

AMERICAN ACADEMY OF PEDIATRICS

Committee on Children With Disabilities

Counseling Families Who Choose Complementary and Alternative Medicine for Their Child With Chronic Illness or Disability

ABSTRACT. The use of complementary and alternative medicine (CAM) to treat chronic illness or disability is increasing in the United States. This is especially evident among children with autism and related disorders. It may be challenging to the practicing pediatrician to distinguish among accepted biomedical treatments, unproven therapies, and alternative therapies. Moreover, there are no published guidelines regarding the use of CAM in the care of children with chronic illness or disability. To best serve the interests of children, it is important to maintain a scientific perspective, to provide balanced advice about therapeutic options, to guard against bias, and to establish and maintain a trusting relationship with families. This statement provides information and guidance for pediatricians when counseling families about CAM.

ABBREVIATION. CAM, complementary and alternative medicine.

STATEMENT OF THE PROBLEM

The use of complementary and alternative medicine (CAM) is increasing in Western countries. Indeed, more than one third of the adults in the United States have used CAM in recent years.^{1,2} Pediatric use of CAM is especially likely among children with chronic illness or disability. Up to 50% of children with autism in the United States probably are using some form of CAM.³ In many instances, the physician providing medical care is unaware of the concurrent use of CAM. Increasingly, pediatricians providing care for children with chronic illness or disability are discussing CAM with families or are asked to prescribe such treatments. Pediatricians' expertise in biomedicine may not adequately prepare them for discussion of CAM.

BACKGROUND INFORMATION AND DEFINITIONAL ISSUES

CAM has been defined as "a broad domain of healing resources that encompasses all health systems, modalities, and practices and their accompanying theories and beliefs, other than those intrinsic to the politically dominant health system of a particular society or culture in a given historic period."⁴ An enormous array of unconventional therapies may be used as alternative therapies (instead of conven-

tional treatments) or as complementary therapies (in addition to conventional treatments) (see Fig 1).

Currently, courses on CAM approaches are offered in the majority of US medical schools.⁵ The US government established the Office of Alternative Medicine (now the National Center for Complementary and Alternative Medicine) in the National Institutes of Health to carry out scientific study of CAM.⁶

Biomedicine is based on laws of science and the rigorous applications of the scientific method. It may aptly be called scientific medicine or evidence-based medicine. Disease is explained by pathophysiologic processes, and treatments are designed to affect these processes. The term *biopsychosocial medicine* has long been used to describe a biomedical model that recognizes the importance of psychosocial factors.⁷ Biomedical treatments are based on accumulated evidence of effectiveness from peer-reviewed scientific research. There is a hierarchy of research evidence, at the top of which is the controlled clinical trial. Many accepted biomedical treatments lack evidence of effectiveness from controlled clinical trials (eg, the use of physical therapy in the care of the premature infant). Unproven therapies also may be based on pathophysiology and limited research, but they lack accepted standards of proven effectiveness (eg, the use of immunoglobulins in the treatment of autism).⁸ Alternative therapies are based on a variety of non-biomedical beliefs and usually have not been subjected to clinical research. Most are supported by anecdotal evidence, but some alternative therapies have proven effectiveness. For example, preliminary studies of acupuncture in addiction treatment show positive results.⁹ In time, such proven therapies may come into wider use and lose their "alternative" status.

Biopsychosocial medicine and CAM have at least one thing in common: both recognize that the relationship between physician-healer and patient is integral to the success of treatments offered. This is part of the age-old "art" of medicine and is a basis of the placebo response.¹⁰ The emphasis of biomedicine on pathophysiology and on technical outcomes has reinforced the perception among some families that physicians undervalue their relationships with their patients. The failure of biomedicine to recognize and respond adequately to individual differences among patients is one reason families turn elsewhere and has contributed to the increasing use of CAM.

The distinctions among unproven therapies, CAM, and biomedicine may become especially blurred in the care of children with chronic illness or disability.

The recommendations in this statement do not indicate an exclusive course of treatment or serve as a standard of medical care. Variations, taking into account individual circumstances, may be appropriate.

