COMPLEMENTARY AND ALTERNATIVE MEDICINE INVOLVING CHILDREN: WHEN IS IT ACCEPTABLE? WHO DECIDES?

By Andrew P. Milroy

The issues surrounding complementary and alternative medicine (CAM) need to be carefully examined. The use of CAM is simply too widespread to ignore or merely pass off as a fad. Ethical issues surrounding CAM are numerous. Fraught with unresolved questions concerning evidence, safety, and the ability to provide informed consent, they touch on some of the very core issues in bioethics. These problems are difficult enough when the patient is an adult, but when the patient is a child, the dilemma is even greater. The time for simple recognition of these problems has passed. The purpose of this paper is to help physicians address the issue of CAM when they are confronted with it by providing them with an overview of the general consensus in the medical community as to how it should be handled. This paper examines how the issue of CAM should be approached; reviews the importance of communication in the patient-physician relationship as it pertains to CAM; examines when CAM is considered a viable treatment option; and reviews how decisions involving children should be made.

DEFINITION

For the purpose of this paper, CAM is taken to mean any nutritional, biological or chemical agent, or any behavioural or physical therapy administered for therapeutic benefit which is not recognized as a conventional treatment.[1] Typical CAM therapies are

chiropractic, acupuncture, homeopathy, naturopathy, and therapeutic touch. Many CAM have an underlying aspect of spirituality, and naturalness to them.

HOW TO APPROACH THE SUBJECT OF CAM?

Above all, CAM should be approached with an open-minded attitude.[2] The first step physicians should take is to encourage their patients to disclose any use of CAM, while at the same time avoiding any disparaging remarks on the issue.[3] Although not all new therapies should be blindly accepted as effective,[4] they should also not be ignored and ridiculed. Physicians need to try and attain a better understanding of CAM for themselves.[5] By evaluating the scientific merits of specific therapeutic approaches, and identifying any risks and potential harms associated with CAM, as well as benefits, the physician will be in a better position to address patient concerns and requests.[6] As much as possible, the physician should document the case in order to increase the available literature on the subject.[7] This will help the medical community better ascertain the value of CAM.

THE IMPORTANCE OF COMMUNICATION IN THE PATIENT-PHYSICIAN RELATIONSHIP WITH REGARDS TO CAM

The importance of communication in the patient-physician relationship cannot be overemphasized. The value of it is stated in virtually all of the written material relating to CAM, and yet still not enough is being done. A report of a study, published in 2001,

showed, that not all physicians ask about the drugs their patients are on, let alone specifically about the use of alternative drugs.[8] An even greater number of physicians do not check the side effects and possible harmful interactions of the drugs their patients are taking.[9] One possible explanation is that physicians may assume when asking about all the drugs patients are on, that they will mention any CAM they are taking. This assumption, on the part of the physicians however, must be false. If it were true, then the roughly sixty percent of people who do not disclose CAM use to their physicians[10], would have done so when questioned. Physicians should not only ask specifically about CAM use but ensure that their patients understand clearly what they are being asked. They need to realize that a breakdown in communication can be dangerous.

Certain CAM can be potentially harmful due to possible unknown drug interactions or improper dosages. Failure to properly communicate may cause unnecessary deaths. With infants and young children for instance, preparations containing eucalyptus oil should not be applied to their faces because doing so can lead to glottal or bronchial spasms (through asthma-like attacks) or even death by asphyxiation.[11] Physicians need to increase their knowledge of CAM, or at least know where they can find reliable information on the subject, so that they can make valid medical decisions. This however, is currently not the case, and decisions are being made with dangerously inadequate information by both patients and physicians. This is not entirely because the information does not exist, but also because the dissemination of the information on the subject has not been effective. The report by Silverstein and Spiegel, *Are physicians aware of the risks of alternative medicine?* supports this: “Physician’s knowledge of the side effects and contraindications

of ten commonly used herbs was dismal."[12] With the increase in use of CAM this needs to change. The risk for dangerous drug interactions is too great. Understandably, some believe that seeking information on CAM use should become a part of the medical history of the patient, as other drugs are.[13] The communication problem has become so bad in fact, it has been said that a reluctance to communicate on the subject of CAM, and failure to keep up to date on CAM practices, is a failure to do that which is in the patient's best interest, is morally objectionable, and is possibly a form of malpractice.[14]

Physicians who do not want their patients using CAM, yet are not talking to them about it are actually contributing to the increase in CAM use. One of the five main reasons why people turn to CAM practitioners is because of the personalized, in-depth service provided to them.[15] Studies show that not only do patients want their physicians to talk to them about CAM[16], but that their level of trust in their physician would increase if they did so.[17] Studies have also shown that patients expect disinterest, disapproval, or ignorance regarding CAM, from their physicians.[18]

Increasing communication should be considered the central goal, in order to help solve many of these problems. Communication is not important so that physicians can dissuade people from using CAM. Rather, communication is important in order to find out what the truth of the matter is, and to learn more about it. This is what is in the best interest of patients. They will trust the physicians more, and they will then be in a better position to be protected, if need be, from CAM practitioners who are deceptive and potentially

dangerous. Whether it is CAM, or conventional medicine, it must be carefully evaluated to ensure only the best available treatments are provided.

