

PEDS CLERKSHIP HUMANITIES SESSION 12/08

Hi, -- and --. Just wanted to let you know I thought you did a terrific job on your little educational booklet about pediatric asthma. It was funny, engaging, and informative. You demonstrated great sensitivity to understanding how a chronic illness such as asthma might affect a kid's psychology as well as his physical health. I liked the fishbowl analogy a lot. As I mentioned, it's used in asthma meds advertising, and I think it's effective because it really speaks to the subjective experience of the asthma sufferer. The illustrations were memorable. Thinking of the pet snail still makes me smile :-). Best, Dr. Shapiro

--, I appreciated several aspects of your presentation: 1) the way you developed a narrative arc, so that we, your listeners, actually experienced some of the shock resulting from the unexpected turn this case took 2) the Socratic nature of your class presentation, in that you refused to allow your colleagues to be a passive audience, and compelled them to actually wrestle with the questions your case raised 3) your willingness to do a little research on your own, to deepen your understanding of the perspective of the Jehovah Witness mother 4) your appreciation for the complexity and nuances of this situation, which involved moral, knowledge, legal, and pragmatic questions. Your work was very impressive. I'm glad the IVIG treatment went ahead. Best, Dr. Shapiro

Hi --, you chose a critically important topic and your execution of the project was superb. In a single page, you documented the nature of the problem, highlighted two widespread sources of pediatric injury, and provided key information about how to reduce risk both at home and in the car. The visual aids were eye-catching and involving. Good luck with your research. Best, Dr. Shapiro

--, I thought doing an LP was an extremely important topic to address. Causing pain in patients, especially child patients, has got to be an emotionally difficult issue for student-physicians, residents, and even experienced pediatricians. You know of course that you are acting to help the patient, but you are still causing distress, which is exactly what medical treatment is trying to eliminate! I really liked your alternating voices. They showed so well how the natural differences in perspective between patient and doctor can diverge to the point of complete disconnection. The resident you portrayed is not doing anything wrong – but she is not doing enough right. Of course the simple solution is lidocaine! But perhaps the more important answer is to be willing to acknowledge the unavoidable pain that medicine sometimes causes, and support the patient in that suffering, rather than ignoring it. Finally, just in terms of the writing itself, I found the

repetition of the opening line at the end of the writing to be incredibly poignant. In that image “he lay naked on the table” you captured powerfully the vulnerability and helplessness of that little child. That’s what no doctor should ever forget, no matter how important the placement of the needle is or the hydration of the patient. Thanks very much, Dr. Shapiro

Thanks for your touching essay, --, as well as for your many excellent comments in class.. I thought it was especially wonderful that, although you are not heading for a career in Peds, you could appreciate the value of the training and make the effort to learn as much as you could, figure out as much as possible, and connect with your patient and her family. I would only beg to differ with one statement: “While we had not done much for either of them in the hospital...” You really did accomplish “something real.” Think about it – you explained a new and frightening diagnosis to the mom, you kept a scared little kid “happy” under difficult circumstances, you didn’t overpromise no matter how tempting, yet you did your best to help make your patient’s wish come true. I think she wasn’t the only “magician” that day :-). Best, Dr. Shapiro

Loved your project, -- and --. Cute illustrations, and great topics. The angry, demanding monster-parent is a fixture on pediatric wards. Without minimizing her aggravating effects on the team, you were also able to understand and even empathize with what drives a parent to behave in this way. I’d never heard about the liability issue leading to the hospitalization for otherwise healthy patients, but the drawing was very poignant. I did want to share that one of my daughters had two premature infants (in AZ). When the first one was born, he spent 3 weeks in NICU, and went home on a fetal heart/lung monitor. When the other was born, he spent 6 weeks in NICU, even though he had far fewer problems. When I asked why, my daughter explained that because of the hospital’s inability to guarantee parental compliance with the monitors, the legal team had advised that premies had to remain hospitalized until they were safe to go home without monitoring! It was a very long 6 weeks! Thanks for your presentation, Dr. Shapiro

I liked your stream of consciousness effort on behalf of the unrepentant screamer. You represented really well the perspective of a little kid subjected to the horrors of the well-child exam. Seen through his eyes, it did seem pretty unfair! I especially liked the eaten-down popsicle stick. Through this humorous account, you also raised important questions about the helplessness and vulnerability of the patient, and the sense of betrayal that is easy to feel while undergoing medical care, despite everyone’s best intentions. I thought the kid’s fixation about “taking something” was especially insightful. Inevitably, patients feel they are losing something – health, wellbeing, self-sufficiency, trust in their body, not to mention at times limbs and organs. Sometimes screaming is the only defense remaining to the patient. Very nice work, --. Best, Dr. Shapiro

I am *so* glad you two chose this topic. In medicine, it is easy to lose sight of larger social issues in the day-to-day focus on individual doctors and patients. Thank you for reminding us of one of the more horrific atrocities in the world, the plight of children recruited into soldiering. My conception of the specialty of pediatrics is that it assumes advocacy on behalf of all children harmed physically and emotionally by the exploitation and abuse of adults. Your project falls squarely into this category. By the way, the documentary I referred to is called War Child. If you are interested in this issue, I think you'd get a lot out of it. Best, Dr. Shapiro

