COMPLEMENTARY AND ALTERNATIVE MEDICINE

On Pins and Needles? Pediatric Pain Patients’ Experience With Acupuncture

Kathi J. Kemper, MD, MPH*; Rebecca Sarah, LicAc, MPH‡; Ellen Silver-Highfield, LicAc§; Elizabeth Xiarhos||; Linda Barnes, MA, MTS, PhD¶; and Charles Berde, MD, PhD#

Abstract. Introduction. Despite its increasing use as a complementary therapy to treat pain, acupuncture is rarely considered by pediatricians, in part due to perceptions that it will not be acceptable to pediatric patients. We wished to describe pediatric pain patients’ experience with acupuncture treatment for chronic pain.

Design. Retrospective case series.

Methods. Subjects were pediatric pain patients referred to the Pain Treatment Service at Children’s Hospital in Boston, who went to a pediatric acupuncturist. A research assistant not involved in the patient’s care conducted the survey by telephone. Data were analyzed qualitatively and descriptively.

Results. Of 50 eligible patients, 47 families were reached by telephone; all agreed to be interviewed. Patients had a median age of 16 years at the time of referral, 79% were female, and 96% were white. The most common three diagnoses were migraine headache (n = 7), endometriosis (n = 6), and reflex sympathetic dystrophy (n = 5). Patients had a median of 8 treatments (range: 0–60) within 3 months (range: 0–48 months); 85% of families paid out-of-pocket. Acupuncture therapies included needle insertion (98%), heat/moxa (85%), magnets (26%), and cupping (26%). Most patients and parents rated the therapy as pleasant (67% children/60% parents), and most (70% children/59% parents) felt the treatment had helped their symptoms; only 1 said that treatment made symptoms worse.

Conclusion. Pediatric patients with chronic, severe pain found acupuncture treatment pleasant and helpful. Additional, prospective studies are needed to quantify the costs and effectiveness of acupuncture treatment for pediatric pain. Pediatrics 2000;105:941–947; chronic pain, acupuncture, pediatric patients, complementary medicine, alternative medicine.

ABBREVIATION. CAM, complementary and alternative medicine.

Chronic childhood pain is a complex problem that often requires a multifaceted, multidisciplinary approach. Pediatric pain treatment services typically provide medications, psychological counseling, biofeedback, guided imagery and relaxation, physical therapy, massage and surgery. Despite this multifaceted approach, pain persists for some children.

Growing numbers of Americans are turning to complementary and alternative medical (CAM) therapies to treat chronic medical conditions. Acupuncture is one of the most popular of these therapies. There are approximately 11 000 licensed acupuncturists in the United States, and the number is expected to double within the next 10 years. Acupuncture is one of the CAM therapies most frequently recommended by internists and family physicians. Of the 43 pediatric Pain Treatment Services at North American children’s hospitals, one third offer acupuncture services.

A National Institutes of Health consensus conference concluded that acupuncture is effective in treating some types of nausea and pain in adults, such as dental pain, migraine headaches, back pain, and dysmenorrhea. Animal studies also support the use of acupuncture in treating pain. Fewer studies have focused on the effectiveness of acupuncture in treating pediatric pain.

Reports of serious adverse effects from acupuncture are rare. Although there are case reports of acupuncture-associated fatal pneumothoraces, cardiac tamponade, and serious infections, the reported incidence of serious side effects from acupuncture therapy when performed by a licensed acupuncturist are 1:10 000 to 1:100 000—about the same risk as a serious adverse event from taking penicillin.

Despite its promise as a safe, effective adjunctive therapy in the treatment of childhood pain, pediatricians rarely think of acupuncture as a therapeutic option. This is due in part to the lack of training in and familiarity with acupuncture and a paucity of clinical trials of acupuncture in pediatric populations. But a larger factor seems to be the conventional wisdom that a) children are afraid of needles, b) acupuncture therapy involves needles, and c) kids and families won’t accept another therapy (besides immunizations) that requires needles. These 3 elements are open to debate.
First, children and adolescents suffering from severe, chronic pain that has not been relieved through mainstream treatments, may be willing to undergo short-term discomfort to achieve long-term goals. Second, most persons who receive acupuncture remark on how much less painful it is than conventional needles, possibly because acupuncture needles are solid, very fine gauge needles. Third, acupuncturists can use a variety of nonneedle techniques to stimulate acupuncture points.

