

Considerations of Informed Consent by Proxy in Pediatric Optometry

Paul Abplanalp, PhD, OD,^a Richard T. Hull, PhD^b

^aCollege of Optometry (Ret.) Nova Southeastern University; ^bDepartment of Philosophy (Emeritus) SUBT at Buffalo

ABSTRACT

The ethical and legal doctrine of informed consent may be applied to modern optometric practice. We describe here a hypothetical case involving a child with an intermittent exotropia. Using contrived dialogs as a heuristic tool, we show that the process of obtaining informed consent from a child (or any other individual with limited competence) can yield an added dividend in the form of willing cooperation by the child. Use of dialogs also demonstrates that the process of obtaining Informed Consent is actually much more complicated than the typical terse record entry would suggest.

Keywords: Heuristic Dialogs, Informed Consent, Pediatric Optometry, Surrogate Decision, Willing Assent

The doctrine of informed consent requires that a patient be directly involved in the determination of the elements of their health care. To some extent, the doctrine is driven by legal considerations¹ but we prefer the benevolent guidance that has been articulated by the British philosopher, Edmund Burke. Burke has admonished that, “It is not, what a lawyer tells me that I may not do; but what humanity, reason and justice, tell me that I ought to do.”² This

benevolence impels the inclusion of the patient/recipient in deciding whether or not to consent to certain procedures. The patient must be informed, in understandable terms, what the risks and benefits of the contemplated procedure are, and the optometrist’s role in the process is an educational one.

One could claim that by the simple act of making an appointment with an optometrist, a putative patient *implies* her consent to all of the well-known elements of an optometric examination, most of which have only a very remote likelihood of causing injury. This used to be true, but modern optometry is a very different story. Not only has our profession undergone an enormous expansion of our scope of practice, but these changes have been implemented very quickly, perhaps too quickly. There are those who believe that we should incorporate the fruits of our legislative victories of the last two decades, or so, before moving on, including a greater emphasis on the principles of informed consent.

Enormous bursts of activity followed by quiescent periods of stability are rather common in science. Consider, for example, the staid biological science of evolution. Darwinian biologists considered evolutionary change to be a very slow, gradual, more or less continuous process, but Niles Eldredge and Stephen Jay Gould pointed out that there is no evidence in the fossil record to support the notion of gradualism. Instead, they postulated, evolution was characterized by long periods of stasis interrupted from time to time by intense, relatively short periods of speciation, which they dubbed “punctuated equilibrium.”³ We suggest that the profession of optometry has, likewise, just emerged from a period of “punctuated equilibrium” in the form of enabling legislation that permits optometrists to use diagnostic pharmacological agents (DPAs) and therapeutic pharmacological agents (TPAs). The list of specialties in the 2007 edition of The Blue Book

Correspondence regarding this article should be emailed to paulabplanalp176@gmail.com or sent to Paul Abplanalp, PhD, OD, 33030 Elk Park Road, Trinidad, CO 81082. All statements are the authors’ personal opinion and may not reflect the opinions of the College of Optometrists in Vision Development, Optometry & Vision Development or any institution or organization to which the author may be affiliated. Permission to use reprints of this article must be obtained from the editor. Copyright 2012 College of Optometrists in Vision Development. OVD is indexed in the Directory of Open Access Journals. Online access is available at <http://www.covd.org>.

Abplanalp P, Hull RT. Informed Consent by Proxy in Pediatric Optometry. *Optom Vis Dev* 2012;43(2):60-66

of Optometrists⁴ now includes optometrists who practice *Therapeutic Optometry*. We have reached a point where the available instruments and treatment regimens include some which can bring (mild) harm to patients, even when the procedures are performed correctly. It is particularly prudent, in this professional environment, to enlist the patient as a partner on her own health care team, but there are now and there always have been, better reasons to do this than the avoidance of liability.

A clear and simple explanation of the risks and benefits of a procedure will usually suffice to get the patient's consent to a particular procedure, but what if the patient is incompetent? If this individual is a child, for instance, he may lack sufficient maturity to process the pertinent information. Under circumstances like these, it is acceptable – even mandatory – to involve a surrogate who will be authorized to make the decision on behalf of the child or an otherwise incompetent patient. It is a difficult proposition to recognize when a child has attained sufficient maturity to make decisions about his own health care.

