Complementary and alternative methods in cerebral palsy

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LIST OF ABBREVIATIONS

AHRQ Agency for Healthcare Research and Quality

AST Adeli suit treatment
CAM Complementary and alternative

FES Functional electrical stimulation HBOT Hyperbaric oxygen therapy

NCCAM

National Center for Complementary and Alternative Medicine

NMES Neuromuscular electrical stimulation TES Threshold electrical stimulation

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CONFLICTS OF INTEREST

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There are no published studies specifically addressing complementary and alternative treatments in adults with cerebral palsy (CP). However, national surveys of adults with chronic disabilities document that a majority of them use such treatments, that they are willing to pay out of pocket, if necessary, and that they believe that pursuing such treatment relieves pain, reduces stress and anxiety, and leads to improved feelings of fitness and well-being. Individuals enjoy taking charge of their own health care decisions, and frequently feel more in control with these therapies than with more traditional methods. In contrast to adults, there is some information on complementary and alternative methods (CAM) in children with CP. This article discusses some of the CAM used in children that may be carried over into adulthood, as well as the pitfalls for patients and conventional physicians as they try to sort out what might be helpful and what might be harmful in this arena. Practitioners of both conventional and CAM therapies believe that exercise can be beneficial; accordingly, activities such as recreational sports, yoga, and hippotherapy may be continued from childhood into adulthood. General treatments for stress and anxiety, through such activities as yoga and meditation, though not directed at CP per se, may be more popular for adults than children. Research in this area should first identify what methods are being utilized and then subject these methods to well-designed outcome studies that take into account any associated risks.

While there are many studies of complementary and alternative methods (CAM) in children with cerebral palsy (CP), ^{1–5} there are no known studies addressing such methods in adults with CP. This does not mean that adults do not use such methods, nor does it indicate that conventional practitioners do not need to be conversant with methods that are in this domain of treatment.

The National Center for Complementary and Alternative Medicine (NCCAM) of the US National Institutes of Health (NIH) defines CAM as those approaches and products that are outside the realm of conventional medicine. NCCAM defines conventional medicine as 'medicine practiced by holders of MD (doctor of medicine) or DO (doctor of osteopathy) degrees and by allied health professionals such as physical therapists, psychologists, and registered nurses.' Such definitions can be confusing as conventional practitioners often use CAM. Further,

conventional medicine frequently utilizes methods whose benefits, though well accepted, have not been proven scientifically. Thus, many conventional methods might be considered to be in the realm of CAM on the basis of the NCCAM definition. At best, CAM is a moving target. If a commonly used CAM method becomes acceptable to a preponderance of conventional practitioners and their insurers, it may remain unproven but no longer be considered CAM. Conductive education, hippotherapy, and acupuncture have achieved this status in many locations.

This article reviews CAM in the treatment of CP, presents examples that may be germane to adults with CP, and suggests how researchers might better study these methods. For the public, and particularly for families whose members include individuals with chronic disorders such as CP, it is a daunting task to sort through which

treatments might help, given the many claims by wellorganized groups and individuals purporting to offer legitimate treatments for patients in whom conventional methods have either failed or have little to offer. These groups often have sophisticated websites, a home institution, a charismatic public proponent, literature, newsletters, and even parallel charitable foundations. The basic questions in evaluating CAM are the same as those associated with evaluating any medical method. The issues are whether scientific evidence exists, whether the methods are effective for the conditions for which they are intended, and whether they are safe as employed. The word complementary refers to the use of scientifically unproven modalities in association with more conventional medicine, while alternative refers to modalities used in place of conventional methods. According to the NCCAM, a third term, integrative medicine, refers to the use of CAM for which there is strong evidence for safety and effectiveness in a cooperative setting with conventional medicine.

