

### **Narrative Discussion Group Handouts on Exploring Stigma and Bias in the Care of Patients**

Below are six excerpts from personal stories published in *Narrative Inquiry in Bioethics*. They can be used with the [guide on facilitating narrative discussion groups](#), entitled “Teaching Ethics with Narratives,” which provides discussion questions that can be posed after reading an excerpt (or a section of an excerpt).

Facilitators may want to distribute to group participants one or more excerpt for discussion. Each excerpt in this document addresses an aspect of stigma, bias, or stereotyping in the context of patient care.

During a 1-hour discussion, it is unlikely that more than 2 or 3 excerpts can be explore in depth, so it is appropriate to select excerpts that are most pertinent to your participants.

## **1. I'm Your Patient, Not a Problem**

*Author: Lauren Moore*

Fall 2014 Volume 4, Issue 2: Obesity

### **Story Excerpt:**

Before talking about the kind of discussions I have with medical professionals, it is important to note that visiting a doctor's office can be problematic physically as well as mentally.

I don't fit. Before I even talk to my doctor, I am set apart from the other visitors by my size. Chairs in waiting rooms and treatment rooms may be too flimsy for me, or have arms that prevent me using them. Sometimes I attempt to sit on an examination table and it groans, or I will be asked not to sit on it at all. More than once I have had to stand during my appointment, or ask for another chair, or sit on the floor whilst waiting to see someone.

Every visit to a doctor begins with the anxiety that this will happen, and the embarrassment of dealing with it if and when it does. This is the starting point for my interactions with doctors—the physical reminder that I am apart and different and that it is not their job to take care of me but my job to change and accommodate them. In this way the physical limitations of a doctor's office are emblematic of the relations between patient and doctor.

This is the first thing that all my visits to doctors have in common. The second thing is that since I first hit my teens and was told I was obese, I have never had a doctor's appointment where my weight was not under discussion. Since I was first told to diet, I have had many different doctors due to frequent movement around the country and large practices not being able to guarantee me the same doctor when I visit. Every one of these doctors, in every one of these appointments, has brought up my weight. This is not something confined to a single doctor, or a single practice.

I can visit for a rash, or a stomach bug, or contraception, or just be registering with a new doctor, but every appointment will become about my weight. No one will explain how my rash is symptomatic of my weight, but somehow it is. As a fat woman, any health problem, however temporary or seemingly unrelated to body size, is put down to my weight. Sometimes my problem may be put down to a condition associated with weight, such as high blood sugar (which I do not have) or high blood pressure (which I do not have), but it is assumed I have because of how I look. Wheezing and heavy breathing due to the flu are considered to be due to my weight. If I contradict, I am considered a liar.

When I talk about my diet no one believes me, because I am morbidly obese and everything I eat must be fast food. If I talk about enjoying long walks, I must be lying, because I'm morbidly obese and therefore can't be exercising. If I talk about avoiding group exercise activity due to discrimination, I must be lying about its occurrence, because they have not experienced the same discrimination. Clearly I am just lazy. When I visit regarding contraception, my doctors are amazed that a woman like me is sexually active. At my weight no one could ever find me attractive, so I must be lying.

To me, a visit to the doctor is something to dread and be avoided at all costs. A doctor's [office] is not, and has never been, a safe place. Explaining my obesity is not something that I should be forced to do. I am a human being, and I deserve healthcare as much as any other human being, regardless of my weight.

## **2. Uniquely My Own: One Woman's Experience of Living with a Physical Disability**

*Author: Stephanie Birmingham*

Winter 2013 Volume 3.3: Living with the Label Disability

### **Story Excerpt:**

I lived just outside Washington, D.C. for a year. Shortly after moving I decided to establish a connection with a primary care physician. My first visit with the doctor was strange and after he said, "I thought only boys got O.I." I knew this wasn't going to be a good fit. Thinking that perhaps it would make more sense to visit a female doctor, I made an appointment with a female internal medicine physician. Getting into the office was an interesting feat in and of itself. The so-called "accessible" entrance wasn't very wheelchair-friendly and consisted of an uneven, steep ramp. Getting in required not only my calling to tell them I was outside, but also the assistance of a fellow patient to lift my wheelchair inside.