The appraisal of a child's level of maturity is frequently resolved by the entirely arbitrary selection of a specific chronological age as a cut-off point. There are (at least) two flaws with this plan of action. First, no matter what chronological age is selected, there will be many children who mature sooner than this point and many for whom maturation lags behind it. Second, while a child may indeed be insufficiently mature to give consent, at the same time, that particular child may transmit information to the optometrist that deals with the child's emergent level of trust; this judgment also matures at a different rate in different children.

In clinical pediatric optometric practice, informed consent protocols may involve three parties: the optometrist, a decision surrogate (typically, but not necessarily, a parent), and the child. Some optometrists may chafe at the very idea that they need to seek informed consent to perform procedures that they, based upon their extensive clinical experience and carefully honed professional judgments, know full well are in the patient's best interests. On the other hand, there is much to be gained by the involvement of patients in shaping their own health care. Chief among these is willing cooperation.

To implement an informed decision by proxy, a surrogate must be identified. If the patient is a child,

the surrogate is likely to be a parent. In that case, we must cope with some pithy issues.

It would be inappropriate for the surrogate to simply substitute her attitudes and feelings for the child's. The surrogate should base her actions on what she believes would be what the child would want her to do, tempered, of course, by her broader world perspective and level of maturity.

If a mildly invasive procedure is contemplated for a child, it is ill-advised to exclude him or her from the informed consent process altogether and allow the surrogate, alone, to make the decision to consent or refuse. As we will see, it may be that the patient and surrogate are actually dealing with very different issues. We will use contrived dialogs as the heuristic tool to make these points, and we will suggest a distinction between *Informed Consent*, which is what the surrogate does and *Informed Assent*, which is what the child/patient does.

When does an individual cease to be a child and acquire an adult perspective and maturity? It can be very difficult to make this determination, and it has become commonplace in our society to finesse this issue by simply selecting an arbitrary age as a cut-off point. While this may give the appearance of objectivity, the range of experiences to which this monolithic criterion may be applied is simply enormous. In practice, a child may be considered sufficiently mature to deal with decisions on some level but not others. Consider two contrasting examples: inoculations against infectious diseases, and chemotherapy for cancer. The first of these, inoculations, are an immutable fact of childhood life. Many of them are mandated by law, so the issue of consent is rendered moot anyhow. Even were they are not mandated, the risk/benefit ratio is so favorable that refusal to consent approaches the level of culpable neglect. Chemotherapy for cancer is an entirely different matter. There is a significant risk of death whether it is accepted or rejected and there is a virtual certainty that intense pain will be visited upon the child/patient with either choice. A particular child may be sufficiently mature to deal with the conditions on one end of this spectrum, but the same child may be incompetent to deal with issues from the other end of it.

How does any of this apply to pediatric optometry? Optometric procedures do not tend to kill, no matter how clumsily they are done; but the importance of the distinction between consent and assent remains. Each element in the typical pediatric triad – child,

parent/surrogate, and optometrist – has a specific role to play in the process of obtaining informed consent (and assent) for a procedure. These roles and the boundaries between them however, are often vaguely described and misunderstood. The optometrist is expected to deliver pertinent information to the surrogate to enable her to give consent and to the child/patient to enable her to give assent. The parent/surrogate listens to the information provided by the optometrist (O.D.), but this is not the only available source of information that must be monitored. While the O.D. provides information about how the procedure will be done, the child/patient also emits information about how it will be tolerated – or not, and the surrogate would do well to incorporate all these considerations in making a decision. While the proximate purpose of the O.D. is to obtain consent to do an immediate procedure, she would do well to consider how the impact of the current procedure will influence the child’s behavior currently and in subsequent encounters, as well.

All informed consent protocols involve the transfer of information – usually from the optometrist to the patient. Verification that the patient actually received and understood this information should occur before he agrees to the performance of a procedure. An astute observer will, however, note that information is also flowing from the prospective patient to the optometrist, and in the case of proxy consent, from the surrogate to the optometrist, too.

We will argue that the decision process should involve three people: the optometrist or physician, the surrogate and the child/patient. But if a particular child is immature enough to require a surrogate, why would we seek the child’s input at all? Part of the answer to this question hinges upon the process by which we estimate a child’s level of maturity and intelligence. One way by which we can determine these features is to allow the child to participate in the conversation between the optometrist and the surrogate and to pay close attention to what the child says. The child is not being asked to permit the doctor to trespass on her body – the surrogate will do that. What we seek from the child is assent (trust).

