PEDS REFLECTION PROJECTS 5/16/16

Dear --, --, --, and --, thank you for such a thoughtful presentation, which highlighted many ethical and moral dilemmas in an unusual case that nevertheless had relevance for many aspects of pediatrics. You delved deeply into the challenges of breaking bad news in a compassionate and skillful manner, including issues of how parents should be informed of a likely terminal diagnosis of their child; how multiple pieces of bad news should be delivered; and how lack of coordination among teams can cause harm to parents by disrupting the plan. You also raised thorny questions about what levels of authority do parents have the right to exercise over children (for example, we don't allow parents to abuse children, or to deny them beneficial treatment for extant disease). Can we allow them to procreate when their children will have a very high likelihood of a fatal medical condition? (I believe this is one of the reasons why there are laws against incest). Another issue you tackled was who is the patient in pediatrics? Certainly the child, but the wellbeing of the child is highly dependent on the parents, so very often you are intervening with parents as well as kid. Finally, you pointed out that, as more and more specialists get involved, it is easy to lose sight of the forest for the trees. Everyone has an opinion about some aspect of the patient, and everyone wants to weigh in. Who is focusing on the big picture, in this case tragically that this little boy is going to die in a couple of years. That is the unavoidable context in which priorities should be set and decisions should be made.

I thought you all did an excellent job of apportioning responsibilities among your team: Anna, the facts of the case, and some of the big questions; --, the cultural differences that might lead to very different perceptions of the ethics or normalcy of incest; --, some of the legal issues involved, and the extent to which parental privacy and decision-making can be regulated by the state; and --, how the medical system rolled into action on this one, for better or worse, and how the parents reacted emotionally to this situation. I also was impressed with the group discussion questions you generated. They were very successful in involving your peers in a vibrant and informative discussion. I think everyone in the room learned something today about how complicated it can be to figure out how to "do the right thing." Thanks for such a provocative topic and forcing us all to think. Best, Dr. Shapiro

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Dear --, the "anti-vax" parent continues to pose significant challenges to pediatricians, and to society as a whole. Your presentation, grounded in an individual encounter, was scholarly and well-researched. You raised many good questions about limits to parental authority; and whether parents have the right to make decisions for their children that will have longterm consequences. Of course we know that society has already established certain restrictions (parents are not allowed to abuse their children; or to withhold likely livesaving treatment from seriously ill children). Vaccination is tricky, because the child is healthy and not in immediate jeopardy. But as you noted, California has used the public school system as a way to enforce compliance. You also made excellent points about

the limitations of herd immunity and about whether pediatricians should refuse to care for unvaccinated kids.

I appreciated that you disclosed your own judgments toward this mom. Most medical professionals would agree with you; and yet, as you recognized, judgment only rigidifies these parents in their attitudes of mistrust and suspicion. When the door remains open to dialogue, there is always the chance that views can change. Otherwise, parents can retreat into a world that only reinforces their beliefs and makes any receptivity to alternative viewpoints unlikely. Thank you for enabling us to revisit this vexing and important topic. Dr. Shapiro

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--, I really appreciated the honesty you displayed in your reflection project. "What problem?" Mom is sick, of course it makes sense that she should stay away from her hospitalized kid who is awaiting surgery. And yet… as you, with the help of your attending's role modeling, realized, the situation is often more complex. As we discussed in class, parents often feel guilty when their children are hospitalized – not because they've actually done anything wrong, but because they feel as if they've failed their child, they haven't been able to project the person they love most dearly. They may ask a lot of annoying questions and always be underfoot to show that they're still good parents and/or to try to protect their kid in the alien and seemingly impersonal environment of the hospital. From their perspective, leaving their child's bedside (even if the parent is sick) may seem like a final act of failure and abandonment.

You did outstanding work on not accepting your initial assessment of the situation (why doesn't this mom just do what's in the best interest of her kid?) but rather digging deeper to try to "see through mom's eyes." Once you engage in such an act of empathy, you develop new insights into what is driving the parent to maintain an apparently illogical position, and you have a better chance of helping her to understand the situation differently. For example, in this case, reassuring mom that she is a good mother, that she obviously cares about her child and would do whatever she could for her might provide a good lead in for framing *not* spending as much time in close proximity to the child until she was well as meeting all these criteria. On the other hand, understanding mom's perspective may make the medical team more understanding of why she can't leave the bedside no matter what. In terms of the kid's wellbeing, while exposure to a virus is definitely not ideal, it might also be very traumatic for the child not to have her mother near at hand. Thus we discover that even an apparently simple and "obvious" decision can be more complicated than it looks! Thanks for an excellent presentation. Dr. Shapiro

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Hi --, and thanks for contributing your poignant drawing of the "baby behind bars." You rightly identified advocacy as an especially important responsibility of the pediatrician, and your project did an excellent job of "advocating" for this little one. The metaphor you created of being "trapped" – by illness, by the IV lines, by the hospital – was powerful and very insightful. The fact that you depicted the hospital room as bare and empty was also highly evocative of the "cold" atmosphere that has

often been noted about hospitals, even children's hospitals. All of this served to highlight the baby's isolation and aloneness, which brought us to your final issue: mom was not much in evidence. This is always a sad and painful situation, and likely has an effect on baby's recovery and healing. It is hard not to judge, but as I've learned over the years, there are many reasons why parents are no-shows: transportation may be very challenging, they may have other kids at home who need them, they may lose their job if they take time off, or (as in your patient's case) they may be wrestling with drugs, alcohol, mental health issues of their own. These situations are heartbreaking, and they force us to confront the limits of medicine: there is no pill that will fix this. Often, in such cases, I've seen nurses (and medical students) step in to provide, at least for the duration of the hospital stay, the love and attention the baby isn't getting from parents. It is not enough, but it is something, and gives that child a little comfort I believe. Sometimes all we can do is what we can do, and then pray that the child's needs will be met (and when appropriate involve social services). Thanks for a touching and emotionally evocative project – it showed great empathy. Dr. Shapiro

