PEDIATRIC ASSENT AND CONFIDENTIALITY IN CLINICAL PRACTICE

LAURENCE B. McCULLOUGH, PhD
AND
FERNANDO STEIN, MD
My objectives, and our objectives with you together this morning, are, first, to identify the components of pediatric assent. This is a very important strategy for decision-making with children, especially adolescents, that's been developed in the literature and then endorsed by the American Academy of Pediatrics. And in their endorsement, actually, they gave it further development. We'll then look at the nature and limits of the obligation of confidentiality, that is, your obligation to prevent unauthorized access to information about your patients. Then we'll give you a six-step workup that we use in our teaching here at Baylor to identify and manage ethical issues in clinical cases. And then together we'll take that workup and apply it to some cases that raise issues of assent and confidentiality in clinical practice.
The concept of pediatric assent was developed in the 1980s, primarily to address decision-making of adolescents with cancer. During the 1980s, when I was living in northern Virginia and teaching at Georgetown Medical Center in the Kennedy Institute of Ethics, I had the good fortune to meet Sanford Leikin, who was then Chief of Hematology/Oncology at Children’s Hospital, National Medical Center in Washington. And Sandy gets the credit for being among the leaders in pediatrics who developed this concept. And I remember him telling me about some of his patients who he said literally, as they got out of the car in the parking lot at his hospital to come in for their chemotherapy, would vomit before they’d even been treated, and would say to him they just couldn’t do this any more. And he began to wonder about what weight he should be giving to children’s decisions, and in most cases to discontinue treatment, but not exclusively. Then he began to develop the idea that children should be involved commensurate with their ability to make decisions. That is, the capacities that are required to participate in decision-making: to pay attention to what your physician and other members of the team are saying, to absorb and retain that information and to recall it, to think through the consequences of your decision, to evaluate those decisions, and then to express a preference. Adolescents are increasingly capable of those behaviors, starting around thirteen or fourteen and as they mature. And especially kids with chronic diseases, at least with respect to their chronic diseases, seem in many cases to acquire these capacities perhaps more rapidly than their peers. And so what he began to do was develop the concept that kids should be able to participate, and their decisions should be taken very seriously. And that when their preferences were well formed, the pediatricians should be willing to accept those and indeed become an advocate for them with parents. And in 1995 the Bioethics Committee of the American Academy of Pediatrics endorsed this concept and actually spelled it out. “Patients should participate in decision-making commensurate with their development. They should assent to care whenever reasonable.” Obviously, if they are legal minors, the power and legal authority
to consent for them still rests with their parents, so one can’t use the word “consent,” one has to use the word “assent.” And parents and physicians should not exclude children and adolescents from decision-making without persuasive reasons. Which turn out to be few. As a rule, children should be involved in these decisions.
Components of pediatric assent:
- Help patient achieve a developmentally appropriate awareness of his or her condition
- Tell the patient what to expect with clinical management
- Assess patient’s understanding and factors influencing how he or she is responding
- Solicit an expression of the patient’s willingness to accept proposed clinical management
  - The patient’s response should be weighed seriously
  - If patient to be treated over patient’s objection, tell the patient: no deception

