. Because when you take medication let's say for the pain, then it messes up your liver, then you need to take something for your liver and/or to cover your stomach, and it goes on and on and on. [P042/F/36/NR]

In terms of barriers to deciding to use acupuncture as well as motivators to decide to join the study, cost and access were clearly important factors.

- I had to take a bus back and forth, so now that's like three buses, so by the time I got home it was like, you know, I was tired and then the pain was back again. [F045/F/61/NR]
- As a matter of fact, a few years back I had [tried acupuncture] and I couldn't afford to keep it up because I couldn't afford to keep paying for it. ... When I had an opportunity to get it again I took it. [P007/F/77/R]
- To be honest, I wanted to continue to go and get it, but the funds were not there. [W008/F/56/R]

Acupuncture process

Participants consistently described several ways in which the experience of acupuncture differed from their typical "medical" experience. First was the type and quality of communication they experienced from the acupuncturists. Although for the most part patients had very positive things to say about their medical providers, there was something different about the relationship with the acupuncturists and about the time they spent listening to the patients' concerns.

- The practitioner takes her time and makes sure that you're all right. Not that my medicine doctor doesn't do that, she's a very caring person. But the process of the whole acupuncture session, it's a lot more one-on-one. ... I guess that I have a good relationship with my doctor, but sometimes everything is like so rushed, and not because of her in particular, because of the schedule. [P042/F/36/NR]
- I wasn't afraid of being judged, like I could say the weirdest things and they would laugh or they would talk about their own similar stories too. [P044/F/28/NR]
- It's just an energy you feel when they're, when they're working and talking to you. It's sort of like, it's sort of a like a feeling you should feel when you're with your doctor. [C021/F/61/NR]
- He understood me ... in different ways. Because he helped me physically, he helped me emotionally and psychologically, and in our relationship by knowing me more and understanding me as a person. [F080/M/60/R]

Some patients did not feel the acupuncturists listened well, however, and for some this had a negative effect on the treatment experience.

• I didn't like the way he was—you know, it was like no matter what I said he wanted to do what he wanted to do, but it was my body. [C038/M/55/R].

Another major difference in patients' perceptions of acupuncture as compared to conventional medical care came across in a very distinct sense for many participants that the process of acupuncture was related to a natural process of healing or correction within the body.

• Your body is healing, like basically just waking up whatever's asleep in there ... it sends the signal to the brain to—your body to start healing itself. [P042/F/36/NR]

- I could feel almost like things moving around like being adjusted. ... It's like not wearing glasses and you put your glasses on, and once you put your glasses on you can see that everything is so clear. ... It was almost like a stream that I would feel in my body. [P020/F/66/NR]
- I think with the acupuncture it addressed the ... communication between my mind and the pain area, whereas the physical therapy only addressed the pain area. [F025/F/69/R]
- Basically what they do is as far as I know is they just put a stop sign on the pain that says go away. ... It tunes. ... Yes, it's all about letting the body heal itself while you're in tune with the rhythm. The chi has to take over. [C038/M/55/R]

Other patients, however, felt they really did not have a clear sense of how acupuncture works, although this did not necessarily mean it was not effective for them.

- It's still confusing exactly how it gets done. I just know needles go in and then within a few minutes of just relaxing and not moving it's like tension and pain and all that is being washed away. [W030/F/34/NR]
- When they said something about the heart and the lung and the liver ... you're thinking that the medical way, oh God, my heart—something's wrong with my heart and they said no, it's not the same. [W022/F/57/R]
- And he told me, we place those needles on certain parts of your body where they ... are like the body alerts. ... I don't know, something like that, he explained to me. So, I said, oh, Mary, how great is God. [C029/F/80/R]

Many patients felt that part of making acupuncture successful required being open to the power of the mind to generate a positive outcome.

- I put positive energy into it. I would say that faith is very important. I felt a faith that would help me. ... Feeling comfortable with a treatment like acupuncture has a tremendous influence on its effectiveness. [F080/M/60/R]
- And I can actually feel the biorhythm going—flowing through my body. And that's only because I was expecting good things out of it, so I was able to be in tune with my body at the time. ... If you have a negative mentality it probably won't work because you're already telling yourself it isn't going to work. [C038/M/55/R]
- I believe everything is mind over matter. ... You have to be open to what's being presented to you for it to have some kind of effect, be it good or bad. [F051/M/46/NR]

Participants were divided on the question of whether acupuncture is a generally painful experience. Some found it quite painful: One patient commented "Don't touch the toes. I can take it any place but the toes."

