

PEDIATRIC HUMANITIES PROJECTS DECEMBER 2010

--, this was an outstanding project. I was impressed by the research you did on pediatric analgesia. You also made an excellent point about giving pediatric patients some small measure of control over their hospital experience. I also appreciated your FUNdamental point that strategies to make the hospital stay a little more pleasurable and a little less horrible can make a significant difference to the patient. You and your team continue to do wonderful work with Music-to-Heal. Finally, the resources you provided were valuable as well. All in all, this was a presentation worthy of a noon conference and demonstrated knowledge of a relevant literature, insight into the felt experience of hospitalized kids, and creative suggestions about shifting the nature of the hospital experience. Thanks for this hard work, Dr. Shapiro

I enjoyed your haiku, and they *are* hard to write. Clever way of testing your colleagues on developmental milestones. You also managed to address several important topics in pediatrics, such as r/o sepsis, otitis media, parental resistance to immunizations, and asking parents to leave the exam room when interviewing adolescents on sensitive topics. Your haiku were smart and funny. Thanks! Dr. Shapiro

Although it sounds as though you will soon be leaving, welcome to this country! Thank you for your interesting and well-researched presentation (so sorry the electronics failed us). You highlighted a critical issue of global child health. It is easy for medical students to become somewhat absorbed in their own concerns – shelf exams, nights on call – and to lose sight of the larger picture of suffering throughout the world. Thanks for the reminder! Dr. Shapiro

Hi --. Thank you for drawing our attention to the condition of scoliosis, and more broadly to chronic disease in adolescence, through your lighthearted poem. As you learned from your sisters, while the outcome can be very positive, this condition also presents many challenges, especially during a time when teens are forming their identities. As we discussed, often in the presence of a chronic medical condition, issues of self-image, independence, noncompliance, parent-child relations

become intensified and complicated. I appreciated the insights your poem contributed. Dr. Shapiro

-- and --, this was a very strong patient advocacy project. Shaken baby syndrome is a significant problem, especially because many people who would shake an infant would never think of this as abusive or endangering the child. Pointing out the hazards is the first public service your pamphlet performs. The handout is pleasingly concise, written in accessible language, and full of really important information that parents might not know. Best of all, it contains many realistic and easy to implement strategies for soothing a crying baby. Excellent work! Dr. Shapiro

--, thanks for starting us off down the road of haiku. I liked the way you used this brief, pithy form to highlight complex social issues implicated in pediatric medicine, such as coping with chronic illness, denial, and mistrust of physicians. It would be nice if we could encapsulate the solutions in the 5-7-5 format. Unfortunately, there's no shortcut to working with human beings. I especially liked the way you "hung in" despite the initial lack of common ground, overcame your patient's suspicions, identified a way (through sports) to get him to take an interest in his illness, and transformed a patient from noncompliant to compliant. Thanks for this nice work. Dr. Shapiro

Hi --, you did a very thorough and informative job of presenting information on falls to your peers and professors. Not everybody in the room is going to be a pediatrician, but most of your fellow students will probably become a parent one day; and when this happens, I hope they've hung on to your educational sheet. Thanks for this good work, Dr. Shapiro

What a creative project you came up with! (And thanks to your boyfriend for his cooperation :-)). The themes of vulnerability, isolation, helplessness, and fear that these 8th grade students identified in writing about their visits to the doctor's were really insightful. I was impressed how they opened up in these essays (a tribute, I suspect, to the classroom atmosphere their teacher has established!). Thanks for helping us all to see a doctor's visit from a kid's point of view. Dr. Shapiro

--, is was very enjoyable to hear all those developmental milestones rolling by in verse! You managed to squeeze in an awful lot of information into one fairly short poem. It reminded me just how hard it is to be an involved and conscientious parent; but your lighthearted rhymes created a sweet context. Very nice work, Dr. Shapiro

--, thanks for being the one to highlight one of the most critical health issues facing the country today – childhood obesity. The current statistics and future projections, as you noted, are frightening. Pediatricians join parents on the front lines. Increasingly, people are recognizing that this is a public health issue and requires social interventions. It cannot be solved entirely by motivated moms, dads, and doctors. However, individual physicians certainly have a role to play, both at the individual patient and at the community level, advocating in schools and corner stores for healthier food selections. I was really hoping someone would address this topic, so thank you! Dr. Shapiro

Thanks for your project on child burns. I actually learned a lot from it, especially regarding the hazard of beach bonfires. I'm sure I was not the only one unaware of the risks involved in this seemingly innocuous activity. Very informative and educational. Dr. Shapiro

--, the tragedy of the story you shared still lingers in my mind. I really liked the way you recognized your identification with this sweet little boy (“two nerds” :-)). Of course, seeing a bit of yourself in him only intensified your feelings of devastation at his terrible diagnosis. But, if you had actually been his physician, this awareness would have been the first step in figuring out how to be empathic and supportive without being overwhelmed by your own anxiety.

