

PEDS HUMANITIES/ADVOCACY PROJECTS APRIL 2010

--, you are a really talented musician, both in the music and the lyrics. The words of your song were funny, but also drove home the message. Truly, I think if your song played in the outpatient Peds waiting area, more parents would take these lessons to heart than through the typical mini-lecture delivered by a white-coated physician. Thanks for making us laugh; and implicitly challenging us to think about how to bring more creativity into practice. Best, Dr. Shapiro

Dear --, you created a beautiful mobile. Even though it didn't "answer your questions," or even increase your empathy, personally I found it very moving. Its delicacy and fragility reminded me of these aspects of life itself; and to me conveyed just how easy it is to make a wrong choice; and end up going down a very wrong path. I don't know if this is understanding – and it certainly doesn't "justify" such choices, especially when the victim is an innocent child – but it helped me to be less angry about the extremely distressing situation you described. For me, your sculpture was very healing. It didn't change the baby's awful circumstances, it didn't change the mother's inexcusable behavior, but it somehow gave me some (irrational?) hope that there are lots of possibilities in the world, and that things *can* change. Thank you for this. Best, Dr. Shapiro

--, thank you so much for choosing to share the story of your little girl's (thankfully) minor illness. For those of your classmates who are not parents, I think it can be very difficult at times to understand just how much a child's illness can distress and upset them. On Peds, doctors are almost always kind to their little kiddies, but sometimes regard anxious parents simply as obstacles who complicate their patients' care. True, parents can be annoying; but if you remember their fear and love, their annoying behavior is much more understandable. Your essay also helped remind us that, whereas to the pediatrician, a simple cold is routine and uninteresting, to the parents it can be very stressful, both because of their concern for their child; and because of how a "simple" illness can reverberate in the family life. These are both crucial things to understand in pediatrics, and you did a great job of illuminating them for us.

Also, thank you for your poem. I'm so glad I found it hidden on the back of your page :-). I think it captured sweetly and poignantly your daughter's misery. Poor little thing – your essay told us how uncomfortable she felt, but your poem *showed* it. Very nice work, -- (and I'm glad your sweetie-pie is now recovered!). Dr. Shapiro

Dear --, thank you for such a thoughtful essay. I'm really glad you drew our attention to the issue of chronic childhood illness. Unlike the acute appendicitis that we heard about, there is no respite from chronic illness; it may have exacerbations and remissions, but there is no cure, and the impact on the life of the child, the parents, and other siblings is profound. The article you cite well supports your observations about the intrusiveness, indeed at times dominance, of medical technology in such kids' lives.

The more I thought about your rattle, the more I think I finally "got" what you were trying to convey – the discordant reality of a "normal" and fun toy composed out of elements of medicine that, although designed to heal, also inflict discomfort. This awkward juxtaposition is a metaphor for the life of a child with chronic illness, where pain, physical difference, doctor visits, hospitalizations, medical equipment and drugs are routinely superimposed on "normal" childhood. It still can be kind of fun, but like your rattle, it doesn't quite work, at least not in the way it's supposed to. This was a powerful and effective metaphor, and I was really impressed by the multiple layers it contained.

Altogether, extremely well done. Best, Dr. Shapiro

All I can say is, yum! Cute project you guys, which also served a serious purpose. Celiac disease can be incredibly difficult to manage, especially in a child who longs for all the foods her peers are indulging in. Even though it produced some snickering in your classmates, I really liked what you said about undertaking a journey as a team. Yes, the object was making cupcakes, but it was a journey fraught with challenge and peril. Knowing how to work together is of course an essential skill in medicine – and producing a gluten-free cupcake I'm sure can be almost as daunting as many medical procedures. Good work, team, and delicious cupcakes :-). Dr. Shapiro

--, your project took a great deal of courage, and I commend for this. People dislike and resist being made uncomfortable, and you made us all feel uncomfortable. But to a good end. Coming from a different generation that was immersed in racial tensions, I'm always struck by how members of your generation always insist that they are entirely tolerant and multicultural. Without doubt, there have been huge changes and real progress since the 1960s. But bias, prejudice, and discrimination are difficult things to eradicate – and sometimes they are closer to us than we'd like to admit, either in the giving or the receiving. Your exercise reminded us that intolerance, even hatred, are still part of our society (and perhaps even at times part of us). Al Gore pointed out the inconvenient truths of global warming. This exercise brought our attention to another inconvenient truth. I am confident that, although your classmates squirmed today, the next time they encounter an overweight adolescent, or a teen from another country, they will be a few steps more sensitive and aware. Great job, --. Dr. Shapiro

