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Shared Decision Making in Complementary and Alternative Medicine Therapies

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Abstract

Objective—This paper provides a structured approach for pediatricians responding to requests from patients and their families about the complementary medicine treatment options.

Methods—Using a case-based narrative review approach, the authors outline practical strategies for addressing conflict, uncertainty, and challenges in explaining alternative health paradigms in routine pediatric care. Reflections are drawn from the clinical experience of the authors, the literature, and recent high-profile cases in the United States.

Results—The discussion of common case-based scenarios illustrates a general guide for approaching conversations about complementary medicine in the care of the pediatric patient that is responsive to evidence and informed by patient and family values.

Conclusions—The principles of shared decision making can guide constructive conversations in this area in an effort to facilitate improved satisfaction for patient, family, and provider.

Practice Implications—Discussions of complementary and alternative medicine in pediatrics pose a specific challenge with regard to patient and/or family preferences and the duty of the provider to advocate for the safety of the child. The proposed structured approach is useful in navigating these important conversations.

Keywords

Complementary and alternative medicine; pediatrics; healthcare communication; shared decision making

In Minnesota, thirteen-year-old Daniel was ill and felt even worse after going to see his doctor. The experts said he could die without treatment for Non-Hodgkin's Lymphoma, but Daniel and his mother opted to pursue a seemingly natural healing therapy: an American Indian tradition called Nemenhah, for which the scientific community has little evidence of benefit. After an emotional battle with the Brown County District Court and a multi-state

search for Daniel, chemotherapy was mandated and Daniel's parents were allowed to retain custody of their son, promising to adhere to the medical treatments recommended by Daniel's oncology team¹.

High profile cases like these illustrate the poignant interpersonal and legal challenges that arise when pediatric patients and families choose alternative therapies while rejecting conventional medical care for children. When the stakes are high, such as in cancer therapy, conflicting opinions can pose serious challenges for conventionally trained healthcare teams. Additionally, many clinician identify a lack of knowledge regarding alternative therapies and feel poorly equipped to discuss these issues with families². Nevertheless, treatment decisions that utilize the principles of shared decision making (SDM) – collaborative deliberations informed by the best available evidence while accounting for patient values – remain the ideal in these complex situations³.

Unlike the above example, the circumstances in which most pediatricians encounter complementary and alternative medicine (CAM) are thankfully less dramatic, but no less important. Recent data suggests that 1 in 9 children use some form of CAM^{4, 5}. In most of these cases patients and families may not be fleeing conventional care, but rather are seeking ways to blend a variety of conventional and alternative health approaches, with the common goal of maximizing health, mitigating illness, and preventing disease. Thankfully, the American Academy of Pediatrics (AAP) recently published a report describing many common CAM therapies encountered by pediatricians⁶. Implicit in this report's brief concluding suggestions for discussing CAM was a commitment to SDM, advising physicians to “work together with parents as a team to consider and evaluate all appropriate treatments”.

Despite the challenging nature of such discussions, we argue and develop in further detail that discussions of all treatment options in a collaborative manner can enable patients, families, and providers to strengthen the therapeutic alliance and encourage an active role in improving health, while avoiding conflict. SDM is an ethical and practical ideal of clinical conversations between patient, family, and provider that outlines benefits and risks of each available treatment option, solicits preferences of the patient/family, and deliberates about a practical solution^{7, 8}. SDM has been proposed as the ideal model for the clinical relationship for choices considered to be “preference-sensitive,” where the evidence of benefit is uncertain and there is a large role for patient values⁹. The integration of CAM into discussions in pediatric care is a prime example of circumstances in which SDM should be employed in order to address the motivation and inclinations of the patient and family, while teaching children and adolescents about their active role in promoting health. How to best engage patients and families in constructive conversations about CAM treatment remains unclear¹⁰. Through use of a more participatory model, patients and families can increase their understanding of health care decisions and over time exercise discernment about alternative and complementary options.

Here, we present a structured approach for responding to inquiries about CAM from the perspective of the pediatrician committed to SDM. The subsequent cases illustrate a range of scenarios in which CAM may enter the healthcare dialogue and as well as to highlight specific themes from the structured approach and how they can ultimately be resolved.

