

PEDS REFLECTION SESSION 2/12/18

Sean Denny, Kevin Roy, Aditya Mantha

Thank you for challenging your classmates (and faculty!) to ponder some extremely fraught ethical issues, specifically who is the responsible decision-maker in a situation where parents are divorced or disagree; and how much information, if any, should a child be given about their condition. Although in some cases the legal decision-making status has been clarified, either by the parents themselves or by a court, proceeding according to legal guidelines alone should be the last resort, rather than the first. The amount of emotional trauma inflicted on the child (assuming he/she is aware of the conflict between parents) is immense (and of course parents – and doctors and nurses – suffer too) when the path forward is not mutually agreed upon but rather legally imposed. You are of course correct that the physician's most fundamental obligation is always to his/her patient. But problems arise when the child's interests are opposed to parental wishes. Sometimes this is inevitable, and a judge must become involved. Whenever possible, it is preferable to resolve such disagreements through a family conference that facilitates mutual understanding of difference, and seeking common ground.

Within the context of no right answers, I personally come down on the side of providing some sort of information to most child patients. Most kids, especially those with chronic illnesses, very quickly develop an impressive medical sophistication. This means that, at the least, they are quite aware that something is wrong (hey, they're in a hospital!). And from an ethical perspective, it is their life that's being decided. I think sometimes physicians avoid talking with pediatric patients about difficult diagnoses not to spare the child, but to spare themselves. Of course, any such conversation needs to take into consideration the factors mentioned above; and should be negotiated with parents whenever possible.

I admired the way you actively engaged everyone in a thoughtful and nuanced discussion. The primer questions you prepared in advance were excellent. These questions, although hard or impossible to fully resolve, are really worth pondering. Engaging in such a process makes us all less likely to indulge pat answers, and more likely to be open to alternative perspectives. Best, Dr. Shapiro

Alexa Love, Jennifer Nam, Valentina Park, Sami Dwabe

Thank you for tackling the problem of childhood obesity through the One Plate approach. This is a useful tool in educating parents and kids, although as we discussed it skirts the larger societal issues

(such as food deserts, convenience and cheapness of junk food, and the emotional connotations of providing longed-for food to kids) implicated in the obesity epidemic. Your team made many excellent points about how to conduct successful nutrition/exercise education, such as recognizing that what's obvious to the doctor is not always obvious to parent and patient; starting with what the kid is already doing that's healthy, and building out from there; changing the child's lifestyle as little as possible; tailoring suggestions to the kid's readiness and motivation for change. I particularly appreciated your avoidance of rote prescriptions

("eat more vegetables," "avoid sugar," "exercise more"). Unless you are fortunate enough to have a highly motivated patient, in my view you might as well save your breath. You all took a much different, hands-on approach, that involved situation-specific problem-solving, creativity, and dare I say it, fun! This is a complex issue that is probably ideally approached on family, school, community, and societal levels. Nevertheless, there are concrete steps the individual physician can take to support healthy habits in pediatric patients, and you outlined many of them. Best, Dr. Shapiro

Rachel Sunico, Robert Bucayu

Dear Rachel and Robert, Hope you were not offended by my gentle teasing about your haiku ☺. It was really a cute one, and at the same time it stimulated a fascinating and valuable discussion about how to approach parents who oppose vaccines or other treatments for their children. As you pointed out, the key is patience, nonjudgmentalness, and acknowledgment of the parents' perspective. Thank you also for providing reflection points to guide the discussion. These were both thoughtful and helpful.

Indeed, as you observed, it is essential to get parents and physicians on the same page, and how you do that is a skill in itself. There are multiple sources of "knowledge," and frankly many people trust their own idiosyncratic sources, such as word of mouth or personal experience more than a research study or the doctor's prescription. Working through skepticism and mistrust is a slow process, and sometimes it is not possible at all. But keeping your patients engaged in dialogue always holds out hope that in the future you can establish common ground. Your point that parents may value a pronouncement from a physician is spot-on.

It all goes back to trust. If the parents don't trust you, they will not trust your opinion or your information. Building trust involves respectful listening, paraphrasing to show you actually heard the patient, and searching for shared values and priorities. It can be time-consuming, but it pays big dividends down the road. Best, Dr. Shapiro

Victoria Oppenheim

Dear Victoria, thank you for contributing the poignant photograph of your nephew. It reminded me of all that is beautiful in childhood – a chance to celebrate the wonders of nature in the company of someone safe and protective. I appreciated the way you contrasted your nephew's good health with the serious illnesses and medical conditions you've encountered on Peds. Your conclusions seem exactly spot on – such suffering reminds us of the fragility of life while encouraging us to be grateful for the health and wellbeing in our lives. I also liked your observation that these reflections cemented in your mind the vital importance of the physician's commitment to preserving/restoring the health of her patients, and the importance of caring for the whole person of the patient. As Dr. Murata commented, I think adult medicine could learn a lot from the pediatric approach! A very thoughtful and perceptive project. Best, Dr. Shapiro

Connor Nathe, Anadjeet Khahera

Dear Connor and Nandy, thank you for posing the unanswerable questions that nevertheless deserve being thought through with care and compassion. Your description of this young child and his parents

was really heartbreaking. Who can know what is the “right” thing to do in such painful circumstances? Yet your presentation, and the discussion you facilitated, brought out key points to consider: e.g., the age and personality of the child; the dynamics of the family; the quality of life likely to result from each treatment choice.

There was an interesting side discussion about physicians who are also parents. While I agree with the points made about medical knowledge making it easier to explain certain things to a parent-physician, it is really important in my view not to make assumptions about parental understanding or to treat this parent as a doctor rather than as a parent. One of the roles of the actual physician in such difficult situations is to remind the physician-parent to be a parent, which is a lot scarier. Falling into doctor-mode can be comforting, but it creates a distance from the situation that ultimately will limit the parent’s ability to effectively process the intense emotions involved.

Thanks for such a thought-provoking project. Dr. Shapiro

Connor Byrne

Dear Connor, thank you for such an interesting and perceptive essay. Your observation that, especially with younger Peds patients, the partnership posited in adult medicine does not exist; rather the physician becomes a kind of parental surrogate. As you point out, this can become complicated because the kid already has actual parents. Most of the time, the priorities and perceptions of parents and doctor align; but when they do not, because of the child’s vulnerability and complete lack of control over his/her own health, the doctor ends up in a difficult situation, wanting to advocate for his/her patient yet also being limited by the parental decision-making authority. You point out correctly that the partnership must be formed between parents and pediatrician. As in most situations involving human beings, the best hope for achieving this is respectful listening and ongoing dialogue.

The conclusion of your essay is a lovely tribute to pediatricians, and explains why so many of them are such passionate advocates for the kids they care for. When you describe making a difference in a kiddo’s life as “euphoric” I think most pediatricians would agree. Making a difference in anyone’s life of course is awesome, but there is a special happiness with children, perhaps because they have such potential, and to see that infringed on or cut short is devastating. This was a really excellent reflection, thank you for digging deep into what it means to practice pediatrics. Dr. Shapiro