CAM is frequently concerned with mind-body concepts of medicine. For CAM practitioners, the absence of disease is not necessarily equivalent to good health. They believe that good health entails feeling fit and well (hence the mind-body concept). They also feel that the body can be affected by the state of the mind. The placebo effect has been well studied and may well be an example of this.^{7–12} Alternative therapies such as meditation, prayer, and mental healing, or creative outlets such as art, music, and dance, are further examples of this approach. Sometimes this concept is incorporated into more formal rituals, such as yoga or the Feldenkrais method, in an effort to promote a feeling of well-being and to relieve stress, even in individuals with significant illness. Additional groupings of CAM include biologically based methods (herbs, food, vitamins); manipulative and body-based practices (osteopathic manipulation, massage); and energy medicine, which in turn is divided into biofield (therapeutic touch, craniosacral therapy) and biomagnetic (pulsed field, magnetic fields, alternating and direct current fields) therapies.⁶

SCOPE OF CAM IN ADULTS

The most recent survey of adults using CAM, (available online from the Centers for Disease Control and Prevention), involved 31 044 non-institutionalized US adults aged 18 or older. ¹³ The number of persons with CP in this group is unknown. Thirty-eight percent of survey participants used some form of CAM; this percentage increased to 62% if megavitamins and prayer were included. The most common reason for seeking CAM was not dissatisfaction with conventional care; rather, individuals were attempting to augment conventional treatments. Nonetheless, a substantial portion (28%) believed that conventional treatment

would fail and that CAM offered more hope. This finding is consistent with a 1998 survey by Astin¹⁴ that found that the majority of alternative medicine users were not necessarily dissatisfied with conventional medicine; they simply found CAM methods more congruent with their own philosophies about what constitutes good health. Compared with users of conventional medicine, users of alternative methods tend to be in poorer health, to be better educated, and to want to take more control over their treatment. In a survey of physicians in family practice, 26% of the responding professionals said they had suggested their patients try CAM. This is not surprising, as 47% of medical professionals in the same survey used CAM themselves.¹⁵

Authors of two other surveys, including one from the Centers for Medicare & Medicaid Services, have estimated that Americans spent between \$36 and \$47 billion on CAM in 1997. 16,17 At least half of this sum was out-of-pocket expenses that were not covered by insurance. The figure is substantial: it is equivalent to all that was spent on US hospitalizations in 1997, and about half of what was spent on out-of-pocket physician services. Women, people with higher educational levels, and those who had been hospitalized in the past year were more likely to use CAM. While no specific survey has been done on adults with CP, there is no reason to suspect that these individuals use CAM any less frequently than the general population. The most common CAMs in these surveys were prayer, natural products, and deep breathing. Meditation, chiropractic, yoga, and massage were also among the top 10 treatments. The most common conditions treated were back, neck, head, or joint aches, or other pain, a finding that has definite implications for adults with CP. The one thing that most advocates of alternative methods have in common with conventional practitioners is a belief in the beneficial effects of exercise, both for strength and for a feeling of fitness and well-being. At one time it was believed that strengthening spastic muscles was detrimental, but it is now known that exercise is beneficial and does not increase spasticity.¹⁸

CAM IN CP

Despite the expansion of the NCCAM budget (from \$2 million in 1992 to \$121.6 million in 2008), no NCCAMsupported publication has focused on CAM in CP in adults or, for that matter, in children. The record is better with the US Agency for Healthcare Research and Quality (AHRQ), which commissioned and published a literature review of hyperbaric oxygen therapy (HBOT) in 2003 using the terms 'brain injury,' 'cerebral palsy,' and 'stroke'. Unfortunately, the study concluded that there was not sufficient evidence from which to draw any conclusions as to whether the benefits exceeded the risks. 19 HBOT is discussed in detail below.

