PEDS REFLECTION SESSION 5/13/19

Ron Goubet, Chinh Tran, Chloe Krasnoff, Phuonganh Le

Dear Team BBN, thanks for tackling the difficult topic of breaking bad news through such a creative medium as a comic strip. As you pointed out, the medium aligns very well with what kids enjoy. In your discussion, you made the excellent point that for the medical student it is a very different experience when the patient is already aware of their diagnosis and its implications; versus when they and their parents are learning this difficult information for the first time. Chloe, I appreciated the insight that patient, mom, and medical student will all have different emotional reactions; and that it is important for the student (later physician) to be aware of everyone's reaction, including her own, and calibrate her response so that it reflects that patient and family need in that moment (which as you also pointed out will be different in each case). The comic strip captured very well the courage of the kid, the exhaustion of the mother, and the emotional upheaval of the student.

Ron I was so struck by your statement that, when you were part of a team delivering bad news about a 16 mo old, you "didn't know where to look." When we look at the "face" of another (as the philosopher Levinas observed), we acknowledge them as a human being. Sometimes this is not an easy thing to do, especially when we must contemplate their suffering. Still, by doing so, we also offer human connection, which patients and families desperately want in these moments. Yes, they also want answers and a treatment plan, which as a third year student you may not be able to offer. But you can always extend your humanity.

Anh, I also appreciated your bringing in the perspective that bad news does not always mean life-threatening or terminal diagnosis. Sometimes it means a kid who loves to play sports suddenly becoming medically fragile. One of the biggest mistakes I've seen in medicine is when physicians do not take seriously enough the distressing nature of information they provide because it so often seems routine to them. A diagnosis of diabetes to the patient is life altering, but to the doc it's just a run of the mill communication. Thank you for highlighting this issue in your presentation.

Chinh, you also added a great insight about silence – those very uncomfortable moments when no one is saying anything. As you observed, too often physicians fill those pauses with more words, more information, to which the patient and family aren't listening. It may be comforting to the physician to move their mouths, but it isn't helping the patient/family. What they need is a little space and time to absorb what is being conveyed. Giving that to them in these devastating moments is a great gift.

This was an outstanding presentation about a subject that matters greatly to every physician, yet which many physicians lack the skill to do well. As you noted, the student (or physician) must be aware of all the emotions swirling in the room, including their own, and craft their response with honesty, clarity, and compassion. Most patients never forget the moment they heard a difficult diagnosis; but the doctor can do a lot to ease their fear and distress by showing them a way forward paved with both competence and caring. Thanks again for doing such a great job, Dr. Shapiro

Irene Chang, David Ju

What a creative and insightful sketch! The image of the mournful, depressed child, reflected in the tearful eye of her mother, was beautiful and very moving. Irene, as you pointed out, the drawing conveyed so well that an illness such as depression ripples out from the patient to affect family and friends.

David, I appreciated your honesty about the helplessness and frustration you feel when you are doing everything right yet it is so hard to connect to the patient. You definitely had a double challenge – a teen, PLUS a depressed teen. No one can do this easily. It sounded as though you were able to break through some of her defenses when she teared up – but even then she quickly withdrew into her shell. Unfortunately, progress in winning over patients, as you both know, is not a simple upward trajectory. The important thing is to keep reaching out, trying different strategies such as those that emerged from the excellent class discussion your project triggered.

I also thought the comment you made, Irene, about our seeing only a small piece of the story was very true. In medicine, we have checklists and algorithms to make diagnoses; and on the whole they work pretty well. But it should keep us humble to know that there is always much that we do not see or understand in any situation. Thank you for this poignant, thought-provoking project. Dr. Shapiro

Nica Sabouni, Gaby Stetz

Dear Nica and Gaby, you presented an interesting and troubling ethical dilemma about an infant with a serious condition who medically was ready to return home but to a mother who seemed overwhelmed and ambivalent about whether she had the internal and external resources to care for the child. There was a lot of uncertainty in the case: What was going on with the family? What did it mean that the mom kept raising the issue of adoption only to back away from it? Why did the father unilaterally decide to take the infant home?

I think you both and everyone in the room were troubled by the lack of clarity in this situation. The mom's history of a psych diagnosis added to the confusion and concern. Although it is often a hard call to involve CPS, sometimes this can be done as a kind of consult, to get guidance from experts who have a lot of experience in distinguishing between anxiety and neglect, being overwhelmed and being abusive. Similarly, as one of your classmates suggested in the thoughtful discussion your project generated, a family conference might have been useful in better understanding whether, with support, the family could function to take care of this baby; or whether, at least temporarily, the baby needed to be placed outside the home. As we discussed, a family conference can also be useful in getting everyone, medical team and parents, on the same page.

