

PEDIATRIC HUMANITIES PROJECTS 4/08

Hi, and thanks for participating in this strange American custom of writing poetry about patients. (Actually, it's pretty strange for most American medical students too :-)). I really appreciate your poem, and your effort to see your patient with cp from a different perspective. The question and answer form was very effective, because the questions are exactly the questions that everyone (including medical students, including doctors) ask about someone who is strange to them. The answers you provide are full of imagination and beauty. They invite us to see beyond the distortions of the cerebral palsy to the person within the body, the child who is "smiling inside." I was touched by this poem, and am glad you shared it with us. Best, Dr. Shapiro

--, I was tremendously impressed by both your project and your comments in class today. You had the courage to challenge conventional wisdom, a rare but precious ability. Is "denial" always a bad thing? Do patients have to think like doctors? Can physicians tolerate different definitions of hope in patients and families? Do we compel patients toward a "realistic" view for our benefit as much as theirs? By no means am I trying to romanticize a patient's or family's struggle to come to terms with devastating diagnoses, but I am certainly applauding your willingness to consider that this might look different from patient to patient; and within one "case," might look different in doctor, medical student, patient, and parent. Further, up to a point, this might be okay, even a good thing. As your essay powerfully suggests, to make a complete whole, we may need all voices present: the voice of science, the voice of faith, the voice of realism, the voice of hope. If we allow space for these voices to converse without panic or judgment, we might all benefit. Thank you for such fine work. Dr. Shapiro

--, thank you for tackling this very difficult but critical topic with such sensitivity and insight. Your poem is very moving and involving. You manage to capture with complete conviction the voice of an abused, victimized teen whose helplessness and hopelessness lead her to rage and violence. The language you employ throughout is powerful ("a raging ocean where my soul sinks"), disturbing ("...so I indulge"), and absolutely credible. The ending lines are amazing, and filled with terrible ambiguity. Does she hope no one will notice her guilt? Her abuse? His crime? Her crime? You have a real talent for creating images that make the reader uncomfortable but do not allow us to turn away. Congratulations on such strong work, and for bringing our attention to a terrible and all too prevalent problem. Dr. Shapiro

--, I think you were way too modest about your poem. The underlying insight is the fundamental basis for empathy – we are all in the same boat, we are all suffering, we all want to go home. You also did a really fine job of capturing the different points of view of pediatric patients, attending, and medical student, with humor granted (some very funny and very grim lines – “at the wrong end of some cruel joke”; “the parents, not so much”; “the sense god gave a cow”), but with a lot of understanding of the agendas, perceptions, and priorities of each. This was a great contribution to our discussion. I also appreciated sharing your thoughts about your cousin with cp. By the way, I will be pondering for quite awhile how much sense exactly did God give cows. Dr. Shapiro

--, I thought it took real courage to talk so openly about your brother, and how much serving as caregiver/companion/interpreter/cultural mediator cost you. It is very challenging (and rewarding too in some ways) to be the sibling of a chronically ill or disabled child. I can certainly understand both your assumption that you would be drawn to peds and your discovery that the emotional issues triggered by constant responsibility for sick children would be really complicated to deal with. Your essay was poignant and very moving. You represented perfectly the reality of this sick little guy, how much suffering he endured, how much he needed his family – you and your mom – and your own great helplessness and great love. One of the most compelling aspects of the essay was your use of the little phrase “and/or” which conveyed precisely the interminable, repetitious, monotonous dimension of his and your despair. This was very fine work exploring a crucial part of your life that has had and continues to drive your pursuit of doctoring as a profession. Thank you for sharing this story with us. Dr. Shapiro

Hi --. I thought you did an amazing job of trying to enter into the world of this severely disabled little girl. I loved (if that is the right word) how you so matter-of-factly introduced one devastating limitation after another – can’t speak, can’t walk, can’t see, can’t eat. Your ability to imagine her life is a testament to the time you spent with the grandma, and the close and respectful listening you must have practiced. Your reflection also shows very well the huge challenges faced by families with kids with disabilities (the mom “not wanting” the child) – and the incredible resilience they often show in meeting these challenges. You enabled us see the joy, the devotion, and the love in this family as well as the suffering. In doing so, you helped all of us move from pity to respect and appreciation. By the way, thanks for going the extra mile and providing detailed, clearly presented information about schizencephaly which helped create a context for understanding your creative “journal entry.” All told, this was really excellent work. Dr. Shapiro