The most recent review of CAM in children with CP, published in 2005, was by Liptak.³ He reviewed common CAM therapies and the current evidence, or lack thereof, to support their effectiveness. He stressed the need for research in this area as well as the importance of greater awareness of confounding issues in conducting such research. Specifically, when children participate with their parents in such studies, the outcomes are affected by the attention that their participation engenders (Hawthorne effect)²⁰ and by the heightened expectations that result from rigidly complying with a treatment routine (adherence effect). Other factors that may confound attempts to study CAM are the positive influence that may arise from a selection effect, in which the most motivated patients are entered into trials; an active-placebo effect, in which the sham treatment is not as inert as expected; and an increased compliance with therapy and ancillary treatments during a clinical trial. Contact with and reinforcement by other participants or with health-care personnel, even when blinded, may also contribute to positive outcomes, regardless of intended treatment variables.²¹

A good example of how these issues play out in CAM may be found in a 2001 Quebec-based, government-supported study of HBOT in children with CP.²² The study involved 111 children who were randomly assigned to a placebo group or an active-treatment group. For this study, 1.3 atm chamber pressurization was provided to the placebo group, compared to 1.75 atm for the active-treatment group. (At the time, 1.75 atm was the usual chamber pressure for a 1-hour treatment). Results indicated improvements of about 3% on the Gross Motor Function Measure (GMFM) in children in both the placebo and the active-treatment groups. On the basis of these results, the authors concluded that active treatment had no real effect. HBOT advocates, however, pointed out that a pressure of 1.3 atm could have been active treatment as well. Moreover, the fact that both groups improved provided even more evidence of the efficacy of hyperbaric oxygen. There is no mention of a placebo in the final publication, and the only conclusion that the reader could draw is that HBOT offered no advantage over slightly pressured air. The study did note that the PO2 at 1.3 atm could be obtained with 28% bottled oxygen without the attendant need or expense of a pressurized chamber. The finding had little effect on practice, and it does not appear that bottled oxygen therapy is being offered in place of chamber therapy in the treatment of CP. Bennett and Newton²¹ have pointed out that the results could imply an effect of pressure itself. Alternatively, such results could be due to a participation effect within the study.

Future HBOT studies may overcome the active-placebo issue by controlling chamber gas content such that when it

is pressurized to 1.3 atm to provide the sensation of pressure, the actual PO_2 is that of room air. This will separate the pressure effect from the O_2 effect, but will not address the other issues that confounded study results. There is general agreement that adverse effects are not well reported in research on CAM, and it is important this area be emphasized as studies move forward. A truly benign treatment may be worth a try; one that has not been proven but that may have frequent or severe side effects may not.

CAM FOR ADULTS WITH CP

Liptak's review included a chart of the more popular methods used for children with CP (Table I).3 Many of these methods are designed to be included in the school curriculum. For example, conductive education and the Move Program, designed to be utilized in special education settings, emphasize activities that will help in daily living situations. By adulthood, these goals are either well established or not. Other methods, such as threshold electrical stimulation, are relatively easy to test using sham instrumentation, and evidence shows that they do not work any better than placebo. Craniosacral and other touch therapies have also been subjected to blinded examiners and found to be applied inconsistently and without benefit. Patterning is usually applied to children, who are lighter and easier to manipulate by trained personnel and recruited neighbors.³ By adulthood, enthusiasm for this technique is limited. Neurodevelopmental therapy has been found wanting by an outcome review of the American Academy for Cerebral Palsy and Developmental Medicine.²³ Adeli suit therapy combines intensive active and passive physiotherapy with special clothing adapted to allow the attachment of elastic resistance bands. Patients participate in a daily program over a 4- to 6-week period. This method is very popular for children,²⁴ but has not yet caught on in adults. Recently, clothing such as Theratogs²⁵ has been introduced for children with CP and adults with strokes and other neuromuscular conditions, but the evidence to support advantages over conventional physical therapy is anecdotal. The remaining methods that might have some popularity among adults include hippotherapy (horseback riding in a controlled environment so that safety is ensured), relaxation therapies such as yoga and meditation, motion-oriented therapies such as Feldenkrais, HBOT, and acupuncture. Each of these methods is discussed below.

