PEDS REFLECTION SESSION NOV 5 2014

Dear --, I hope it wasn't too unpleasant to try your hand at a poem ☺. Your effort had some pretty funny lines and some very good insights. Despite portraying the mom as somewhat demanding and entitled, your narrative also emphasized the reasons she might be behaving this way and your awareness that trust between mom and healthcare system had been broken. You came up with excellent strategies for trying to win her back: transparency about the team's thought processes regarding her kid; inclusion of mom in a meaningful way in treatment plan and decisions; and (most interesting) using data to persuade and reassure. These approaches demonstrated your skill at adapting your interaction to the patient's personality and background. Your project generated an interesting discussion and definitely engaged your classmates. Strong work ☺ Dr. Shapiro

---

Hi --, thank you for highlighting the ethical dilemmas that can be triggered by the principle of autonomy in your thoughtful essay. Thank you also for your case presentation, and for bringing the voice of Brittany Maynard into our discussion. To me, these two cases differed in important ways. In your patient's situation, the parents objected because the grandmother had died under anesthesia, an outcome extremely unlikely for their son, whose life might be saved by a more aggressive work-up. In Brittany's case, she had a terminal diagnosis that intervention might only postpone marginally, with significantly impaired QOL. To me, the contrasts show both the uses and misuses of autonomy.

As I mentioned in class, it was very powerful to hear Brittany's thoughts about death with dignity, as well as those of her husband and mother. The medical system often makes it difficult for the patient to speak for herself – so much of what we learn of the patient is filtered through others (doctors, but also nurses, social workers, OTs). Listening to Brittany in my view showed a young woman who had come to a very difficult, heart-wrenching decision in a thoughtful and reflective manner that honored who she was and her deepest values. I see this as an ideal example of the exercise of autonomy. I am less comfortable with accepting the dominance of autonomy when the patient/parent seems to be acting out of fear, anger, helplessness, or some other strong emotion; or when they do not truly understand the implications of their decision; or a myriad other factors that might compromise the quality of decision-making. Your presentation really made us all think about how best to honor patient wishes, especially when they go against mainstream medical thinking. You brought great insight, compassion, and careful thinking to the discussion. Best, Dr. Shapiro

---

Dear --, first, thank you for such a clear and well-informed explanation of HLS and its treatment options. As a layperson, I really appreciated your clarity, and imagined that if I was a parent of a child with this syndrome, I would at least have had a good understanding of what this meant and the implications of intervention. How brave of you to ask yourself the impossible-to-answer question, the question parents often ask: What would you do if this were *your* child? As we discussed in class, such a question needs to be approached with humility, because of course we *can't* put ourselves in their shoes, we can't imagine what it would be like. But as a thought/heart experiment, I think it can have value because it moves us closer to the suffering parent when much in us wants to flee as far away from them as possible.

Your presentation followed very nicely on --'s discussion of autonomy because it also raises the issue of how to respond when patients (or parents) make choices different from what you would make as a doctor (or a patient or a parent). For example, suppose you felt that palliative care only were the most humane and compassionate decision? How would you feel if the parents opted for palliative surgery? I don't think it's as simple as saying, "It's their choice." Of course that's true, but only on the other side of a careful, nonjudgmental exploration of the implications of various options, a process that honors but is not driven by the emotions that will inevitably arise in facing such heartbreaking choices. It was obvious how moved you were by this tragic situation, and how much you wanted to help guide parents toward the best decision. In the end, each case will be different, and a good doctor will be able to help parents do what their personal values and ethics dictate. Thank you so much for tackling such a hard question with such authenticity. Dr. Shapiro

