

## Reflections from Students in PLME Senior Seminar, Doctoring Courses

*The first reflection based on a prompt in the PLME Senior Seminar asking students to “think about when they or a family member may have been a patient.” The preceding classes were breast cancer-related with genetic testing, choices about treatment if BRCA genes were identified and included a patient panel discussion with patients presenting their perspectives on their choices. After reading the submission, I would use the opportunity to send back comments and additional questions. For Eric Bai’s reflection, for example, I would ask about “empathy” and how a physician might have addressed his family’s needs. I would ask about cultural competency and how the US health care system might have integrated some traditional Chinese medicine into the care of his grandfather and finally, I would ask about Eric’s reaction to dealing with death and dying.*

### PERSONAL REFLECTION ON END-OF-LIFE CARE

ERIC BAI, PLME '16 SCB COMPUTATIONAL BIOLOGY, MD '20

Earlier this year, I saw how difficult it was for the doctor, patient, and family to decide not to proceed with treatment for a terminal condition. When I went back home last winter break, my grandpa (my mom’s dad) had just checked into a local hospital a few days before I arrived, after weeks of a weak appetite and worsening jaundice. The doctors do an MRI and find two suspicious nodules in his pancreas. They operate a few days later and find late-stage pancreatic cancer. His symptoms are a result of the tumor impinging on neighboring vessels.

Everyone in my family, especially my grandpa and mom, takes this news with a businesslike trust in modern science. They had seen how much allopathic medicine worked – how “there was a pill for that” – and, coming from the spotty medical care of Communist China over twenty years ago, had spent their lives building trust in this paradigm. My mom wants to find “the best” treatment through whatever means possible, but it is very difficult since we were nearing the no-man’s land between Christmas and New Year’s. Somehow, we land an evaluation at City of Hope, one of the biggest cancer specialty hospitals in our area and also the closest out of all of our options, a few days before Christmas. And they take Medicaid. We think our luck has turned.

Grandpa is discharged from Whittier Hospital and, on the drive over to City of Hope, my mom talks on and on about all of the new treatments available for these types

of invasive cancers, throwing around phrases like “radiofrequency ablation” or “targeted therapies.” We get there, sit in a wonderfully sterile waiting room, and, a few hours later, find ourselves in a sun-filled exam room with a young Asian-American oncologist probably no older than 35. He speaks a valiant, if somewhat broken, Chinese and, on this foundation of a fluctuating language barrier and hope bordering on desperation, the conversation begins.

My mom clutches her paper filled with notes carefully transcribed from a phone call with a doctor-friend. She methodically runs through a list of possible options – what about X for his constipation? How about Y for appetite? Can we do Z to see if the tumor can be reduced? She looks over at me with a hopeful smirk: “I am a patient advocate who knows what’s up and we are going to get this all sorted out.”

My grandpa speaks no English and has only one question: “What can I do to live?” He says that he’ll do anything, even chemo. Ever since I was very young, he’s been afraid of dying. And so he pushes the question and my mom willing and gladly translates. She adds on all of the new therapies that she read about online earlier that day.

The oncologist looks thoughtful and starts laying out some options: “Don’t rush. We have to see the best course of action.” He seems to be the model of good physician behavior: he listens, answers questions, and addresses concerns. But he does not offer any of the guarantees that we are looking for. Nevertheless, he agrees to check my grandpa in that very same day.

So begins the long penultimate stay. Some combination of my dad, mom, sister, aunt, grandma and I take shifts at his bedside. We go in the morning. Another crew goes in the afternoon. My mom takes a few months unpaid leave from work. We bring him porridge, some preserved vegetables, chicken soup. We go hunting for fucoidan at all the local vitamin shops, because that’s what the Chinese newspaper says cures cancer. We find it on Amazon and do next day. We give him 6 pills of fucoidan extract and a cup of lingzhi mushroom extract each day. Grandpa is restless and too independent. He doesn’t listen to his nurses. He scares them.