Hi all. Very nice work on your breastfeeding pamphlet. First, I appreciated the fact that you *noticed* a prevalence of bottle over breastfeeding for many of your little patients. Awareness of a problem is the first step toward solution. Next, I really liked the design of the pamphlet – it was easy to read, not too overwhelming in terms of quantity of information, but really highlighting factors that might sway a mom. Further, the organization into “categories” of benefits was really ingenious, because some moms might be motivated by benefits to themselves, some by benefits to their child, and even some by benefits to their community (breastfeeding is green!). As we discussed in class, and as I know you all know, education and information are often just the beginning, not the end, of behavior change. There are often multiple factors involved in choosing or rejecting - a particular behavior. Finding out what is motivating a given mom to choose bottle over breast helps target the most effective intervention. Your pamphlet makes an excellent start of this complex process. Very well done! Dr. Shapiro

Hi --, --, and --. You contributed an excellent project. I really liked the way you each identified a “phase” in this child’s experience; and then eloquently expressed what it might have been like through the child’s eyes. --, you imagined a wealth of detail for this sick little kid. By plunging deeply into her perspective, you moved all your listeners closer to what it must be like to suddenly have ordinary life interrupted by an acute illness episode. --, you really brought to life the encounter with medical terminology and equipment, all completely baffling (ultrasound was a particularly good touch, not only the implication of the name, but also the unintelligibility of the picture). You did a very nice job too of portraying both doctors who ignored the kid in favor of the mom; and doctors who tried to allay the child’s confusion and fear. --, to me the best part of your writing was the contrast between the kid’s priority (basically, get me home) and the medical team’s need to ensure adequate recovery and safety. I hope that someone was able to acknowledge this little patient’s desire. When that happens, even if it can’t always be immediately met, it usually helps the person feel heard. (I also thought the whole hamburger exchange was hilarious, and so true to reality :-)). All in all, your “dissection” of the hospitalization experience from first symptom to discharge made very real what this must be like for a pediatric patient. Very fine work! Dr. Shapiro

Thank you for your touching poem. The poem did an excellent job of conveying this kid’s suffering and isolation. I imagine one of the hardest things in medicine is when you are able to diagnose, but not effectively treat. Then you become merely a witness to the patient’s ongoing distress. Yet this is an important function as well, especially when the patient feels alone and abandoned. Your writing gave a voice to this child, and we all heard it. It was a moving experience to hear you read it. Best, Dr. Shapiro

Dear --, thanks for contributing the frustrating dialogue with the apparently clueless (or worse) mother of the FTT kid. It presented very well the physician's concern and the mother's obliviousness. It is a sad truism that nothing productive is likely to happen in this situation until doctor and mom can start hearing each other. This is where that old standby communication skill paraphrasing really can play a role: "Mom, it sounds like you feel baby is fine. But I need you to hear that I have real concerns." In the mother's account of her previous interactions with the baby's pediatrician, again it was obvious that this parent had not been successfully recruited by her doctor into being a responsible, engaged guardian of her child. Maybe that is an impossible task. Maybe it will take the marshalling of additional resources, as Dr. X helpfully suggested. But until mom and doctor can establish common ground, baby can be "fattened up" during an inpatient stay, but nothing fundamentally will change. I appreciate your bringing this very frustrating and not uncommon scenario to our attention. Best, Dr. Shapiro

--, you raised a great issue when you realized that, sadly, some children see the hospital not as a necessary evil, but as a place of happiness and refuge, because it is so much better than their normal environment. Your essay was also insightful in terms of recognizing the student's/medical team's perspective of frustration and annoyance that this kid was using up valuable resources for no good reason; and the dawning awareness that, from his point of view, the hospital might be the best thing that had happened to him recently. I agree that it is hard to imagine a family not visiting their sick child in the hospital. Yet, there again, just as it is almost impossible to imagine that a kid would *like* to stay in the hospital, it is sometimes hard to realize the family dysfunction, stressors, and problems that result in parents not showing up at this same place. I'm not making excuses for the family, but only saying that it is sometimes a situation of very different worlds colliding within the hospital walls; and until we can at least begin to understand the patient's world, we will not get very far with him.

I'm sorry that before you had a chance to act on your new resolve, your patient was discharged. However, that's what learning is all about. We are not perfect people, and we are especially not perfect when we don't understand a situation very clearly, but *think* we do. I was very impressed that over the course of your caring for this patient, your perceptions evolved and became more compassionate and nuanced. You were able to understand and empathize with your patient. Although you were not able to express this directly toward him, I guarantee that you will toward your next "difficult" patient. As you summed it up so eloquently, you've learned to leave the judgment all of us so easily feel "outside the door" until you better understand what's going on. We cannot ask any more of ourselves – or each other – than that. A truly excellent and inspiring essay! Dr. Shapiro