Since 1995, the Boston Children's Hospital Pain Treatment Service has referred children and adolescents suffering from chronic pain unresponsive to mainstream treatments to a licensed acupuncturist in private practice (E.S.H.) who specializes in treating children. This licensed acupuncturist serves on the faculty of the New England School of Acupuncture and has developed a systematic approach to preparing pediatric patients for acupuncture therapy (Fig 1). The referred patients typically suffered from severe, chronic pain. Despite having been seen, evaluated and treated by their primary physicians and specialty physicians, these patients still had severe symptoms.

We wished to know how patients and families experienced acupuncture treatments and the extent to which they believed it helped or hurt their condition. We designed this study to assess qualitative questions about patients' and families' perceptions of acupuncture therapy to evaluate the feasibility of undertaking quantitative studies on acupuncture.

METHODS

This was a retrospective case series conducted by telephone interview. Subjects were eligible for inclusion if they were referred by the Pain Treatment Service at Children’s Hospital, were ≤21 years old at the time of referral, and attended at least 1 visit with the acupuncturist. They were excluded if they could not be contacted by telephone (eg, moved and left no forwarding telephone or other contact information).

The study was primarily a qualitative interview. However, data collection also included demographic and diagnostic information extracted from the medical record. Pilot interviews were developed and tested among 4 parents and 3 adolescents who had received acupuncture therapy, but who were not eligible for the study. Based on this pilot information, the questions were modified for this study. The Appendix provides a list of survey questions.

The Director of the Pain Treatment Service sent a letter to all eligible patients and families informing them about the purpose of the study (to better understand and improve services). They were told that a research assistant would call to ask if they were willing to participate, that participation was voluntary and anonymous, and that their participation or nonparticipation in the project would not affect their ongoing medical care.

Families were called and a parent or guardian was asked if they would be willing to participate in the survey. In some cases, the parent suggested that we instead interview the patient who was an older adolescent or was over 21 by the time they were called. Some children did not want to come to the phone themselves, but told their parent what to say, such as “Tell them it didn’t hurt.”

Quantitative data were entered into an Excel (Microsoft, Redmond, WA) spreadsheet and simple descriptive statistics were calculated.

RESULTS

Of 50 eligible families, 47 agreed to be interviewed. In some cases, the parent deferred to the child (eg, if the child was over 18 or living away from home); in other cases, the child preferred for the parent to be the only or primary respondent (eg, younger or shy children).

The sample was typical of patients seen at the...
Children’s Hospital Pain Treatment Service—primarily female (79%), white (96%) teenagers (15 children were 12 years old or younger while 32 were 13–20 years old [Table 1]). They had a wide range of diagnoses; the most frequent were migraine headaches (n = 7), endometriosis (n = 6), and reflex sympathetic dystrophy (n = 5). Only 15% of patients reported insurance coverage for treatments.

The median number of acupuncture treatments was 8. Most patients completed treatments within 3 months (Table 1). One child was referred, but refused all treatments; this was a developmentally delayed adolescent girl.

All but 1 patient was treated with regular acupuncture needles. A 5-year-old boy refused needles, but accepted nonneedle therapies, having a total of 6 treatments. Nearly half (45%) of patients also received intradermal (retained) needles. The most common nonneedle methods of point stimulation were moxibustion or heat (85%), cupping (26%), and magnets (26%). Percentages add to >100% because many children received >1 type of point stimulation.

Parents’ initial reactions to the recommendation for acupuncture therapy ranged from those who said that they themselves had suggested it, through “pleased,” “willing to try anything,” “open,” “skeptical,” to “afraid.” The most common response (10/42) was “pleased.”

Of the 30 patients, 20 (67%) reported that acupuncture had been a positive experience (Table 2). For example, a 17-year-old girl diagnosed with endometriosis, chronic fatigue syndrome, and headache said that “Acupuncture was not painful, and was very relaxing.” Most parents (60%) also felt that acupuncture was positive. For example, 1 father stated, “(My daughter’s) visits to the acupuncturist were anticipated positively and she had a better attitude for studying, better appetite, and less pain afterward.”

Perceptions of treatment tended to become more positive over the course of therapy. A 17-year-old boy said: “It was strange and weird, but then it became pleasant. I felt calm; it was better than taking all the meds.” An 18-year-old girl with reflex sympathetic dystrophy responded, “At first I was really scared, but then it wasn’t so bad.” No children or parents felt more negatively about acupuncture over the course of treatment.

