

PEDS REFLECTION PROJECTS 2/15/19

KATHERINE MORAN AND ALI DUFFIN

Dear Katherine and Ali, you chose a really critical and much-neglected topic to explore for your Peds project. Family dynamics play a vital role in a child's development, yet typically physicians who see kids (pediatricians and family docs) pay insufficient attention beyond the HEADSS query, how's everything at home (which by the way is a good start). But as you point out, more probing may be necessary to get a sense of what home life is like and where the stressors lie. Your pamphlet (aimed at health professionals) does a great job of highlighting families who might be under special stress (to which I'd add rather obviously unemployment, immigration status, and chronic illness); different dimensions of the child's life that might be affected; a thorough list of signs kids might exhibit; and most importantly, what next steps might look like, as well as a parental resource.

The idea of a pamphlet is a really good one. Not only does it summarize important things to keep in mind, but its very existence serves as a reminder to consider the family situation in any evaluation of kids' behavioral, psychological, academic, and even health problems. And the color scheme really added to its appeal!

Finally, I appreciated both of you disclosing that something as "common" as divorce can have significant and long-lasting effects. This took some courage on your parts, but it made the presentation very real and personal. Not only were you saying, these issues might affect our patients, but these issues affect *all of us*. We can't ensure that children have stress-free lives, but we can do a better job of being aware of how much family, which after all is pretty much a child's world until they are pre-teens, will affect kids' wellbeing.

Thanks so much for bringing this issue to the attention of your classmates. I hope that, regardless of what specialty they choose, they will keep in mind how family dynamics interact with the way people respond to illness and other life stressors. Best, Dr. Shapiro

AVITAL FISCHER, KIRA TURNBULL

Dear Avital and Kira, it is pretty standard at every Peds Reflection session, we spend time talking about anti-vax parents and how to overcome their resistance to immunizing their kids. It was so interesting to hear another perspective, i.e., the possibility of allowing kids themselves of a certain age to make this determination for themselves. For some reason, this had never occurred to me, yet already we allow minors to receive birth control, to consent to the HPV vaccine, and also have the legal construct of the emancipated minor. Further, in many treatment and end of life decisions, older minors are routinely included in the decision-making process. All these indicate that there are already many circumstances in which a minor is allowed to make choices, or at least be actively involved, in decisions about their own bodies. On the other hand, one of your classmates made a good point that what is true for consent might equally apply to refusal. In any case, it was a fascinating perspective on an intractable and increasingly serious issue.

Bringing the case of the young man who as soon as he turned 18 chose to receive all the immunizations he'd been denied by his parents to the attention of your classmates raised many interesting ethical issues and generated a lively and thoughtful discussion. That is exactly the purpose of these sessions – to engage students with topics relevant to Peds that they might otherwise not have a chance to think about – and your project succeeded very well in accomplishing this goal. Best, Dr. Shapiro

Mark Rupasinghe, Jenny Tang

Dear Mark and Jenny, I have a soft spot for poetry, and I really loved your poem, although it was heartbreaking. It contains some devastatingly beautiful lines: “The flowers across your head/were slowly scorched by fever,” “the cough that murdered your words.” The double entendre of the line “Your heart was no longer in it” really struck me (as I imagined ultimately the child’s heart might have failed). The chronology of the poem shows how hard you and the team fought for this patient from the beginning of her life and seemed to be winning, only to have a preventable disease destroy everything that had been gained. The poem captures very well the sense of hope that the resilience of children engenders, as well as the dread that medicine cannot always save their little lives. These two conflicting emotions characterize Pediatrics generally, but when you overlay them with the , become almost unbearable.

Your project raised many excellent questions for the group to ponder: How do we respond to the death of an innocent child, especially a death that could have been avoided? How do we manage our attachments to our patients? How do we manage our anger at and judgment of the parents? Your classmates were both moved by and engaged with this work, and it stimulated them to explore their own feelings in authentic and transparent ways. Best, Dr. Shapiro

Celia Cheung, Donald Tang, Khody Goshtasbi

Thank you, Celia, for making us all think about how the immigration issues that have divided our country reverberate in the healthcare. The image of a 5 year old accompanied by his undocumented mother wearing an ankle monitor, afraid to answer any questions, was devastating. It is a sad commentary on the state of the nation when we have parents trying to safeguard the wellbeing of their children but afraid that any contact with any official body, even a healthcare clinic, may lead to their deportation. This example showed us the impossibility of walling off larger social problems from the individual patient-doctor relationship.

Thank you Khody for sharing the article on providing life-saving services for undocumented children. As you educated the class, provisions for coverage vary from state to state. Unfortunately, lack of awareness of such services can lead to bad outcomes for kids; and as was discussed, in a climate of increasing fear, families may be reluctant to avail themselves of what resources do exist. In this regard, Donald’s point about “public charge” was also well-taken. For families desperate for the legitimacy of a green card, as the federal government tightens guidelines, many will avoid any sort of public assistance in fear it might jeopardize their chances, even if this is to the detriment of their children’s health.

From your project, it is impossible to avoid the conclusion that if physicians want to take optimal care of all who seek their help, they must actively engage in larger questions about whether healthcare is a right; and if so, who deserves that right. As Dr. Murata pointed out, there are many ways to engage, from individual advocacy to political action, but there is no longer a way to be a doctor oblivious to all the societal issues in which medicine is embedded. Thanks for helping us all see this. Dr. Shapiro

Boback Hedayati, Justin Devera, Patrick Penalosa

Dear Boback, Justin, and Patrick, the case you presented of a missed diagnosis of VACTERAL led to a very valuable consideration of disclosure of medical error. Should the pediatrician who initially examined this baby and did not catch the lack of an anus be notified? How should this situation be presented to the parents, who were young and medically unsophisticated? Does the family have insurance to cover the upcoming series of surgeries that the child will require?

Some of the really interesting points that emerged from the discussion you facilitated were:

- 1) The importance of bringing this outcome to the attention of the physician who missed it. This speaks to the larger issue of a cultural tendency within medicine to hide/ignore/cover up medical error when possible. The way to counteract this understandable impulse is to reduce shame and blame while promoting discernment and openness. We are all human, imperfect, and fallible. We all make mistakes, and we must find a healthier, more supportive, but more honest way of addressing them.
- 2) The importance of making sure that the “explanation” does not leave the parents more confused than they were. I have too often seen explanations given where it is clear the family does not understand that medical error has occurred.
- 3) The value of medical students as part of the team. Precisely because even experienced attendings miss things or commit errors, multiple eyes matter. As medical students, it is critical for you to overcome the medical hierarchy and be empowered to speak out when something does not make sense. Many times you will be wrong, and that is part of your learning, and hopefully attendings and residents will value your queries. Sometimes you will be right, and will have made a significant contribution to the wellbeing of the patient.

The educational pamphlet you prepared was informative and I am sure would be useful to parents overwhelmed by the cascade of facts and figures they were receiving from their child’s doctors. Thank you all for such a thought-provoking project. Dr. Shapiro