What are the components of this? The Academy has spelled these out very nicely. First it’s, “Help the patient achieve a developmentally-appropriate awareness of his or her condition,” that is, using a vocabulary and concepts appropriate to the age and developmental capacity of the child. “Tell the patient what to expect with clinical management.” This is very important. I have personal experience of this that dates from 1956, the Dark Ages of involving children in decisions of pediatrics. I broke my nose when playing hockey on a pond near our house in Needham, Massachusetts. I hadn’t learned how to stop yet, which is a very important skill when you’re playing hockey, as I learned because I stopped by smashing into my neighbor friend Johnny Novak’s cheekbone. His cheekbone was just fine. My nose was spewing blood. We made a face off circle with the blood and discovered that blood doesn’t melt when you skate across it. So I fell and banged my head, I think, not my nose. And basically since it’s filled with rocks, coal, and swirling dust, there was no injury caused. My parents were of the belief that if you weren’t a Harvard doctor, you weren’t a doctor. So from Needham to Mass General Hospital, which is about fifteen or sixteen miles, I think, we passed lots of good hospitals on the way, and I was taken there and prepped for surgery and the like. But the previous summer I had had a near drowning incident off the shores of Cape Cod. I was caught in an undertow and pulled out several hundred yards and had to swim up through thirty or forty feet of water. And it was a very unpleasant experience. And when the anesthesia mask, or ether mask, whatever it was back in ’56, was put on my face without any warning, I felt that I was drowning. So I slapped the anesthesiologist. To this day I don’t know if I got him. I kind of hope I didn’t. When I woke up, they had me strapped me down, head to toe and of course as soon as they took the straps off, I left the hospital against medical advice, as I learned later to call it, and actually got as far as the lobby of the
hospital before they caught me and took me back to my room. Obviously we don’t treat children that way any more. We explain things to them and get them oriented to what’s about to happen to them. So this is actually a concept very close to my heart, as you can understand. You assess the patient’s understanding and factors influencing how he or she is responding, for example, anxiety about their illness. But also parental pressure, one way or the other, needs to be taken into account here. And then solicit an expression of the patient’s willingness to accept the proposed clinical treatment. The patient’s response should be weighed seriously and if the patient is to be treated over the patient’s objection, the patient must be told. No deception is permitted under this approach. And obviously if the patient is physically resistant, that problem has to be dealt with. We were very influenced by Sandy’s work at Georgetown, where I taught in the Pediatric Intensive Care Unit. I remember vividly two cases from the mid-1980s where we began to apply this concept. One was a young man who had lost his left leg below the knee to bone cancer, and he had widely metastatic disease at that point and was hospitalized. And basically the only thing that was available to him was a Phase I trial. His parents felt that he had been through enough and declined that. But on rounds, we said, “Well, here’s this concept that Dr. Leikin is developing. It seems pretty good. Let’s talk to him and see what he would like.” It was about four days before Thanksgiving, and he said one of his major goals before he died was to get out of the hospital and get home for Thanksgiving dinner, so that his parents and his siblings could remember him that way rather than in a hospital bed. And so he said, “I’ll give it a try.” It was explained, “Probably not going to do any good. We don’t know the nature of the Phase I trial.” But he said he wanted to do it anyhow. As soon as his parents heard that, they were obviously very moved and supported him. And he did take several rounds of the treatment. I’m not sure if it did any good, but it did get him home for Thanksgiving morning, at least; and he came back in the hospital that evening and died with his family around him. But that wouldn’t have happened, and he wouldn’t have been able to give the gift of that memory to his parents and his siblings unless we had gone and asked him. Almost at the same time there was a young woman, almost the same age, dying very painfully, even despite the best management, having a lot of discomfort from metastatic cancer. And her mother wanted everything done for her. And she wanted to stop. And when we found out that from her, and presented that to her mother, and her reasons, her mother was at first resistant. But then as she thought about it and talked with her daughter, she came to agree with her daughter’s decision. So it goes both ways. It’s not necessarily designed to support children exclusively when they refuse treatment, but sometimes they may want things that their parents are disinclined to have for them. So it’s a very powerful concept, and as we’ll see shortly when we get to the cases, has a reliable clinical application as one thinks it through.
Our next topic for this morning is confidentiality. This is a perennial and persistent and day-to-day problem in the practice of pediatrics because parents rightly need to have information about their minor children in order to consent for them for treatment. Confidentiality is the obligation to prevent unauthorized access to information about the patient. And that’s quite different from privacy. In the United States we are all aware of the new HIPAA regulations, the Health Insurance Portability and Accountability Act – which actually sounds like an upper airway spasm when you say it, but actually induces central nervous system seizures in hospital administrators and all of us who have to deal with it. There’s real confusion about privacy and confidentiality. And what people cite when they’re concerned about privacy in the hospital is all the people who can see your chart when you are in the hospital. And this dates back to an article by Franz Ingelfinger called “Arrogance” in The New England Journal, which he was the former editor of that journal. And it’s about his experience being in a clinical trial for his cancer at Mass General, and the enormous pressure he felt, as a patient of his own doctor, to enroll in his colleague’s trial. But in the course of the article, he notes that he got curious one day with all the people who were coming by his room to see him and he figured out that something like 130+ people had authorized access to his chart. Authorized. They were all under an obligation of confidentiality to protect that information. So while his privacy may have been at risk – people found out all sorts of things about him that they otherwise wouldn’t know – it was not really at risk because everybody who found that out was obligated to keep that from getting into unauthorized hands. So that when physicians consult with each other, when nurses talk to physicians or other nurses about patients, everybody is under the same obligation of confidentiality. The obligation concerns not letting people who have no authorization for that information to get at it. Now this has been recognized throughout the history of
medical ethics, around the world, as a very strong obligation. In the ancient West, in the Hippocratic oath, the sentence that addresses confidentiality essentially creates an obligation for which there are no exceptions. And it’s not only medical information; it’s what you even may learn in social contacts with your patients. So it is a strict obligation. You are prohibited from releasing any of it. But it was a very easy obligation to keep because there were no written records. All the records were recorded in the physician’s central nervous system, so as long as he – they were all men in those days – didn’t say anything to anybody, the information was safe. In eighteenth century Great Britain, among other places, with the rise of the modern hospital, especially as a teaching facility, written records began to appear. Physicians kept written diaries of their patients. There were official hospital records. And oftentimes those records were dictated to medical students who would then write them down. That, and bedside education, was the basic clinical teaching of medical students in those days. And the issue arose for physicians in that era, “We’ve got a written record now. Are we obliged to protect it?” And John Gregory, a very important Scottish physician of the eighteenth century, makes the argument that we still have the same absolute obligation to protect it. Starting in the late nineteenth and early twentieth centuries, a series of legal cases began to emerge that slowly, legally, began to put constraints on the obligation of confidentiality and the rising ability to deal with public health threats, especially that patients with infectious diseases pose, also became a concern. Obviously the public health threat is easy to understand. If I pose a threat to the health of others, and are exposing them to serious health events without their consent, that’s not ethically permitted on my part and any claim I would have to confidentiality would collapse if it was necessary to share the information with others to protect them.
Confidentiality -2