These can be very tough calls to make. In the end, what was most uncomfortable was that rather than a conscious, well-reasoned decision that all parties agreed was in the best interests of the child, the father took an action whose consequences are unknown. It might all work out well, the family might be able to marshal its resources, and the baby might thrive. But other worse outcomes also seem possible. Decision-making is often complex and uncertain. But if there is clear, compassionate

communication, if everyone feels safe enough to speak honestly about concerns, it is more likely that a good decision will emerge.

Thank you for reminding us how difficult these situations can be; and how important it is to take steps that ensure the safety and wellbeing of the most vulnerable stakeholder – the infant. Best, Dr. Shapiro

Aricia Shen, Allison Slater, David Avila, Marlene Torres, Daniel Meller

Dear Aricia, Allison, David, Marlene, and David, great topic (childhood obesity), and very sensitively analyzed. I loved the sketch of the kid looking into the mirror. He looks so cute but simultaneously so sad. Marlene, it was heartbreaking to hear that when Dr. Taylor asked him, "What do you like about yourself?" he couldn't think of anything. As you and Aricia noted, Dr. Taylor is a terrific role model, and sharing her positive, reinforcing, and holistic approach was a real benefit to your classmates. Her courtesy and respect in asking the patient whether they could talk about his weight and her emphasis on identifying a few attainable goals demonstrated useful, nonjudgmental ways forward in dealing with this very complex issue.

Allison and David, your clinical anecdotes contributed the essential point that, until family stress and conflict are worked out, it is very difficult if not impossible to tackle weight issues. We know there is an emotional component to eating, and when parents are fighting, the kid will often seek refuge in food. As you perceptively observed, it is easy for the pediatrician to align with one parent against the other. Unfortunately, such alliances often serve to exacerbate the family conflict and put the child in the middle. Remembering that the motivated mom and the sabotaging dad each have their own perspectives, their own stories, and trying to understand both rather than making snap judgments usually positions the physician to get the best buy-in possible from both parents.

Finally, Daniel, the "helping hands" model is both cute and practical, and I like it for both reasons. Portion size is surprisingly hard to figure out, but we all have palms and fists, right? Further, it makes the whole experience of changing eating habits just a little less onerous and a little more fun. It's important to remember how much shame, blame, and stigma are attached to weight. The physician's obligation is to help free their overweight patients from this additional burden, which only serves to complicate health living goals.

Thanks again for addressing the difficult issue of childhood obesity. As you pointed out, it is a multifactorial problem, rooted in complex social and class dynamics, fueled by Big Food's pursuit of profit. As we discussed in the excellent class discussion your project triggered, at least acknowledging this reality to patients and their families can help lessen the sense of personal failure, while empowering them to resist structural exploitation. Best, Dr. Shapiro

Nazeen Sedehi, Mark Lieber, Stephanie Noh

Thank you for addressing the emotionally traumatic but essential topic of child abuse. Mark, you made an excellent point that once we know – or even suspect – that someone has been abusive, it

colors our whole understanding of that person. We forget that they are also a human being (still) and categorize them only an abuser. Please understand – I am not in any way trying to mitigate or excuse child abuse, which is perhaps the worst thing imaginable. People who abuse children deserve punishment to the full extent of the law. But we should not lose sight of the complexity of abuse, the fact that many abusers were themselves abused as children, sometimes coming from families in which abuse goes back generations. It is up to the physician to break that cycle, while not forgetting the humanity of the abuser.

Nazeen, you found the ray of hope in these otherwise heartbreaking situations. As always, your writing is wry, acutely observed, and humane. Like you, many times I've witnessed nursing staff, medical students, residents step forward to "be the family," if only for a few days, for a child who's been neglected, abandoned or abused. It is really a precious, joyous thing to witness. It does not change the child's situation and often it seems like such small acts in the face of the enormity of the problem. But it affirms the shared bonds we all feel, and our impulse to care for those most vulnerable. It truly is a celebration of our better angels. Stephanie, the accompanying painting was not only artistically beautiful, but conveyed perfectly the idea that we are all "mothers," the world itself is a "mother," ready to nurture and hold up those who have been abandoned and discarded. The project was both moving and powerful.

Great work, all of you! Dr. Shapiro