

PEDS REFLECTIONS 4/4/2016

Hi Team Kawasaki, you came up with a creative way of illustrating key signs and symptoms of Kawasaki's disease, both through visual demonstration and a clever poem (you integrated a lot of medical words that don't often appear in poetry with considerable success). --, thank you for reminding us just how cute and how resilient kids are – it is one of the lures of Peds. --, thank you for not shying away from the pain of seeing serious disease overwhelm even the most resilient of spirits. You made an excellent point that kids do not have the life experience that can develop effective coping skills. I agree, and yet it is astonishing how often sheer life force (or something) carries children through difficulties it is hard to imagine enduring. In any case, your project was ingenious in the way it employed active learning techniques to engage your classmates and test their knowledge. Best, Dr. Shapiro

--, I appreciated many things about your project. First, that you did it. It was an important reminder of the importance of knowing your community. Too many physicians blithely counsel patients to “go to a gym” or “find a dance class” or “get tutoring” or “learn a hobby” without bothering to become familiar with the opportunities existing in a particular neighborhood to actually do any of these things. You did the homework, and discovered that often the resources we expect to find are non-existent or require expenditures families living on the edge cannot make. This can be hard knowledge, but helps physicians avoid facile advice-giving that ignores realities on the ground.

Second, I thought your suggestions were really creative. In addition to the omnipresent sports referrals, you included theater, music, and chess. Not everyone is an athlete! Your ideas could help kids dream beyond certain pop culture stereotypes. Finally, I appreciated your emphasis on developing leadership skills in kids. Too often, the entire emphasis is on receiving “help”. You showed you understood that these kids had a great deal to give as well. Very useful and informative project. Thanks for putting in the work! Dr. Shapiro

--, you did a beautiful job of using the HEADSS exam to really *hear* this young man's story. You demonstrated sensitivity and skill – knowing when to ask mom to leave the room, creating a safe nonjudgmental space, and just being willing to listen. Giving a patient this time and attention is the farthest thing from “doing nothing.” This kind of encounter helps to heal the wounds of the heart and soul that this patient struggled with and for which there are no medications. You also reminded us how difficult life circumstances are for so many youth. Adolescence is a challenging time for anyone, but how much more so having to deal with drugs, family instability etc. Your project was a superb example of what an essential role third year students play on the medical team; and how you all embody qualities of caring, respect, and humility that sadly more senior physicians sometimes forget.

Best, Dr. Shapiro

I really appreciated your writing your essay from the mom's perspective. You succeeded in bringing her voice into our awareness that made it harder to avoid the judgment and blame such parents sometimes evoke in healthcare providers. Yes, she was angry and confused. But when we heard her story through her eyes, considered the long history of dismissive encounters and lack of respect for a mother's intuition, her behavior becomes more understandable. You also captured very well just how intimidating the constantly changing teams of doctors can be, how frightening and dispiriting it is when each team offers a different opinion, how from the patient's/family's perspective no one seems to be in charge, and worse, no one seems to really care. You provided the class with an excellent opportunity to consider how to address situations where there is no certainty and no immediate answers. I was struck that you were the one attempting to reassure mom that indeed, the doctors were working on her behalf. Searching for a diagnosis is clearly the highest priority; but there is no reason this cannot occur within a context of awareness of the parent's anxiety and distress.

I am so sorry that, after such a tumultuous and stressful course, this little girl ended up having a bone cancer with a poor prognosis. Sometimes life is terribly unfair. I also hope that, in facing a very difficult future, the parents will be able to receive the support and guidance they will need.

A very thoughtful and insightful project, with great empathy for the mother's point of view. Dr. Shapiro

--, what a moving and beautiful piece of writing you "channeled" in the voice of the patient. I hope you keep writing in your future because you have a powerful way with language. As you could see, your classmates were deeply affected by the story you told. As I noted in class, I was particularly struck by the contrast between the dry objectivity of diagnoses such as GAD and major depressive disorder, and the lived experience of this young Latina woman. You *knew* this patient, not just her diagnoses; and you apprehended the enormous challenges she faced in just trying to navigate her life day to day. You captured her aspirations to "fly higher" counterbalanced by the demands of her family, the lure of drugs, and the dangers of misguided love. You discovered her shame, her poor body image, and the despair which led to a suicide attempt. Your patient filled the room with her presence, and we could not avoid her humanity. Thank you so much for bringing her to life in a way none of us could ignore and many could connect to in an intimate, human-to-human way. Best, Dr. Shapiro

--, your poem "What Can I Do?" was a very nuanced, balanced exploration of the responsibilities of the medical student/physician to the innocent child patient when faced with parents who, while not outright neglectful or abusive, are clearly overwhelmed by their own dynamics and the complex needs of a seriously ill child. As you surmised, these situations do not have easy solutions. Social service

involvement may not be appropriate; and placement in a foster home is not always an ideal answer. You are absolutely right that, in these circumstances, your first obligation is to be an advocate for the child. The difficulty lies in figuring out how best to do that. Often, physicians and social workers can work together to help parents simplify the medication schedule and organize other care needs in ways that are not so burdensome. Unfortunately, as you discovered, serious illness in a child often intensifies rather than ameliorates dysfunctional family dynamics. It is a long and sensitive process to overcome these so that everyone is working in the best interests of the child. Thank you for getting us to realize that these situations are not black and white but shades of grey. Best, Dr. Shapiro