- Exceptions based on competing values (vary among legal jurisdictions)
  - Promote public health and safety
    - Reporting child neglect and abuse
    - Reporting communicable disease
  - Public interest demands disclosure
    - Dangerousness to others
    - Gunshot wounds

So the exceptions that have emerged over time are public health and safety. Obviously one affecting pediatrics is reporting child neglect and abuse, including suspected neglect and abuse. Obviously this is a tremendous threat to the privacy of families and to their integrity as a unit, and there’s growing concern in many communities around the United States, at least, that perhaps the pendulum has swung a bit too far. I’ve got a friend who teaches ethics at the University of South Carolina Medical Center and in Columbia, South Carolina, he reports there is growing concern in the African-American community that they seem to be reported more frequently for abuse and neglect than Anglo parents are. It’s a perception, but obviously a perception that can drive behavior. And obviously reporting communicable diseases to protect the community is important so that contact tracing can occur. That of course can be done without releasing the name of the index case. People need to know they’ve been exposed and to get appropriate management. Public interest also demands disclosure. Dangerousness to others in one’s behavior. And I’ll talk shortly about the famous Tarasoff case from the State of California. And for those of you from Texas, I’ll explain Tarasoff does not apply here. That is, Tarasoff created a legal duty to warn when patients’ behavior, not their disease state but their behavior, is a danger to others. And then you are obliged to report – this usually applies to emergency department personnel – gunshot wounds. Now this is clearly an extension of the police authority of the State. It overlaps with public health concerns. But this is obviously an attempt – the assumption is that if someone has a gunshot wound, it occurred almost certainly during criminal behavior, and we need to know about that and indeed obtain the bullet or missile so that it can be used for purposes of evidence.
Now, when you’re dealing with older adolescents, you come across the concept of what’s called the mature minor. When the minor is mature enough to be unaccompanied by an adult for his or her examination, confidential information should not be provided to parents without the patient’s consent. So it’s the same exceptions as for adults. And the Academy calls for the same level of confidentiality for adolescents as for adults. So one tries one’s best to maintain confidentiality here. The immature minor, who is a child not capable of making decisions on his or her own, confidentiality may be breached when necessary to enable a parent to make an informed decision, or when necessary to prevent harm to the patient. And we’ll see one of the cases that Dr. Stein and I will discuss with you, precisely this borderline issue is going to have to be addressed. Those of you from different jurisdictions or other countries that may have this covered by statute, you need to familiarize yourself with this. In the United States, medical practice is governed by the states and very little of it is governed by the federal government in Washington. They control drugs and dangerous substances, but licensure traditionally in our country has been done by the states, and so there is variation among the 53 jurisdictions. Other countries license centrally, and there is a single jurisdiction, making life either more or less complicated, depending on how you think about state power.
Now, when patients pose a danger to others, there are really two basic different positions in American law. There has always existed a permission to warn. That is, you are free to notify the endangered party that, “I have good reason to think you are in danger. You should take some measures to protect yourself.” The question is whether there is an obligation, that is, a strict duty to make such a warning. In 1976 the Supreme Court of the State of California created such a duty in that jurisdiction. This was a case of a man, I believe his name was Prosenjit Poddar. He was a student at the University of California at Berkeley, and had come there from a country in South Asia, and was dating Miss Tarasoff. They apparently kissed several times on dates. In his culture, that he took to be tantamount to betrothal. She, as a typical American, put no stock in it whatsoever. And when they ended their relationship, he became – oh, it’s, you live in a multicultural society; you’ve got to be careful. And she ended the relationship. He became very despondent and depressed and actually went to get counseling from the campus psychological counseling center. He expressed his anger toward her, and the campus psychologists thought that he did pose a danger to her and they notified the campus police, who detained him for questioning, thought that he was not a danger, and let him go. So the psychologist exercised the permission to warn. The campus police were involved. They reached a judgment he was not dangerous. And did not notify Miss Tarasoff. When she returned from a holiday, he murdered her in revenge for breaking up the relationship and her survivors brought suit against the Regents of the University because they are the corporate entity that’s responsible for the University system. And when it got to the Supreme Court in California, they ruled that the public peril creates a limit on patient confidentiality. So what they said was, “Patient confidentiality ends where the public peril begins.” This of course had a terrific impact all across the country because the