---

Hi --, thank you for an interesting cross-cultural perspective on childhood obesity. I suspect that this is not the problem in Norway that it is in the U.S.; sadly one of the effects of globalization is that lifestyle-based health issues travel across national boundaries as easily as infectious diseases thanks to transnational corporations that promote cheap (although innutritious) processed food. As we discussed in class, individual obesity is only the endpoint of a problem that has larger social roots; yet individuals are the ones who are blamed, ostracized, and penalized. It is important that such judgments are not inadvertently perpetuated in the doctor-patient relationship. Interventions to shift widespread obesity must occur on individual, familial, community, and societal levels. Between individual doctors and patients, change is most likely to occur in kids when parents and siblings are involved and when strategies are tailored to a child's interests and motivation. Like your clever "empty bottle" project, activities that are fun and nonjudgmental have a much better

chance of engaging a kid. But the physician has to remember that the patient is swimming upstream against many powerful forces, and that change is difficult and conditional. Thanks for focusing our attention on what has been called an epidemic in this country with, as you pointed out, significant adverse health consequences for both individual and public health. Best, Dr. Shapiro

---

Dear --, I appreciated your raising the issue of female genital mutilation with the class. As a result of your report, I became interested in the question of FGM in the U.S. Thanks to google, I learned that approximately 228,000 girls in this country have either suffered the procedure or are at risk to experience it. Further, like Norway, FGM is a crime under federal law punishable by up to 5 years in prison (so very similar to your country); as well as a crime in 22 states (including thank goodness California). Also, as in Norway, transporting a girl to another country for the purposes of FGM is also a crime punishable by up to 5 years in prison.

FGM is an extreme example of "cultures colliding." We cannot simply accept the argument of cultural relativism – "different cultures have different customs" – because this particular practice does irreversible and lasting harm to a minor. As you pointed out, FGM is listed as a human rights violation. As you also pointed out, it is a private ritual that, no matter how barbaric, has deep familial and cultural roots. Because it is a private ritual, legal penalties while necessary are insufficient to change the practice. This requires education and dialogue, something that will become increasingly needed as national boundaries continue to become more porous. Thanks again for bringing into our awareness something we probably would prefer not thinking about! Dr. Shapiro

---

--, your poster to promote healthy lifestyle habits "Health Starts at Home" in kids and families was creative and appealing. I could easily see it hanging in a pediatrician's or family doc's exam room. It was colorful and game-like (although adapting "CandyLand" might have an irony you did not intend ☺), and I imagine kids would be intrigued. You made an excellent point that of course children do not have autonomy to make choices for themselves – they are dependent on the food parents provide, the food offered in the school, the opportunities available in the community for exercise etc. Therefore, as you recommended, a family approach will be more effective than simply haranguing the poor kid to "eat less, exercise more."

You also made an important observation when you noted that counseling kids (and adults) about lifestyle changes is a time-consuming process and is a role well-suited to third year medical students who often have a little more time to spend with patients. Third years have

a great deal to offer patients in terms of listening to their stories and helping to guide them to solutions to problems that may have medical consequences but are not primarily medical in nature. While it is true you cannot fix all the problems patients are dealing with, you can at least take a more whole person approach.

Thanks for sharing your project with the class. It highlighted a very important public health issue that so far has defied solution. A few of your posters scattered throughout outpatient clinics couldn't hurt! ☺ Dr. Shapiro

---

Dear --, thank you for your extremely well-researched project identifying alternative educational resources for at-risk youth. I was impressed by your realization that, although this was a healthy adolescent with "nothing wrong," he was floundering. The willingness you showed to "look outside the box" of biomedicine gave him a chance to walk another path. I admired this flexibility in defining the appropriate scope of assistance to a patient. I also admired your unwillingness to give up on him, your determination to find a program or option that might spark something in this kid. You know, a lot of primary care medicine is like that – looking for the way in to reach the patient, not being discouraged when at first you don't find it, but continuing with each visit to hope that something will click. Motivational interviewing can be very useful in this regard, but as you know, teens are a world unto themselves. Your patience and commitment are what every patient hopes for. Really interesting project! Dr. Shapiro

---

--, thanks for your interesting and thought-provoking narrative of an adolescent patient with vomiting who denied drug use on the HEADSS exam, but later acknowledged marijuana use to the GI consulting physician. It sounded as though you did a thorough and conscientious job of the exam, while being careful to protect the patient's confidentiality. The GI doc managed to elicit different history, which then somehow became known to the patient's mother, to the patient's distress. You also commented that the residents' were quick to latch onto the diagnosis of cannabinoid hyperemesis syndrome, despite the fact that the patient's history did not neatly fit this profile.

