Provider Perspective on Integrative Medicine for Pediatric Sickle Cell Disease–related Pain

Punto de vista del personal sanitario sobre la medicina integral para el dolor relacionado con la drepanocitosis en niños

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ABSTRACT

Objective: Integrative medicine (IM) approaches are sometimes used to manage sickle cell disease (SCD)–related pain. The purpose of this research is to (1) understand provider perspective towards the use of IM for pain in children with SCD at a large urban children’s hospital and (2) provide recommendations on how to better promote IM for children and adolescents with SCD.

Methods: After approval from the institutional review board, a qualitative case study approach was used with criterion-type purposive sampling to select providers from the division of hematology to adequately inform the study. Semistructured interviews were completed using audiotape to facilitate transcription. NVivo 10 analytic software (QSR International Pty Ltd, Doncaster, Victoria, Australia) was used to organize data into themes to answer the study questions.

Results: Ten provider interviews were completed. Attitudes were generally positive, and most providers felt that IM is generally helpful. All providers reported that they do not optimally use integrative therapies for children with SCD. The barriers uncovered focused on lack of process for integration of IM, specifically that IM resources seem transient and based on short-term funding. Provider attitude towards CAM is generally positive, but provider comfort level is highly variable. No providers are completely comfortable with their knowledge base about IM, and increased knowledge is desired. Conclusions: Creation of protocols and processes to incorporate IM into management plans for patients with SCD could help to promote its use. Education of providers about utility and efficacy of IM for SCD-related pain and about existing resources would aid in promotion of IM for children with SCD.

SINOPSIS

Objetivo: Los enfoques de la medicina integral (Integrative Medicine, IM) a veces se utilizan para manejar la enfermedad de células falciformes (Sickle Cell Disease, SCD)–relacionada al dolor. El propósito de esta investigación es (1) entender el punto de vista del personal sanitario sobre el uso de la medicina integral para el dolor en los niños con drepanocitosis en un gran hospital infantil y (2) proporcionar recomendaciones acerca de cómo promover la medicina integral para los niños y adolescentes con drepanocitosis.

Métodos: Tras la aprobación del consejo institucional de revisión, se usó un enfoque cualitativo del estudio de un caso con una muestra intencional basada en el tipo de criterio para seleccionar al personal sanitario de la unidad de hematólogos para proporcionar la información adecuada al estudio. Se realizaron entrevistas semiestructuradas usando grabaciones de audio para facilitar la transcripción. Para organizar los datos en temas para responder las cuestiones del estudio se utilizó el software analítico NVivo10 (QSR International Pty Ltd, Doncaster, Victoria, Australia).

Resultados: Se realizaron diez entrevistas con proveedores. Los puntos de vista generalmente eran positivos, y los proveedores sentían que la medicina integral es en general útil. Todos los proveedores reportaron que no utilizan de manera óptima las terapias integrativas para niños con SCD. Los obstáculos identificados se centraron en la falta de proceso para la integración de IM, específicamente que los recursos de IM parecen transitorios y basados en el financiamiento a corto plazo. La actitud de los proveedores hacia la medicina alternativa (CAM) generalmente es positiva, pero el nivel de comodidad del proveedor es variable. No existen proveedores completamente cómodos con su base de conocimiento sobre IM, y se desearía aumentar de conocimiento. Conclusiones: La creación de protocolos y procesos para incorporar IM en los planes de manejo para pacientes con SCD podría ayudar a promover su uso. La educación de los proveedores sobre la utilidad y eficacia de IM para el dolor relacionado con SCD y sobre los recursos existentes podría ayudar a promover IM para niños con SCD.
integración de la medicina integral, específicamente en que los recursos de la medicina integral parecen ser pasajeros y basarse en la financiación a corto plazo. La actitud del personal sanitario frente a la medicina complementaria y alternativa es generalmente positiva, pero el nivel de comodidad del personal sanitario es altamente variable. Ningún miembro del personal sanitario está totalmente cómodo con su base de conocimiento acerca de la medicina integral y desean un mayor conocimiento.