The child may, indeed, be incompetent to assess what is being proposed in terms of its health impact and the medical constraints that the treatment entails; that is why the decision is in the hands of the surrogate. But a child – even a preverbal child – is competent to extend or withhold the element of trust,

and a child is likely to be able to transmit information about his level of trust in both the surrogate and the optometrist. It is possible for trust to be withdrawn at any point during the procedure for which informed consent is sought. That is the reason that we regard the informed consent protocol, including assent, as a continuous process.

A notation in a patient’s chart that is made when informed consent is obtained for a procedure is likely to be very terse. It is an entry that is put there as a defensive measure, but its brevity obscures what really happened between doctor and patient as it is filtered through the surrogate. Examine the following dialogs in this context. Both of them are likely to generate identical record entries that merely declare that informed consent was obtained, but they are clearly vastly different from each other.

Case Description: J.W. is a seven year old girl who has intermittent exotropia of her left eye and complains of diplopia. Uncorrected visual acuity is 20/20 in each eye. There is no refractive error in either eye. Acuity in the left eye was 20/20 when a visual examination was performed one year previously. The child’s mother declares that the frequency of deviation is increasing, but it is not yet constant. The clinician has explained to the mother – without the child present – that the child’s left eye may develop a constant exotropia. The clinician has also explained to the mother the importance of prompt intervention to correct the strabismus and preclude the attendant loss of depth perception. The alternatives are a surgical referral or a program of optometric vision therapy procedures. The clinician has emphasized the need for the child’s extended cooperation if optometric vision therapy (OVT) is selected.

Dialog 1

P – parent (surrogate)

C – child (patient)

O – optometrist

P: Molly, Dr. Rush wants to talk to you about the eye examination that you just went through. I want you to pay attention to what she tells you. OK?

C: I hope she doesn’t want me to wear glasses. The rest of the kids at school make fun of me already.

P: She wants to do whatever is best for you, and that’s what I want, too. Why don’t you just

wait to hear what she says before you start to worry about glasses?

O: Hi Molly. Your eye examination went really well, don't you agree? You tried really hard, and you did everything I asked you to do, didn't you?

C: Yes ma'am. Am I gonna have to wear glasses? I really don't want to do that.

P: Molly, didn't I tell you not to worry about glasses? Pay attention to Dr. Rush, like I said. You're going to have to do what she says.

O: (speaking to the mother, but Molly is right there hanging on every word.) Well, as you know, you brought Molly in last year because you noticed that her left eye turned outward from time to time. You are noticing that it turns more often, now, and Molly is experiencing double vision. I am concerned that she may eventually suppress or turn off the left eye to get rid of the double vision, but she will also lose much of her depth perception when she does so.

P: What must we do to correct this condition?

O: There are two alternatives. We can refer Molly to an ophthalmologist who will perform surgery on the muscles that control the position of the left eye. That has a fair likelihood of success although it may take one or more surgeries, and it can be completed quickly; but it is rather expensive. Or we can have Molly complete a program of OVT. This also has a high likelihood of success - but it takes several sessions to control the eye turn and it is highly dependent on the diligence, motivation and cooperation of the patient. It can also be less expensive than surgery. In most cases, some follow-up visits are required about twice per year to maintain the improvement that the therapy generates initially.

P: Which of these methods is better? If Molly were your child, what would you do?

O: We probably shouldn't think in terms of which method is better. Both methods work. The surgery is a quicker procedure, but it is expensive, and surgery of any kind is scary for a child. The therapy may be less expensive, but takes longer to be effective, and the patient has to be conscientious about doing the therapy procedures.

C: Do I have to get an operation on my eyes? I'm scared about that. My friend in school, Caroline, had an operation on her 'pendix, and she said it hurt for almost a week.

O: Well, Molly, we don't necessarily have to do an operation. Instead, we could have you do vision therapy with your eyes so they both work together. But you would have to do this every day; you would have to do this in the morning when you first wake up and in the afternoon right when you come home from school.

P: (addresses the optometrist with Molly present): That creates a problem for me doctor. I don't get home from work for about an hour after Molly gets out of school, so there won't be anybody there to supervise her. And she is not very good about doing any of her chores after school, so there isn't much likelihood that she will do the therapy regularly, either.

O: Well, we could arrange for Molly to come to my office after school and my technician could supervise her.