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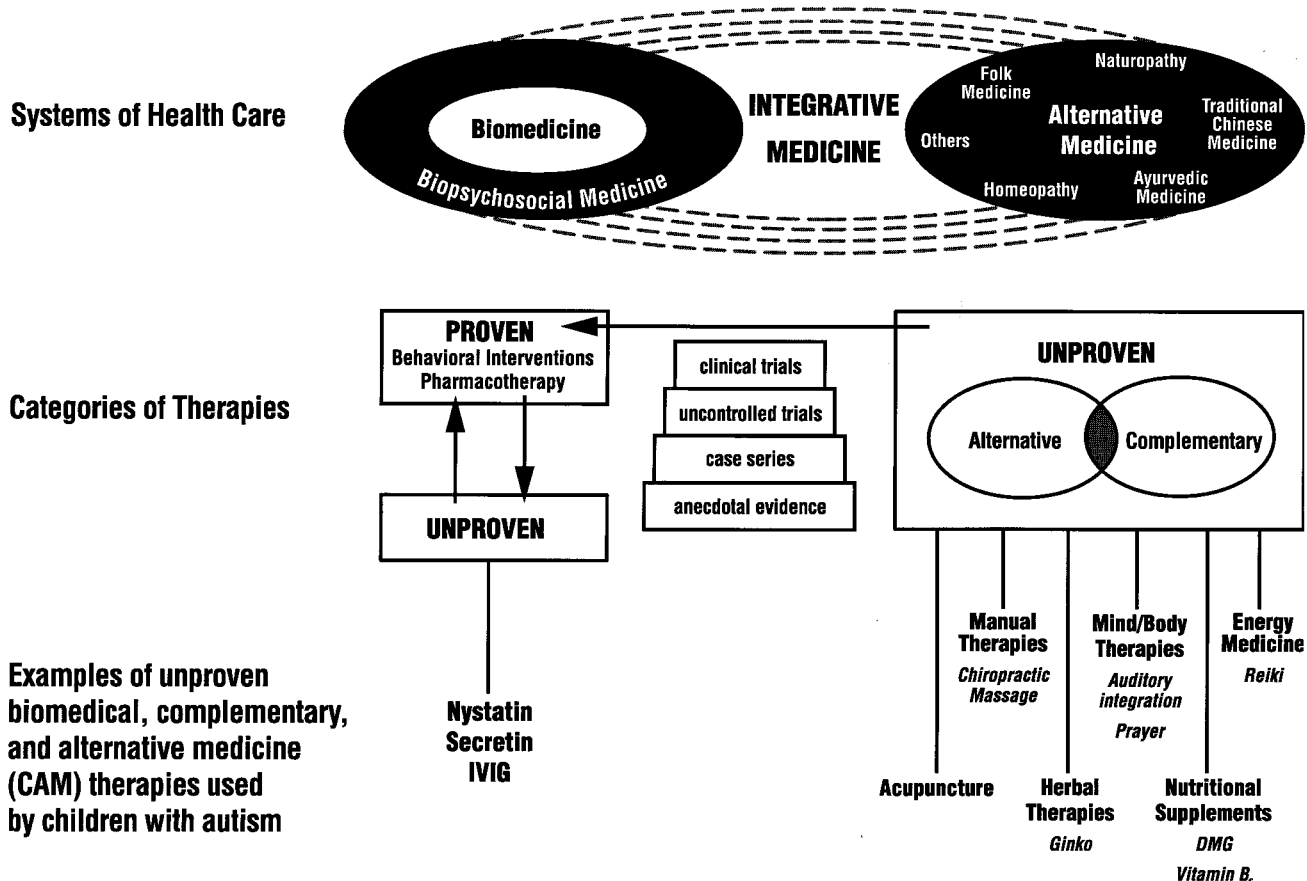


Fig 1. Biopsychosocial medicine and alternative medicine are broad systems of health care that encompass theories, practices, and therapies. Integrative medicine is a term loosely used to describe these systems used in combination. Therapies (whether biomedical, complementary, or alternative) are considered proven or unproven based on a hierarchy of evidence.

Some conventional biomedical therapies lack proof of effectiveness, and some unproven and alternative therapies may in time prove effective. Also, some alternative therapies conceivably may have placebo effects, which confer additional therapeutic gain and enhanced quality of life. These factors may present significant challenges to the health care professional. Moreover, there are no published clinical guidelines regarding the use of CAM in the care of children with chronic illness or disability.¹¹

WHY PARENTS OF CHILDREN WITH CHRONIC ILLNESS OR DISABILITY CHOOSE CAM

Parental questioning of a child's diagnosis, treatment, and prognosis reflects a normal process of adjustment to the permanence or chronicity of the condition and the desire to ensure the best possible outcome for their child. Many parents become frustrated with biomedical therapies because of complexity, discomfort, bewildering technology, or uncertainty of cure. Indeed, for some conditions, biomedicine has little or nothing to offer. Also, families may be frustrated because they have not been sufficiently involved in the development of a care plan. The media, condition-specific publications, and parent-to-parent contacts provide essential opportunities for families to learn about resources, including CAM. Furthermore, the Internet has dramatically increased exposure of families to sophisticated market-

ing, testimonials, and unproven claims. Some parents are attracted to simple explanations of causality, some by an approach perceived to be more "natural." Many try a succession of alternative therapies, believing that any approach that does no harm is worth a trial. For almost all, CAM approaches represent an attempt to gain a sense of control over their child's chronic illness or disability and to improve quality of life.