The project raised many important issues: 1) the importance of preserving patient confidentiality 2) the difficulty of gaining a patient's trust, especially around vulnerable disclosures such as drug use and sexual habits 3) the difficulty of the physician/medical student trusting the patient, once the patient has been shown not to be truthful 4) the lure of the definitive diagnosis, even when it might be beneficial to keep an open mind.

I was impressed with the way you identified so clearly how much was actually in play with this one encounter. A good doctor manages to recognizes and address all (or most!) of the complex issues going on in any given interview. It is a bit like juggling – drop one ball, and the whole effort collapses. The good news? Like juggling, with practice it becomes second nature ☺ Best, Dr. Shapiro

---

Dear --, I could see how much you struggled with this patient's and family's situation. I deeply admire your dedication and commitment to trying to help them. As I noted in class, it seemed to me you ended up shouldering too much of this burden on your own. Perhaps your team felt you could deal with the family because of your "shared" heritage. But it is the responsibility of the team to pay attention to the toll the disease is exacting not only on the patient, but also the parents, and the team members, INCLUDING the medical student.

In this case, the family seemed to become increasingly skeptical and suspicious of "American doctors" when days passed and more and more studies were done without their precious baby improving in any tangible way. The need for the PDA surgery was the last straw, despite this being a reasonable candidate to explain the baby's FTT. I can't help thinking that, with so many language and cultural factors in play, things shouldn't have been allowed to get to this point, with only the medical student standing in between the family and their complete disengagement from the healthcare system. This was too much responsibility for one MSIII, indeed for anyone. This is why we have TEAMS, but the team must be ready to address not only medical complexity but also familial and cultural complications.

For whatever reasons, this didn't happen with your team; and as a result you were overwhelmed by carrying this emotionally exhausting situation for all intents on purposes by yourself. I think this is why you didn't want to acknowledge the father when you saw him walking – a fear of getting sucked back into an emotionally crushing situation. --, I think the sign of a good doctor is someone who wrestles with such difficult encounters, and tries to understand what can be learned. In this case, perhaps one lesson is to appreciate that when you are able to share the burdens that are an inevitable part of clinical medicine with your colleagues they do become lighter. I hope as you continue with your medical education that you will have many opportunities to experience this for yourself. In the meantime, you behaved with great integrity and courage under extremely challenging circumstances. Dr. Shapiro

---

Dear -- and --, what an incredibly empathic and thoughtful project! The "thought experiment" of writing a reflection in the voice of the patient with HLHS or parent dealing with HLHS in

their child is an effective way of moving closer to the human experience of those actually enduring this tragic diagnosis. Sometimes doing so will actually provide insights into the patient (this is partly luck, and partly because you may have heard patient or parent say something that didn't register as important for the HPI but rises in your consciousness in this more reflective process). But even if your hypotheses or imaginings about the patient/parent are not accurate (and remember to hold them lightly! – the patient/parent has the final say about what is true for them), the fact that you've tried to enter into their perspective reminds you of their humanity. So good for you for taking this on.

--, your point of view writing about the mom who struggled with and then decided on abortion was a compassionate portrayal of a woman who desperately wanted this child yet did not want to inflict a brief life filled with suffering and limitations on her. --, you empathically imagined a child tired of surgeries, longing for normalcy, who felt like a burden on his family. Again, in real life, different people (parents and children) might have different reactions to the same set of difficult circumstances. But the responses you imagined are plausible, and brought your audience face to face with the overwhelming emotions and thoughts that are a part of HLHS.