- Well, it hurts. It's like somebody just takes a needle and just sticks you, a pin and just sticks you. Once it's in it's not that bad. It's not bad at all. [P007/F/77/R]
- It was good two or three times and then the last time I got scared because he punctured me in a place where I felt total pain. [C038/M/55/R]

 And I said maybe I won't go back, because that was really, really painful. Oh my God, it was that painful. [F050/F/58/NR]

Other patients felt that acupuncture treatment was not painful at all.

- Sometimes it was like ouch, this is really hot. But it was weird that it wasn't painful. I mean you have hot needles smoking coming out of your skin and it didn't hurt. [F051/M/46/NR]
- I said I'll give it a shot and then when she started sticking the needles in me, I said, that doesn't hurt. Everybody says, oh, it's going to hurt you, I said no, it doesn't hurt. You just feel a little pressure and then it's gone. [C056/F/63/R]
- It doesn't hurt. I don't think it's bothersome or painful or burns or anything. For me, it works. [C10/F/79/R]

Impact of acupuncture on health

Several themes emerged from the interviews in terms of how patients described the effect of acupuncture treatment on their pain and on their lives in general. For many participants a critical part of the benefit of acupuncture had to do with its effect on stress and the experience of deep relaxation and quiet during the acupuncture treatment and with the concept that acupuncture was treating the mind as well as the body. Several patients described the calm and quiet they felt during acupuncture treatment as unlike anything they had experienced previously.

- I feel relaxed. I drift away. I start to levitate. Then when they come and take the needles out, I'm a completely new person. ... When they give you treatments, you feel more relaxed and you can move your body more. [C10/F/79/R]
- The heaviness of whatever was going on in my head that day was pretty much gone. I felt at ease. I felt light-spirited. [F051/M/46/NR]
- It will relax me and then it'll—like you're walking on a cloud, like you feel good. ... All the bad energy goes out of you and you feel relaxed and ... it's like walking on air. [C056/F/63/R]

Although it was pain that led the participants to try acupuncture, many reported that acupuncture treatment had benefits for conditions other than just pain. Many patients mentioned depression, anxiety, and sleep, along with several gynecologic issues. The effect on these non-pain conditions often had major ramifications for quality of life.

- They treated my whole body ... my depression, my asthma, my aura. [F025/F/69/R]
- I had problems sleeping, but I slept like a baby. I really did. I slept really well. [P020/F/66/NR]
- My menstruations were very heavy. And she actually did a treatment to not only slow down the bleeding because it was so heavy but the cramps literally I did not cramp for I think 4 months. [P023/F/52/R]
- I also suffer from endometriosis, and for years, I will bleed for 30, 40, 50, 60 days continuously. And, believe it or not, my period's down to 4 days. ... I feel a lot more positive because once my period has been controlled, I feel more that I could go out and be more active. ... I joined a salsa dance. [F078/F/42/R]

- It helps me to sleep, it makes me feel better. It improves your coordination, too, and your focus, in a psychological and physical way. [F080/M/60/R]
- You know, with the whole me becoming disabled, it really had a reaction on my mood, the depression and everything. ... I actually felt like I could possibly get back to being me. [W030/F/34/NR]

Some claims that the acupuncturists made were nevertheless met with some skepticism from participants.

• Well, she said that with the process of when she was putting in the needles that they would help to clear up and help me to cope with my other medical issues. ... She said that the procedure she was doing would probably help with my diabetes, and I'm kind of confused about that. I didn't know if it worked or not because my blood sugar goes up and down.[W030/F/34/NR]

In terms of improvement in pain with acupuncture, although the overall experience was positive, many patients commented that the relief was temporary.

