

PEDIATRICS HUMANITIES SESSION JUNE 2009-06-19

intimate

Hi -- and --, it was so nice to see you guys! I know there is concern, and rightfully so, about the lack of inclusion of GLBTI issues in the curriculum. You both did an incredible job of educating all of us on the importance of this topic to future physicians. Some of your statistics were truly shocking. I also appreciated the slide that pointed out increased risks for substance abuse, depression, suicide etc. were not because kids were gay, but because of societal response. You are obviously extremely well-informed, and the two foci of your presentation (GLBTI adolescents and kids of same-sex parents) highlighted to overlapping and crucially important issues. You did a fantastic job of facilitating the follow-up discussion. It was obvious some of your colleagues were struggling with discomfort and uncertainty, and your points about specific but judgment free language were very helpful. SOM really owes you a debt of gratitude. I'm glad to hear you will be making a similar presentation to the faculty. Many of us need reminders! Best,, Dr. Shapiro

Thanks, --, for contributing a more light-hearted note to our session yesterday. I'm really glad you chose to focus on music. Even more than movies or poetry or art, people form intimate connections and associations with certain songs or pieces of music. I would not be surprised to learn that Small World or one of the other selections you played got a Ytrough a bad night. As I mentioned in class, the other aspect I really appreciated in your presentation (aside from the simply-too-adorable babies!) was the reminder that the natural state of kids is happy, joyful, and playful. Often this is not how you see them in the hospital; and sometimes we forget that patients are attached to real lives. Your slideshow brought that truth back into sharp focus, and was a great reminder of what we all should be working towards.

Thanks also for your essay. What an interesting comment from your V.A. patient. I agree in the sense that there is so much hope in children. How great that you had such a positive experience with parents. Having a sick kid, especially a really sick kid, can make parents kind of crazy. And that's understandable, when you think that most parents really love their kids and just want to protect them and keep them safe. So I'm glad that the parents you encountered were helpful, and cooperative, and understanding of your role as a medical student. The kids, even the uncooperative ones, are always pretty amazing. You tell some wonderful stories, it's obvious that you did a lot of learning on Peds, on multiple dimensions. Thanks so much, --, for all the work you put into this assignment.
Dr. Shapiro

Thank you all for helping the group yesterday to focus on the ramifications and ripples of chronic pediatric illness. --, you did a comprehensive job of establishing what a pervasive problem this is. Personally, I was shocked to learn how many kids are on regular medications. Then, the way you grounded this in the personal voice of mother and patients was very compelling, and a good reminder that these patients are not simply statistics.

--, I found your friend's insights into her daughter's violent outbursts so illuminating. Of course, violence begets violence; and a little child is not going to make nuanced discrimination between invasions meant to help and those meant to hurt. --, your portrayal of the 14 yo girl with Crohn's disease was really heartbreaking. You captured well the beginnings of what will be a lifelong struggle for this young person; and the prescience with which she realizes that her disease will pose a long string of "interruptions to her life. You also were perceptive about the day-to-day realities about life in the hospital. --, I am very sorry for the loss of your friend, and I thank you for sharing her voice with us. Perhaps because she was your friend, you really made us feel what it might be like to be 19 and dying. You didn't shy away from her confusion and anger and efforts to cope (all of which as you recognized come up short); and your courage enabled the rest of us to see her more clearly and honestly.

Taken together, your presentations made all of us think about how hard it is to have chronic and life-threatening illnesses, of course for the patient, but also for family and friends. Further, even with the best possible outcome, your work showed that it is never really "over," and that going through such experiences changes all concerned. This is by no means an entirely bad thing (although we do have to be careful about the ways in which we "rationalize" suffering), but it gives the lie to facile statements about "going back to the way things were." Your presentations helped us see that that is rarely an option. Thanks very much, Dr. Shapiro

Okay, so I admit I had no clue about the disease you profiled, but thank goodness for google. I was also intrigued by the verb "to telescope," which I'd never heard either. So you definitely contributed to my education! You turned out a cool picture too. But what I really got out of your project is that there is definitely something fascinating about all the weird and strange things that can go wrong with our bodies. To pretend otherwise would be dishonest. Here's to taking a step back – or more likely, just to the side – and saying, this stuff is cool! Best, Dr. Shapiro

--, you chose a great topic (and represented it with a thought-provoking visual!). As you saw, this is a hot-button issue that provides significant ongoing challenges to pediatricians (and indeed, in terms of public health implications, to all physicians). It is natural to feel frustrated and angry in such a situation. There is a lot at stake. I think, as we discussed, that all you can do is keep the lines of dialogue open: establish common

ground (“we both want what’s best for your kid”), paraphrase the parent’s arguments and “evidence” (let them know you really hear them and take them seriously), and try to present your information and perspective in a way that doesn’t ridicule, threaten, or demean. As Dr. X noted, with a die-hard non-immunizer, your chances of being persuasive are small. But there are a lot of people “in the middle” – confused, uncertain – and this group can often be moved toward a spaced-out vaccination schedule. Thanks again for bringing this to our attention. Dr. Shapiro