California Supreme Court is regarded as one of the leading and most scholarly of the state Supreme Courts in the United States, and so other states often look to it and follow its precedents, although they are under no obligation to do so. And that includes Texas. The very next year, 1977, Texas passed a statute explicitly aware of Tarasoff not creating a duty to warn in such cases in Texas. And in a case decided by the Supreme Court in Austin in 1999, that originated here in Houston, called Thapar versus Zezulka, the Estate of Thapar brought suit against Dr. Azulka who had not warned Mr. Thapar that his son-in-law, I think it was, or stepson, was intent on killing him because he exercised the permission to warn negatively. That is, did not warn. The stepfather, Mr. Thapar, was subsequently murdered. And the case went through litigation up to Austin. And the Supreme Court said, “The Legislature did not create an exception in this case, and we are not going to create a duty to warn because it would not be fair to physicians.” Now when I teach this to Baylor students and residents, I explain, “This is an example of lawyers being fair to doctors.” And I get the same reaction from them I’m getting from you. Well, turns out they were being fair. They said, “Look, this is a catch-22. If we create a duty to warn, and doctors warn, then they’re liable to civil damages under breach of confidentiality.” Which in fact are very minor, and very few cases. Nonetheless, it’s a real exposure. “Otherwise, and if they don’t warn, and we create a duty, then they are liable to even more significant risk and exposure. That’s not fair. We’re not going to do it. And besides, the Legislature didn’t carve out this as one of the exceptions in the statute.” And as a “small c”, conservative judiciary – they’re also a “capital C” conservative – but many states defer to the Legislature. And that’s good jurisprudence because the main public policy bodies in the American form of democracy are the legislatures. When they have spoken, the courts are to defer to them unless there’s some very compelling constitutional reason to the contrary, and the Court couldn’t find one. A subsequent case involving HIV infection, where a clinic did not tell a patient’s spouse that he was HIV-positive, which she subsequently contracted from him, she brought litigation. Similarly the Court ruled, “There is a permission to warn, but no duty.” And there in Texas we actually have a statute that does create a permission to warn an HIV-infected patient’s spouse. It is silent on other human beings who may be exposed from blood-borne pathogens, or semen-borne pathogens, or other forms of infection from this patient. You may warn, but you’re not given any legal protection if you do. So Texas tends to defer to the medical community in this area and give considerable protections. And we’ll see that will become an issue in one of the cases we’re going to look at.
Reproductive medicine is an area fraught, obviously, with ethical controversy. Here it’s important to appreciate that in American law, which strongly shapes practice in this area, the concept of privacy is what shaped this law. Now the constitutional concept of privacy is read into the Constitution of the United States and the Bill of Rights. Privacy does not appear there as a word anywhere. But in the Fifth Amendment, I think it is, against illegal searches and seizures, there’s obviously an implied privacy of your home and property. And other amendments to the Constitution are read as implying a right to privacy. In 1963 the first of these cases reached the Supreme Court from the State of Connecticut, where Connecticut had outlawed the prescription of birth control and devices to married couples in order to prevent promiscuity. Obviously something interesting was going on among married people in the State of Connecticut during the 1950s and ‘60s. The Supreme Court struck down the legislation. It was a wonderful classic American case. The doctor was fined $100. The director of the Planned Parenthood Clinic was fined $100. Because it was not a criminal offense, it was a civil statute. And so a $200 case reached the Supreme Court of the United States. And the law was overturned. And Justice Douglas, a very prominent liberal jurist, I believe appointed by Franklin Roosevelt – Justice Douglas sat on the Court for a long time because he was appointed at a very young age – he ruled that the marital bedroom is a private place, and the State may not intrude there unless it has compelling reason to do so. And he said, “If the State of Connecticut wants to prevent promiscuity, it has lots of measures. It can merely prevent the sale of birth control devices or drugs, and not interfere with anybody’s privacy whatsoever.” So it was much too intrusive. Then he said something extremely important for medicine. “The doctor-patient relationship is protected by privacy.” Now in the law that means there’s a zone of decision-making and behavior into which the State may not intrude without compelling reasons. And he said the State doesn’t have compelling reasons because it can