**Conclusiones:** La creación de protocolos y procesos para incorporar la medicina integral en los planes de tratamiento para los pacientes con drepanocitosis podría ayudar a promover su uso. La formación del personal sanitario sobre la utilidad y la eficacia de la medicina integral para el dolor relacionado con la drepanocitosis y sobre los recursos existentes podría ayudar a la promoción de la medicina integral para los niños con drepanocitosis.

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**INTRODUCCIÓN**

La enfermedad de células escuálidas (SCD) es una enfermedad hereditaria hemoglobínopatía afectando a más de 3.000,000 de personas en el mundo, incluyendo a 1 en 500 árabes. La SCD es caracterizada por anemia y daño orgánico en forma de dolor crónico y de repetición, que comienza en la infancia. El dolor es debido a la compresión de los capilares, de los vasos sanguíneos y de los tejidos blandos. La osteofartositis se caracteriza por dolor intenso y articular y es una complicación frecuente de la enfermedad de células escuálidas. El dolor es debido a la compresión de los capilares, de los vasos sanguíneos y de los tejidos blandos. La osteofartositis se caracteriza por dolor intenso y articular y es una complicación frecuente de la enfermedad de células escuálidas. En general, los niños con SCD tienen dolor de piel, dolor abdominal y dolor muscular.

![Imagen](https://via.placeholder.com/150)

La creación de protocolos para incorporar la medicina integral en los planes de tratamiento para los pacientes con drepanocitosis podría ayudar a promover su uso. La formación del personal sanitario sobre la utilidad y la eficacia de la medicina integral para el dolor relacionado con la drepanocitosis y sobre los recursos existentes podría ayudar a la promoción de la medicina integral para los niños con drepanocitosis.

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**COMPLEMENTARY AND ALTERNATIVE MEDICINE (CAM)**

Complementary and alternative medicine (CAM) is defined as any medical system, practice, or product that is not thought of as standard of care. The term in used in medical literature to refer to a very wide range of therapies including traditional medicine, healing arts, nonpharmacological approaches, herbal remedies, and diet and exercise interventions. Examples include acupuncture, acupressure, massage, aromatherapy, and Reiki. The Academic Consortium for Integrative Medicine and Health defines integrative medicine as follows: "Integrative medicine (IM) and health reaffirms the importance of the relationship between practitioner and patient, focuses on the whole person, is informed by evidence, and makes use of all appropriate therapeutic and lifestyle approaches, healthcare professionals and disciplines to achieve optimal health and healing."9

Existing literature on the use of IM in children largely focuses on children without SCD. Much of the existing pediatric literature uses the term CAM; here we use IM in reference to our work and modalities that fall under the definition of IM and CAM when describing studies that favor that term. IM approaches that have been found to be effective in treating pain in children include massage, acupuncture, and cognitive and behavioral strategies.10-12 In general pediatric clinics, studies have shown that parents would be willing to discuss the use of IM with their child’s pediatrician, but most of the time, they do not, and the reasons for this apparent lack of communication are not well defined.13-15 Limited evidence suggests caregivers of children with SCD do seek CAM therapies to manage SCD-related pain. Prayer, spiritual healing, massage, and relaxation are among the most commonly used.16 The use of these techniques is more common in patients with SCD who report more severe disease or require more than one medication to manage pain.16 Most caregivers report that they are interested in discussing CAM with their child’s hematologist; however, they most often do not.16,17 The small body of quantitative literature suggests that caregivers of children with SCD perceive that their medical providers may not be interested in CAM, and this is cited as a hypothesis for this gap in communication between providers and parents.16,17