BALANCING FAMILY-CENTERED CARE WITH THE ETHICAL RESPONSIBILITY OF THE PEDIATRICIAN

The "medical home" concept emphasizes that care should be compassionate and family-centered. Mutual participation in decision making and informed consent are essential elements of respectful care.¹² Decisions and plans should be made through a process of collaborative decision making in which the family receives complete and unbiased information needed to understand and make informed decisions. The quality of the relationship between the health care professional and patient with chronic illness has been shown clearly to affect outcomes.¹³ Honest and supportive relationships with health care professionals can help parents cope¹⁴ and promote the child's independence.¹⁵ Such relationships are strengthened when health care professionals understand the perspectives of the family, provide care with flexibility, and attempt to meet the family's needs and expecta-

tions. Clearly, it is optimal for children with chronic illness or disability to receive health care in a setting that is family-centered. At the same time, pediatricians have an ethical responsibility to guard the welfare of children by ensuring that any treatment they endorse is "in accordance with science and proven experience."^{16,17} Dilemmas may arise when families ask their pediatrician to endorse or to provide a therapy that is considered by the pediatrician not to be in the best interests of the child. There may be evidence of the possibility of direct harm, unknown risks, or concerns about indirect harm to the child. The pediatrician is in a position to balance a commitment to family-centered care with the ethical responsibility to guard the welfare of children.^{18,19}

SUMMARY/CONCLUSION

The use of CAM approaches in the United States is increasing, especially among children with chronic illness or disability. Distinctions among unproven therapies, CAM, and biomedicine may become blurred, presenting special challenges to the pediatrician. To best serve the interests of children, it is important to provide balanced advice about therapeutic options, to guard against bias, and to establish and maintain a trusting relationship with families. Although the focus of this statement is chronic illness or disability, the recommendations that follow also may apply to the use of alternative medicine in other pediatric domains.

RECOMMENDATIONS FOR PEDIATRICIANS WHO DISCUSS ALTERNATIVE, COMPLEMENTARY, AND UNPROVEN THERAPIES WITH FAMILIES

1. Seek information for yourself and be prepared to share it with families.

Families are likely to be appreciative of information you have obtained through literature searches. Reviews of CAM discuss currently popular alternative approaches and their attendant risks.^{3,20-22} Also, Appendix I shows several Web sites that may be useful resources.

2. Evaluate the scientific merits of specific therapeutic approaches.

Critical evaluation of claims of effectiveness requires training in the scientific method and an understanding of processes of disease. This training is equally important for evaluating conventional biomedical treatments and alternative therapies. Many CAM approaches are based on inconsistent or implausible biomedical explanations, and claims of effectiveness rest on anecdotal information and testimonials. The pediatrician can be uniquely helpful to parents seeking an assessment of the merits of specific therapies by evaluating such therapies and providing guidance.

3. Identify risks or potential harmful effects.

Alternative therapies may be directly harmful by causing direct toxic effects, compromising adequate nutrition, interrupting beneficial medications or therapies, or postponing biomedical therapies of proven effectiveness. Indirect harm may be caused by the financial burden of the alterna-

tive therapy, other unanticipated costs (eg, the time investment required to administer the therapy), and feelings of guilt associated with inability to adhere to rigorous treatment demands. If a child receiving alternative therapy is at direct or indirect risk of harm, the pediatrician should advise against the therapy. In some circumstances, it may be necessary for the pediatrician to seek an ethics consultation or to refer to child welfare agencies. If there is no risk of direct or indirect harm, a pediatrician should be neutral.

4. Provide families with information on a range of treatment options (avoid therapeutic nihilism).

Although effective treatments to cure the underlying condition or restore function may be lacking, there may be adjunctive treatments to improve quality of life, address specific concerns of the child or family, or modify environmental conditions that may be causing additional problems. Consultation with pediatric specialists may suggest therapeutic options. Discussion of a range of treatment options may avert feelings of frustration and powerlessness that drive families to alternative sources of care.

5. Educate families to evaluate information about all treatment approaches.

Families should be informed about placebo effects and the need for controlled studies. The pediatrician should explain that anecdotal and testimonial evidence is very weak. Families also should be advised to be vigilant for exaggerated claims of cure, especially if such claims are for treatments requiring intense commitment of time, energy, and money on the part of the family.

6. Avoid dismissal of CAM in ways that communicate a lack of sensitivity or concern for the family's perspective.

Some alternative therapies considered by families may warrant independent review and evaluation of scientific merit by the pediatrician. Respectful family-centered care rests on the pediatrician's willingness to listen carefully and to acknowledge the family's concerns, priorities, and fears, including social and cultural factors that may affect their choice of therapies. If CAM is chosen against the advice of the pediatrician, he or she should continue to offer care to the child.

