Treating Teens: Considerations When Adolescents Want to Use Complementary and Alternative Medicine

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KEY WORDS

adolescent, complementary therapies, jurisprudence, ulcerative colitis

ABBREVIATIONS

UC—ulcerative colitis
CAM—complementary and alternative medicine

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abstract

In this article we examine decision-making about complementary and alternative medicine use when the patient is an adolescent. A case scenario describes patient-parent conflict when a 14-year-old boy who was diagnosed with ulcerative colitis that has continued to progress even with medication refuses recommended surgery despite his physician's and parents' support for that option; he prefers homeopathy instead. We address (1) who has decision-making authority about treatment for young people, (2) how to determine if a young person can consent to or refuse treatment, (3) special considerations when counseling and treating adolescents (whether they can decide about treatment for themselves), and (4) parent-child conflicts about treatment. In addition, we suggest ways that health care providers can foster a trusting relationship with patients and parents. *Pediatrics* 2011;128: S161–S166

Christopher G. is a 14-year-old boy who was diagnosed with ulcerative colitis (UC) at 11 years of age. His disease is severe despite aggressive medical therapy. His face is cushingoid, he has had growth failure from a prolonged course of high-dose steroids, and his symptoms deteriorate whenever attempts are made to taper the dose. His physician has tried a series of medications to control his disease but has had little success. Because he has had hypersensitivity reactions to immunosuppressive therapy and is beginning to develop steroid dependence, Chris's physician suggests that he consider surgical options. She informs him and his parents that surgery for UC is curative and that satisfactory results are obtained by 70% to 90% of children who undergo an ileoanal anastomosis (ie, surgical removal of the large intestine and creation of a natural pouch to collect waste). She also warns them of potential complications of surgery, including pouchitis and intractable diarrhea.[1,2]

Despite the risks, Chris's parents are encouraged by the surgery option and consent to having it performed. Chris, however, is vehemently opposed. He says that he has researched his condition and knows that other therapies, including homeopathic treatment, are available. He says his pain is still manageable and wants to delay surgery and continue taking medication while consulting with a homeopath.

His physician advises that the surgery should be performed sooner rather than later because of the dangers of long-term corticosteroid exposure and the inevitable deterioration of Chris's quality of life. She suggests that the timing of the elective surgery is important for reducing morbidity and mortality.

Although Chris remains steadfast in his desire to pursue homeopathy and avoid surgery, his parents believe that he is scared and too young to comprehend the potential adverse consequences of postponing surgery. They do not agree with homeopathy and ask if they can force their son to undergo a procedure they consider essential.

In this article we examine decision-making about using complementary and alternative medicine (CAM) when the patient is an adolescent. We address (1) who has the power and authority to decide about treatment, (2) what decisional capacity means, (3) special considerations when counseling and treating adolescents, including the legal effect of child-protection proceedings, and (4) parent-child conflicts.

ETHICS

Adolescents with complex and chronic health problems must contend with expectations that, as persons on the brink of adulthood, they will behave responsibly while having to face the challenges associated with lack of experience and overall dependence on their parents for most things. Professional caregivers should acknowledge and respect adolescents' emerging autonomy, values, and personhood while doing what they can to reason with patients whom they believe are making unreasonable choices.

It is around the age of 14 years when adolescents are believed to have developed the ability to make their own health care decisions,[3,4] although decision-making capacity may vary from person to person. It is important to determine this capacity in Christopher's case and probe his understanding of his illness and the options for treatment. His physician should also attempt to determine whether Chris's choice is based on his personal values and is consistent with his wishes and hopes for a particular outcome rather than fear and immaturity. The arguments supporting surgical treatment should be explained to him, and his reasons for preferring homeopathy should be explored. He is the one experiencing the illness and is also the one who will have to live with the consequences, whichever course of treatment is pursued.

The ethical principle of respect for people grounds our obligation to honor the autonomous choices of those who are capable of making rational choices that are consistent with their deeply held values, are voluntary, and do not cause harm to others. In the health care of adolescents, a countervailing ethical principle is that we must protect vulnerable children who are at risk of harm. Pediatric practitioners are often confronted with ethical dilemmas that involve conflict between these 2 principles and may sometimes have to mediate between parents and their child.[5] "Forcing" surgical treatment would be difficult to do and could cause significant physical and psychological harm. If it is determined that Chris is not capable of making his own decisions independently of his parents, efforts to persuade him to agree to surgery should be made. His parents should be asked to take seriously his request to pursue homeopathy as well.

LAW

Who Decides?