Hippotherapy

In theory, the horse sets up patterns of perturbations that its rider must master in order to maintain balance and feel comfortable and secure. Sterba et al.²⁶ in 2002 had 17 chil-

Table I: Summary of selected complementary and alternative treatments for cerebral palsy (CP)^a Adverse effects Therapy Theory/benefits Evidence Comments Hyperbaric Uncontrolled studies show Awakens dominant brain Ear trauma More evidence is required oxygen tissue surrounding the pneumothorax, improvements in the treated before recommendations original injury fire, and children. Controlled study can be made; e.g. what is explosions showed improvement in treated the role of increased and controls pressure without supplemental oxygen? Adeli suit Resistance across muscles Discomfort from No conclusive evidence either in suit; expense for can improve strength, support of or against the use of posture, and coordination intensive therapy the Adeli suit and for travel to centers that prescribe the suit Patterning Passively repeating steps in Time, energy, and Results of uncontrolled studies are Cannot be recommended normal development can expenses required consistent; controlled trails show overcome brain injuries for treatment no benefits Electrical More evidence is required stimulation before recommendations can be made Threshold Increase blood flow from Expense for unit; Some uncontrolled trials show electrical electrical current will lead generally safe subjective improvements; stimulation controlled trials are inconclusive to stronger muscle **Functional** Expense; infection Evidence somewhat more positive Increase muscle neuromuscular contraction will improve from needles; than for threshold stimulation stimulation strength and function discomfort but still inconclusive Conductive Problems with motor skills None known Uncontrolled and controlled Conductive education is education are problems of learning; benefit; controlled trials are implemented in many new abilities are created mixed different ways making out of teaching generalizations from a single program difficult Hippotherapy Riding a horse can improve Trauma from a fall: Uncontrolled and controlled trials Horseback riding also muscle tone, head and allergies shows beneficial effects on body increases social trunk control, mobility in structures and functioning participation the pelvis, and eauilibrium Craniosacral Therapy is used to remove None known No study showing efficacy in CP; impediments to the flow some question the basis of the therapy of cerebrospinal fluid intervention within the cranium and spinal cord Feldenkrais Change of position and None known No study showing efficacy in CP; directed attention can studies in other conditions are equivocal relax muscles, improve movements, posture, and functioning Acupuncture Acupuncture can help to Forgotten needles, Controlled studies show Appears promising, but restore the normal flow of pain bruising, and improvements in several areas; more studies are required

Qi, or energy

infection

before specific

made

recommendations can be

two controlled trials also showed

improvement

^aFrom Liptak.³

dren with CP ride for 1 hour/week for 18 weeks and noted improvement on the GMFM, specifically in the walking, running, and jumping portions. This was supported in 2004 by Cherng et al.,²⁷ who noted that the improvements lasted at least 16 weeks after the therapy. Recent reviews have concluded that hippotherapy is effective in improving motor skills.^{28,29} Furthermore, participants report that it is fun and, when done in the community, increases socialization, which is an implicit goal of the International Classification of Functioning, Disability and Health as detailed by the World Health Organization.³⁰ Moreover, hippotherapy can easily be carried over to adulthood. Other recreational activities have not been studied, but wheelchair sports and adaptive skiing offer other venues for research into how certain sporting activities might promote health over the longer term.

Hyperbaric oxygen therapy

The 2001 study by Collet et al.²² is the only randomized, controlled study of HBOT, and its use of what some have considered an active placebo (i.e. 1.3 atm of pressure) has left the believers continuing to believe and the doubters looking elsewhere. Complications of the chamber rides, usually barotraumas, are a matter of continuing concern.³¹ At 1.75 atm the, incidence of perceptible barotrauma doubles, from approximately 25 to 50%. Some feel this may be due to the more rapid compression/decompression rate to achieve 1.75 atm, as compared with 1.3 atm, over a 10minute period.²¹ No one knows the significance of the findings, and they rarely interfere with continuing the treatment. Other complications, such as seizures, are very rare, and not considered a contraindication. An AHRQ study reviewed hundreds of articles on HBOT, graded each, and organized the findings by level of proof. The authors could not conclude that HBOT was effective or that its benefits exceeded its risks.¹⁹ Among conventional practitioners who care for individuals with CP, this modality has largely been discredited, but it is still thought to be useful for other medical problems, such as diving injuries, carbon monoxide poisoning, and wound healing, none of which was examined by the AHRQ. Yet to be explained is why 28% bottled O2 has not been utilized by the proponents of HBOT, as the Collet study showed its equivalence to the PO2 obtained at 1.3 atm.