Attitudes towards IM therapies of providers who care for SCD patients are not well described in the literature; however, several studies have explored the attitudes of general pediatricians towards CAM therapies for their patients.18-20 Data suggest that pediatricians view the use of CAM by their patients as common, with 80% to 90% of pediatricians reporting that some of their patients are using CAM.18,19 A national study conducted by the American Association of Pediatrics documented that almost 90% of general pediatricians reported being asked about a CAM therapy by a patient’s family in the 3 months prior to the survey.19 The majority agreed that “pediatricians should consider the use of all potential therapies, not just those of mainstream medicine, when treating patients.” However, only a minority felt comfortable discussing CAM with their...
patients, and most desired more information about CAM. More recently, general pediatricians felt that the most effective CAM therapies for children included acupuncture/acupressure, chiropractic medicine, herbs, hypnosis, massage, prayer for healing, biofeedback, and relaxation/yoga. Pediatricians who tended to refer for CAM were younger (<45 y), female, use CAM themselves, often talk to patients about CAM, and would like more education on CAM.

The literature suggests that a pediatrician’s personal and professional experience and training frame their attitudes towards CAM and IM therapies for children. Here we use this idea as the basis for a conceptual framework to investigate attitudes of pediatric hematology providers. The objective of the current study is to investigate, from the provider perspective, barriers and facilitators that medical providers face with respect to using IM when caring for patients with SCD. To our knowledge, this is the first study to assess the attitudes of subspecialty pediatric providers who care for children with SCD. The ultimate goal of this work is to facilitate more discussion about IM between patients and clinicians and to develop resources that SCD providers can utilize when recommending IM therapies to their patients.

METHODS
Study Approach and Procedures
Social constructivist theory was used to understand provider attitudes using the assumption that a clinician’s background, experience, patient population, and current work environment will frame his or her approach to the use of IM for their patients. Social constructivism is a philosophical paradigm that is grounded in the assumption that individuals understand reality in the context of the world in which they live and work. This qualitative research was done with a case-study approach, exploring this issue through multiple perspectives within a single setting at Children’s National Medical Center, a large, urban, free-standing children’s hospital in Washington, DC. The methodological approach was a single embedded case study as we collected data from multiple providers across several disciplines to meet the study goals. This allowed us to best inform approaches to care within our single institution. Through semistructured interviews, we attempted to uncover themes related to personal and clinical experience with IM as well as barriers to IM therapies for children and adolescents with SCD. This study was approved by the institutional review board of Children’s National Medical Center.

Study Population
Children’s National Medical Center is a tertiary care institution which is home to one of the largest pediatric SCD programs in the country. The study population is comprised of clinicians who provide care for approximately 1,250 children with SCD in the Washington, DC, metropolitan area. The hematology division is composed of 7 physicians and 5 nurse practitioners (NPs) who treat patients with SCD. Two SCD social workers, 2 nurse coordinators, and 2 psychologists care for patients with SCD.

Sampling Strategy
In this case-study approach, our most broad level of sampling was the SCD program. Within the case study, we used criterion-type purposeful sampling to select physicians, nurses, and NPs from the division of hematology as well as providers from the nonmedical disciplines described above to adequately inform the study. The participants share the same criteria in that they provide direct patient care to children with SCD. The individuals were contacted by a member of the study team (CMN) via e-mail and asked if they would be interested in participating in a voluntary study that aims to learn about provider attitudes towards the use of IM therapies for pain management for children with SCD.

Interview Method
Semistructured interviews were conducted using audiotape to facilitate transcription. Verbal consent was obtained at the start of the interview, and each study participant received an information sheet about the study. A standardized script was used for each interview; a list of interview questions can be found in the supplemental Table. After 2 interviews with medical providers and 2 interviews with nonmedical providers, the guides were reviewed and adjustments to questions were made as needed.

Analysis
Analysis for this work combined both inductive and deductive approaches. The initial step in this qualitative analysis was listening to and transcribing interview recordings. Through this exercise, notes and memos were recorded that framed tentative ideas about categories and relationships emerging out of the data. Additionally, content analysis based on the conceptual framework for this research was completed. These steps resulted in definition of categories and themes. NVivo analytic software (QSR International Pty Ltd, Doncaster, Victoria, Australia) was used for further categorization of study data. The data were organized into broader themes and issues to answer the study questions through generation of queries and matrix coding.