The law strongly protects people's rights to bodily integrity and autonomy, which in the health care context means that health care providers must obtain consent before treating.[6] To give a legally valid consent, the person concerned must be competent (sometimes referred to as decisionally capable), which means that he or she can both understand and appreciate the nature and consequences of the recommended treatment, alternative treatments, and nontreatment.[7–9] He or she also must be able to make a decision that is voluntary (ie, an expression of will rather than a direction

from others). Some young people (referred to in law as "mature minors") meet both of these requirements, although the younger the patient is, the less likely he or she is to do so.[9,10] Absent additional statutory or common law constraints, minors who are decisionally capable can make their own decisions about treatment.[9–12] If a minor does not satisfy these minimum requirements, then a substitute decision-maker, usually a parent or guardian, has the legal authority to consent to or refuse treatment on his or her behalf.

Especially when there is conflict between parents and their child or between a child, the family, and health care providers, it is important to establish who can consent to treatment: the minor or his or her parents. The question is both legal and factual, because laws that govern capacity vary among jurisdictions, and minors differ in whether they can make mature, independent decisions. Determinations about decisional capacity can be challenged in court or, in some jurisdictions, by application to a specialized tribunal.[13,14]

Decisional Capacity

Decisional capacity can be particularly difficult to assess in adolescents. The law recognizes the degree of understanding, and appreciation of the consequences of treatment and its alternatives required will vary with the gravity of the decision and the circumstances of the minor.[13,15] Refusing treatment needed to preserve life or prevent a serious risk to health legitimately requires greater appreciation of the consequences than does refusing more minor treatment, and so does a difficult and complex decision.[15,16]

Would the determination about whether Chris can make his own treatment decisions be affected by the fact that the conventional treatment recommended has achieved satisfactory results in a large majority of those who have undergone it or by the alternative nature of the treatment option that he wants to explore? In theory, if he is decisionally capable, it should not. Decisionally capable adults are free to refuse treatment and pursue other options for whatever reasons seem sufficient to them. However, when minors are concerned, it is not clear that the same result will follow.

When challenged, older minors' decisions about treatment have not always been upheld by courts, for a number of reasons.[13]

- There is some support in the jurisprudence and academic literature for the argument that when health risks are serious, a minor, even if mature, can only consent to care that would be of benefit (ie, a minor can only make those decisions about medical care that others would consider to be in his or her interests).[17,18] This reasoning, referred to as the "welfare principle," challenges the extent of the commitment in law to mature minors' interests in self-determination and autonomy and weighs in favor of acceding to the minor's decision only if he or she opts for the recommended treatment.
- In some jurisdictions, legislation may impose other conditions before the minor can prevail (eg, a minimum age or concurrence of treating physicians).[11,19,20] In the United States, although many states recognize that mature or emancipated minors can decide about treatment, not all of them do.[21]
- Child-protection proceedings (which can be triggered by refusal to obtain needed medical intervention that will have serious consequences for the child's life or health) may limit minors' decision-making. Child welfare legislation typically allows a court to authorize treatment that it determines is in the best interests of a child found in need of protection, even against the child's and parents' wishes. However, the Supreme Court of Canada has held that even in that context, courts must interpret the best-interests standard "so that a young person is afforded a degree of bodily autonomy and integrity commensurate with his or her maturity."[22] Thus, in Canada, if an adolescent can establish that he or she is able to exercise mature, independent judgment about the treatment in question, then his or her decision should be respected.

When deciding whether a minor meets the test for decisional capacity and can make a voluntary decision, health care providers (and, ultimately, courts) should take into account the nature, purpose, risks, and benefits of the recommended treatment, the basis and reasons for the minor's decision, and the decision's likely consequences, which will assist in determining whether the minor has the necessary information to decide and the understanding, appreciation, and independence required to do so.[15,23,24] In *Re D.(T.T.)*, a 13-year-old boy who was suffering from osteosarcoma wanted to refuse medically recommended chemotherapy and amputation of his leg in favor of herbal remedies and other less aggressive treatment favored by his parents. The court held that because he had been given only partial and inaccurate information from limited sources (his father, not health care providers), and because of family dynamics, he had neither sufficient information nor sufficient independence to make a truly voluntary decision. Consequently, he could not decide whether to consent to or refuse treatment himself.[25,26]

In our scenario, refusing treatment that is likely to achieve good results

and wanting therapy not shown to be effective for this condition raise legitimate questions about whether the patient is properly informed and has the necessary decisional capacity. This situation should be explored further.

