

## PEDIATRIC REFLECTION PROJECTS 5/15/7

Jacqueline Kulwin, Nick Bove

Dear Jaqueline and Nick, thank you for helping us to think about the ethical dilemma you posed: should women who abuse drugs and who have previously had drug-addicted infants be incentivized to either have temporary birth control implanted or undergo permanent sterilization. This is a heavy question! Your presentation was extremely thoughtful and nuanced. You resisted easy judgments, and outlined compelling arguments on both sides.

As I mentioned, sometimes we need to expand our thinking and avoid seeking exclusively downstream solutions for upstream problems. As you rightly pointed out, the potential for racist and classist abuse of such a practice is not inconsiderable. As well, although we can all agree that women using addictive drugs should not become pregnant, there is something queasy about deciding that groups of individuals are not “fit” to reproduce (the slippery slope to eugenics). As you also observed, unless the sterilization is permanent (which most of us shied away from), it is a short term answer for a complex problem, and does nothing to address the drug use of these women, or the possibility that they may become pregnant again. I was also troubled by the lack of rigorous follow-up data to evaluate the actual outcomes of the program.

These criticisms are not meant to cast aspersions on the program’s originator, she is focused on avoiding the birth of drug-addicted babies, certainly a worthwhile goal. Ultimately, however, we as a society need to grapple with the root causes of opioid abuse. The fact that as a group we found no easy answers was proof of the care with which you presented all sides of an intractable and heartbreaking dilemma. Thank you for getting us all to wrestle with a topic many of us would probably rather avoid. Best, Dr. Shapiro

Lauren Rosario, Michael Butler

Dear Lauren and Michael, I thought the focus of your information sheet on healthy snacking was quite original. Snacking is a big problem (for adults as well as kids), and it is often barely mentioned in patient/family education sessions by pediatricians and family docs.

As we discussed, this is a problem that physician can address on an individual level, but has its roots in much larger societal forces, including the big food industry, the existence of food deserts etc. Michael, I think it was you who pointed out positive counterforces emerging in society, such as improving the quality of public school lunches (now under threat by the Trump administration), chefs designing low-cost meals that are both tasty and nutritious, taxing high sugar beverages etc. These are all positive trends and physicians can work to support them.

In terms of the physician’s interaction with individual patients and parents to promote healthy eating, your project pointed out important principles, such as focusing on discrete and modest goals, filling the home with ONLY healthy choices, taking a family approach to eating, and avoiding even a hint of

shaming/blaming parents. It is a really challenging issue, and your hand-out provided your classmates with much valuable information with which to address it. Best, Dr. Shapiro

Maryte Gyls

Dear Maryte, thank you for tackling the issue of health care professionals' frustration with parents of pediatric patients. This is a not uncommon complaint! As you pointed out, sick kids, even aggravating sick kids, are just too innocent and adorable to really dislike. But parents who are demanding, controlling, resistant, intrusive can try the patience of both learners and their teachers.

There is no question that such parents can be challenging to deal with. The key, as we discussed, lies in understanding their perspective. These parents are scared to death that their child has become ill. They see themselves as advocating for their children, protecting them from harmful interventions, and defending their uniqueness. As in your situation, parents may resist accepting that their child is seriously ill or has a serious developmental delay. Doing so means the alteration or even death of many of their dreams for that child. They desperately seek more benign explanations: "My child needs for freedom," "I was a little slow and I turned out okay." So in a way their resistance makes sense (to them) because letting go of it opens the door to a frightening and uncertain future. Starting with where the parents are – with their disbelief, their denial – and acknowledging and respecting it (which is different than colluding with it) – is the first step toward finding common ground from which to move forward. This was a very interesting and thoughtful reflection on how parents can become obstacles rather than allies; and triggered a valuable discussion about how this can be ameliorated. Best, Dr. Shapiro

Suzanne Klaus, Michael Salvaggio

Dear Suzi and Mike, you managed to craft a humorous poem about a serious and sad subject without losing sight of the humanity of all concerned. I admired that you and the medical team persisted with these very worried, distressed, and fearful parents. In the class discussion, the difficult transition from "healthy" to seriously ill child was highlighted. How hard it must be to accept that your beloved child has developed a disease which may present life-long problems. I was awed by the father's final admission, "We're done fighting you." As you observed, this showed both insight on his part as well as a willingness to shift the parents' position. I think this transformation (which no doubt will continue to be accompanied by backsliding and flashes of denial) was due in large part to the team's willingness to continue to hear the parents' concerns, to negotiate blood draws, and to provide continual updates. Despite your own frustration, you were able to practice patient/family-centered medicine in an ambiguous and stressful. Bringing the parents on board, as you skillfully did, will ensure much better ongoing care for your patient on the hard road ahead.