Feldenkrais

The Feldenkrais method is purported to enhance mental and physical functioning by one of two techniques.³² With functional integration, a coach uses hands-on and light-touch stimulations to guide a patient through various motion patterns. In the awareness through motion approach, the teacher verbally directs participants through

various movements, breaking down complex motions into smaller sequences and varying the order and types of motion. It can be done in a live class or at home with audiotapes. The goals are to improve flexibility, posture, mental status, and comfort. Proponents report that individuals may develop greater endurance, improved ease in walking, and a smoother gait. However, there are very few studies of the Feldenkrais method³³ and there is no evidence that it is effective for individuals with CP

Acupuncture

Acupuncture is perhaps the most traditional example of CAM. It has been used for some 2000 years and is based on the idea of maintaining an uninterrupted flow of life energy, or Qi, which travels along 14 meridians, or channels, between acupuncture points.34 Needles are placed with great flair, and often a twirling motion, in order to stimulate these points and to restore flow and balance of yin and yang. When the procedure was developed, it is not known whether the needles were stimulating nerves, giving a tingling sensation during treatment, or whether today we might refer to the phenomenon as bioelectric in nature. It is clear, however, that the concept of energy flow was born in the early days of this technique. The terms vin and yang, used to describe polar effects of a particular phenomenon, are grounded in philosophical concepts rather than science; for example, winter and summer could be described as the yin and yang of the seasons of the year. Keeping yin and vang in balance is a focus of acupuncture interventions. Critics claim that acupuncture does little more than produce a placebo effect, even when, or particularly when, touted for its analgesic effects.³⁵

Placing needles at specific points is the hallmark of treatment. However, over thousands of years, modifications have crept in. Contemporary acupuncture may use nonmeridian or trigger points at which touch or pressure will elicit pain, aside from the traditional acupoints, and the methods of stimulation include hand, needle, blunt probes, laser, or electrical current. Although acupuncture is most often identified with pain control in the USA, it has been used to treat virtually every affliction, from ankle sprains to allergic rhinitis. Numerous randomized, controlled trials, along with systematic reviews and meta-analyses, have looked at its clinical efficacy. It is considered effective for reducing emesis after surgery or chemotherapy in adults and for relieving nausea of pregnancy. Plausible mechanisms include the activation of endogenous opioid pathways, specific regional effects on the brain, and gene expression of neuropeptides.³⁴ For these reasons, it is not surprising to find that it has been used for CP for more than 25 years. 6,36 In China, it is considered low risk, and is widely used to treat motor activity, sensation, speech, and

other neurological problems.³⁷ There are protocols for, but no completed studies of, the use of acupuncture for CP in the Cochrane database.³⁸ There are numerous uncontrolled but enthusiastic studies in the Chinese language portion of the database. One study using the GMFM found an improvement in motor function of CP participants following a short course of acupuncture.³⁹ A 7-yearold child with hemiplegia treated by electro-acupuncture was described in detail by Svedberg et al. in 2003, 40 and the same authors investigated the temperature effect of acupuncture on neurologically impaired children and showed that it would indeed raise the temperature of cold extremities both acutely and over time with continued treatment.41 While there is no proof that acupuncture works for CP, many studies support the concept, and parents seem pleased with it.