- I have days where it worked and I have days where it didn't I remember one time I went and it made it worse. [C038/M/55/R]
- And I used to go, and I used to feel better that day, that one day. And then a day or two later, the pain would come right back. [C056/F/63/R]
- A bit of relief, yes, but not as much as I would have wanted or so, because my knees are still the same. [C042/F/88/R]

Even for those whose pain relief was temporary, however, there were often unexpected benefits from acupuncture. Many patients reported learning new strategies during their treatment, which helped them care for themselves more effectively. For many, these lessons were very empowering and had a major effect on re-enforcing their sense of agency to take care of their own illnesses.

- I learned to rest, to sleep better, and to rest positively, in a positive way, a relaxing way ... to be more confident, to know that ... I could feel better and feel relief and get rid of that intense pain, improve the pain. [F080/M/60/R]
- I felt like they gave me tools that would help me even after the study, like I still use them today like with the migraines, the pressure point by myself. I have the migraine, I'm sitting on a train and I just apply pressure and I remember the study and it's like because even though the study is over, what they told me I'm still using it. [P044/F/28/NR]
- I learned spots to massage when I wanted to relax. I learned that the—my stomach is the core of my being. And that anytime I got upset or whatever I will have to massage that in order to relax again and stop my ulcers from bothering me.[F025/F/69/R]

Discussion

The themes that emerged in this ethnically diverse, lowincome population were very similar to those that have emerged over the past decade of qualitative research on the 718 KLIGLER ET AL.

acupuncture experience. For example, in a qualitative analysis of patients receiving acupuncture for low back pain in the United Kingdom, Hopton et al.²³ found that important facilitators of acupuncture acceptability included "relaxation, psychological benefit, and reduced reliance on medication" and that the common barriers to acceptability— "needle-related discomfort and financial cost"—did not detract significantly from patients' overall experience. They also found, as was seen in this analysis, that "treatmentrelated mediators of time, therapeutic alliance, lifestyle advice and the patient's active involvement in recovery" were important factors in acceptability. The current finding that similar factors are at work in mediating the acceptability and effectiveness of acupuncture in a medically underserved patient population potentially less familiar with acupuncture as a practice—along with the authors' previously published quantitative work showing acceptability of the service and effectiveness in reducing pain in this population—suggests a readiness and a need for more access to acupuncture services in this population.

Although much research has focused on the role of expectancy and other cognitive constructs in mediating the experience and outcomes of acupuncture, the current study found—as did Bishop and Lewith in their study²⁴—that more psychological and emotional factors, such as hope, optimism, and open-mindedness played a major role in the decision to try acupuncture. The complexity of the processes that go into the decision to try acupuncture—and which potentially may affect the outcomes of acupuncture treatment as well—appear to be similar in the current population to those identified in previous studies.

Given the high prevalence of comorbid depression and anxiety in patients with chronic pain in underserved settings, as well as the well-documented effect of stress on pain experience, another important finding here is that participants reported substantive benefits in mood and a new perspective on how stress influences their pain. This is consistent with qualitative work by Rugg et al. 25 on patients with complex and medically unexplained symptoms that "acupuncture, initially accepted as 'just another referral'-one like many others that had been tried and proved unsuccessful-was valued for the amount of time allotted with a caring practitioner who listened and responded, as well as for the interactive and holistic nature of the sessions." Patients in that study, as in the current one, reported "changes in their health that spanned physical, psychological, and social dimensions...as well as feelings of greater personal control, calmness, and relaxation."

The current patients identified access and the cost of care as a major barrier. This is also consistent with previous literature both in the United Kingdom²⁶ and the United States.²⁷ Community or group acupuncture—which can be offered at a much lower per patient cost—has been proposed as a possible solution to this issue^{28–30} and is in fact the subject of a recently launched Patient-Centered Outcomes Research Institute—funded trial in the authors' network comparing both the outcomes and the experience of patients receiving individual or group acupuncture for chronic pain.

One significant limitation of this study is that because of the need to complete the quantitative analysis before proceeding with the interviews to ensure adequate representation of both responders and non-responders, interviews were conducted at least 6 months and in some case as much as 18 months after the end of the participants' acupuncture treatment; this may have biased the participants' perspective on the experience in some cases.

In conclusion, the experience of receiving acupuncture for chronic pain for patients from a low-income, ethnically diverse population has major elements in common with that of other populations studied to date. New models are needed to address issues of cost and access to care for this patient population.

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