Of 30 patients, 70% felt that acupuncture had definitely helped their pain (Table 3). A 17-year-old girl with endometriosis said, “It definitely helped the pain. I recommend it to other people with endometriosis; it really works and is not painful, and it brought my energy back.” A 17-year-old boy replied, “Yes! It helped the pain. I’d tried a lot of treatments. This was the last resort, but the best. I wish I had tried it first. I had a lot of twitching because of nerve problems; after the acupuncture treatment, which eliminated the pain and twitching, it changed my life.” A few patients felt it had made no difference; a teenager with endometriosis stated, “No, acupuncture did not help, but I’m open to having it again.”

Among the parents, 59% felt acupuncture had definitely improved the child’s pain. The father of an adolescent with endometriosis said, “It appears to have helped enormously. She has had an endometriosis situation for 4 years, had a bad flare-up last weekend (10 on a scale of 1 to 10), but saw the acupuncturist that day and had a miraculous recovery.” He noted that if pediatricians at Children’s Hospital had not referred him, he would not have considered acupuncture for his daughter. The mother of the 17-year-old boy remarked, “Yes, it helped that [the pain] and also with relaxation. He

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**TABLE 1.** Subject and Treatment Description

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Patient</th>
<th>Parent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age at first treatment: median (range)</td>
<td>16 (5, 20) y</td>
<td>16 (5, 20) y</td>
</tr>
<tr>
<td>Gender</td>
<td>79% female</td>
<td>79% female</td>
</tr>
<tr>
<td>Race</td>
<td>White 96%</td>
<td>White 96%</td>
</tr>
<tr>
<td>Black</td>
<td>2%</td>
<td>2%</td>
</tr>
<tr>
<td>Other</td>
<td>2%</td>
<td>2%</td>
</tr>
<tr>
<td>Payment</td>
<td>Self-pay 85%</td>
<td>Self-pay 85%</td>
</tr>
<tr>
<td>Third party pay</td>
<td>15%</td>
<td>15%</td>
</tr>
<tr>
<td>Number of Treatments: median (range)</td>
<td>8 (0, 60)</td>
<td>8 (0, 60)</td>
</tr>
<tr>
<td>Came but refused treatment (0)</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>1–5 treatments</td>
<td>14</td>
<td>14</td>
</tr>
<tr>
<td>6–12 treatments</td>
<td>19</td>
<td>19</td>
</tr>
<tr>
<td>&gt;12 treatments</td>
<td>13</td>
<td>13</td>
</tr>
<tr>
<td>Duration of course of treatment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;1 mo</td>
<td>19</td>
<td>19</td>
</tr>
<tr>
<td>1–3 mo</td>
<td>12</td>
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</tr>
<tr>
<td>4–6 mo</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>&gt;6 mo</td>
<td>11</td>
<td>11</td>
</tr>
<tr>
<td>Type of point stimulation</td>
<td>Needle 98%</td>
<td>Needle 98%</td>
</tr>
<tr>
<td>Moxa/heat</td>
<td>85%</td>
<td>85%</td>
</tr>
<tr>
<td>Cupping</td>
<td>26%</td>
<td>26%</td>
</tr>
<tr>
<td>Magnets</td>
<td>26%</td>
<td>26%</td>
</tr>
</tbody>
</table>

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**TABLE 2.** What Was Acupuncture Like?

<table>
<thead>
<tr>
<th>Experience</th>
<th>Patient</th>
<th>Parent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Positive or pleasant, eg, relaxing</td>
<td>20 (67%)</td>
<td>25 (60%)</td>
</tr>
<tr>
<td>Negative or unpleasant, eg, scary</td>
<td>4 (13%)</td>
<td>3 (7%)</td>
</tr>
<tr>
<td>Other/neutral, eg, strange</td>
<td>6 (20%)</td>
<td>14 (33%)</td>
</tr>
<tr>
<td>Total</td>
<td>30 (100%)</td>
<td>42 (100%)</td>
</tr>
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</table>

* Of the 47 families interviewed, 30 patients and 42 parents responded to this item. In some cases (eg, older adolescents), parents deferred to the patient; in other cases, the patient (often a younger or more shy child) wanted the parent to answer.

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**TABLE 3.** Did the Treatment Help or Hurt?