CLINICAL RESPONSE

Although UC poses a significant burden for a patient of any age, pediatric patients may be particularly afflicted, because they often have a more acute and severe form of UC than adults.[27,28] Both the disease itself and the medications used to treat it can cause permanent disability in the form of growth failure.[29–31] Although most pediatric patients can be managed effectively with medical treatment, ~25% to 40% of patients with UC eventually require surgery.[32,33] The current gold standard for surgical therapy of UC is the restorative ileal pouch-anal anastomosis, which is considered curative, but the timing of surgery is considered crucial. Despite a complication rate[34] of ~30%, and the persistence of issues related to diet restriction and fecal incontinence (daytime continence ranges from 47% to 100%),[34–37] most patients nevertheless seem satisfied with the outcome of the surgery and report an improved quality of life after surgery. Ileal pouch-anal anastomosis is recommended for those with severe UC, because it will allow the patient to lead a normal life postoperatively and have quality-of-life, self-esteem, and mental health indicators equivalent to those of healthy children.[35]

The process of developing an appropriate and individualized treatment plan for a patient is complicated further when a patient wants to include CAM. There may be many reasons why people, including adolescents, do or do not consent to surgery and its permanent effects or why they choose CAM. Studies have confirmed that a number of patients are motivated by the prospect of avoiding surgery.[38] Physicians should explore reasons for CAM use with their patients.

There are few data regarding the use of homeopathy for irritable bowel disease to gauge potential efficacy. A systematic review by Dantas and Rampes[39] revealed that when prescribed by trained professionals and in high dilution, homeopathic medicines are generally safe and unlikely to cause severe adverse reactions. However, the authors also found it difficult to make definite conclusions because of the low methodologic qualities of the reports they were using. Thus, there is little evidence of safety risk but little evidence of efficacy for UC.

Given this information about the effectiveness of ileal pouch-anal anastomosis for severe UC, Chris's physician and parents have a strong case in favor of surgery. There is concrete evidence for its health benefits, and the delay of surgery and potential long-term consequences, including increased risk of complications, are worrisome. It is understandable that they do not wish to delay. That said, delaying surgery would not be fatal or necessarily immediately dangerous, and forcing Chris to undergo surgery when he is unwilling and psychologically unprepared could be damaging. Even if Chris is not decisionally capable, his physician should consider his preferences nonetheless, including those for alternative options, attempt to ascertain whether there is evidence about its use for this condition, and assess the likely impact on Chris's health.

RECOMMENDATIONS

Decisionally Capable Patients

The physician must determine if Chris is decisionally capable of consenting to or refusing treatment. The more serious the condition and consequences are, the more searching the scrutiny of him and the decision should be.[15]

The physician should strengthen her relationship with Chris and ensure open, honest, and respectful dialogue and explain the reasons for the recommendation, including the likely effects of delay. She can initiate conversation by inquiring about why he is hesitant to have this surgery and perhaps allay his fears by showing him successful results of the operation or arranging a meeting with a patient who has already undergone the procedure. The physician should not minimize Chris's concerns or the potential negative effects of surgery but should also be clear about the risks of delay. Chris will have an ongoing need for medical care, and trust must be maintained. The physician should share the lack of efficacy data and reassuring safety data about homeopathy with Chris. If he is able to make his own decisions, this will assist in ensuring that his consent is both properly informed and voluntary. If he insists on homeopathy, the physician will need to closely monitor his condition by using conventional means.

Decisionally Incapable Patients

Should a physician determine that a pediatric patient is not capable of making his or her own treatment decisions, the physician must obtain consent from a substitute decision-maker, usually the patient's parents. It is still important and respectful of the child to include him or her in discussions and decisions to the greatest extent possible. In these situations, the child's assent, or appropriately informed agreement, should be sought but is not controlling.[5,9,40] Even if the patient has not yet developed the ability to understand the scientific information and weigh the risks, thus falling short of the legal test for capacity, engaging him or her in conversation about a therapy that he or she independently sought will show the patient that the physician is mindful of his or her independence and respectful of his

or her ability to take part in developing the management plan. A child's sustained dissent, or resistance to treatment, should be taken seriously, and discussions with the parents and team should be held in an attempt to reach a conclusion that all of them can live with.

Mature Minors: Child-Protection Proceedings

Legislation is not uniform across Canada, the United States, or elsewhere regarding older minors' authority to make decisions about health care, especially in the context of child-protection proceedings. Recent Canadian jurisprudence confirmed that child welfare legislation must be interpreted to allow adolescents the opportunity to demonstrate sufficient maturity and independence to have their decisions about particular treatments respected.[15] Given variations in both jurisprudence and legislation, it is important that health care providers have regard to the law in the jurisdiction in which they practice and consult as needed to do so.

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