7. Recognize feeling threatened and guard against becoming defensive.

Families may express their opinions in ways that challenge the professional expertise of the pediatrician. They may bring to the discussion of CAM a number of biased assumptions that contribute to an atmosphere of distrust and an adversarial relationship. It may be helpful for the pediatrician to make empathic statements that acknowledge the families' deep concerns, thereby avoiding angry or defensive reactions.

8. If the CAM approach is endorsed, offer to assist in monitoring and evaluating the response.

The pediatrician can help to establish clinical outcomes and target behaviors or symptoms that can be observed and measured. Sometimes, the

pediatrician and family can agree on a time-limited trial of the proposed approach.

9. Actively listen to the family and the child with chronic illness.

The pediatrician should be aware of their concerns, their understanding of the condition, and their needs for support. Support groups and community networks can greatly enhance family comfort with the management of the chronic illness or disability.

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APPENDIX I

Helpful Resources on the Internet

1. University of Texas Center for Alternative Medicine Research, <http://www.sph.uth.tmc.edu/utcam/default.htm>
2. The National Institutes of Health Office of Alternative Medicine, <http://altmed.od.nih.gov/>
3. The National Council for Reliable Health Information, <http://www.ncahf.org>

4. The Consumer Federation of America, <http://www.quackwatch.com>

REFERENCES

1. Eisenberg DM, Kessler RC, Foster C, Norlock FE, Calkins DR, Delbanco TL. Unconventional medicine in the United States: prevalence, costs, and patterns of use. *N Engl J Med.* 1993;328:246–252
2. Eisenberg DM, Davis RB, Ettner SL, et al. Trends in alternative medicine use in the United States, 1990–1997: results of a follow-up national survey. *JAMA.* 1998;280:1569–1575
3. Nickel RE. Controversial therapies for young children with developmental disabilities. *Infants Young Child.* 1996;8:29–40
4. Panel of Definition and Description, CAM Research Methodology Conference, April 1995. Defining and describing complementary and alternative medicine. *Altern Ther Health Med.* 1997;1995:3:49–57
5. Wetzel MS, Eisenberg DM, Kaptchuk TJ. Courses involving complementary and alternative medicine at US medical schools. *JAMA.* 1998;280:784–787
6. National Center for Complementary and Alternative Medicine (NCCAM). General Information about CAM and the NCCAM. Bethesda, MD: National Institutes of Health; 2000
7. Engel GL. The clinical application of the biopsychosocial model. *Am J Psychiatr.* 1980;137:535–544
8. Gupta S, Aggarwal S, Heads C. Dysregulated immune-system in children with autism: beneficial effects of intravenous immune globulin on autistic characteristics. *Autism Developmental Disord.* 1996;26:439–452
9. Brewington V, Smith M, Lipton D. Acupuncture as a detoxification treatment: an analysis of controlled research. *J Subst Abuse Treat.* 1994;11:289–307
10. Harrington A, ed. *The Placebo Effect: An Interdisciplinary Exploration.* Cambridge, MA: Harvard University Press; 1997
11. Practice and Policy Guidelines Panel, National Institutes of Health Office of Alternative Medicine. Clinical practice guidelines in complementary and alternative medicine: an analysis of opportunities and obstacles. *Arch Fam Med.* 1997;6:149–154
12. Barber B. Compassion in medicine: toward new definitions and new institutions. *N Engl J Med.* 1976;295:939–943
13. Kaplan SH, Greenfield S, Ware JE Jr. Assessing the effects of physician-patient interactions on the outcomes of chronic disease [published correction appears in *Med Care.* 1989;27:679]. *Med Care.* 1989;27(3 suppl):S110–S127
14. Frey KS, Fewell RR, Vadasy PF. Parental adjustment and changes in child outcome among families of young handicapped children. *Top Early Child Special Education.* 1989;8:38–57
15. Gordon N. Independence for the physically disabled. *Child Care Health Dev.* 1992;18:97–105
16. Roth RB. Medicine's ethical responsibilities. In: Veatch RM, ed. *Cross Cultural Perspectives in Medical Ethics: Readings.* Boston, MA: Jones and Bartlett Publishers; 1989:150–155
17. Lynoe N. Ethical and professional aspects of the practice of alternative medicine. *Scand J Soc Med.* 1992;20:217–225
18. Eisenberg DM. Advising patients who seek alternative medical therapies. *Ann Intern Med.* 1997;127:61–69
19. Sugarman J, Burk L. Physicians' ethical obligations regarding alternative medicine. *JAMA.* 1998;280:1623–1625
20. Spigelblatt LS. Alternative medicine: should it be used by children? *Curr Probl Pediatr.* 1995;25:180–188
21. Fugh-Berman A. *Alternative Medicine: What Works.* Baltimore, MD: Williams & Wilkins; 1997
22. Kemper KJ. Separation or synthesis: a holistic approach to therapeutics. *Pediatr Rev.* 1996;17:279–283