

PEDS REFLECTION SESSION 8/11/14

Dear --, your essay had many vivid images. I particularly liked the metaphor of a crib as a “jail cell.” I’m sure it might sometimes seem that way to both kids and their parents. In this case of non-accidental trauma, this “perfect baby boy” was probably safer in that “jail” than in his home. I also thought the way you discussed “doctoring tools” was especially effective because tools are things we use to fix things and make things, and tragically little could be fixed or made whole in this situation.

I was also glad that your resident was able to show his strong emotions. As a medical student, you are not always sure how to react, especially when confronted with such a devastating set of circumstances. Having a “tough” male be emotionally shaken, and be willing to share his distress, to me is a very healthy thing; and gives you permission to hang on to your own humanity. It is natural and understandable to feel helpless and angry when you encounter child abuse. It is such an inconceivable act and violates every instinct we have to protect and succor children.

What can be done? Sadly, not enough. As you discovered, even reporting in the absence of sufficient evidence does not always lead to consequences for or punishment of the parents. Children are not always removed from potentially dangerous situations. Even when they are, sometimes their living arrangements are not ideal. Yet all you can do is utilize the options you have available – take what steps you can to protect the child, and as you and -- did, give them affection and kindness while they are under your care. Thank you for bringing this difficult topic up for discussion. Best, Dr. Shapiro

Hilarious limericks, -- 😊 These were cleverly and well-written, and as we mentioned, very well-suited to the atmosphere of pediatrics. Yet within a humorous framework, you managed to capture the essence of Peds, ranging from “vaccine unbelievers” to stool as the essence so to speak of the specialty, to the archetypal Terrible Two who strikes terror in the heart of the most seasoned pediatrician. Your verses triggered a valuable discussion that ranged from how to dialogue with parents who refuse immunizations of their vulnerable children to how to placate rampaging toddlers. Thanks for the note of levity while at the same time making us think. Best, Dr. Shapiro

Dear --, I was impressed that you took the time to repeat the HEADSS exam in the face of discrepant evidence (not everyone would have). This scenario also showed that you were actively thinking about your patient’s presentation, paying attention to all sources of information, and noting contradictions. Very nicely done.

The “tips” for conducting an effective HEADSS assessment were really excellent. You skillfully highlighted that communication is a delicate art, and even a seemingly straightforward term such as “sexual activity” can be open to many interpretations, especially if the patient is eager to avoid acknowledging her own behavior. The method of the “roundabout question” was also a very good idea.

Overall, I think, your main point was to avoid judgment and build trust, easy things to say but sometimes hard to do. By circling back with your patient, you demonstrated to her that you truly wanted to

understand, that you were interested in something more than completing your checklist – you were interested in *her*. We could all learn a valuable lesson from your attentiveness and concern for this patient. Best, Dr. Shapiro

--, your project was a wonderful exercise in empathy. Every aspect of your presentation showed how you tried to put yourself in this patient's shoes – or at least move closer to him because, as you acknowledged, it is almost impossible to understand what his life has been like for the last 7 months. It was moving – and humbling – how much the card the medical team prepared for the patient meant to him. It is so true that little acts of kindness and caring are deeply valued by patients, and cost the healthcare provider so relatively little. I also was glad you shared how the surgeon stringently limited the flow of information to the patient so he would not be frightened about the upcoming major surgery until his doctor had the opportunity to present what lay ahead in the manner he wanted. The surgeon did not mince words, but he gave this kid hope. You clearly learned a lot from this positive role-model. I thank you for sharing your insights and your compassion with your classmates and faculty. Best, Dr. Shapiro

Dear --, I liked the way you decided to write in the voice of this young girl with Crohn's disease. As an exercise, this is an excellent way of moving closer to the perspective of the patient, and it can be especially effective when you do not naturally have a great deal of common ground.

What a sad statement your patient made: "I get more attention here [in the hospital] than at home." It is very hard to see patients whose parents rarely visit. Yet as we unpacked this situation in our discussion, it became apparent that many factors (other children, inflexible jobs, transportation, misunderstandings about the purpose of hospitalization) may play a role in the behavior of these "invisible parents." Understanding does not excuse, but it may soften our judgment and provide a basis for urging these parents to try harder to support their sick kid.