Structured Approach

To bring further specificity to a very difficult and vague process, we propose the following structured approach in guiding pediatricians' discussions with patients and families regarding CAM therapies [figure 1]. Key considerations in this model include patient and family preferences, evidence of safety and efficacy of the CAM therapy, and trade-offs

associated with any available conventional treatment options. In addition, this approach accounts for important mitigating practical concerns including time, finances, and CAM variability, while maintaining the emphasis on the underlying concerns of the patient and family. As children become more able to articulate their concerns and preferences, they are encouraged to take a more active role in this dialogue. Below we briefly highlight the key features of the proposed approach.

Assessing patient/family values, preferences and concerns

A sound starting point for deliberation about alternative therapies will almost always require a thorough understanding of the request. Thus, we suggest that clinicians seek to understand the motivation in relation to the CAM treatment and refrain from dismissing out of hand a request for a non-standard or unfamiliar therapy. This can help to foster a sense of trust and responsiveness with both the child and family. Through an exploration of patient experience, the physician will learn about the potential for side effects and lack of fit between alternative and conventional treatments and the patient's lifestyle. Additionally, the physician can gain insight into the level of understanding of the patient/family regarding treatment options. Adolescents in particular often appreciate feeling understood in this context and such clinical encounters help to cultivate the young person's relationship with the provider. This process sets the relational tone for deliberating about the available evidence.

Evidence of Safety

Once the preferences and values of the patient and family are elucidated, discussing the available evidence, focusing first on safety, is the next logical step. Physicians' duties to present and appraise available evidence of safety and efficacy are no less important for CAM treatments, which carry complexities such as lack of standardization, contamination, herb-drug interactions, and adverse events associated with some therapies¹¹⁻¹³. Until recently, high-quality evidence from rigorous research in CAM was the exception¹⁴. While the quality of that evidence is improving, current evidence of safety may be in the form of case reports or observational studies, which are admittedly less convincing. Consequently, conclusions about safety must be tempered by this reality. Nevertheless, ways of dealing with weak evidence have been proposed¹⁵, and increasingly, resources exist to help physicians translate that evidence into clinical conversations such as Natural Medicines, Natural Standard, Consumer Labs, and nccam.nih.gov. Ideally, tools such as age-specific decision aids could eventually be available to illustrate patient options while transparently presenting evidence to children and parents, which would help facilitate SDM about CAM.

As an advocate of the child and based on the ethical principle of nonmaleficence, the pediatrician is obligated to counsel families about any known risks associated with a particular CAM treatment. If the CAM therapy is deemed to be unsafe for use in children, the physician has an obligation to discourage its use and thoroughly explain the detrimental effects associated with the treatment. This step is especially important in pediatrics to ensure that the child's welfare is being prioritized. While the clinician's opinion regarding an inappropriate option should be firm, other safe treatments can be proposed in the place of the originally requested therapy. This re-focusing is a crucial step in helping to empower the child and family towards health, despite a negative response to the requested CAM therapy.

Opportunity costs associated with conventional treatment options

If the CAM treatment has no known evidence of serious harm, the conversation about use of the therapy can proceed to focus on how the treatment fits with the available conventional treatments. Are there any conventional therapies that should also be used to treat the child? Can the conventional and alternative therapies be used in conjunction with each other? A clear presentation of the available and safe treatment options, the evidence

supporting them, and any reasonable combinations of the treatments will help engage the patient and family as significant stakeholders in the decision making process. If the conventional treatment has known efficacy and the child would likely suffer harm if the conventional treatment were postponed or refused, a physician can recommend against delaying conventional care. It may be possible to use a CAM treatment cooperatively with the conventional treatment, to avoid treatment delays. If such accommodations cannot be reasonably arranged, the physician must advocate for the welfare of the child and discourage the use of the CAM treatment in favor of a conventional treatment with known efficacy. Particularly in pediatrics, affirming a “safety first” posture toward the integration of alternative therapies with available conventional options is crucial in maintaining the professional obligation to “do no harm” while respecting family values and preferences.