achieve its goal in another way. And what he left out, and what all subsequent privacy doctrine covering contraception and later abortion, in the famous Roe versus Wade case, is the age of the patient is not mentioned in these cases. So privacy extends to reproductive decisions, regardless of age. And hence you get the conundrum, in some jurisdictions, as low as the age of 14 or 13, young women can make decisions about contraception or termination of their pregnancy, but they can't make decisions for medical management if they're not a mature minor. And so, because the mature minor concept rests on the capacity to make decisions and consent and assent, privacy makes no reference to that. So if you are wondering why reproductive decisions are special and drive you crazy when you're trying to think, “This young woman or young man really lacks capacity to make decisions,” but nonetheless gets protection, that explains why. Texas has a parental notification law. These have been upheld by the Supreme Court as not constituting an undue burden on decision-making. It allows for judicial bypass. The young woman can go to a judge and explain her reasons for why her parents should not be involved, that is, just simply notified. They don't have rights of decision-making. And the bypass is working fairly well. Most judges are granting this. Including one case that reached the Supreme Court in Austin. The Academy calls for respect for confidentiality within legal limits, and encourages parental involvement with the patient’s agreement. So obviously a strategy that is trying to balance the concerns of confidentiality, privacy, and the real problem of children whose capacity to make decisions lacks maturity.
Now how does one take concepts like this and put them into clinical practice, which Dr. Stein and I are about to do for you. Let me just explain a simple, a six step workup we use in our teaching here at Baylor with our students and residents that works really well. It’s a way to organize one’s thinking, and to reach reasoned judgments about how to handle conflictual situations, and also how to prevent them from occurring. Obviously the first is information gathering. The cases we are going to describe to you are brief, and we’ll ask your indulgence in that. But normally one has to undergo a thorough information gathering process. You then identify the ethical obligations of the physician to the patient on the basis of four ethical appeals. What are the consequences for the patient in terms of protecting the patient’s health and well-being? And for others who may be affected, obviously in pediatrics that includes parents, also other people with whom the child may be engaging in behavior that could affect their health. What are the rights of the patient? That is, to make his or her own decision, and to have those taken seriously under the concept of pediatric assent. The virtues of the physician are extremely important. Two at least are really worth considering. One is integrity. That is, physicians should practice medicine consistent with standards of intellectual and moral excellence, and not compromise those. So Dr. Weisman’s presentation on preventing RSV infection, you should not compromise on those infection control standards ever, because that’s what integrity requires in order to protect children from preventable infection. So integrity is the bedrock virtue, and has been recognized as such throughout the history of medical ethics. The other is compassion. I think that will be relevant to the cases. It is to recognize when patients are in pain or distress, and to respond to try to relieve that to the best of your ability. Justice concerns allocation of resources. I don’t think that will come up directly with the cases Dr. Stein and I will discuss with you. This is a major issue in all countries. In the
United States, we do spend about 14% of our annual gross domestic product on health care. In the year 2000, that was one trillion, three hundred billion dollars. That is a number I can say. I have no concept of it. It’s too huge for my poor philosophical mind to get itself around. It’s an enormous sum of money; but even so, we’ve got over 40 million people without insurance and regular access to health care. Many of them children. Obviously a major public policy issue that may or may not get into this election cycle in the United States.
Next is to look to where these appeals converge. How do they reinforce each other to create obligations? And then where are they in conflict? And then when they are in conflict, to give an argument for how those conflicts should be resolved.
And then why one should act in a particular way. That is, which ethical appeal or set of ethical appeals that reinforce each other should take precedence over the others and how might one reasonably critique that argument so one is aware of the limitations of one’s ethical judgment in the clinical setting. And then a very important clinical skill is to think about how one might have prevented that ethical conflict from arising. To look at one’s own practices. To look at organizational policies and practices to see if they need some revision and updating, so that they are less a source of ethical problems than not. Let me just give you a simple example of this. When I first came to Baylor and started teaching, not only at Children’s but also at the Veterans Affairs Hospital here in Houston, we needed to revise the DNR form because it wasn’t giving enough flexibility to respect patients’ and families’ choices about sort of a step-wise approach to letting patients die at the end of life. Patients and their families were sometimes comfortable with modified intervention, then less intervention. The form really didn’t allow for that. Actually modeling on a form that had already been developed at Children’s, we adopted a new form. Then within about a year, there was a concern being expressed that pain management of patients who were dying wasn’t as good as it should be. And we looked at the form, and analgesia and seizure control and other things weren’t on there. So what we thought was a really good policy had actually inadvertently created a problem for us. And that’s what one needs to watch for in practice. I’ll ask Dr. Stein to come up.
Discussion of Cases:

Dr. Stein: What I would like to do is what we've done in previous years when we've done the one hour that is required for ethics, and that is ask you to express an opinion and participate in the discussion. So I'm going to present the first case. Mind you, these are real cases that we've had to wrestle with in our intensive care. MS is a 17-year-old who presents to the pediatrician with profuse menstrual bleeding. Her family practitioner has used hormone therapy without success. You have been her pediatrician since birth, and she is asking for your help because she has now converted to being a Jehovah's Witness. Her parents do not know, and she wants you to arrange for a hysterectomy instead of a curettage so that she does not require a blood transfusion. This patient actually presented to our intensive care because she had a hemoglobin of 7, and she was about ten days shy of turning 18. And we had to make some clinical decisions. So, would you like to try starting with gathering more information, if you need more data, which is step one of the workup? The usefulness of this is that it allows all of us to have at least a method of analysis. I cannot guarantee you a happy answer, but at least a method of analysis. Any more information anyone wants?

She had a normal blood profile for preexisting clotting conditions.

In terms of having an age of maturity, our position was that the accidental 10 days from being of maturity age and therefore legally able to refuse care was most irrelevant. I mean, in ten days she could be just refusing all care and allowing herself to die if she wanted to. So if we managed to keep her alive until then, we would manage to not have any type of ethical problems. If she wants to die, she goes.

Her father was a philanderer alcoholic who was not adept to any type of church-going. Her mother was a very passive person. And around the age of 13, she had converted into being a – or adopted the Jehovah’s Witness religion, and had been faithful to it ever since. Well, perhaps that’s one of the important questions. Is this truly a reproductive decision that she has the freedom to make because of the age? But in fact she's not pregnant. But it is one of the questions.

Why don’t we continue in the stepwise fashion, and I think that we can follow that. What are the consequences of one action versus another? Her goal is to not receive a blood transfusion under any circumstances. And the consequences clearly are those of sterility. The comment is that persons of the Jehovah’s Witnesses faith prefer to die than to accept a blood transfusion. And for many of them, receiving a blood transfusion is akin to dying.

Even if she underwent a hysterectomy, we couldn’t really guarantee that that procedure could be successfully completed without the need of a blood transfusion. Would you like to comment?
Dr. McCullough: The question is, can you perform either alternative bloodlessly, and is that consistent with the integrity of clinical practice? Now keep in mind that before HIV, a lot of surgeries used a lot of blood. And after HIV, when blood-borne pathogens became dangerous for operating room teams, we learned how to do a lot of blood-sparing and even bloodless procedures. So the question is whether her request is medically unreasonable. That is, could you do bloodless management without having to do the hysterectomy?

Dr. Stein: It is important to note that in our institution, when Texas Children’s was part of St. Luke’s, and that’s why I refer to it as our institution, Dr. Denton Cooley published a series in 1985 of 1,000 consecutive cases of open-heart surgery without the use of blood in Jehovah’s Witnesses. And the study is a landmark study because it compared as best they could with matched controls patients that underwent the same operation, roughly of the same age and same type of condition, and the mortality and morbidity of the group that received no blood transfusions was significantly lower than the group that had received transfusions. That has been repeated in some other regions of the country with the clear implication that maybe – and I’m emphasizing that word – somehow people are more careful with those patients in whom we are not going to be able to transfuse. Fewer blood tests are obtained. Fewer lines are applied. So my conclusion after reading this study is that when I need coronary heart surgery, I will say that I am a Jehovah’s Witness, and I will convert in the recovery room.