After a week of procedures and tests, we go to the hospital in the late evening, around 4 p.m., to meet the oncologist for the final report. He and my mom stand outside of grandpa’s room. He starts talking and the first two words that come out are, “I’m sorry.” Bad news. You can see the realization

dawn on my mom. Her eyes dim. Her shoulders sag. But she continues to nod graciously and starts asking about next steps and what the handoff is going to be like. Ever the knowledgeable consumer.

The oncologist then goes into the room to break the news to my grandpa. Armed with his broken Chinese, he starts talking about quality of life and how chemo at such an advance age and state of disease would do more harm than good. My grandpa grabs the doctor's hand and begs for chemo. He says no. But my grandpa won't let go. This was one of the hardest things to watch.

And so he is discharged from the hospital and gets transferred to a hospice in Whittier a few blocks from Whittier Hospital, where he started this journey and where my sister and I were both born. They say he has one more month to live. They take him off all of his medications. Palliative care they say. He just needs to be comfortable. Stronger painkillers. His feet are grossly swollen. They lift them up to help the fluid flow out. My mom is concerned that the nurses aren't giving him enough attention. She puts up notes all around his room instructing the nurses on what to do. We go one morning and find him shivering without covers next to an open window. My mom is furious and we bring our own blankets. He doesn't eat much anymore. He gets fainter. He used to hold our hands when we went to see him but now,

just a few days later, his eyes are blank.

Zheng Zhi Bo passed away at around 1:12pm on 1/12/2014. His room number is 112. He is a few years past 90. All told, this process goes from 12/19/2013 to 1/12/2014. Just 25 days. He is peaceful, no longer in tremendous pain. And we are glad to see him go.

My mom still somewhat clings to her alternative histories. If only he had been transferred to a higher-level facility sooner. If only his damn family physician had been more mindful of his complaints earlier. If only the nurses hadn't forgotten to cover him that morning.

For me, I can't know any alternative histories and the matrix of interactions is too complex for me to trace any meaningful trail of blame. I think about how difficult it must have been for that oncologist to say no, show restraint, and turn away in the face of such an eager, willing, and determined patient. I think about how my mom looked everywhere for sources of information to know how to proceed in the face of a condition that worsened by the minute. I think about what it is like to work in a place where people go to die. From this all, I know that restraint, patience, attention, and empathy are gold-star traits of a good physician. We can't predict what might be different, but we can listen to work towards the most humane outcome.

## Reflections from Doctoring Courses

*Similarly this type of reflection is submitted by students in the Doctoring courses year one and two of medical school. Each small group has a physician and a behavioral science faculty who similarly respond to the narratives. This student reflected on the "Check Lists" that the Doctoring course uses to help students with taking medical histories in a complete and orderly fashion.*

**Reflection for Doctoring:** *"You come to medical school like anyone else." (A reflection on lists) As a Doctoring small group leader, we are asked to read and respond to our students' thoughts on medicine and medical school. While I was not Sarah's small group leader, if I had been, I might have taken the opportunity to push her to think more about "death" and how she was dealing with it based on her writing about her cadaver. I might ask her if she thought she "belonged" in medical school as so many students have doubts about this early on...and perhaps I would ask her how she was going to take care of herself as she progressed on her medical educational journey.*

## CHECK LISTS AND THOUGHTS IN THE ANATOMY LAB

SARAH MAGAZINER, MD '19

There is a unique, somewhat arbitrary transition that occurs when a person is accepted into medical school. I remember, for example, the concern people had for my significant other during revisit weekend when we spent an hour in the anatomy lab peering into open chests, cradling various organs and limbs, and admiring the superior ventilation system. The assumption seemed to be that since my partner had not gone through the motions of a pre-medical student he was somehow less equipped to handle the sight of a cadaver – that the act of being accepted into medical school had automatically elevated the rest of us to a level of preparedness to deal with the complexity and intimacy of the lab and its contents, prematurely setting us apart from those *not* destined to be doctors.