When parents (often motivated by fear or guilt) are aggressive toward health care personnel, as in this case, it is easy to see why overworked doctors and nurses (who after all are only trying to help their patients) react defensively and aggressively in turn. But this type of escalation rarely leads to a positive outcome, and the one who suffers most is often the patient. It can require almost superhuman patience, but ideally you want to approach situations that trigger judgment with curiosity and kindness. Learning what underlies people's behavior, even very frustrating behavior, is often the first step toward persuading them in the direction of change. A very thoughtful, insightful, and empathic project. Best, Dr. Shapiro

--, I loved your sharing about the 1000 cranes project. This story has inspired so many and with good reason. The story of your 17 year old patient who had such hope for his future, despite the difficult hand life had dealt him, was likewise inspiring. I wish one point we had highlighted was that making an origami crane takes some work, and making a thousand, or even 10 or 20 as you made, is real labor. This makes me think of all the emotional and physical labor that goes into (trying to) restore

another person to health. It is not easy, but like the cranes, it is beautiful and worthwhile work. Your cranes were a wonderful tribute to your patient. Thank you, Dr. Shapiro

Dear --, thanks for your humorous poem about hand, foot and mouth disease spreading like wildfire within this poor family. As Dr. X pointed out, tis indeed the season, and apparently a great many of her patients are afflicted! You caught both the highly uncomfortable nature of this illness and its rather ridiculous name, which as I'm sure you're aware, often lead to its being confused with hoof and mouth disease, resulting in some understandable parent confusion, especially if a blue phone is involved. However, all's well that ends well and fortunately, for these momentarily miserable kids, it usually does. Best, Dr. Shapiro

Dear --, your peds clerkship reflection project was a really interesting reflection on the extensive in-hospital work-up that yields – zilch! And as your attending attempted to emphasize to the parents, zilch is usually by far the best alternative in these cases. You captured very well how baffling it can be for parents who each day are confronted with a new and upsetting possibility, only to be told the *following* day latest results are negative.

I also liked your “Greek chorus” of parents nodding, seeming to understand, and having no questions. Sometimes it means the parents *do* understand. Sometimes it means they are confused and fearful but unable or unwilling to give voice to their concerns. It is always a good idea to take the time to figure out which is the case for your particular patient/family.

I agreed with Dr. X that you should be commended for taking time to sit with the parents and trying to help them grasp the big picture of what might be going on with their son. Although they ended up with yet another misunderstanding (our kid has *epilepsy?!!*) in my mind the fact that the baby had seizures would almost certainly have suggested this diagnosis regardless. Fortunately, the resident discovered this confusion, and you were able to clarify. The true lesson, in my mind, is not that doctors should avoid explanation and education, but that they must be prepared for just what a slippery slope “communication” is; and how much work it can take to get it right. You did the work, and eventually it came out right. Thanks for reminding us that communication is indeed an art. Dr. Shapiro

--, thanks for sharing the Turtletalk video. That was great. Even more valuable was your analysis of *why* this program was so effective with peds patients. As you pointed out, interacting with the turtle gives kids much needed positive attention and boosts their confidence. Your poem also highlighted that play is therapeutic, as well as being a great way to assess developmental milestones.

You had an important insight that Illness results in loss of control, and play (fantasy) is one way to restore that control. Think about Turtletalk – it's a makebelieve world in which a talking turtle singles out a sick kid and makes him or her feel special and smart. What a great experience! Thanks for showing us that play is an essential element of healing. Dr. Shapiro

Dear --, I'm so glad you brought up the topic of the difficult parent and then proceeded to "unpack" it for us so that we realized "difficult" parents are usually desperate, frightened, distressed, out of control parents. In this particular case, your presentation made it clear that what had been a source of pride for this mom (seeing to the nutritional needs of her severely disabled daughter) had become a symbol of failure and loss of control. The proposal of the medical team, while undoubtedly medically sound, also likely represented another step down the road of increasingly disability and loss of normalcy (eating vs. tube-feeding).