During my first (and only) visit with the doctor she proceeded to complete a basic physical exam. She asked me questions about my health history, current social history and it seemed like things were going just fine. Until, much to my dismay, after having shared with her that I graduated from a private liberal arts college with a degree in Political Science, she proceeded to ask me, "Did you go to a special school as a child?"

I couldn't believe it! Did she really just say that? With as much composure as I could muster I replied, "No. You do realize that my disability has nothing to do with my intellectual abilities, right? I went to a mainstream school just like my friends. My disability means that I am short, can't walk, and my bones break easily."

At this point all I wanted to do was get out of the office. I knew I'd never make another appointment with her again and this was confirmed as she tried to "push" my wheelchair as I exited the exam room. What exactly she was thinking as she tried to maneuver my wheelchair out the door I am not quite sure. All I can say is that it felt like the doctor only saw me as a medical diagnosis. Assumptions were made about my intellect based on my size, even despite having been given a bit of background on me as a person. On a brighter note, I did end up finding a female physician's assistant who was absolutely wonderful.

### **3. Obesity as Disease: Definition by Desperation**

*Author: Jeremy Shermak*

Fall 2014 Volume 4, Issue 2: Obesity

#### **Story Excerpt:**

I hated removing my shirt. Each visit to my doctor's office, following a blood pressure and temperature check, the nurse would instruct me to take off my shirt so the doctor could examine me further. She would then leave the room. I remained perched atop the exam table, now half exposed, and a mirror on the wall would not leave me alone. In the reflection, I saw my oversized breasts and "fat roll" oozing out from my pants, hiding my belt. I tried to straighten my back—breathe in, no wait, breathe out—to resculpt the appearance, but it did nothing. I hated myself. Soon, a gentle knock at the door would interrupt the loathing and I'd shake hands with my doctor.

I have been obese for the majority of my life—from childhood until I turned 34, when shortly thereafter, I had gastric bypass surgery. Since that time, I have lost 155 pounds and now write this at a comfortable, healthy 180 pounds. That said, my mind remains "obese". My thinking remains shrouded deep within the obese personality that I embodied for all of those years. I still automatically walk to the big-and-tall section of clothing stores; I don't recognize the 34-waist pants when they come out of the dryer; I'm not used to seeing my ribs; and I'm still terrified of that exam room mirror.

The best outcome...would be for doctors—perhaps even more than patients—to approach obesity as if it were a "disease". I have been told "exercise to avoid weight gain" and "your heavy middle section is going to have long-term health consequences" only to have the exam end, even after asking questions, without any kind of direction or assistance to solve these matters when I had been doing what I believed was right. A good doctor would not ignore fatigue, blurred vision, fever, or any other alarm bells. There would be a battery of tests and follow up. For obesity, there is nothing. We are told what we already know but given nothing to pursue it.

My life changed when I visited a wonderful endocrinologist in Chicago. Our initial appointment lasted an hour and 45 minutes. We discussed my entire medical history, my eating and exercise habits, my medication, and much more. She ordered tests—everything from vitamin levels to a sleep study. I left there with hope that I had never felt before. That hope translated into my success as a bariatric patient and continues to support me to this day.

My greatest fear, both now and when I was obese, is to be called "lazy". Even when my large midsection, heavy breathing, and brow sweat told the world otherwise, I was working hard to be healthier. When addressing my weight with doctors, I always felt an assumption of laziness and ignorance. Instead of giving patients reminders of their obesity and its consequences, doctors should pay close attention to the echoes of bells ringing with the mention of the word "disease". They should hear these echoes as a call to action to assist those begging for help.

#### **4. Homesick**

*Author: Anonymous One*

Spring 2011 Volume 1.1 Experiences of Psychiatric Hospitalization

##### **Story Excerpt:**

When my mother, whom I had helped care for the previous ten years, and who suffered from COPD and other ailments, died, my life went from bad to worse. I was extremely anxious, terrified of medication and doctors, but I had nowhere else to turn now. I was afraid of everyone. I felt horribly betrayed by my family, and by people I considered friends.