RESULTS
Ten providers from the Division of Hematology participated in a 45-minute interview. Three physicians, 3 NPs, 1 registered nurse, 2 psychologists, and 1 social worker were interviewed. The psychology and social work providers had experience administering therapies such as relaxation, guided imagery, biofeedback, and Reiki. The participants reported 2 to 22 years of experience caring for SCD patients. The following themes emerged in answer to our research questions.

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Hematology Provider Attitudes Toward Integrative Medicine Are Generally Positive

Providers in hematology were generally positive about the potential benefits of IM for children with SCD-related pain, despite having minimal education about IM and recognizing the lack of evidence documenting efficacy of many IM interventions within this population. While providers had varying levels of knowledge with respect to IM therapies, most felt that heat, massage, acupuncture, distraction, relaxation, guided imagery, and biofeedback were generally helpful when used by their patients. The providers had less understanding about Reiki, chiropractic medicine, herbs, aromatherapy, and yoga; however, those who did have experience all cited patients for whom these treatments helped. Many medical providers had tried some form of IM therapies on their own, and their experiences had been generally positive. Medical providers had no, or very minimal, education on IM therapies, and psychology and social work providers were trained only on the treatments that they administer but also lacked education about IM therapies. Those who work with chronic pain patients and nonphysician providers were most positive about the potential benefits of IM, and all providers reported that, within our current system, they did not optimally integrate IM therapies for children with SCD. The following quotes illustrate the generally positive attitudes that providers had towards IM.

Oh yeah, Reiki! So yeah, Reiki is actually something that one of our Social Workers is trained in, so she has done Reiki with some of the patients. We had a patient who was in the hospital for about 10 days with pain when I was on service last month. Our social worker tried it with her and I thought that it did help.—Physician

I haven't had anybody who's had acupuncture not want to have it again. Everybody likes it. Sometimes not necessarily for pain, but it helps with anxiety surrounding the pain, and it helps them relax and get to sleep.—NP

I believe in it, I really do. I believe in the breathing, I definitely do the breathing. I attend a lot of workshops where you learn different exercises, so I definitely do this with myself.—Social worker

Barriers and Facilitators

A number of barriers (Table 1) and facilitators (Table 2) were identified with respect to the recommendation and use of IM for patients with SCD. The barriers described focused on lack of process for integration of IM at this institution, specifically the fact that IM resources seemed transient and based on short-term funding or provider interest. This made it difficult for providers to know what was available at a given time. While provider attitude was generally positive, provider comfort level in recommending IM was highly variable and based entirely on experience—both personal and professional—and minimally on education. No providers were completely comfortable with their knowledge base about IM, and increased knowledge was desired by all participants. Many providers expressed that they tended to discuss these treatments at the wrong times, such as during a hospitalization for