--, I loved this poem in the voice of this little patient. Even before I understood just how sick this baby was, I thought you captured with fantastic insight what the hospital experience might be like (given your patient is pre-verbal, and doesn't think yet in language!). All the particular details you supply are what make the poem so convincing. Above all, you help us to see just how bewildering and frightening being in the hospital it is (I would add for adults as well as children!). Hearing your poem (and then rereading it) activated all my compassionate impulses. I just wanted to reach out and pat that baby and sing to her. I suspect your fine work made other people feel the same way. Thanks very much for participating in this exercise. Dr. Shapiro

--, thanks for bringing both your perspectives, as parent and as student-physician, to your essay, and your comments in class. Your ability to move back and forth between them really helped us all see how conflicting agendas and priorities can all too easily emerge, despite the "common ground" of wanting the best for the child; and how it is incumbent on the physician, when such conflicts occur, to figure out how to get back on the same team as the family, to use your metaphor. I do believe that emphasizing the common ground is often, sometimes the only (!), place to start when confronted by such situations as the ones you describe. I also found your concluding advice to both parents and physicians to be insightful and practical. Parents need to be able to let go of some of the control they (appropriately) have as parents when they are in the medical setting; and trust the medical expertise of the physicians. Physicians, on the other hand, need to respect the particular expertise parents have about their children. Both will do better to do a lot of active listening, letting the other know they understand their point of view (understanding does not need to imply acceptance). This was very thoughtful work, and your examples were great, ones which I'm sure we all connected to Dr. Shapiro

Your project was really terrific, --! The finger-painting was the perfect choice, since it definitely evokes childish play, and at the same time you were able to express a lot through this work (these are really good paintings – I especially liked the one that moved from childish, benign ABCs to the dreadful acronyms of medicine). I also appreciated the essay in which you brought up the topic of resilience in kids (and to some extent in all of us, I think, adult patients, doctors, medical students!). There is so much to admire and cheer on - what's been called the "collateral beauty" of the horrors of illness. People are often (not always :-)) pretty amazing, and kids especially so. Great point about "going up" to the floor! It is emblematic of all the disorientation, dissociation, and confusion that inevitably arises in the hospital setting. What your essay demonstrates is the enduring

strangeness and alienation of hospital routines. You can still see that perspective – don't ever lose it, as all this stuff becomes increasingly routine, familiar, and "normal" to you. Believe me, it isn't normal! Thanks for putting some real thought into this project. Dr. Shapiro

Hi --. I didn't receive a written project from you (that's okay), but I did want to let you know that I was very moved by the way in which you talked about your pediatric patients. As we learned from other accounts in class, personal experience with illness can affect us differently. Sometimes it may evoke emotions that are so powerful and overwhelming that they can complicate the ability to practice compassionate medicine in the context of emotional balance. Sometimes, as in your case, you can turn personal suffering into ties that bind you in caring and empathic ways to your patients. I commend you for your ability to use your experiences in a way that will benefit your future patients. Best, Dr. Shapiro

Hi --. Thanks for getting the ball rolling yesterday. Your essay was so great, as was your ability to honestly reveal to your classmates your different ideas and feelings about developmental disabilities prior to your encounter with little E. If people were honest, we would all acknowledge feelings of otherness toward many (if not virtually all!) patient groups – poor patients, patients with AIDS, obese patients, drug-addicted patients, demanding patients, mentally retarded patients, burn patients... on and on). You were brave enough to give voice to these feelings. You also modeled for all of us the emotional and cognitive flexibility to be open to different conceptualizations and different understandings. Even Down syndrome (often although not always one of the milder dd diagnoses) is no cakewalk for child or family, involving many challenges right from the get-go, including sucking problems, vision, hearing, and language impairments, developmental delay, mental retardation. There is plenty of heartache, frustration, disappointment, anger, and fear. But that's not the whole picture, as you were able to discover. Being able to encompass the totality of the experience – a thousand joys, a thousand sorrows, as the Buddhists say – makes it much more likely that you will meet the family where they are, and deliver care in a way that honors their experience.