The second point you raised, Suzi, was a really excellent one. The patient, at 13 and fully participatory in her own care up to this point, needs to be included in future conversations as well; above all, she needs to comprehend the nature of her disease. It is understandable that her parents want to retain control of this process; and giving them a little time to think through how it should be approached seems reasonable to me. However, the question must become, how should we share this information,

rather than whether. Thank you for your sensitivity to this patient's need and right to be a part of her own healthcare. Best, Dr. Shapiro

Andy Trong, Jacquelyn Phillips

Dear Andy and Jacquelyn, what a lovely artwork you created, perfectly attuned in its spirit to Peds. It was a beautiful way of celebrating the diversity and uniqueness of patients in Pediatrics. The title "The Animal Clinic" was a lot more endearing than "The Hospital"! The bright colors and fun representations seem designed to appeal to kids (and to the kid in all of us). You may know the game of imagining yourself as an animal – it is fun to play with both children and adults, and often reveals interesting insights into personality and character. Your decoration would make a revealing Rorschach to see which animal a given kid would most identify with.

Andy, I liked what you said about the importance of paying attention to the nuances of the patient's personality. This is true in general in medicine, and particularly so with kids who may not be able to express themselves entirely verbally. You both showed empathy for these little patients, and a genuine commitment to raising their spirits and maintaining a positive environment. Your poster would certainly add to that goal. Best, Dr. Shapiro

Jonathan Schilling

Jon, this was an outstanding project. You really wrestled with the emotional impact on the parent of learning that their beautiful, perfect child has become seriously ill. I appreciated both the humility with which you acknowledged that we can never understand another person's feelings; and your diligence, throughout the different twists and turns of this infant's course, trying to imagine the range of emotions that the parent might experience. That is a valuable exercise, because it opens you to the emotional experiences of the parent, and reminds you to pay attention to this vital dimension.

You also made an excellent point that medicine tends to promise a "restitution" story (restoring the ill person to their previous state of "perfection" and health) and society has come to expect this; although it can't always be delivered. The inability on the part of both physicians and patients/families to accept the limitations and shortcomings of medicine leads to much useless intervention and ensuing heartbreak. As we discussed, one of the most toxic results of these unrealistic assumptions is self- and other-blame.

Another important issue you raised is the extreme stress on parents of caring for a severely disabled child. Although there are more resources available these days in terms of respite care, home nurses etc., a great burden does fall on parents; and if they cannot sustain it, again the response of medical professionals should not be blame but creative problem-solving, including out of home placement. These heartrending situations must be approached on a case-by-case basis and the intention to do what is best for all concerned.

You did a really impressive job of raising questions that are difficult to think about, and even harder to answer. Yet they must be asked so that medicine does not detach from its ethical moorings. Best, Dr. Shapiro

Mia Shan, Chris Vo

Dear Mia and Chris (sorry to have missed you, Chris, but thanks for the poem!), this was a very creative project. I thought the cut-out of the baby's head, superimposed (and partially concealing) all the information about the patient, was a superb metaphor for what we can learn (and all that remains hidden) about the patient. Mia, you made an excellent point that the process of discovery can be especially difficult with infants and small children, who cannot speak for themselves; so that already you are relying on second-hand information. As I shared, this metaphor seems relevant to other patients as well because, despite history, labs, imaging, so much about the person remains a mystery. The poem itself was quite lovely – I thought it was a humbling touch that, even when the sick infant is treated and recovers, she is still crying, much to the mom's dismay. Babies are hard to decipher, and so are the rest of us! Thank you for this affecting and thoughtful work. Dr. Shapiro

Helene Nepomuceno

Dear Helene, first let me commend you for your active involvement with advocacy efforts to improve the health of children. The initiatives you've worked on – vaccination legislation, taxes on cigarettes and sugary beverages - are all highly significant in terms of their impact on the health of the state's young people. It is inspiring to see medical students recognizing that their daily clinical work is embedded in a larger societal framework, and that they can exert an influence the nature of this framework.

In terms of the specific issue you presented - DSD (a term with which I was not familiar, so thank you for educating me) – this project provided excellent information and much food for thought. In particular, the binary approach medicine historically has taken (reflecting societal views in large part, but also legitimizing them with an aura of pseudo-scientific expertise) to these kids needs rethinking. One of the key question you raise is, who should make the (life-changing) decision? Should decisions about sexual genitalia be left entirely in the hands of "expert" physicians guiding anxious parents toward genital-normalizing surgeries; or does the child him or herself deserve a voice? Considering sex as well as gender on a continuum opens up new possibilities for these kids and their families.

Thank you for raising a too-little contemplated issue and for presenting it in such a professional, well-researched, and thoughtful manner. I think we all learned a great deal. Best, Dr. Shapiro