Evidence of efficacy

Once safety and the relationship with conventional options have been entertained, examine evidence of efficacy of the CAM treatment in children. Especially if coordination of a conventional treatment with the CAM treatment is possible, or if there is no known efficacious conventional treatment, then one can reasonably accept weaker evidence of benefit. Conversely, therapies which have direct evidence of benefit may be recommended readily if they are appropriate for the child's situation. More often, many CAM treatments have been found to be equal to placebo in benefit, which prompts the provider to consider the pros and cons of placebo efficacy, as well as the ethics of doing so in the pediatric setting¹⁶. If a treatment can be confirmed to be non-toxic, and a possibility of benefit exists for the child, those potential benefits can be weighed against other costs of the therapy in an open conversation.

Some might argue that without definitive evidence of efficacy, any therapy including alternative medicine is unwarranted. Such a standard suggests that we need a high burden of proof in order to justify recommending a treatment for any child. While this is a respectable position, we argue that such a standard (which if applied consistently would preclude most current pediatric interventions) sets the bar too high for evidentiary standards and would needlessly limit options that are worth trying. Especially in situations where the stakes are low, the treatment is cheap, safe, and readily available, not having definitive evidence of efficacy in children is arguably of secondary importance.

Other key mitigating issues: cost, conflict and care context

In circumstances where there are no safety concerns but the evidence of efficacy for the CAM treatment is uncertain, deliberations using an SDM approach might focus on other key mitigating issues, including costs to the family's finances, time, and the child's energy. Here, the family preferences often play a large role in whether or not pursue the CAM treatment. If there is a strong preference from the child toward trying a CAM treatment, a discussion of practical considerations might lead to an agreement to try the requested therapy. However, if the child and/or family was merely curious about the CAM treatment, a discussion of all the possible options might identify other avenues.

Some conflicts are harder to unravel. Family members may persist in their resolution to pursue unsafe treatments. Pediatricians may fail to establish a bond of trust and open communication with the family. Particularly in pediatrics, the physician must consider the risk to the child that comes from delaying conventional care and might be obligated to take action to prevent harm. These decisions should not be made lightly and must consider the longitudinal value of the therapeutic relationship with the child and family. Physicians must clearly communicate a recommendation from the medical community that represents the balance of risks and benefits to the degree that they are known and promote the wellbeing of

the child. If done in a way that allows the child and family to feel respected and their preferences recognized, these difficult conversations can build trust in the therapeutic relationship, promoting honest communication and continued care across time, and only rarely conclude in conflict.

Other contextual considerations affect these important discussions as well. Unfortunately, busy, overbooked clinics with phone messages about the appropriateness of therapies are not ideal scenarios in which to promote SDM. A scheduled appointment devoted to a specific request improves the ability to more fully explore these issues empathetically. Even without specific knowledge of the CAM treatment, the provider can help guide a patient and family through a discussion of all treatment options in a collaborative manner which can enable patients, families, and providers to strengthen the therapeutic alliance and encourage an active role in improving health, while avoiding conflict.

Below, we apply the proposed framework to three case scenarios that are commonly faced in pediatrics.

Case Analyses

Case 1

Noah is a 5-month-old male infant whose mother, Susan, seeks recommendation regarding the use of the herbal remedy Fenugreek, which her friend says can stimulate lactation. She wants to make sure that it is safe to use when breastfeeding. The physician is unfamiliar with this supplement, and is reluctant to recommend it after a quick search of the medical literature yields a description of common side effects and little information regarding its efficacy.

Discussion—Patients often look to the medical community for the verdict on whether or not to buy in to the claims made by manufacturers and proprietors of herbal supplements. In this case, the mother hopes her pediatrician has advice on whether or not to trust anecdotal evidence from a friend. She understands that the purported benefits of the supplement align with her goals of providing support for her nursing child. The clinician is skeptical of the effects, due to a perceived or real lack of medical literature on the subject, and hesitates to promote a supplement which costs the patient money but may offer little prospect of benefit.