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Dear --, what a beautiful story you shared about dressing up as a Disney princess to visit a very sick little girl in PICU. First, I appreciated that you shared your initial ambivalence to "cheering up a sick kid," when she was not your patient, you could have just gone home to study – or as you acknowledged, more likely sleep! Struggling with the inevitable burn-out at the end of third year, at first it seemed "just one more thing," "not medical," "not a learning experience," perhaps even silly and a waste of precious time. Your question, "Am I even qualified to make a kid feel better?" was both funny and poignant, as it highlighted how, in some ways, medicine, although at its core is dedicated to "making people feel better," often provides its practitioners little guidance in terms of how to go about doing so. Doctors may know how to relieve pain, but they are often baffled about how to alleviate their patients' suffering.

What you discovered, and what you offered so eloquently to your classmates, is that this might have been the most important "learning" of your entire year. Paradoxically, by giving to someone else, for no reason other than to alleviate this child's suffering just a little, you noticed that your burn-out decreased. This is such a valuable insight. Burn-out can be addressed by taking a vacation, but it can also be addressed by reconnecting with why you're doing what you're doing – not the more day-to-day reasons of acquiring medical knowledge or preparing yourself for a good residency (although these are important), but to help people who are suffering. Along these lines, I especially appreciated your point that, while you might not don a Disney princess costume for a hospitalized adult, these patients also have needs and dreams that sometimes you can help fulfill, even imperfectly as with the Disneyland expedition. As you observed so astutely and so touchingly, for those moments you were able to restore the "kidness" of this sick little girl. The impulse to encounter your patient at this deep level of meaning is what will sustain you in medicine. An extremely authentic, perceptive, self-aware, and empathic project. Thank you. Best, Dr. Shapiro

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-- and --, you put together a collage that triggered many different associations to the "spectrum of parenting." --, I appreciated your honesty in talking about the difficulty of connect with kids who often lack the language or the maturity to be able to fully explain their problems. I think a lot of students feel that way on Peds, and it raises good questions about how we relate to others across barriers of language, culture, cognitive development etc. that exist beyond the pediatric setting. Thank you also for disclosing your judgment of the Pepsi and chips mom. This was a funny story, but as you rightly realized, it had very worrisome health implications for this adorable little girl. In these circumstances, it is easy to blame parents. But as we discussed, such an approach is not helpful in supporting parental change. Rather, aligning yourself with the parent, acknowledging the tremendous difficulties they are contending with, being supportive but persistent, making use of motivational interviewing are more likely to yield positive results.

--, your honesty in sharing your own pessimism about effecting lifestyle changes in so many of the obese and overweight kids we see was admirable. I think not just medical students, but residents and attendings have the same feelings. It is hard to kindle hope when there is so much evidence to the contrary. That's why the example of the exercise class was especially wonderful. There you saw an example of an out-of-the box activity that was fun rather than punitive (as the lecture in the doctor's office can often be); involving members of the family rather than just the "identified patient". As a result, what you witnessed was proactive engagement and enthusiasm rather than resistance and defensiveness. What is interesting is that often the same parents who shrug their shoulders talking with their pediatrician will show up to such an activity and engage with gusto. People are rarely one way or the other. Most patients are ambivalent about lifestyle change. What's important is that their doctors keep looking for the "moment of readiness," for the right approach that strengthens the part of them that is motivated to try. Sometimes doctors must believe in their patients when the patients don't believe in themselves.

Thank you both for an excellent, insightful, and empathic project. Dr. Shapiro

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Hi --, nice to cross paths with you again. You are such a good writer – I hope you see essays about medicine as part of your future. You express yourself clearly and cleanly (I can see that PhD mind at work), with the occasional humorous twist. A pleasure to read. In your class presentation, I appreciated two things in particular. One was your sharing your worries about your daughter. Here you were speaking as a parent, not a PhD, not a medical student, and I think it made your (apparently childless) classmates realize that these anxieties and concerns are *real,* it's not just something "patients' parents" do but it's what we all do when we become responsible for another precious life.

The other thing you disclosed was that sometimes, despite your parent status (or perhaps because of it), you slipped into attitudes of judgment toward parents who were not taking good care of their kids. We all do this, and what's important to figure out is does this advance the therapeutic relationship in any way? Does it benefit the kid? In extreme cases (e.g., when a child is removed from the home) we pray that our judgments have improved – or saved - the child's life. But in other

circumstances, judgment can push parents away and destroy the small possibility that you might be able to form a partnership to promote the child's best interest. These are always challenging and frustrating situations, but as your presentation indicated, the more we listen and the less we judge, the better chance we can move in forward in a positive direction.

Hope you continue to "worry effectively." Best, Dr. Shapiro