On another note, please think about pursuing the humanities/arts patient-student workshop idea for next year. If the -- grant proceeds, perhaps we can work it into that. In any case, I'd be eager to act as faculty supervisor, and coordinate "experts" from campus to help us. As you probably know, there are no longer selectives in year one, but perhaps we could offer it as either a 1st/2nd and/or 4th year elective. Let me know if you see your way clear to proceeding; if so, I'd love to work with you! Best, Dr. Shapiro

Great project, --, a very creative execution! The real challenge in counseling any patient is that there is no formula for success. Perhaps the most important thing is to have plenty of arrows in your quiver, and be able to read your patient so that you can figure out if you're going down the right road, or need to change your strategy. That having been said, a tough love approach from physician to adolescent patient runs the risk of accessing transference (and countertransference) issues in the teen: i.e., she'll see you as a parent, the very people she's rebelling against. On the other hand, many teens need help setting limits; and if you are too much of a "friend" it will be hard to help them develop this skill. One thing that your role-play brought out exceptionally well is that by not being condescending, by acknowledging your patient's fear, by assuring her that the point is her welfare, not your judgmentalness, you increase the likelihood that the patient will be less defensive and more honest. Both of these options hopefully are beginnings, not endings; and in both the patient has a long way to go. I think, however, that you might have more likelihood of moving the dialogue along with approach #2. Thanks for sharing such interesting ideas. Best, Dr. Shapiro

Hi --. How nice to see you again after all this time! Congratulations on completing your Ph.D.! What a long journey – but I'm sure a rewarding one.

Thanks for this essay about X. What a tragic situation. You raised an extremely important issue – what to do when parents and physicians have very different understandings of the child's situation. This is bound to produce a great deal of anxiety and frustration. In these circumstances, it can be helpful to ask, *why* is it important to share a similar perception? As we discussed in class, unrealistic expectations may interfere with adhering to a treatment plan; or may lead to feelings of deep frustration or even rage, which in turn might endanger the patient in some way. However, these are extreme possible outcomes that can be anticipated and guarded against. There is nothing inherently necessary or good about parents and physicians having identical understandings, expectations, or hopes for the patient. As we mentioned, it may be the physician's role to introduce some reality-testing; it may be the parents' role to pray for a miracle. It is probably more important to pay attention to how beliefs and expectations affect behavior and feelings of those involved. Further, such differences can be negotiated; and in fact usually evolve over time. For example, the physician can say, "I want to share with you that in my experience, and based on everything I know about your child's condition, I think it is unlikely she will ever function as she used to before the accident. I know that you are praying for complete recovery, and I respect that. But it is my job to share what I know with you."

Finally, it is not at all uncommon for parents from other countries, particularly developing countries, to make great sacrifices to bring ill and disabled kids here, hoping for a miracle cure from "American medicine." It can take time for such parents to realize that, even in the most powerful country in the world, there are limits to what our medicine can do.

--, you asked important and thoughtful questions that do not have clear-cut answers. But by reflecting on these questions, you make it much more likely that however you handled this dilemma would involve patience, compassion, and clarity. Thanks for this essay. Dr. Shapiro

--, thank you for your sensitive essay. I particularly liked the way you brought in all the different perspectives – child, mother, doctor, med student. You did a wonderful job of finding each of their voices: the little boy only understands the pain; the mom has become untrusting of physicians, although grateful her kid isn't even sicker than he is; the doctor has an expert grasp of the medical issues, but seems somewhat detached from the suffering of the patient, and pretty much unaware of the mom (!); the medical student (thank goodness for medical students :-)) is concerned with the emotional trauma the child has endured, but worries as to whether there was any way to avoid it. The answer, based on your description, sadly is probably not. However, your empathy is the first step toward solution. One thing that interested me was the mom's ability to perform the anal irrigation relatively successfully. By acknowledging the mom's expertise (not just technical but emotional), the health care team might develop insights into how to reduce this little patient's traumatic fear. Well done, --! Dr. Shapiro

Hi --. I didn't receive a written essay from you (that's fine), but I did want to let you know I thought the clinical dilemma you presented (parental resistance to childhood immunizations) was an excellent one. It is a perfect example of a conflictual intersection between medical expertise and popular culture. It is very frustrating from the physician's point of view to try to explain the benefit of immunizations and to debunk the research linking immunizations to autism and other problems. However, as you pointed out, there are many groups and organizations encouraging parental fears, so unfortunately this issue cannot simply be dismissed. When kids' welfare is at stake, feelings (on both sides) run high. The conversation between parents and doctor must be conducted with respect and patience; and sometimes you may have to agree to disagree. Thanks for bringing up this subject, it arises often in pediatric practices. Best, Dr. Shapiro P.S. I apologize I kept calling you X at our session. You two were sitting next to each other, and somehow my brain just scrambled the names. So sorry!

--, thanks very much for completing this project even though you had a day-off voucher. Your ER memory was very cutely written, although you sounded pretty miserable. I especially enjoyed your view of the weird, smerfy-looking, stinky, cretinous,

manipulative resident/medical student. Welcome to your worst nightmare, right? :-). I hope your wish came true, and that was your last experience in an ER (until now). Thanks again for participating long-distance. Best, Dr. Shapiro