The weekend was punctuated with moments that illuminated this hazy distinction and made me feel as if I had crossed an invisible threshold. When an admissions officer read aloud a list of impressive facts about the newly admitted class, I felt like I had only just been pressing my nose up against the glass, peeking into a world that I hoped to gain access to, and now I was magically on the other side and the people they were describing were my peers. I had somehow

made my way onto the admitted list, and I am continuously reminded that it is a highly privileged place to be.

In our Doctoring course we have been taught a list of questions to ask regarding a patient's chief complaint and the history of their present illness. And each day when we enter the anatomy lab, we are presented with a list of structures to find, accompanied by beautifully precise diagrams with color-coded labels. In either case we are told beforehand that the reality won't be anything like the books and there are moments when I realize that the list can't apply and the lines grow blurry and panic sets in: the veins aren't blue and the arteries aren't red, the structures are abnormal and the questions need to be modified because the patient isn't complaining of physical pain, she's worried about weight gain so on a scale of one to ten her pain is...different.

And in real life, my pain is different, too.

My most recent position didn't make it onto the highlight reel of profound accomplishments, prestigious jobs and exotic experiences, and it certainly can't be found on a list of pre-medical requirements. That is because the last job I held before coming to medical school was that of a full-time patient. I have accrued my own list of experiences and questions; my own private tally of fears, scars and discomforts. And like the infections that invaded my body, they remain invisible to the outside world. I often wonder if my ability to fully feel like a medical student is at all compromised by the fact that I have lists of medications to take each day, that I still spend a considerable amount of time in the doctor's office receiving treatments, or that I identify much more with patients than I do with doctors. As I get to know my classmates and start connecting faces and personalities to the impressive resumes, in my mind, the patient version of myself still cowers behind the glass feeling slow, clumsy and self-conscious about all the healing I have yet to do.

The more I get to know my new peers, it is not hard for me to understand why this group that I am now a part of is one that commands respect and responsibility before we have even truly earned it. Yet, as Robert Lowell points out in his essay *The Body of Strangers*, given the lack of "any real change in our abilities to help people," this transition represents a sudden inheritance of "more power than is yet deserved," and an expectation of "readiness" that others are not assumed to possess.

Writing this reflection only hours after removing a human heart and holding it steady while my classmate sawed through it, I remain humbled by this reality and increasingly aware of the parts of me that linger behind the glass, looking in at my current self. I admire how convincing I look in my scrubs, scalpel in hand; hear myself rattle off the names of the nerves in the posterior mediastinum; watch as I inspect what my classmate calls a "crazy looking tumor" on the lung of the cadaver on the next table. But I also think of my own experience with the grueling uncertainty of illness and wonder, as we sort through her insides, if we are addressing any of *her* unanswered questions; if this intimate vantage point

sheds light on how she struggled in her final days. I see the slight shudder that goes through me when I glance past the gaping thoracic cavity and catch site of the cadaver's arm. I am reminded of my grandmother's soft papery skin and have the fleeting thought that maybe I should cover the cadaver up so she doesn't get cold. I think of her family, surrounding me in my position behind the glass, and have the urge to protect them, too. And I realize that my preparedness for this particular task is not intrinsically linked to how much I can separate myself from my humanity, how fully desensitized I can become, or to what extent I can repress my identity as a friend, a member of a family, or a patient. In reality, the glass is a mirror and the parts of myself that feel at ease in this environment are not that separate after all from the parts that remain fearful and uncertain, or even sick.

In fact, I think they need each other.

I expect that one of the more fulfilling aspects of medical school will be fostering these different parts of myself while accepting that they can, in fact, co-exist. I anticipate coming to acknowledge the hidden vulnerabilities that lie within others, appreciating the abnormal structures I encounter, and embracing any and all deviations from the lists. If it comes to a point where I struggle to do so, all I will need to do is hold up a mirror.