Dr. McCullough: But that’s obviously her integrity, and the integrity of her religious beliefs, has to be respected. The question is, is it against the integrity of clinical judgment and practice to offer her bloodless management, or blood-sparing management, of her problem?

Dr. Stein: Okay. I’ll spare you the pain so that we can go on to the next case. What – everything was tried. She had an infusion of a combination of formaldehyde and other things that obstetricians do to try to stop the bleeding. And that didn’t work. But we managed to keep her alive until she was of majority age, at which time she said, “Well, I’m ready to go.” Refused blood transfusion. We watched her in despair as her hemoglobin went from 7 to 4 to 3 to 2. Stopped bleeding. And the hemoglobin went from 2 to 3 to 4 to 5. Which always is a reminder to us, what is our threshold of intervention, and the effectiveness of such? And how much we truly know. Her life was clearly endangered. I mean, we thought she was going to die. But she didn’t.

Dr. Stein: In this second case, GQ is a 13-year-old male. He comes to your office to help him deal with his homosexual tendencies. He confides that he has been having homosexual thoughts ever since he can remember. From the age of 11 until now, he has had multiple male friends, and with many he has engaged in various types of unprotected sexual activity. He also wants to know his HIV status, and demands absolute confidentiality from you.
Dr. McCullough: Obviously this case concerns the limits of confidentiality. So what would be the consequences for him and for others of respecting his request?

Dr. Stein: The question is whether his choice is truly a choice, or whether he has been the victim of sexual abuse by older males. And as best as he could tell, he has always felt that way, and he’s never been abused, and all of his partners have been peers, friends, and people he knows. He appears healthy.

Dr. McCullough: So he needs to be counseled about his risky behavior, and how to protect himself and his sexual partners.

Dr. Stein: The question really, in managing this case, is, if he has insurance, he probably is under his parents’ insurance. And when a blood test appears, and frequently insurance bills have exactly what tests were obtained, his parents are going to know what type of testing he underwent and why.

Dr. McCullough: The question is, is there a clinic where he could go and get confidential HIV testing? But there’s a prior ethical question. It is, should his request for confidentiality be respected? For example, might his parents, with your guidance and maybe advocacy, be supportive of him? They have to obviously deal with the kind of information they are about to get, and need a chance to work that through. But there’s an assumption here that his parents won’t be supportive. Well, they might be. So that would have to be explored, right. So the question is whether that request for confidentiality should be respected. He’s only 13.

Participant: How did a 13-year-old get to your office without his parents actually even knowing he was there?

Dr. Stein: Which is one of the elements of this case. Remember that in our workup, a minor that is able to access your office on his own and request medical care, is considered to have the rights.

Dr. McCullough: If this case – this case, in Texas, this patient has no spouse. So that statute that gives you permission to warn his spouse doesn’t apply. The law creates no duty to warn anyone. All right. So if you don’t try to find out from him who his partners are and warn them, you’re in no legal trouble at all in Texas. You might be in other jurisdictions, but not in our state. And you still have the issue of, is he mature enough to make these decisions? And should you involve his parents? Now I think the literature that has looked at the capacity for assent for children without chronic conditions sets it usually around 14 or 15 where children might be capable of the conditions of assent. Legally he might be a mature minor. Or the law is trying to solve the problem of, legally who is in charge of his care, himself or his parents? It doesn’t settle the ethical issue of whether he has enough capacity to make his own decisions.
Dr. Stein: For your information, in the City of Houston, the Covenant House and the Montrose Clinic provide this type of service free of charge and with, in the first case, with absolute confidentiality, and in the second with anonymity. So there is — and, free of charge.

Dr. McCullough: Well, why do you want to maintain confidentiality in cases like this? You want to encourage patients who are at risk for HIV infection to come see you, and to learn how to, first of all, prevent their getting it. If they have it, to prevent its spread to others. And of course, if they have it, to get treatment for it started. And to learn how to live with that disease and its long-term clinical management. So there are lots of good consequences for patients of maintaining confidentiality in this setting. And that's what drives offering the anonymous testing. The assumption is, if we don't offer that, people aren't going to get it all, and then we are going to have a worse public health problem than the one we already have. So while it's not the best way of management among the least worst choices, it's the least worst.