Understandably, in these circumstances tensions would run high on both sides. How wonderful that you had such an admirable role model in the attending, who listened carefully, responded compassionately, and never wavered in her desire to guide the parents toward what had become medically necessary for their daughter. It would be nice if everyone, doctors and families, always behaved with kindness and consideration. But even when parents do not, physicians have a special obligation to remember their patients' and families' suffering and treat them as your attending treated these parents. Thank you for sharing all you learned with us. Dr. Shapiro

--, your reflective essay did a great job of contrasting the understandable excitement you felt about interviewing a new patient with the helplessness of being unable to interact with or really connect with a patient with severe autism. As we discussed in class, no matter how much you know, how much experience you have, you can never be completely prepared for every eventuality. This reality emphasizes the need for both humility and for cognitive flexibility, the ability to be a bit of a "jazz musician" in the clinical encounter.

You and your team addressed the immediate priority well – to restrain the patient sufficiently so that her urgent medical needs could be attended to. Your presentation did raise a larger question of how, with a patient of such limited functioning, you can form some sort of relationship. In the inpatient setting, even in the outpatient setting, I suspect this would be difficult indeed. But, perhaps by expanding the parameters of what we mean by "relationship," it would not be impossible.

You also helped us remember not to make snap judgments about parents who place their children in care facilities.

Through your essay we were able to imagine ourselves (at least a little bit) into what must have been truly an overwhelming situation; and your unflinching portrayal of the reality of that situation made us realize that platitudes about connecting to patients are often not that easy to translate in complex clinical situations. Thank you for making us all a little more uncomfortable than we like to be. Dr. Shapiro

Hi --, I really liked how you repurposed unused stickers to make this beautiful butterfly, which also resembled the malar rash presentation of the terrible disease of lupus. It reminded us that often horror and wonder are closely connected in medicine, in this case a courageous patient burdened with an awful disease. Thank you very much also for sharing how the HEADSS assessment was not

positive for depression, yet the patient had a history of depression. As we discussed in class, *how* you ask these questions can be important; and also, no matter how carefully you ask, sometimes patients are simply not ready to open up. Your searching the patient's chart so carefully showed you were actively trying to understand her situation and were sensitive to her struggle with "feeling different." It was especially important that you highlighted the resource of support groups, which can really ease the psychosocial burden on adolescents suffering from lupus. Thanks for a sensitive and empathic presentation, Dr. Shapiro

Dear --, thank you for having the courage to draw on your personal experience as a pediatric patient. Your generosity with your personal story allowed us all to move a little closer to the experience of a hospitalized child. You spoke with undeniable authority about the confusion, fear, and often shame that children can experience. You also showed just how impactful a hospitalization can be and how much children remember from these experiences.

Your point about the violation that results from healthcare professionals lying to children, or giving them false choices that will be overridden offered an extremely important lesson. Doctors and nurses often dissemble with kids out of a well-meaning impulse to protect them, but this approach almost always backfires. As you conclude so wisely, children deserve the same respect, honesty, and concern for their comfort as we extend to adult patients. Truth always matters. Thanks again, Dr. Shapiro

Dear --, what a truly empathic and insightful essay. I have great respect for the way you took time to imagine yourself into something approximating the life of this little kid. This showed you really wanted to understand his experience as well as take to heart what his life might mean for how you lived yours. You are certainly correct that watching what is required for his daily life to "work" puts the problems most of us face into perspective. Really beautiful!

You also made a great point about this 7 yr old kid being "seen in pieces" by so many different specialists. This is a very common experience for children with congenital disabilities, and although from a medical perspective, it makes sense, it can be very dehumanizing – the person of the child disappears in a constellation of medical problems.

The video was really interesting as well. Although of course it helped us see how much effort was required for even simple tasks of daily living, I don't think your patient would see it this way – his life is just his life, and normal to him. That doesn't mean that he is "just the same" as others – of course this would be a gross simplification. But being "inspired" by people with disabilities can also have the unintended consequences of putting them in a different category than "ordinary" people. So I'd say, yes this little guy is an amazing kid – and he's also just a kid. I think your presentation captured this dual reality with great sensitivity and awareness. Thanks for sharing his story and your thoughts with us. Dr Shapiro