Also, great job of finding the study of physicians who had expertise in treating HLHS. I found it fascinating that a third would choose palliative surgery, a third would choose compassionate care only, and a third simply did not know what they would do. A survey like this forces respondents to move closer to the lived experience of the families they care for – and to me this is a very good thing.

Finally, I really liked the way you "brought home" these questions to the class, attempting in similar fashion to encourage your classmates to consider questions no one ever wants to have to answer. It is easy to say we can't imagine what this would be like – and that is true – but I think it is good for the soul to spend a few minutes grappling with such questions, even – or perhaps especially - when no answers emerge. Thank you for taking down the fourth wall and creating a situation in which we were forced to engage. Best, Dr. Shapiro

---

Dear --, you reflected on several issues which I don't think good physicians ever fully resolve, only continually wrestle with. How can you maintain an emotional connection with patients without becoming emotionally exhausted and overwhelmed? How can you ethically inflict suffering on others, even for a positive end result, and especially when the outcome is uncertain? How do we come to terms with the limitations of medicine, the inability to "fix" all the patient's problems (especially social problems)? You will likely never find definitive

answers for these questions, but you are acting with integrity by recognizing that these questions are implicated in every aspect of clinical medicine.

My view is that being a doctor takes a lot of courage in that it requires you to learn how to be open to the suffering of others (sometimes suffering you the doctor has caused), to ameliorate it when possible, but always to witness it, to be present and walk *with* the patient, and not abandon them (emotionally if not literally). It seems to me that this is what you did with little --. You couldn't take him out of foster care, you couldn't give him a loving family, apparently you couldn't even kiss him, you were part of the team that kept him NPO for 36 hours – and all these things were limits/requirements of caring for your patient. But you could connect with him, you could visit him and give him a hug. Imagining the toddler, the boy, the teen he would become, when he was discharged, you could take a moment to wish each of these well. You were part of the team that repaired his medical condition and gave him a chance to grow and thrive. You cared about your patient. As you become more experienced in clinical medicine, I hope you will find ways of navigating that balance between unattached and too attached. I suspect that, if you continue to ask such excellent questions, you will. Best, Dr. Shapiro

---

--, thank you for your beautifully imagined point of view writing in the voice of a young patient with a rare diagnosis that fundamentally altered her life. You did a great job of capturing the perspective of this patient as she goes deeper and deeper into the hospital system, as well as her confusion of the patient (PISU I thought was particularly funny, and probably is how some patients feel there). Even better, you were able to imagine her priorities that perhaps seemed irrelevant to the team in the exciting hunt for a diagnosis, but of course to the patient meant everything. She's a dancer and she wants to dance. Did anyone talk to her about whether she could return to dancing. Your essay showed her experience of doctors who talked in jargon, didn't make eye contact. I loved the line "I watched him speak, felt the sound go in one ear and out the other." That is truly the experience of so many patients. You imagined that was happening, but how often attendings wonder whether that might be happening? Doesn't matter, words were spoken, time to move on.

I also liked very much that you indirectly alluded to the issue of iatrogenic opioid dependency. I envisioned this patient 5 years down the road, asking for specific narcotics by name to control her pain, and some resident rolling her eyes and saying, "Another drug-seeking patient, and she's only 19." The health care system does not yet do a good enough job of addressing chronic pain in ways that sustain the patient's wellbeing.

Finally, you asked an extremely thoughtful and humble question at the end of your presentation. "Is this all just projection?" Sometimes writing in this manner (or at least thinking about what the patient might be experiencing) will actually provide insights into the patient (this is partly luck, and partly because you may have heard patient or parent say something that didn't register as important for the HPI but rises in your consciousness in this more reflective process). But even if your hypotheses or imaginings about the patient/parent are not accurate (and remember to hold them lightly! – the patient/parent has the final say about what is true for them), the fact that you've tried to enter into their perspective reminds you of their humanity. This is a good thing.

Thanks again for a very well-written and well-imagined essay. Dr. Shapiro