<table>
<thead>
<tr>
<th>Helpfulness</th>
<th>Patient</th>
<th>Parent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes, improved</td>
<td>21 (70%)</td>
<td>26 (59%)</td>
</tr>
<tr>
<td>No better, not worse</td>
<td>8 (27%)</td>
<td>15 (34%)</td>
</tr>
<tr>
<td>Worse, side effects</td>
<td>0 (0%)</td>
<td>1 (2%)</td>
</tr>
<tr>
<td>Neutral, not sure</td>
<td>1 (3%)</td>
<td>2 (5%)</td>
</tr>
<tr>
<td>Total</td>
<td>30 (100%)</td>
<td>44 (100%)</td>
</tr>
</tbody>
</table>

* Of the 47 families interviewed, 30 patients and 44 parents responded to these items. In some cases (eg, older adolescents), parents deferred to the child’s answer; in other cases, the patient (often a younger or more shy child) wanted the parent to answer.

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Intradermal needles are 3 mm long; they are inserted very shallowly nearly parallel to the skin surface rather than perpendicular to it. They are taped in and remain in place for up to 3 days. Very careful follow-up instructions are given with this form of treatment.
had head-thrashing, violent twitching of his head, but all that’s left is a twitch in his eye. If anybody ever wanted to speak to me, I would love to because it was such a good, positive experience.” Some parents felt that acupuncture had made the child neither worse nor better. The mother of a 17-year-old boy with chronic back pain and migraine headaches said; “It took the edge off, but he was never pain-free.”

Twelve families mentioned things they did not like about the acupuncture treatments. These included a) initial fear of needles, b) dislike of the smell of moxa burning in the office, c) time for commuting and treatment, and d) presence of trainees in the office. Only 1 parent reported that her child’s pain seemed worse after the treatment.

Four parents spontaneously reported that they were glad to see doctors at Children’s Hospital recommending alternative therapies. Two others mentioned that they wished acupuncture had been started sooner. The mother of a child whose symptoms had not been helped by acupuncture said, “I’m very grateful for the acupuncture. It had great value for me, let me feel like I was doing something, like I was a good mom.”

DISCUSSION

Acupuncture is one of the most popular therapies in the field of complementary medicine. However, this is the first study to examine children’s and families’ subjective experiences with acupuncture therapy. Our primary purpose was not to evaluate the effectiveness of acupuncture in treating specific types of pain, but to assess patients’ qualitative experience.

The patients in this study were typical of those seen by the Children’s Hospital Pain Treatment Service in terms of age, gender, race, and diagnoses. They typically received 8 treatments within 3 months; the vast majority (85%) paid out-of-pocket for acupuncture services. Most families found acupuncture pleasant and helpful, even for pain that had been very resistant to standard treatment. Although some began with anxiety about the needles and misgivings about the treatment, many developed more positive attitudes over the course of treatment.

This study has several limitations and potential biases. It was limited to highly motivated patients who were referred by specialist physicians in a pain treatment service at a children’s hospital. Its results are not necessarily generalizable to patients with less severe conditions who are self-referred or who are referred by their primary care physician. Nor can it be generalized to general pediatric patients. Most of the patients in this study were adolescents; younger children’s experiences might be quite different.

This study provides no information on acupuncture therapy for other pediatric conditions. In the United States, acupuncture is increasingly being used to treat a variety of conditions—from postex- tube laryngospasm, to asthma and allergies, to abdominal complaints. Future studies will need to examine children’s and families’ experience with acupuncture for the entire spectrum of illnesses for which it is used.

All of the children in this study were treated by 1 pediatric acupuncturist who may not be representative of all acupuncturists. Because most acupuncturists rarely treat children, it is possible that patients treated in other settings may have different experiences.

The survey was also limited to patients who actually went to see the acupuncturist. In this retrospective series we were unable to determine the full denominator of referrals. Thus, our data may overestimate families’ acceptance of and positive experience with acupuncture. This bias might be enhanced by the fact that the interviewers identified themselves as affiliated with Children’s Hospital, which might have led some families to respond more favorably about their experience.

Because of the chance that those who respond to retrospective surveys may differ from those who do not respond, we made every effort to reach all patients who had been treated by the acupuncturist. Of the 50 families who were eligible for this study, only 3 could not be reached. The remainder were assured that their answers would be kept confidential and would be used to help improve clinical services; they were encouraged to be honest, even if they didn’t like something or felt it had not been helpful. Several parents spontaneously mentioned other things at Children’s Hospital that could have been improved (eg, waiting times and delays in returning phone calls). Although 47 families agreed to be interviewed, only 30 patients responded directly; it is possible that nonrespondents had more negative attitudes about acupuncture.

