

PEDS REFLECTION SESSION 2/24/14

Thank you for such a creative and insightful presentation. Truly, your artwork demonstrated that a picture can be worth a thousand words. As one of your classmates commented, you taught us all a great deal about the medical conditions involved in each case with such informative drawings. Perhaps even more impressively, each drawing provided insight into the effect of the disease on the child's life – from the prominence of the trach which pushed the child herself into the background; the “baby in the liquor bottle” representing FAS; the highlighting of the physical manifestations of Turner's syndrome, Down syndrome, and Klinefelter's that single out their possessor as “different” or “less than”. Your project showed the stigmatizing aspects of these conditions from the patients' perspectives, while point out that these kids can often go on to have fulfilling lives with the right medical attention and family support. Thank you as well for highlighting just how challenging the diagnosis of a chronic condition can be for a family. As you pointed out, parents rarely sign up for this duty (even when they've had genetic testing and can “anticipate” the difficulties), and a period of adjustment is required. I'm sure you would agree that it is awesome and humbling how often families find the wherewithal to care for these kids day in and day out; and how often this becomes a fulfilling and meaningful experience. Your project was educational, original, and thought-provoking. It also showed excellent teamwork. All in all, great job! Dr. Shapiro

--, thanks for having the courage to plunge us into at least a few moments' reflection on what it is like when beautiful, tough, funny, sad kids don't bounce back, don't make it – when they die, when medicine cannot save them. This one fact – dying kids – has propelled many medical students away from Pediatrics. It is an almost incomprehensible thing to face and impossible to make sense of. I also appreciated your sharing about the family conference in which your attending had to tell the parents that if this experimental drug didn't help, there was “nothing more that could be done.” As a parent and grandparent, I can't imagine what it must be like to hear those words. It is astonishing to me that parents can absorb this news with some measure of grace and acceptance. Nothing can truly ease such a moment, but I think physicians who can convey, in addition to the hard reality that they cannot save the child's life, their absolute commitment to supporting the child and family in all ways possible. Best, Dr. Shapiro

Dear --, Thank you for such a thoughtful project. You made such an excellent point that, in the midst of all the pressures, priorities, and responsibilities of the medical student, it is easy

to lose track of the simple reality that it is terrible to be sick; and especially terrible when you are a frightened, confused little kid. Your project showed great empathy for the patient's perspective. I found it truly disquieting that the particular patient you discussed had developed a reputation among the team for "exaggerating" his pain. As you know, this accusation is often leveled against adult patients (sometimes with good reason). But to be so skeptical of a little kid seemed awful. Then, the searingly honest and uncomfortable retrospective questions you asked at the end were the kind of questions that every medical student should ask regularly during their training. What is your moral obligation to speak up when you are concerned about some aspect of care? How do you balance concern for your patient with concern for your evaluations? How do you come to terms with being a part of a process that fails the patient? These are questions without clear answers – but it seems absolutely important to ask them, and more than once, as it is only by thinking about issues that you can continue to affirm your own personal and professional values. Best, Dr. Shapiro

Dear -- and --, you presented us with the archetypal mom from hell. First, I want to commend you on the careful attention you gave this mother. You observed her closely and interpreted her actions cautiously. Unfortunately, there are circumstances where "communication skills," "perspective taking," and "empathy" will not be enough to turn the tide. When a child's wellbeing is at stake, which was the case in this situation, that becomes the first priority. I think the team behaved correctly in holding multiple family conferences, calling for a psych consult, and involving CPS. However, I think you and the class as a whole well understood the complexity of this situation. Mom might have had a psychiatric disorder, perhaps an Axis II disorder. But from her (distorted) logic, she was trying to be a "good" mom – staying in control of a situation where she didn't trust anyone; feeding her cachectic child; wanting her child to have "healthy" food and plenty of medication to control her pain. Mom came across as "crazy," "manipulative," "demanding," and I agree that would be the "felt experience" this person would leave in her wake. But these are just labels by which we judge her. The biggest problem is likely that an unstable, perhaps frightened, desperate, confused woman is responsible for the health and welfare of a defenseless child. You must protect the child (however imperfectly) first; and then hope that there are sufficient social resources to put the pieces back together. Thank you for sharing this very difficult but thought-provoking case. Dr. Shapiro