Six months later, I got an infection in my leg that brought me to the emergency room. Although it was a serious staph infection, as soon as I mentioned I had a psychiatric history, I was put in the psychiatric evaluation section, even though the infection was rapidly worsening and I was terrified to be in the hospital where I was afraid it would get worse due to super-bugs. Revealing that fear and my psych history was, of course, a huge mistake on my part. I had a terrifying experience where I was forced to disrobe, had all of my belongings taken from me and, when I asked for the doctor one too many times (because I wanted to go home), I was pinned down by four orderlies and shot up with Haldol and put into a blackout.

## **5. Fitness, Fatness, and Aesthetic Judgments of the Female Body: What the AMA Decision to Medicalize Obesity means for other Non-Normal Female Bodies:**

*Author: Sara R. Jordan*

Fall 2014 Volume 4.2: Obesity

### **Story Excerpt:**

In terms of health, then, I am a paradox: according to one standard, I am healthy and fit, according to another, I am unhealthy and fat.

As this new physician picked apart my weight, suggesting I should lose between 15 and 20 pounds to bring myself to “full health”, I found myself quite annoyed. He was a small, rail thin, man with greying hair, tired eyes, unpressed khakis, and a beaten pair of black-ish grey “Crocs” on his feet. He looked disheveled and as if he had not seen the inside of a weights room in his life. As I listened to him address my history, current vitals, and how being overweight in my 30s could lead to being “fat and 40”, I looked him over and made a snap judgment of “I could bench (press) you [right out this window]”. While I was angry with his delivery, I tried to remind myself that he was an overworked physician in a multilingual office, trying to operate under a new paradigm in healthcare policy, practice, and diagnostic categories. Specifically, prompted by the medicalization of the condition of obesity by the American Medical Association, my physician was reflecting the professional wisdom that I suffer from a condition needing preventive treatment. He was trying to be a good practitioner to recommend preventive treatment, but to me, he was being a terrible physician.

I left my physician’s office angry. To me, a physician that could not see fitness on a distinctively fit patient would probably also not be able to see other conditions. I wondered if this physician would recommend I see a psychiatrist for obsessive compulsive disorder if I came in to obtain a referral to a sports medicine practitioner for a nagging wrist injury related to a period of intense twice a day training for a major competition?

## **6. Disability Embodied: Narrative Exploration of the Lives of Two Brothers Living with Traumatic Brain Injury**

*Author: Douglas E. Kidd*

Winter 2013 Volume 3.3: Living with the Label Disability

### **Story Excerpt:**

An example of medical personnel's attempt to disable me occurred during a consultation with a physical therapist. The therapist observed my gait, and then made various measurements. At the end of the initial consultation, she provided a list of home-therapy exercises and instructions for me to my fiancé. Understand, I sat right next to my fiancé and the therapist looked directly past me and did not engage me in the conversation. As I stayed in the hospital's ICU, the therapist knew about my medical history. I can only assume that when she evaluated the severity of my brain injury, she considered me to be incompetent. The reason I suggest the therapist attempted to disable me is that she failed to recognize my mental competence and thereby she negated my humanity. I use the word "attempt" above, because I insisted and the therapist finally engaged me directly. We went on to have a good therapeutic relationship as I greatly refined my ability to walk with her help, but clearly, my ability to self-advocate meant that the therapist would recognize my humanity and help me deal with my impairment.

I believe when some non-disabled people encounter disabled individuals, they respond from a subconscious sense of superiority that sometimes overrides the autonomy and rights of those who are physically different.