| Barriers | Descriptive Quote |
|----------|-------------------|
| Lack of process | Well, in short, unfortunately there isn’t a great process for these things, and it’s very dependent on what and who is available at the time. —Nurse practitioner (NP) |
| Lack of resources (providers to do the treatments) | And then also having enough people that are certified and trained to do these things like Reiki and acupuncture. It’d be nice if we had access to them, but I don’t know how many people are truly certified to do these things. —Physician |
| Buy-in | I think the big thing for me is if you can get the patients/families to buy in to it. So I think part of that is in sort of the presentation of how you talk about these strategies as being helpful. I’m very careful never to say that this is going to take all your pain away, because that is unrealistic and sets up a bad expectation. —Psychologist |
| Cost | I mean some of our patients can’t afford to park here! The last thing that they are thinking about is going and having a massage! —Nurse |
| Lack of provider comfort/training | I’m not so familiar with it [Reiki] so I don’t discuss it that often. I don’t like talking about things I don’t know anything about. —NP |
| Lack of time | I think that...um, we have a limited about of time per patient, and so we hit them with the things that are tried and true, and mainstream, and you know, if you have an extra 5 min, you may bring it up, or if the family brings it up, you may talk about it. But otherwise, you usually don’t have enough time to talk about these therapies. That’s another barrier, in terms of one of our barriers, a physician barrier. —Physician |
| Lack of evidence | There are many things which we think may be beneficial, but they have not been clearly tested in a clinical trial or some other setting. —Psychologist |
| Difficulty of teaching a skill or a new modalities during an acute pain episode | I think when you are in the midst of a crisis, we can teach the strategies, but at least anecdotally, it’s not necessarily going to be as effective as if they had been practicing all along and had trained their body to be able to respond to the cues. —Psychologist |
an acute painful episode or late in a patient’s course when disease is severe. Many providers commented that patients would benefit from teaching about IM at a younger age; however, study participants felt that this does not generally happen due to the other barriers described in Table 1.

**Creative Solutions**

Discussion about barriers and facilitators led to generation of creative solutions (Table 3) by the participants. The most common themes were related to standardizing the process for patients and families to learn about IM and providing resources to help providers in the form of educational sessions, training sessions, patient handouts, and community resource lists. Participants viewed the culture at the institution as one where people are generally open to new ideas, and this likely contributed to the generation of these creative solutions.

**DISCUSSION**

The SCD program at this institution takes a multi-disciplinary approach to patient care among providers and has a culture of openness and mutual respect that includes openness to the use of IM. As in most medical settings, there are competing interests in terms of patient care goals, research interests, and physician time. While most medical providers are open to the use of IM for their patients, medical needs and evidence-based medical interventions seem to, appropriately, take priority over a holistic approach to pain management, given the

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**Table 2 Facilitators for Use of Integrative Medicine for Patients With Sickle Cell Disease**

| Facilitators | Descriptive Quote |
|--------------|-------------------|
| Buy-in       | I think in general, I tend to have the most success, and that usually means the most buy-in from the kids, when we’re talking about diaphragmatic breathing and guided imagery or distraction. But again, I think a lot of it really depends on the person. —Psychologist |
| Culture of collaboration | Children’s has this . . . everybody’s forward thinking. Nobody’s really closed off. —Nurse |
| Starting early and reinforcing often | I think that we have to start early, like during those first pain crises at introducing it [IM], because I think once kids already have a chronic pain phenotype, then I think it’s really hard to reverse that, and you have to do these drastic measures like pain rehab programs and stuff. —Physician |
| Research documenting efficacy | I also come from a training place where we are all about evidence based medicine, so really CBT and relaxation strategies are the ones that I tend to gravitate the most towards, largely because that is where the largest evidence base is right now. That being said I know there is a lot of emerging evidence about massage, and there is certainly evidence of for acupuncture as well. —Psychologist |

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**Table 3 Creative Solutions to Promote Integrative Medicine for Patients With Sickle Cell Disease**