This study focused on experiential aspects of treatment as opposed to objective efficacy. We did not specifically evaluate physiologic aspects, medication requirements, or frequency of hospitalizations. Future studies may wish to use independent measures to verify symptomatic improvements. On the other hand, the extent of symptomatic improvements reported by families in this study highlights the necessity of physicians knowing all the different treatments used by patients. Without knowing which treatments a child is receiving, symptomatic improvements might mistakenly be attributed to other treatments that are potentially more costly or toxic.

Despite the limitations in this qualitative assessment of children’s and families’ experience with acupuncture treatment for severe pain, we believe it offers important information and understanding about acupuncture therapy for children. First, such therapy is feasible and acceptable to pediatric patients, at least for pediatric and adolescent patients suffering from severe, chronic pain, and attitudes toward therapy become much more positive over a course of treatment. Second, substantial numbers felt that acupuncture had offered clear benefits when nothing else had. Third, the study offers guidance for future studies in this field: 1) prospec-
tive design; 2) a sample of children with diverse symptoms and conditions in addition to pain; 3) referral from primary care or self-referred in addition to referrals from tertiary care institutions; 4) inclusion of objective, independent measures of disease and functional status; and finally 5) an analysis of the costs and benefits of acupuncture versus other therapies. While such studies are in progress, pediatricians can begin to consider acupuncture as a potentially helpful and acceptable treatment option, at least for some children and families.

APPENDIX

SURVEY ITEMS

"Hello, my name is EX/RS. I am calling from the Children’s Hospital. I work with the Pain Treatment Service. We are trying to improve the care we give, and I would like to talk to some of the patients and their families. Any thing you say will be confidential. No information from this interview linked to your identity will be given to your acupuncturist or to any of the treating health care providers at Children’s Hospital."

1. Are you willing to talk about your and your child’s experiences at the Pain Treatment Service?
   YES   NO

2. Is this a good time to talk? YES    NO.
   If not, is there another time that would be better? __________

3. I understand that your child received acupuncture treatment. Is that correct? YES   NO

4. What was your reaction when acupuncture was first suggested?
   Describe: __________________________
   (Answers grouped into categories: Surprised   Pleased   Skeptical   Other)

5. How old was the child when he/she started acupuncture? __ years

6. What was acupuncture treatment like for your child?
   Describe: __________________________
   (Answers grouped into categories: Pleasant/Positive   Unpleasant/Negative   Neutral   Other)

7. After the first treatment, how did the child feel about continuing treatments?
   Describe: __________________________
   (Answers grouped into categories: Positive   Negative   Mixed feelings   Neutral)

8. Did the acupuncture help the child?
   Describe: __________________________
   (Answers grouped into categories: No   Yes, helped the pain   Yes, helped another way   Not sure)
   IF YES,
   How much improvement did the child have?
   None   Small   Moderate   Large   Complete relief

9. Were there things about the acupuncture treatment that your child didn’t like? YES   NO
   Describe: __________________________

10. Did insurance cover the cost of treatment? NONE   SOME   ALL

11. Do you have other comments you would like us to know?
    Describe: __________________________
    May I talk with your child, and ask these questions of him/her?
REFERENCES

11. Lin Y, Lee AC, Kemper KJ. Acupuncture services provided by pediatric pain treatment services in North America; Pediatric Academic Societies Meeting; May 3, 1999; San Francisco, CA

APPENDIX
SURVEY ITEMS for PATIENT

1. What was getting acupuncture like for you?
   Describe: ____________________________
   (Answers grouped: Positive/pleasant       Negative/unpleasant       Other       Neutral)

2. After the first time, how did you feel about having acupuncture again?
   Describe: ____________________________
   (Answers grouped: Negative           Positive          Mixed feelings     Neutral)

3. Did the acupuncture treatment help you?
   Describe: ____________________________
   (Answers grouped: No, got worse           No better/no worse           Yes, helped pain     Yes, helped another way     Not sure)

   IF answers to #3 was "YES",
   How much did it help? None Small Moderate Large Complete relief

4. Is there anything else you would like to tell us?
   Describe: ____________________________

How much did it help?
<table>
<thead>
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<th>Reference</th>
<th>Title</th>
</tr>
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<tr>
<td>Kemper K, Lee A, Highfield E, Berde C.</td>
<td>Practice and pediatric characteristics of acupuncturists in Boston; Pediatric Academic Societies Meeting; May 2, 1999; San Francisco, CA</td>
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*Pediatrics* 2000;105;941

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