When speaking with a patient about CAM, it is very important to be open-minded, so that the patient can feel as comfortable as possible talking about CAM.[19] Hubristic and conceited attitudes should be avoided.[20] A physician's agreement or disagreement with a certain treatment, should not affect the level of comfort and attention provided to a patient. Initial discussion with the patient should try to ascertain what the goal of the treatment will be. There are five general possible goals of treatment, each of which will change the usefulness of possible therapies. These are:

- Curing the disease
- Managing or minimizing symptoms
- Preventing disease
- Promoting wellness or resilience and minimizing stress or toxins
- Achieving inner peace and harmony[21]

Once the goal of treatment is agreed upon, further questions can be used to provide patients with the individualized, in-depth care that they are entitled to. Gregory A. Plotnikoff et. al. provide nine questions to help.

- What do you think caused your problem?
- What do you call it?

- Why do you think it started when it did?
- How does it affect your life?
- How severe is it?
- What worries you the most?
- What kind of treatment do you think would work?
- Have you used any remedies or treatments for your problem?
- Have you consulted any other healers?[22]

These suggested questions are meant merely as a starting point for physicians. Further questions should be asked whenever the physician feels that doing so will either enhance the quality of care given to the patient, or will strengthen the patient-physician relationship. Information gathered from this discussion should be considered when making health care decisions in order to adequately address the individual's specific desires and needs. All treatment options can be effectively discussed only when there is open communication between the patient and physician.

WHEN IS CAM AN ACCEPTABLE MEDICAL OPTION?

According to Eisenberg, physicians should begin to discuss CAM as a viable treatment option, only after three prerequisites have been fulfilled.

The patient:

- has undergone a complete conventional medical evaluation, including diagnostic assessment and, where indicated, referral to consultants
- has been advised of conventional therapeutic options
- has tried or exhausted conventional therapeutic options or refused these options for reasons documented in their record[23]

The apparent consensus in the medical community is that CAM is an acceptable treatment option under the following conditions:

- Conventional medicine has been tried[24,25]
- Using CAM will not interfere with known beneficial treatments[26]
- There is no accepted proven treatment[27]
- The physician believes that the patient receiving the CAM will benefit from it.[28]
- The CAM will not expose the patient to any degree of risk/harm with no proven, offsetting, benefit.[29,30]
- The decision to use CAM will be an informed one[31]

In these situations CAM is an option. Only after there has been adequate physician-patient communication and the viability of CAM as a treatment option has been assessed, can a decision on the course of treatment be made. Ideally, it should be a combined decision with all the parties involved reaching an agreed upon treatment. Realistically though, this does not happen as often as it should, so it is important to know who makes decisions for the child, how decisions should be made, and when a decision is acceptable.

WHO DECIDES FOR THE CHILD?

The question about who makes the decision begins with the child. Children are becoming increasingly recognized as being able to make some of their own medical decisions.[32] Generally the older the child, the longer a child has had a specific illness, and the more severe the illness, the more weight is given to his or her desires.[33,34] Giving more weight to the desires of children however, does not equate with allowing them to make the final decision. Only when children are competent, or emancipated, can they make the decision alone. Competent children are capable of making non-coerced decisions, and understand how all of the pertinent information applies to them.[35] Since children cannot fulfill these requirements the majority of the time, a surrogate decision-maker is appointed for them when needed.

HOW SHOULD DECISIONS FOR A CHILD BE MADE?

There are two main types of surrogate decision-making: substitute judgment and best-interests standard. In the case of children, the best-interests standard of surrogate decision making must be followed.[36] The rationale behind this is that children do not have the required personal values, goals and beliefs to make substitute judgment a viable option.[37] If substitute judgment were to be used, and done correctly, it would actually be the equivalent of recognizing the child as legally competent,[38] something few people would be willing to accept. Thus, the best-interest standard is to be used. A surrogate decision

using the best-interests standard for a child whose values, goals, and beliefs are unknown, or who has never reached the level necessary for making substitute judgment an option, would be based on the best obtainable estimate of what reasonable persons would consider the highest net benefit among available options.[39] A treatment said to be in the child's best-interests but which has unknown risks or a possibility of direct or indirect harm, to the child should be seriously critiqued.

WHO IS IN THE BEST POSITION TO DECIDE FOR THE CHILD?