--, I thought your essay was simply outstanding. I loved the way you used narrative conventions to create a certain feeling and set of expectations. In the first few paragraphs, you show us, your audience, an adorable, precious, *healthy* baby with whom you establish a special connection, as well as sharing some humorous moments. And then the bombshell: mom is HIV positive. Ah, that changes everything... or does it? One of the best sentences for me was when you wrote, "...I resisted the urge to put gloves on." Of course, medically at that point there was no good reason to do so. But emotionally and psychologically, you were at a choice point regarding whether or not to turn this baby into "the other," a contaminated, and contaminating presence. When you decided not to put on gloves, it was this conceptualization that you were resisting. I also was very moved by your disclosure that you went back to look for characteristic "HIV facies" (I've heard of facies associated with HIV treatment, but I'm pretty sure there are no HIV facies, right?) and found that the baby "looked exactly the same... normal." This was such a powerful realization, and reinforced your decision to accept him as normal, not other. Finally, despite the potential tragedy of his situation, you avoided the temptation to pity this child. Instead, you saw his strength, resilience, and wisdom, an "old soul" ready for whatever life might bring. As far as I am concerned, doctoring can't get any better than this. Thank you for sharing your wisdom. Best, Dr. Shapiro

--, I really liked your metaphor of going to the ER as a difficult boat trip that often gets worse before it gets better. As your charming drawings suggest, it can be a rough ride full of stormy weather. Sometimes, literally, all the kid and her parents can do is hold on for dear life. Your portrayal of the helpless, bewildering, and frightening feelings of a sick kid is insightful. Once in awhile, very sadly, the ship founders and sinks. Most of the time, we hope for an ending full of rainbows and sunshine. Best, Dr. Shapiro

--, your reflection essay raised many difficult questions, many of which you asked yourself. Especially troubling to me was the removal of the patient from her home. It is

quite true that sometimes parents are overwhelmed by the needs of a multiply-handicapped child; and need “permission” from the pediatrician so that they don’t feel they are bad parents for placing the child elsewhere. It is also true that, even if parents “feel” they are doing a good job, in the face of medical evidence to the contrary (in this case, severe malnourishment), intervention on the part of the child is necessary. There is obviously a wide range of options between floundering home care and placement; and I can’t help wondering if the parents shared a language and culture with doctor and social worker whether the group home option would have materialized so quickly.

You also pointed us toward the extremely difficult issues of quality of life and resource allocation. At there intersection, when does aggressive intervention improve qol and when might it actually be doing the opposite? Even more problematic, even if such treatment does improve qol, should there be any upper limits? Like you, I find myself with more questions than answers. Thanks for a thoughtful and thought-provoking essay.
Dr. Shapiro

Hi --. Thanks for sending in your peds humanities project. Although you were writing about a tragic situation (a little baby with cf), I loved every part of your essay. I loved that you allowed yourself to connect with this little being, to “get hooked.” I loved that you accessed a similar loss in your own life, to look for similarities and differences that might help you understand more deeply the situation of this family. I loved the questions you asked about coping and quality of life for both child and parents. Finally, I loved what you learned from this mother, in terms of her incredible courage, commitment, gratitude and peace. It is the wisdom of accepting the “isness” of life. My only cautionary note is this: When this attitude emerges out a deep religious convictions or other deeply held beliefs about the nature of the world, it is profoundly inspiring. However, sometimes patients/family members think that they “should” adopt this attitude because it’s expected of them; or sometimes they may feel this way one day, but another day need to express feelings of bitterness and frustration. It’s important that, as a physician, you honor the truth of the patient/family’s experience, *whatever that might be, and however it changes*. When they inspire and teach you, be grateful. When they need your tolerance of their anger or fear, give them that. You learned something precious from this mother – live fully and unregretfully what is. Treasure this lesson. Best, Dr. Shapiro

Thanks for writing up this assignment even though you had a “voucher day” ☺. Your essay was really wonderful (in a heartbreaking kind of way). You did a wonderful job of juxtaposing the two views of medical student and 2 year old patient. In your voice, I heard both your efforts to reach out to this little child, and your frustration that you couldn’t reach her, and your guilt that you would be “abandoning” her. These are such understandable emotions in this very difficult situation. We all want our efforts to make a difference. Yet sometimes, although we do everything we can – and even a bit more than we’re required to – it isn’t enough; or at least not as far as we can detect. This is where

humility must enter it. It is a hard thing to accept that your affection and caring over the course of a few weeks couldn't turn this kid around, couldn't get her to trust, couldn't get her to open up emotionally. But you should be very proud of yourself for trying. Another aspect of humility is being able to tolerate uncertainty. You didn't create the effect you desired in X, but who knows? Perhaps your kindness created just the smallest crack to let later love and kindness in – if she's lucky enough to get them.

Your portrayal of X's voice was devastatingly accurate. Her idea that she lives in a box with bars, and that other children get to go to "other boxes" was heartwrenchingly brilliant. And the longing for a "same lady" to kiss and hug and sing was similarly powerful. You understand perfectly why this child prefers to remain a porcelain doll than risk uncertain and unreliable attachment.

This encounter is a good example of something very wise a family physician colleague once shared with me: "As a doctor," he said, "You have to be willing to climb into the patient's boat. And you have to be willing to climb out." You had to leave X behind, and you have to learn to be okay with that. You also have to be okay with loving and caring for her while you were with her. Best, Dr. Shapiro