A respectful inquiry into the mother's thought process may reveal that she wants to better care for her child's health and her own health, a goal shared by the physician. By first gaining greater insight into the mother's beliefs and values, the provider might be able to constructively refocus the conversation from a binary conflict over a specific treatment into a discussion that can uncover unaddressed concerns, working to create a mutually agreeable solution.

Some herbal supplements are detrimental to health and clearly should be avoided, particularly in breastfeeding women. It is the physician's duty to clearly warn against these adverse effects, as a matter of nonmaleficence (the ethical obligation to not promote harm). More frequently however, alternative therapies have an uncertain safety profile. In the case of Fenugreek, a common culinary spice, Traditional Chinese Medicine has promoted its use as a galactagogue, but commonly reported side effects include allergy symptoms such as rhinitis and wheezing, and mild gastrointestinal upset¹⁷. In this case, the common side effects merit at minimum advice to the mother about symptoms associated with use of fenugreek, if not discouragement of use. Depending on the reputability of the product's manufacturing, there may be legitimate concerns about the purity of the formulation that could increase the physician's opinion against recommending its use.

At this point, the clinical decision is clarified considerably, but the physician's job is not done. Because the physician took time to recognize the underlying apprehension on the part of the mother, the opportunity exists to engage collaboratively in deliberating about how best to meet the perceived needs of the child without exposing him to harm. This effectively and constructively reframes the mother's concerns and allows affirmation of the mother's desire for the baby's optimal wellbeing. This could go a long way toward achieving their shared goal of improved health, regardless of whether the specific herb in question is agreed upon. The primary determinants of the clinician's opinion in this case relates to the safety profile of the requested therapy and the value structure of the mother. If the herbal product is deemed safe, there is latitude to accommodate a trial of the product for a specified and limited time. If the product has serious safety concerns, such a trial would not be advisable from the medical prospective, even if using the product was consistent with deeply held beliefs, due to the potential exposure of the mother and baby to risk.

Case 2

Christina is a 7-year-old female with an acute onset of sore throat. Her Rapid Strep Antigen test comes back positive. As the physician writes the prescription for antibiotics, her parents state that it is important to them to get a remedy from a yerbero (a traditional medicine man) in order to cure their daughter prior to taking any conventional medicine. The physician knows that antibiotics should be initiated within 9 days of symptom onset for a Group A Strep infection to prevent potential complications and feels frustrated that the family might chose to delay treatment in order to consult their an alternative healer.

Discussion—Strep throat is a common diagnosis in pediatric practice. While it is rarely fatal, pharyngitis from Group A Strep can have lasting effects if it is not properly treated. Aware of an available, low-cost, effective antibiotic treatment, the pediatrician may be understandably worried about the family's preference to delay the start of medication. This case illustrates a poignant tension between respect for autonomy of the patient/family and an obligation of the physician to advocate for the welfare of the child. Is a peaceful patient-centered resolution to this apparent conflict possible?

The collaborative process proposed by SDM can guide a provider in this situation and help to reduce conflict. As discussed above, the physician can begin with a non-judgmental inquiry into the beliefs and culture of the patient/family, seeking to understand their prioritization of one health system over another, as well as any cultural stigma that might be associated with forgoing a traditional treatment. It is important to acknowledge in these types of situations that conventional medicine does not hold all of the answers to healing, and that there are risks associated with many medications. By building a foundation of enhanced understanding and communication, the physician can begin to mitigate the specter of animosity, which might hinder open dialogue.

Safety is a tricky issue to navigate in this case due to the unpredictability of the treatment that the child might receive from the yerbero. A brief internet search would show that most commonly a yerbero uses herbs and plants in creating a treatment. What are these herbs and are they associated with any toxicity or drug interactions? This question represents a large and critical unknown in this case. The physician will need to know this information in order to assure that the child is not harmed, and that treatment by the yerbero would not interact negatively with the conventional therapy known to be helpful.

A discussion of opportunity costs will also be central to the process of SDM in the resolution of this case. While taking care to acknowledge the importance of belief and culture, it is important that the physician explain to the family the known progression of the

disease and the potential consequences of postponed antibiotic therapy. Ideally, with a better appreciation of the disease, the family might choose to hasten their pursuit of cultural healing options so that any prescription medication can be started in an appropriate amount of time to diminish the possibility of developing rheumatic fever. On the other hand, the physician should seek to discern if there is a psychological burden associated with not seeing a traditional healer that might negatively impact the child. Such an approach demonstrates respect for the family's traditions, focuses on harm reduction, and also avoids making potential ideological differences the central focus of the therapeutic relationship.