As I said in class, the innocent suffering that is seen in pediatrics is particularly hard to accept. Kids are on this earth to eat ice cream and ride bikes, not contract horrible degenerative terminal illnesses. I don't know that there is any way to understand or make sense of such cosmic unfairness. But what is perhaps more important than “making sense” of such situations is to remember that these children and their families must somehow figure out how to endure the unendurable. Having a

compassionate, caring physician courageous enough to take such a journey with patient and parents is a great gift. It does not solve anything, but at least they are not alone. Thank you for focusing us on something many of us would prefer to ignore, yet from which ethically we cannot turn away. Dr. Shapiro

Bannayan-Riley-Ruvalcaba syndrome is what they diagnosed you with. You inherited an autosomal dominant disorder that causes some of your cells to grow uncontrollably. You already had your colon removed and even had your thyroid removed because they found a cancerous nodule. What's left of your GI tract is filled with multiple polyps that cause you to have loose stools (losing about half to three-fourths a gallon a day) and therefore lose your sodium, albumin, and other vital proteins. You're here not because you chose to, but because you needed to be replaced with what you're losing.

Commented [A1]: Kim, I really liked how you addressed Cody directly in your essay. It made this little baby much more of a person.

When I walked into your room for the first time, I felt like I was in someone's house. There are family pictures up, blankets, toys, and video games – anything to cover the fact that you are imprisoned in the hospital by your own medical condition. Your mom even has her own set up where she sleeps every night and works tirelessly on her laptop trying to understand your condition. Your mom is your number one supporter and huge protector. She only has good intentions and wants the least harm done on you, even though it means going against our medical advice. One time, she didn't want you to get poked so many times so she made the decision to place a PICC line in you even after we told her the risks of it. Unfortunately one night, your arm and face swelled up because you developed a clot. The next morning when I checked up on you, I walked in slowly, and all the lights were off. The only light I could see is the light coming from your mom's laptop and the reflection off her face, as she *intensely* looks online researching who knows what. When I asked how you were doing, she yelled at me for even asking. I understood that she was just hurt and frustrated that her choice caused you more pain. Because of your mom's reaction to me and everyone else on the team, I was told not follow you anymore and to pick up another patient, but I requested to stay on because I wanted to learn from your complex, interesting case.

Commented [A2]: I think you're acknowledging both how hard parents try to humanize the hospital environment; and also how impossible it is to completely overcome the reality that it is indeed, in some respects, a prison.

Commented [A3]: This was such a nuanced and complex insight into this mom. She "difficult" because she can resist medical advice. She's also a loving, committed mom trying to do what's best for her kid.

We decided to keep your PICC line and gave you blood thinners to try to get rid of your clot. You already had SVC syndrome, so we monitored your arm and face every single day. You were on TPN and medications to keep your sodium and albumin in check, but the underlying problem of all this was still to be solved. Colonoscopies, images, and multiple laboratory tests were done to try to figure out why you were losing so much. Days go by, and in the interim, your father had to sell his business to help your mom share the time spent with you and your siblings at home. Your family is understandably going through a rough time, and it doesn't help that in the meantime, your family dog died from an aggressive cancer. Through it all, there are

Commented [A4]: You are showing incredible empathy for this mom, at a time when you very easily could have been offended.

Commented [A5]: I really respect this decision. Patients (or parents) will not always treat you kindly and respectfully (usually having a lot more to do with their own fear and anger than with you personally), but it is important not to abandon them when the going gets a bit rough, but rather have the emotional fortitude to stay the course.

Commented [A6]: It is also quite admirable that you knew these sad details of the family's life – another sign to me of your caring and concern.

moments when everyone is in good spirits and has a positive attitude, even your mom who eventually simmered down, but it is rare.

Commented [A7]: It can be pretty hard to be upbeat and positive in such an awful situation, can't it?

Finally the decision was made to remove some of the polyps via colonoscopy to relieve your symptoms. I go down to the ground level where they will do your procedure. You lie innocently on the table as they put you under and intubate you. I've only seen xray images of your polyps scattered throughout, but I had no idea what to expect. The respected Dr. X performing the procedure tells me more about your interesting case and told me he only had one patient with the same syndrome. She unfortunately died when she was 16. As we perform the colonoscopy, it was like entering a mysterious abyss. Your colon was just filled with multiple polyps looking literally like cluster of grapes, and every single turn we took with the scope popped up with polyps of various shapes, sizes, and even color. I never really realized the extent of your disease until finally seeing it for what it is.

Commented [A8]: It sounds as though being present for the surgery helped you understand at an even deeper (literally!) level just what this disease entails.

After a few hours, we ended up removing 50+ polyps from your small intestine, and plan on going in again to remove even more. We are hoping this will help with your symptoms and cause you to have less stool output and pain. Pain, not only from the anatomical perspective, but also from the emotional pain placed on you and your family. So, thanks little man, for letting me follow you around and help in your care. I hope you get to go home soon to have a wonderful, happy Christmas with your family. And hopefully one day there will be a cure.

Commented [A9]: Kim, how nice that you are sensitive to this aspect of the family's suffering. Yes indeed, the patient is experiencing plenty of physical pain, but that reverberates throughout the family as emotional distress.

Commented [A10]: I hope so too!