When determining who is in the best position to make a medical decision on the course of treatment for the child, there are four proposed qualifications. The person should:

- Have the ability to make reasoned judgments
- Possess adequate knowledge and information
- Be emotionally stable
- Have a commitment to the incompetent patient's interests that is free of conflicts of interest and free of controlling influence by those who might not act in the patient's best interests.[40]

It is most often the case that the parents are in the best position to make the decision for their child.[41] They generally are the most knowledgeable of and interested in the child, and are usually most affected by the consequences of these decisions. Accordingly they are seen as most capable of doing the best job possible for the child.[42] There are times

however, when parents are not in the best position to make decisions for their child. These include:

- When the parents are incompetent to make decisions for themselves
- When there are irresolvable differences between the parents
- When they have clearly relinquished responsibility for the child (emancipated minors).[43]

The fourth qualification which Roy et. al mention (that the parents must also act in the best-interests of their child) should not be used, in my opinion, in the determination process. The reason for this is that currently the focus is on who is in the best position to make the decision not on whether the decision is acceptable. Should not the qualification process to determine who should decide be done prior to any treatment decision? Does it not seem odd to say that someone is not in the best position to make a decision after they have been given the chance to make one, and have been told they were in the best position to make it? It would be analogous to telling someone they can play goalie for a hockey team then after finding out they are not a good goalie, kicking them off the team. It should have been the case that the screening process was more stringent, thus not allowing that person to play goalie in the first place. A system which tells someone they are qualified to make a decision, only to take it away when they make a decision not in accordance with what someone else would have decided, (who was not deemed in the best position to make the decision in the first place) seems irrational. To alleviate this problem an additional qualification could be added stating that when making a proxy

decision for someone with no known values, goals, and beliefs, the person must have the values, goals, and beliefs that lead to acceptable treatment decisions. An acceptable treatment decision would be one which would be made for all children in the same situation with the same medical condition. This is consistent with the prevailing idea that proxy decisions for children should be done through best-interests standard in accordance with what a reasonable person would decide.[44] Until this proposed criterion is accepted, the prevailing position, that a qualified person to make the decision for the child can make a wrong one, will be accepted. It is now important to examine when a decision by parents, previously thought to be able to make a medical decision for the child, can be overridden.

WHEN CAN PARENTAL AUTONOMY BE OVERRIDEN?

Parental autonomy to make the best-interests proxy decision for their child can be overruled when following that decision would cause serious harm to the child.[45] Gaylin and Macklin provide three criteria which can be used to indicate when overriding parental autonomy is acceptable.

- When the medical profession is in agreement about what non-experimental medical treatment is right for the child
- When the expected outcome of that treatment is what society agrees to be right for any child, a chance for normal healthy growth toward adulthood or a life worth living

- When the expected outcome of denial of that treatment would mean death for the child[46]

Each of these are necessary conditions to warrant overriding parental autonomy. Gaylin and Macklin go on to say that parental autonomy is not acceptable in the following situations:

- When there is no proven medical procedure
- When parents are confronted with conflicting medical advice about which, if any, treatment procedure to follow
- When even if the medical experts agree about treatment, there is less than a high probability that the non-experimental treatment will enable the child to pursue either a life worth living or a life of relatively normal healthy growth toward adulthood[47]

The prevailing ideology in clinical ethics today is that only in extreme situations should parental autonomy be superceded. Overriding parental autonomy cannot be taken lightly. Before physicians override parental autonomy they should ask themselves if they have done everything possible, and if there is anything more they could do, to avoid such a course of action.

RESPECTING AUTONOMY

Physicians must at times balance a respect for autonomy with the duty to promote the highest quality of health possible. This is nearly always the case when dealing with CAM. On the one hand, people should be able to make their own informed decisions; on the other hand, it is also reasonable to take this right away when the informed decision is a harmful one and is being made for another person, especially when the other person is a child.

Multiculturalism is a large aspect of the Canadian identity and as such, respect is traditionally given to another's culture, beliefs, and religion. This should not change in a medical setting. Not properly respecting another culture because of a lack of interest or a closed mind is unacceptable.[48] At the same time however, it is important to remember that health is not culturally relative.[49]

> The obligation of pediatricians to educate and even to urge parents to adopt practices likely to contribute to the good health and well being of their children, and to avoid practices that will definitely or probably cause harm and suffering, should know no cultural boundaries.[50]

While respecting other cultures is necessary, it should not be necessary to follow every tenant of that culture, in order to respect it.[51] People do not have the right to harm others through actions or decisions stemming from their beliefs.[52] When dealing with these difficult situations it is important that physicians recognize their own limitations and consult with colleagues and bioethicists. Physicians should keep in mind that the preferences of a patient are not sufficient grounds to select a given treatment.[53]

SUMMARY

Physicians need to talk with their patients openly about the use of CAM to discover if their patient is taking CAM, and to avoid harmful mixtures of CAM and conventional medicine. The effectiveness of CAM in certain situations though should not be overlooked. CAM is an acceptable treatment in a number of situations. When conventional medicine has been tried already, there is no proven effective treatment, or when the use of CAM will not interfere with known curative therapies, are three situations in which CAM is a viable treatment option. For CAM to be used, however, it must always be an informed decision, the physician must believe that the patient will benefit from the use of CAM, and the CAM must not expose the patient to any degree of harm without a proven offsetting benefit. Decision to use CAM should be arrived at jointly between the child, parents, and physician. If this is not possible, the parents have the most say in the matter, but must make the decision based on the standard of best-interests. If a physician feels that the parents are not making a decision in the best-interests of the child, they are obligated to intervene for the child, and proceed as they feel appropriate. Overriding parental autonomy should never be taken lightly even though it may be necessary. Parents have a lot of weight in the decision making process for their children but physicians have the last say, and should always act in a manner that will promote the greatest overall health of their patient.

ENDNOTES

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