Adeli suit therapy

Adeli suit treatment (AST) is an outgrowth of a Russian program to maintain muscle tone and limit the development of osteoporosis in space, and was adapted and popularized by the Euromed Rehabilitation Center in Mielno, Poland. 24,42,43 The suit is a form-fitting garment with many attachment points for support straps and bungee cords that offer the wearer resistance to movement as well as support. AST includes a rigorous physical therapy protocol. It is an example of an attempt at imprinting on the brain practiced and repetitious motions that are supervised over a month or so. Proponents claim that the suit enhances communication between the brain and peripheral muscles by increasing blood flow, electromyography readings, and electroencephalogram function, and promoting bone calcification, while decreasing ataxia and the intensity of dysarthria. Proprioceptive input via vertical loading is designed to improve the vestibular system. Bar-Haim et al.44 compared AST with neurodevelopmental training utilizing the GMFM-66 and a mechanical efficiency index during stair climbing. AST was more effective in increasing a mechanical efficiency index. With both intensive physical therapy regimens, small but significant time effects were noted after 1 month. At 9 months there was no difference in motor skills between the two groups. The authors concluded that AST might improve mechanical efficiency with a corresponding gain in gross motor skill, particularly in higher-functioning children. AST has proved popular with parents, and there is now similar clothing available for children and for adult stroke patients, in whom it purportedly facilitates rehabilitation. A few poster exhibits have been done on this method, but there are no published studies. Spandex or Lycra garments have been used to provide support, especially to the upper extremities and the trunk, but the inconvenience of wearing the garments has largely outweighed any benefits.⁴⁵ In summary, no controlled study has demonstrated any effects of AST beyond those of conventional programs involving physical therapy of similar intensity.44,46

Threshold electrical stimulation

Threshold electrical stimulation (TES) must be differentiated from neuromuscular electrical stimulation (NMES), in which the muscle contracts, and functional electrical stimulation (FES), in which the muscle contracts during a function such as walking or flexing an elbow. NMES and FES have traditionally been used as part of conventional physical therapy. The intent of TES is to obtain a trophic effect by increasing nutrition to the muscles while the patient sleeps. The current is kept low in order not to stimulate the contraction of muscle. Two controlled studies found that TES had no significant effect, 47,48 but a third study, which used TES in patients who had undergone dorsal rhizotomy, noted a salutary effect.⁴⁹ Kerr et al.⁵⁰ found a trend in improving peak torque with both TES and NMES compared with placebo, but concluded that it was not a powerful enough study to determine significance. In that study, the impact of CP, measured by a Lifestyle Assessment Questionnaire, showed that patients with TES or NMES improved significantly compared with children in the placebo groups. The evidence that TES works is inconclusive, but electrical stimulation in many incarnations remains a popular form of CAM.

Touch therapies

The notion that touch or manipulation can be a significant healing factor may be anathema to conventional practitioners, but many patients still wish to employ these methods, as judged by their popularity on the internet. The basis of touch therapy is that the bones of the cranium and pelvis exhibit subtle motion related to the pulsating of the central nervous system, and that a trained examiner can detect abnormalities and then apply gentle motions that counteract these abnormalities or the effects of strain on soft-tissue structures such as the dura.⁵¹ The sphenoid and occipital sutures fuse by 18 years of age; consequently, in adults, such motion, referred to as a 'cranial rhythm,' would be impossible to detect even if it did exist. Craniosacral therapy has been discredited by many studies.^{51,52} In 2002, Hartman and Norton⁵³ stated that any evidence about the effectiveness of touch therapy was medical fiction and that it should be banished from medical and allied health curricula.

CONCLUSION

The US National Institutes of Health spent \$121 million on CAM in 2008. None of those funds, and no funds in previous years, have been directed specifically to CP. As a result, we do not know how many adults with CP are using CAM, how much they are spending on them, whether this expense can be justified on the basis of efficacy, or how safe the various methods are. The only area that has been examined with any rigor by an NIH agency is HBOT, and the results were equivocal at best. CAM is an area ripe for well-designed clinical trials, taking care to avoid the Hawthorne and adherence effects, as well as the usual placebo effects. All medical procedures, protocols, and devices, where possible, ought to be subject to similar scientific scrutiny. In the end, there ought to be only proven or unproven methods⁵⁴ until then, the public will continue to demand, and the market will continue to supply, methods that promise hope, but do not have the rigor of scientific backing that would qualify them as conventional treatment.

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