P: And you are going to do this for free, of course ... ?

O: Oh no, there will be a fee.

P: Does my health insurance pay for surgery, doctor? I'm pretty sure that it doesn't pay for vision therapy.

O: Perhaps we should attend to what Molly wants to do.

P: (addresses Molly) O.K. Molly, which would you rather do? Would you want to have an operation and get it all over with right away, or would you rather do VT when you come home from school instead of playing with your friends.

C: But mom, I am afraid to have an operation. Which would hurt more, Doctor Rush, an operation or the therapy?

P: (Intrusive) The operation isn't going to hurt, Molly. They will put you to sleep and, when you wake up, it will be all over.

This dialog is not going to be entered in the patient's record. It is unlikely that it will even be summarized for the record. The only thing that is likely to appear is a standardized form with the patient's signature upon it that verifies that some sort of consent was sought and given.

The three participants in the dialog above each have a different agenda and none of them addresses the fundamental element of informed consent, *viz.* an appraisal of the risk/benefit ratio.

The optometrist is transmitting technical information about the treatment options for the child's vision problem, but neither the child nor the surrogate is paying any attention to this information. The optometrist is, ostensibly, describing two alternative procedures to the surrogate: surgery or therapy; but she is not presently seeking consent to perform either one of them.

The surrogate is injecting information into the dialog, but this information is almost exclusively about cost and convenience; it has very little to do with giving or withholding consent for either alternative procedure. She attempts to put this decision back on the physician when she asks "If Molly were your child, what would you do?" This is an indirect plea to relieve her of the only real responsibility she brings to the table. The attitude of the surrogate in her interactions with the child are coercive rather than supportive, when she asks, "... would you rather do therapy when you come home from school instead of playing with your friends?"

The contribution of the child (patient) is very interesting. The child is transmitting information about her level of trust in the two "adults"; she also describes, very powerfully, her anxiety. The child rejects the possibility of wearing glasses which is not even one of the alternatives under consideration, but she simultaneously transmits what is, for her, a much more serious issue when she declares, "the rest of the kids at school make fun of me already."

What does this dialog tell us about consent and assent? Any mode of informed consent is undercut by the obtuse attitude of the surrogate who persistently ignores the issue and directs her entire attention to relative cost and convenience – her convenience. The child is unlikely to give her assent to anything, either, because her fears are simply not being addressed. The issue for the child is trust, and the dialog reveals nothing that is likely to enhance this quality.

Things did not have to turn out this way. Consider an alternative dialog involving the same participants and the same issues.

Dialog 2.

C: I'm glad we are finally done with my eye examination, Dr. Rush. I was really getting tired. Did I do a good job?

O: You did an excellent job, Molly. Remember when we started, I promised you it would only take an hour? Well, here you are – all done – and it took only 50 minutes. Most of my patients take more time than that. I'm going to ask your mom to come in, and I will explain everything to both of you at once. Is that alright with you, Molly?

C: Can I tell my mom some of the tests that we did? She mostly listens to grown-ups even when I'm excited and want to talk about something.

O: Let's do it this way, Molly. You tell your mom about the "fun" things you did, and I'll tell her about the other things. If you don't understand something, just tell me, and I'll go over it again.

O.K.?

The (surrogate) parent is retrieved from the waiting room.

P: Well, that took nearly an hour. How did it go, doctor? Will you be able to correct her lazy eye. Will she need glasses?

O: Things went very smoothly. Molly is a bright and cooperative young woman. Why don't I have her tell you about the examination? After that, I will go over the alternative forms of treatment with Molly and you, and, together, we can decide what to do.

C: Well, mom, the thing I liked best was just reading the letters on the eye chart. I did pretty well, didn't I doctor? And on one of the tests, I saw double.

P: O.K. Molly; that's enough. I want to hear what the doctor has to say. You and I can talk about it on the way home.

O: Well, the good news is that Molly's vision is normal in both eyes, but her left eye is turning outward more frequently than it did last year and she experiences double vision when it occurs. If we don't correct the eye turn, she may simply turn that eye off and lose her depth perception in the bargain.

P: What must we do to correct this condition?