Dr. Stein: Just in passing, how many in here think that his homosexual acceptance or declaration should be explored further? Just a show of hands. Okay. Let me give you an example. What if this same child came and said, “I really love to look at girls of my age. And I have engaged in multiple unprotected sex with some of them.” Granted, you want to counsel about sexually transmitted diseases. But would you explore his heterosexuality at that stage? Well, I think that we are likely to see, if not necessarily this exact type of case, cases where the issues of confidentiality, trying to help the child at the same time that you maintain their integrity in that regard, come to your office.

Dr. Stein: In this third case, AL is an 11-year-old female with acute leukemia. She has always been a back to nature type and refuses chemotherapy because she wants to try natural remedies offered by a Latin American shaman by the name of Lela with a great reputation for cures of cancer and arthritis and AIDS. Let’s take the paradigm of analysis. Any more information? She is afraid of everything. She has seen the Miracle Network and all of the bald kids, and she’s heard of people throwing up when they get chemotherapy, and she knows that none of that is going to happen if she accepts Lela’s remedies. And she is even going to be cured. How do her parents feel about this? They want to force her into therapy. She was just diagnosed. She needs induction. The suggestion is that she should be educated and reminded that she may not be able to enjoy nature, rather, she would become part of it if she doesn’t accept the therapy.

Dr. McCullough: That’s an interesting strategy. Because what you are appealing to the patient is to say, “Look, you’ve told one thing you really value is living as much as you can in accord with natural rules, whatever they might be. And don’t you see that what your goal in that is to enjoy nature, isn’t going to be achievable if you die prematurely.” So what you are doing is listening to what the patient’s own values are and trying to point out inconsistency with those values. Now
Pediatric Assent and Confidentiality in Clinical Practice
Laurence B. McCullough, PhD and Fernando Stein, MD

being a teenager is defined in part as instability of values, and not infrequently acting inconsistently with your own values. That’s going to have to – right, there is a real issue about her level of maturity and ability to even see that as a problem. And the rest of us are supposed to be governed, as adults, by the principle of rationality. When we are told there are contradictions in our lives, we are to correct our behavior forthwith and without question. Which Dr. Stein will tell you I do in every single case. And he has pointed that out to me over the last fourteen years. So I am a flawless example of how one corrects behavior in this area. This is really a hard challenge. But she’s got to think about what it means – if she doesn’t have treatment, what’s the almost certain outcome?

Dr. Stein: But assuming that all of your coercing and educating fails, which is the rule rather than the exception in a child at this age who is frightened, should the parents force her into therapy? And I have a follow-up to that question, to see if we can explore. If the tables were turned, and if it were the parents who were the ones that are refusing the treatment and are choosing some alternative form of treatment, they probably would be criminalized. They probably would be prosecuted as child neglecters, or abusers, or whatever the term would be under the circumstances.

Dr. McCullough: If you think about the capacities for assent, she’s only 11. Her developmental capacity to make decisions is markedly diminished. You have to explore it with her. But the usual assumption is that children who have been living with chronic conditions, who maybe are a little older, need to be taken very seriously. But she’s just found out. She also holds alternative health beliefs. So it’s not clear she’s embraced those with a level of maturity that commands final respect, the way it would in the case of an adult like you or me, who might hold those beliefs. Does she really have the level of maturity? Now what the Academy’s concept of assent says, that if your clinical judgment is that her level of developmental capacity isn’t sufficiently adult-like, then what you would explain is that we can’t take your preference as controlling. Your parents want you to be treated. So we’ve got to work on how we’re going to have that happen. Remember, you have to tell her you’re going to do that. But from the Academy’s own position, it’s unlikely she’s going to meet the conditions of assent that requires us to respect it. I mean, when you’re that age, you are experimenting with ideas. There’s no way in the world you could say that’s a stable belief because six months from now, she could give it up. There’s a larger historical context for this that’s worth considering. And that is that up until about the nineteenth century, in the West at least, before the triumph of microbiological medicine and its concepts of infectious disease, it was routine for the clinical judgment and treatment plans of doctors to be challenged by their patients on intellectual grounds. “Do you know what you’re talking about?” was more or less what patients would say. With the rise of modern science, there’s a claim that you do know what you’re talking about, and that the claims of alternative health approaches that don’t have evidence that they have good outcomes are discounted as intellectually lacking authority. When a life is at stake, you
combine that to get a very powerful argument that her preference should not be taken as controlling. Now there are lots of ethical issues you have to address in how you carry out that judgment, but that would certainly follow here, wouldn’t it?