Dear --, what a pleasure to see you again, almost at the end of your third year! Time flies when you're having fun, right? ☺

And so great you are continuing to integrate your music into your medicine. The poem, while moving, was a little prosaic – but when supported by the music from Les Miz, it took on a density and richness that was incredibly moving. It took real talent and sensitivity to make this match. I so appreciated the point you made as well about being “attentive” to child abuse. It is easy to miss, not only from ignorance of signs, but also from not wanting to see – because it can be messy, uncertain, and is always ugly and terrible. Yet by not “seeing,” we abandon the most vulnerable and helpless, children who may be victims. Child abuse presentations are full of checklists and explanations, but I suspect that this simple poem and the poignancy of that melody (pun perhaps intended) will linger longer in the minds of your classmates. Thanks for a really creative and memorable project. Best, Dr. Shapiro

Dear --, your presentation was fantastic! First, your haiku was well-crafted and emotionally evocative. Many students attempt haiku (perhaps under the mistaken impression they are easy to write because they’re short!), but you really demonstrated a deep understanding of the elements and purpose of the form. Secondly, I very much liked the way you involved your classmates in active discussion. You showed excellent skill in facilitating this activity, listening carefully, being nonjudgmental, and asking probing follow-up questions.. Third, you engaged an examination of your classmates’ emotions in response to your verse. This latter point is especially important in my view; and as you discovered, especially difficult. Physicians are not used to identifying or paying attention to their emotions – and when these emotions are complex, uncomfortable, or even (in the eyes of physician) shameful, it seems either to ignore or suppress them. Long-term, this is never a good idea. When physicians feel too sad, they may withdraw emotionally from the patient. When they feel too annoyed, they tend to communicate (usually nonverbally) their disdain and contempt for the patient. Etcetera. I really admired that you were willing to lead the way into this at times uncomfortable but potentially illuminating terrain. Altogether, a truly outstanding project. Best, Dr. Shapiro

Hi --, thanks so much for contributing your advocacy project to our discussion. I was glad to see you focusing on a stigmatizing issue that adolescents in particular can feel ashamed about. I thought it was a particularly good idea to design a brochure that offered on-line resources. As we discussed in class, when a topic is difficult to discuss, initially it can be easier to do so anonymously. I was also impressed that you actually tried out this approach with patients during the HEADSS exam, and were thus able to evaluate their response. The pamphlet itself was visually engaging, and the information presented in a clear and straightforward manner. This was excellent and important work. Dr. Shapiro

Dear --, --, and --, you made very good use of a lighthearted and charming poem to help us remember just how important developmental milestones are. Two crucial points you conveyed to us were 1) many parents are not sufficiently educated about appropriate milestones, and may not be aware of developmental delays, leading to deferral of expert assessment and 2) despite the humor of your poem, the implications of developmental delays can be worrisome, even heartbreaking. While of course you are all well aware that how children meet these goals can involve considerable variability, parents and pediatricians alike should be paying close attention so that early intervention, if necessary, can be implemented. Thanks for focusing the discussion on this important project. Best, Dr. Shapiro

Hi --, thanks so much for sending in your project, and hope you are feeling better. Your project was very valuable, and I don't recall this particular topic ever being addressed previously. There were several things I especially liked about your brochure. First, it starts with a question that you have heard many times in clinic and therefore that you have a good sense many parents will relate to. Secondly, I really liked the clear division or "Ready"/"Not Ready." My Spanish wasn't always good enough to assess the quality of your explanations, but the ones I did understand were written in simple (but not simplistic), straightforward, and accessible language. I found the pictures especially useful. They were obviously carefully selected, and supported the accompanying narrative really well. Perhaps Dr. X will consider adopting a version of this pamphlet in clinic. I think it would prove very useful for patients concerned about when and how to introduce solid foods. Best, Dr. Shapiro