Case 3

Erin is a 14-year-old female with chronic back pain who has been worked up by neurologist and physiatrist without a definitive etiology. She and her parents are frustrated by the amount of time and money they've spent on medications and physical therapy without much symptom reduction. At this visit to the pediatrician, Erin mentions that she would like to try acupuncture to reduce her pain. Her parents express concern that their insurance might not cover these treatments and ask if the pediatrician will write a letter to the insurance company to persuade them to pay for acupuncture. The pediatrician's search of the literature suggests that acupuncture has been shown to decrease back pain, but is often no better than sham acupuncture in randomized, placebo- controlled trials.

Discussion—Chronic pain syndromes require special consideration in the pediatric setting. While all parties in this case hopefully acknowledge the long-term nature of this condition, they understandably hope to see improvement and observe benefit from the prescribed course of treatment, into which they invest money and time. Aware of her increasing autonomy, Erin asserts her preference in determining her treatment strategy. Her parents express their desire to help their daughter, as well as their practical concern for the financial implications of beginning a course of treatments for which they might be required to pay out-of-pocket. In sharing the evidence, the physician must decide if a treatment merits an endorsement from a medical expert. On the one hand, equivalence to placebo has been the definition of inefficacy in recent decades¹⁸. Yet witnessed placebo effects may give real relief notwithstanding their mechanism.

A solid foundation from which to begin is outlined in our proposed approach. Exploring the patient's and/or family's concerns about the current and/or previous treatments may help inform the provider about the patient's present state and shed light on areas that may be improved.

Thereafter, the physician should review the evidence of safety for acupuncture. While the reported side effects of acupuncture are generally minor¹⁹, there are other important factors to consider and disclose such as standardization among practitioners. Five acupuncturists might offer five completely different treatment plans for a patient presenting with the same complaint, which increases the complexity of researching the effects of these techniques. Some practitioners may mix and match techniques with varying degrees of expertise. This variation amplifies the hesitation on the part of the physician to give the family a recommendation for such therapy because the physician cannot guarantee the type of treatment the patient will receive.

A careful discussion of acupuncture should include the disclosure of the research evidence and any concerns the physician might have about safety or the integration of conventional care with alternative therapies. If the physician believes that the patient would benefit from continued physical therapy, he/she should ask the family if they can support both acupuncture along with physical therapy appointments on a regular basis with regard to

limits on time and/or finances. The creation of timelines for a trial of therapy can be a helpful tool in helping patients and families set realistic expectations and maintain regular contact with the care team.

In cases of refractory, chronic conditions, the addition of alternative therapies can be a reasonable option even if the evidence of efficacy is uncertain, particularly when a patient displays a strong belief that such a treatment will be beneficial. Returning to the question of placebo efficacy, the potential for pain reduction represents a significant benefit to such patients, regardless of mechanism. In this case, for a patient who has tried most or all other options, who presents desiring to try an alternative therapy with a favorable safety profile, the physician would be justified in recommending the therapy. There are times when accepting a lower standard of efficacy such as equivalence to placebo (but superior to no treatment) is warranted, so long as the financial and logistical burdens are not excessive and no other therapies exist that would be more beneficial.

Conclusions

The incorporation of SDM principles in discussions of CAM in the pediatric setting can facilitate thorough and fulfilling clinical encounters between patient, family, and provider even in the constraints of a busy practice. This approach emphasizes integration of the available information about the therapy with the patient and family values, helping the physician to guide constructive conversations about risks, benefits, and recommendations. Through the use of the proposed approach, pediatricians can feel empowered to consistently evaluate a patient or family's request for CAM in a way that engages all participants and aims to enrich the therapeutic alliance through trust and open communication.

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Figure 1.

A structured approach for pediatricians wishing to use shared decision making when responding to a request for complementary and alternative medicine (CAM).