Dear --, thank you for raising such stimulating questions about the best societal and medical response to non-vaccinating parents. As you surmised, this is not simply a matter of parental rights, there are thorny ethical issues involved. In other instances, the state clearly has intervened to put limits on parental autonomy, such as in certain forms of corporeal punishment and denial of potentially life-saving or prolonging treatments (both deemed forms of physical abuse/neglect). You pointed out correctly that the complications arise in considering where the boundary lies: What are the parents' rights to make determinations about the wellbeing of their child? What are the child's rights? What are society's rights (the point about herd immunity that you raised)? As we discussed, the law is a blunt instrument; and criminalizing behavior often has the result not of preventing it, but of pushing it underground. California has taken legal steps to require children to be vaccinated when they enter the public school system, but we have yet to see how this law will affect vaccination rates in the state.

Your reflection, I felt, was extremely valuable, both in its specific exploration of your classmates' views regarding anti-vax parents; and in a more general sense of encouraging your fellow future physicians to wrestle with the moral and ethical implications of many aspects of healthcare. Ideally, we want to prepare the next generation of physicians to not only treat individual patients but to be able to grapple with and address the larger social issues that are implicated in the health and wellbeing of the populace on a broad scale. Thanks for provoking such a worthwhile conversation. Dr. Shapiro

--, thank you for your touching poem from a lonely baby's point of view and your thoughtful comments explaining the situation and the choices you made. This project was commendable in so many ways. First, your awareness that health professionals often cope with being surrounded by suffering by pretending it doesn't exist (ignoring the cries of babies/kids on Peds) was both honest and insightful. You are right that this denial comes at a cost of human feeling and responsiveness. (I think there are ways of remaining aware/witnessing such suffering, even as you acknowledge your own limitations in not always being able to respond because of other duties and responsibilities). Secondly, you chose to enter that baby's room and see him for what he was – not a diagnosis of meth withdrawal but a lonely little being with no one to comfort him. How admirable and courageous that you stepped in to fill that gap. You imagined so eloquently what this little one might be expressing in

his screams: does anyone see me? Does anyone hear me? Does anyone care? Finally, you knew you had to step out of the room. You could not take this baby home (much as you might have wanted!), you could not find him a perfect foster family, you could not solve all his problems. Many, faced with these personal limitations, choose not to get involved at all. In my view, the better moral act is always to do what you can, even if it seems to fall short. I believe cuddling that little kiddo made a difference to him – and to you. Allowing yourself to be human in medicine is an important way of committing to a certain set of values that goes along with the more technical aspects of doctoring. Having the courage to face brokenheartedness occasionally in medicine ensures that your heart stays open. Best, Dr. Shapiro

What an excellent project, --! First, I'm a big admirer of Jodi Halpern, and that book in particular I think is a wonderful argument in favor of an empathic rather than a detached stance in clinical medicine. I also thought it was both creative and involving to write out inspiring quotes about children then have your classmates read and reflect on them. I also appreciated that you put questions of health within a broader social context. Your frame that physicians work "downstream" attempting to improve individual health and resolve individual health problems that often have been created or influenced by large societal forces such as the food industry, environmental pollution, which themselves are influenced by issues of race, gender, and class is vitally important to keep in mind. Physicians sometimes blame patients for problems that are much larger and more complex in scope. Your project was a great reminder that if "babies are such a nice way to start people," we should be doing all within our power as a society to ensure that those babies get the best nutrition, medical care, parental attention, and education so that they can thrive in later life. All best, Dr. Shapiro

Dear --, thank you for sharing a powerful story of how to deal with a distraught, angry, belligerent parent in a way that was humane, compassionate, and also confident and self-assured. In a fraught situation, when the team's attention was focused on the young man who was seizing, you recognized (and were not intimidated by) the needs of his father. I was impressed with the way you were not reactive to the father's abuse (which you rightly recognized stemmed from fear), but instead formed a bond with him by disclosing your own experience, reassuring him, and redirecting him back toward a parental role, i.e., the importance of his being composed and hopeful when his son regained consciousness. Your use of "we" language also seemed very effective, letting the father know that he was not alone at this frightening moment. As well, your strategy to focusing on the solution rather than the problem appeared to give the dad a more constructive role. I was also struck that you chose to stay with patient and family for half an hour after the crisis had passed. It can be frightening for the family to see the team stream out once things are under control. By simply staying, without saying anything, your presence communicated that you were there with them.

The other interesting aspect of your interaction with this family was the issues it raised about patient-doctor boundaries. Should physicians share personal information with patients? Should physicians give out their personal phone numbers? Should physicians get a cup of coffee with patients?