| Creative Solution | Barrier Addressed/Facilitator Utilized | Descriptive Quotes |
|-------------------|--------------------------------------|-------------------|
| Develop protocols | • Lack of process  
• Lack of provider comfort/training  
• Lack of time  
• Difficulty in teaching a skill or a new modalities during an acute pain episode  
• Buy-in  
• Starting early and reinforcing often | I think we almost need to create like a clinic for it. Almost like the infant clinic. And I think if we were to do something like a CAM clinic, that it would probably be someplace that providers would send their patients as part of their routine sickle cell care. —Nurse  
So I think some kind of organizational structure would be helpful, you know if we say that, even if it’s just like one visit every time a kid turns 6, then they see a psychologist [to learn relaxation strategies]. —Psychologist |
| Parent/patient education sessions and handouts | • Buy-in  
• Lack of time  
• Starting early and reinforcing often | I think they [SCD patients/families] would be [receptive to IM], I think when we raise it, most of them, I find, are receptive. But, it’s just kind of a culture of how we teach them about fevers, and penicillin, and managing pain, and how we talk about motrin, oxycodone and all those medicines, we should just frame it in the same way, so it could become part of the treatment plan. Not forcing it, but just making sure they know it’s there, because I find that most of the time, they are receptive to it. —NP |
| List of community CAM providers | • Lack of time  
• Lack of provider comfort/training | I think if we had kind of a go to of resources that were in the hospital, and in the community, it would be a lot easier to talk to families, and to be able to give them something. It’s very hard to say, well you should try this, but I don’t know where you can go, or how much it will cost. —NP |
| Yoga for inpatients | • Buy-in  
• Starting early and reinforcing often | I think it would be really neat if our hospital could have like a yoga program or something for our patients, especially the inpatients. —NP |
| Grant funding to support IM | • Culture of collaboration  
• Cost  
• Lack of time  
• Lack of evidence | A grant funded study that will provide a person that can come in and train, and do 1 or 2 therapies with an endpoint of effectiveness . . . because of the time commitment and lack of reimbursement, you would need it to be on a grant funded study that someone is being paid for their time to do the training and do actually do whatever intervention. —Physician |
| Increase training | • Lack of provider comfort/training  
• Lack of evidence | I would love to be able to know how to teach guided imagery, I would love to be able to sit in on a session by one of our psychologists when they do that. —Physician |

Abbreviations: CAM, complementary and alternative medicine; IM, integrative medicine; NP, nurse practitioner; SCD, sickle cell disease.
limited time and resources. Few standard processes for integration of IM coupled with the wide variability in provider comfort and knowledge of the different modalities make available options for individual patients dependent on provider interest. Patient “buy-in” was identified as critical to the successful integration of IM therapies; however, the current approach does not facilitate this buy-in. If patients first learn about IM therapies late in adolescence or when their pain is most severe, then they may be more skeptical than if they were introduced earlier. Providers need additional education about IM therapies; the lack of evidence to support the use of these treatments is a barrier most often noted among physicians. Psychosocial providers alternatively emphasized the available evidence documenting the benefit of certain IM therapies in children with pain syndromes (though not necessarily SCD patients). Teaching strategies should include presentation of this evidence to medical providers. Additionally, many providers expressed interest in learning how to teach families to do guided imagery and relaxation. All psychosocial providers expressed that they would be willing to teach this in a workshop format to interested physicians, nurses, and NPs. This seems to be an easy and inexpensive intervention that could be implemented. Finally, more work is needed to identify community resources and community providers that could support making IM available for patients with SCD.

This study has several important limitations. The most relevant limitation is the fact that study team members provide care to the SCD patients and have their own personal ideas about the use of IM for treatment of SCD-related pain. The study team’s method of practice is well known to the study participants who know that we support IM; this may create the opportunity for social desirability bias. Furthermore, this analysis is based on the first 10 respondents to our initial request for study volunteers; they were likely to be more interested in IM than nonresponders. Therefore this analysis may not reflect the full picture of providers at our institution. Additionally, our preconceptions may bias the selection of data that “stand out,” which could therefore affect the study results. The study team was careful to keep an open mind and critically evaluate all responses to interview questions. The sampling strategy helps to address
this threat to validity by using multiple providers across different disciplines to validate the responses to interview questions. This allowed us to use triangulation to reduce the risk of chance association and systematic biases, thereby reducing threats to validity.22

To our knowledge, this is the first study to assess the attitudes of SCD providers towards the integration of IM therapies for patients with SCD. As more evidence emerges about the efficacy of IM in this population, it is important to understand barriers that may exist from the provider perspective toward the successful integration of these treatments. Additional investigation into patient experience and beliefs about IM are needed to better understand further barriers or facilitators for using IM.

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