--, I really, *really* liked your project. The title was terrific – it is so easy to forget that what is “routine” to the physician is usually un-routine and frightening to the patient and family. Very important observation on your part. Secondly, I appreciated that you tackled the complex issue of severe disability. Patients such as the 14 yo you saw can raise a lot of questions about what constitutes our humanity, quality of life, etc. I thought your essay was thoughtful and nuanced, and conveyed valuing of the mother’s devotion to this child and the relationship she had constructed with her. It was also so lovely to hear you describe the relationship between mom and doctor. These trusting, committed, and sensitive relationships are definitely out there, and they offer an invaluable lesson about medicine at its best. Thanks again, Dr. Shapiro

Hi --, nice to see you again! I think many pediatricians echo your frustration with parents who intentionally or unintentionally are neglectful; or, as in the case, allowed their personal animosities and power struggles to take priority over their kid’s wellbeing. You were fortunate to have an excellent physician role model who took the approach of empowering the mother to stand up to the husband’s controlling behavior regarding their son (and who probably recognized that the mom was, in part, hiding behind her helplessness to avoid talking responsibility as a parent). If it were possible to get both parents in the exam room at the same time, it might also help to counsel them to work together for the benefit of their kid, and to remind them they’d always be co-parents even if they were no longer married. In any case, as you realized, you can’t help kids without being willing to work with their families, the good, the bad, and the ugly :-). Best, Dr. Shapiro P.S. Here is the medical readers theater schedule. Just let me know any session you’d like to attend.

Hi -- and --. The issue you raised is such an important one, and I was concerned that we didn’t deal with it fully. There are obviously going to be different perspectives, and often different medical perspectives as well. Since I am not a physician, I won’t presume to judge the appropriate medical response. However, what was clear from your presentation is that serious concerns about the patient’s wellbeing from one service got shut down out of fear of confronting a “more powerful” service. This is some of the negative fallout from the authoritarian, hierarchical structure of the medical system. And the real victim

here was the patient. I saw with some shame that when we asked you what should have happened, you got a little disbelieving look on your face, and replied, “Talk to each other” (duh implied). Yes, it is that simple; but unfortunately, this kind of mature, conscientious behavior that prioritizes the patient’s welfare is not always normative in the healthcare system. When two colleagues disagree, rather than intimidation, territorial struggles and peremptory overrides, there should be ongoing dialogue including frequent updates of any changes in the status of the patient until all parties are satisfied with the outcome. I’m sorry that you witnessed a classic case of physician-centered, rather than patient-centered, medicine. No wonder you felt shame at the mother’s grateful response. No wonder the patient lost trust. All I can say – and it’s not enough – is remember this example; and do it better when you are in the position to make the hard decisions. Best, Dr. Shapiro

Thanks for your humorous anecdote, --. I think peds patients strike terror in lots of hearts! :-). They are so small, yet they cry so loudly! You also had a good insight that being “the youngest” in your family circle did not prepare you well for interacting with little kids. You really did a very conscientious job of trying to figure out how to explain anesthesia. True, it backfired a bit :-), but it sounded like you both got through it. And it was very cute that you channeled your inner 5 yr old in order to make a connection with this kid. And you really did have a lot in common. That is the key to all good doctor-patient relationships: even when you feel most separate from the patient, seek out some common ground. It’s always there :-). I’m sure you do have a future in Peds, if you want it :-). Dr. Shapiro P.S. I will definitely respect your request for privacy of this essay.

-- and --, thank you for highlighting a painful but real aspect of life for too many kids: the hospital is not a dreaded place, but a safe haven, a refuge from the even harsher realities outside. As doctors, you can’t change that. But to pretend it doesn’t exist does a further disservice to your patient. One thing I especially liked about your presentation is that you looked beneath the surface of this kid’s “demanding,” “manipulative” behavior to look for explanations. I think it gave you a certain grudging appreciation for the kid’s strength and survival skills. Thanks for sharing this story with us. Dr. Shapiro

Hi --, thank you for sending along your project. -- also chose to do a project on intussusception (which this ignorant non-M.D. had never heard of!), so I got a bit of a heads up already on this patient (I’m assuming it was the same patient, it’s not that common a condition, right?). I really liked your approach of trying to get inside the mind of this sick little guy and express his point of view. A lot of times with little kids it doesn’t even occur to us that they have a point of view, but of course they do, even when they’re too little to express it. You captured very well the patient’s complete disconnect between seemingly cruel and pointless procedures and his severe, persistent belly pain.

It's pretty hard to "explain" the logic behind your actions to such a young child, but in my view you are absolutely on the right track. It is way too easy to write this tyke off and just proceed as if he were an adorable little object. In fact, by attending to his terror and distress, you can exert a calming and reassuring influence. Maybe not entirely, but you can certainly help him to feel safer. He might not understand the words, but he'll understand your concern. Very nice work, --. Best, Dr. Shapiro