## **The Power Of Human-To-Human Contact**

*Author: Viesia Novosielski*

Spring 2011 Volume 1.1 Experiences of Psychiatric Hospitalization

### **Story Excerpt:**

The cost of safety was that the hospital dehumanized both staff and patients. This ran counter to their efforts to help children because help cannot be dehumanizing. You are trying to help human beings, not pathologies. One way that the hospital dehumanized children was that clinical attitudes, protocols and language facilitated an us-versus-them divide between hospitalized children and the staff. This made the staff who worked with us on a day-to-day basis seem amorphous and interchangeable. They had power and authority, we didn't. Their point of view had validity, ours didn't. Usually we interacted with them and reacted towards them as if their individuality had been submerged into their role as staff. Reflecting back on my hospitalization I realized that you can't dehumanize someone else without dehumanizing yourself. And mutual dehumanization was the unfortunate *modus operandi* in the hospital.

Some staff persons tempered their professional roles with human warmth that was more compassionate for the both of us. I was always happy when a staff person didn't treat me as a walking pathology seething with weird symptoms and bizarre behavioral patterns. It was a pleasure when they treated me as a human and I got to treat them like they were human in return. I treasured those occasions when our encounters and communications transcended our roles and we related to each other as people aware of our shared humanity.

In general I don't feel stigmatized for having a psychological condition. There was one time the staff's reaction to my behavior made me feel stigmatized. I was in the quiet room trying to self-soothe by chanting and dancing. But the staff woman was staring at me through the window in the door. It was clear that she thought I was crazy. This upset me and made me feel crazy myself, so I tried to calm myself down by doing yoga. But she asked me why I was contorting myself like that. When I explained what I was doing, it became apparent she had never heard of yoga, for she accused me of making it up. Then the nurse put me on bizarre precautions. This made me feel like a freak on display. So I gave up on trying to make myself feel better and just let my misery take rein. It was harmful to me to be seen and regarded as a freak.

I suppose it is human and natural to be upset by behavior you find strange. As a human, you may find behavior strange, but if you are trying to help someone, judging them is harmful. Somehow you have to have the maturity and poise to observe and manage your reaction. The role of helping people with psychological conditions is difficult. I believe that in order to help, you have to listen and observe like you are watching a play, taking into account context and life story, not studying a pathology in a vacuum. To help you have to be open-minded, tolerant, patient, non-judgmental, calm, and grounded. In my experience you have to be open to be grounded, otherwise you are closed and rigid, which isn't helpful. To help is to foster honest and open communication, mutual care and respect, integrity and fairness.

## **Surprised by Disability**

*Author: Emily K. Michael*

Winter 2013 Volume 3.3: Living with the Label Disability

### **Story Excerpt:**

“I did not use the white cane in daily life until high school. Before my freshman year, I could pass as nondisabled. When I became visibly blind, strangers started to approach me with more regularity. I received unsolicited comments that revealed the discrepancy between who I was and who everyone thought I should be. Unable to mask their disbelief, people said, “You don’t look blind!” or “If you hadn’t used the cane, I’d never have known you were blind.”

To outsiders observing the blind experience, blindness is signified by shuffling feet, stained clothing, wild hair, and a general lack of confidence. A blind woman should look lost, frail, and naive. No wonder Diana and my other students are afraid to look blind; they know the stereotypes and dread fulfilling them.

Called slippage, this attitude insists that the disabled person should be inept at all tasks. Slippage is the idea that impairment in one area, such as blindness, causes all other abilities to deteriorate. Perhaps this is why some people choose to speak to me in loud voices, slowing their words, while others seem amazed when I move without encumbrance.

Because I carry the cane, the performance of routine tasks—swiping my debit card at the grocery store, tying a scarf around my neck, or walking down a hallway—wins me the most effusive praise. This problematic attitude moves indiscriminately among disabled and nondisabled people. Even disabled people can believe in their own incompetence.”

Patrick [a fellow tutor and able bodied person] doesn’t see the cane and dark glasses as signifiers of eternal deficit. His offers of assistance are kind, even-keeled, and respectful. He doesn’t patronize, snatch items out of my hands, or insist on helping after I’ve refused assistance. He respects my agency, my ability to know what I want and need. In essence, Patrick lets me define myself. Perhaps because of his work with disabled people, Patrick has come to understand the absurdity of the stereotypes. Patrick responds to the needs I voice, rather than the issues he perceives. Through these interactions, I remember that I experience disability on my own terms.