O: There are two alternatives. We can refer Molly to an ophthalmologist who will perform surgery on the muscles that control the position of the

left eye. That has a fair likelihood of success, and it can be completed quickly; but it is rather expensive. Or we can have Molly complete a program of optometric vision therapy. This also has a high likelihood of success – but it takes several sessions to complete and it is highly dependent on the diligence, motivation and cooperation of the patient. It is also less expensive than surgery. In most cases, some follow-up visits are required about twice per year to maintain the improvement that the therapy generate initially.

C: When you talk about surgery, that means I will have to have an operation, doesn't it? Will you do the surgery, Doctor? I'm afraid of an operation. My friend at school, Caroline, had an operation on her 'pendix, and she said it hurt for almost a week. But I won't be afraid if you do the operation.

O: No Molly, I wouldn't be the one who does the surgery, but I would do the therapy if that's what we decide upon.

P: I'm the one who makes this decision, right?

O: Yes, you are. But Molly is the one who has to endure the discomfort.

P: O.K, but she isn't the one who pays the bill. My insurance coverage will pay the full cost of surgery, but it is much less generous with a program of vision therapy.

The general tone of the second dialog is substantially different than the first, because the optometrist is actively seeking input from Molly. She gives the child an active role in the exchange of information when she asks Molly to describe the fun things to the surrogate. The surrogate (mother), on the other hand, continues to harp on the expense of the surgical alternative and the inconvenience of the OVT alternative. The child is not attending to the characteristics of the two alternative treatments. Instead, she is developing trust in the optometrist regardless of which treatment mode is eventually adopted. This trust, or assent, is likely to serve the child in good stead by enhancing the likelihood that she will do the prescribed therapy regardless of what time the mother comes home from work. The surrogate's inappropriate injection of the expenses involved places an additional very heavy burden on the child that has nothing to do with her optometric care.

Suppose the dialog continues in the following manner.

O: You see, Molly, we have a kind of conflict here. Your mother and I both agree on wanting to make your eyes work normally. But the conflict is over how much responsibility you are willing to take. If we go with the OVT and you complete them every day, you can avoid surgery, but you will have to work very hard. If we go with the surgery, everything will be over quickly, but it will be more expensive for your parents and a little bit uncomfortable for you

C: You said that if we do therapy, I will have to come back twice a year. Is that so we can be sure it's are still working or what? If we do surgery, will I still have to come back twice a year?

O: Well, Molly, I want to see you about twice a year regardless of which treatment we select, because your left eye is already not as good as your right eye, and we don't want that to get worse. Even if we do surgery, we will probably have to do some therapy to make sure that both of your eyes are working together.

C: Now I feel like I don't know what to say. I know that Mom will make the decision, but I should have something to say about it, shouldn't I?

This dialog continues to develop in a very different manner than the first one, because the child, Molly, is participating more actively. The optometrist is forming a solid fiduciary relationship with the child, and this will benefit all parties when the progress visits begin, because Molly trusts her. The distribution of power has also shifted as represented by the child's final utterance: "... I should have something to say about it, shouldn't I?"

Given this outcome, one may logically ask why there should be a surrogate in the first place, when the child so clearly has a better grasp of the health care issues than the surrogate does. The trouble is that most children are not nearly as mature and articulate as Molly has proven to be, so we need to keep the surrogate in the loop.

The case presented here, as well as the dialog that accompany it are fictitious. As noted earlier, we have employed the dialogs as an heuristic device. Does this tool generate any information that we would otherwise not have gained? We suggest that the answer to this question is, emphatically yes.

The child is not merely giving informed consent to subject herself to a particular procedure. In her view, she is giving consent for a procedure *only if it is done by the attending optometrist*. By contrast, the behavior of the surrogate could better be described as “consent by intimidation”.

An optometrist with a busy practice, upon reading this article, will balk at the prospect of taking so much time just to get started with a procedure and he would be right, of course. Time is a precious commodity in a busy practice and the only way to shorten the process as described in this article would be to exclude the child’s participation. Why would any optometrist go through all of this rigmarole?

Let’s consider, once again, the attitude of philosopher Edmund Burke: “It is not what a lawyer tells me that I may not do (consent - surrogate); but what humanity, reason and justice tell me that I ought to do (assent – child).”

Acknowledgement

We are very grateful to Dr. Deborah Amster for her critical appraisal of the optometric aspects of the case of intermittent exotropia presented here.

Suggested reading:

Recommended curriculum for the teaching of professionalism and ethics in optometry. American Optometric Association 05-31-1996. available from <http://goo.gl/LsLhv> accessed 7-11

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