*In the Doctoring Course, students may use the opportunity to reflect and try to make sense of their "past" lives as they journey into becoming a physician. The following three submissions are from another from medical students either reflecting or writing creatively to help themselves meld their personal and professional lives.*

## REFLECTIONS ON BEING A DOULA

KIRA NEEL, MD'18

Whether the parents-to-be I sit across from are 16 or 35, most conversations start with relatively blank stares and the question, "so...what exactly does a doula *do*?" Some women hear about doulas from friends who have used one, or from magazine articles, while others may learn about doulas from their providers, or pregnancy books. Continuous labor, delivery and postpartum support in the form of a birth doula is becoming more common as the positive benefits to birth outcomes become more widely known; yet doulas are not available to everyone. Doula services are generally paid for out-of-pocket and can cost anywhere from \$400-\$1,000 in Rhode Island. Relatively speaking, compared to the total cost of a hospital delivery, this is not a lot of money, but for many families, the cost is prohibitive. In response to this, national organizations, such as Health Connect One, train and provide community based doulas free of charge to low-income women.

I moved back to Providence in the fall of 2013 after years of working in the theater, and as a doula, in New York City. Upon my return, I reconnected with a mentor who asked if I was available and interested to attend births *pro bono*. I was! The first birth I attended was for a woman whose partner was incarcerated. Throughout labor – between meditating during contractions, receiving an epidural, eating containers of jello, sleeping, telling stories, and texting to remind her kids at home to do their chores – she received regular collect calls on her cell phone from her partner in prison. She kept him updated on the progress of her labor. They cried together sometimes; he consoled her, made her laugh and told her the sorts of sweet things we all hope our partners will say during labor. He told her he believed in her, he apologized for not being there, and yet, he was there, as best he could be. Late that night, she delivered their son vaginally, gave him the name they agreed upon, and began breastfeeding.

After delivery, birth doulas have an additional postpartum visit with parents and new babies at their home. We take that time to tell the birth story, process any remaining questions around the birth, and check in on how the transition home is going. I visited this mom for our postpartum visit on Halloween night. Her elder children were out trick-or-treating, and she was at home with her newborn baby. She shared the challenges of this initial postpartum period – she felt isolated, needed help with breastfeeding, missed the company of other adults, and was generally exhausted. Her sense of isolation was exacerbated due to the absence of her partner, but her feelings of exhaustion, struggles with breastfeeding and missing adults is common with many new moms I've worked with. I tried to connect her to services and mom support groups, but when I heard from her a few weeks

later she had stopped breastfeeding and sounded resigned to making the best of her situation. (Since that time, there is now a Baby Cafe in Olneyville, and another slated to open in the summer of 2015 in South Providence, which is a great resource for pregnant and new moms seeking breastfeeding and social support).

As I transition into medical school, I continue to work as a doula whenever possible. In early 2014, Gina Rodriguez-Drix, Jennifer Rossi and I started the Doula Collective to expand access to free doula services in Rhode Island. We currently provide free doula services to teen moms, in partnership with the Nowell Academy, a charter school in Providence and Central Falls, specifically designed for pregnant and parenting teens.

I am excited to share my experiences and training with my medical school classmates. In the spring of 2015, the Doula Collective will be leading a workshop on doula care with Brown medical students thanks to a Petersen Fund grant from AMS. Lessons learned from my experiences as a doula are invaluable in shaping my vision for what it means to be a doctor: recognizing the importance of community-based partnerships; acknowledging patients' emotional responses to physical processes; navigating the boundaries of being emotionally present and holding space for a family while not making the process be about me; and learning how to take care of myself while on call, during labor, and after a birth. I am so thankful for the trust my clients have put in me, and grateful for the opportunity to be able to share my skills with the Providence community. It is my hope, and that of the Doula Collective, that, moving forward, we can create enough awareness of and access to doula care that the question of the future will instead be, "Hi. So, who is your doula?"