

Communicating Stigma and Acceptance

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I give Maggie a quick hug as she gets in my Miata. "Sorry I'm late," I say with a grimace. I'm always late.

"It's not a problem at all," she says cheerfully. Maggie is always cheerful. I pull out of her driveway as she adjusts her seat belt over her growing belly.

"Look at you!" I exclaim. "You're finally starting to show! How far along are you?"

"Five months," she says.

We chat as I drive out of her neighborhood. I motion toward the lake peeking behind the houses. "I am so jealous! If I lived here, I'd be on the water every single day!" I say.

She laughs. "It's great! I saw your kayaking picture on Facebook last week. It looked like you were having a great time."

I grimace. "I was tagged. I wouldn't have posted that picture of me. I loved kayaking but I swear I looked eight months pregnant in that picture! Where did that stomach come from? I must have been slouching down in the kayak. See? I'm not that fat!" I point to my stomach as I suck it in.

She nods her head. "You looked great in that picture!! Strong!"

I smile at her. I don't believe her, but I'm not in the mood to prolong the fat talk right now. I change the subject. "You look great. Any morning sickness?"

"No, I feel really good," she says. "But, speaking of fat and pregnancy, it's really interesting that people have been asking me how much weight I've gained. I'm really afraid about gaining too much weight. I saw an article in The New York Times this morning that talked about the dangers of being overweight and pregnant [Brody, 2014]. And I've read other research that says that there's a relationship between obesity and birth defects" [Oddy, DeKlerk, Miller, Payne, & Bower, 2009].

I sigh. "First of all, you are nowhere, not at all, in danger of being overweight. Listen to us and our fat talk! Secondly, I read that article also and saw that it admitted that most mothers who are overweight have healthy babies. Even with an increased risk from excess weight to the mother and the baby, the rhetoric about it is overblown. For example, I've read that the increased

risk for neural tube defects in babies of pregnant women who are fat is about 1%. That means 99% of pregnant women with excess weight won't have babies with that defect [Vireday, 2011]. Pregnant women of all sizes need support and information, not rhetorical scare tactics. This is really part of the stigma the medical profession has against obesity and fat. Articles like that are dangerous because weight-loss diets during pregnancy are harmful for the fetus."

"This is a timely conversation, isn't it?" Maggie asks. "Since we're on our way to meet your sister and talk about her experience with weight."

"It really is," I agree. "Maybe that's why we brought it up, but conversations about extra pounds are ones women have all the time."

"Fat talk often leads to us assuring each other that we aren't fat," Maggie mentions. I laugh. "Just like we did!"

■ Fat Talk

Fat talk—negative remarks about our body shapes—is a pervasive social norm that both contributes to and results from body dissatisfaction and lower self-esteem. Fat talk also reinforces the thin body ideal, and the resulting dissatisfaction with our bodies can lead to disordered eating (Salk & Engeln-Maddox, 2011). We engage in fat talk interpersonally, intrapersonally (self-talk), and socially.

I (Cris) can personally relate to body dissatisfaction. I've struggled with weight issues my whole life. I've been smaller than I am now, and I've been heavier. I've been on one diet or another most of my life. When I was growing up, my mom told me constantly I was fat, which I wasn't. She had body issues herself. She had me on diet pills when I was eight years old. I was a size 6 when I was in my 20s, but when I was in my mid-30s, I was heavy enough to be categorized as obese. In recent years, I've maintained a mostly normal size and even got in good enough shape to run a half marathon a few years ago. But in order to keep my size close to normal, I have to exercise extensively and be obsessive about my eating. Sometimes I think I have eating control issues. Sometimes I wonder why, at my age, I bother. I frankly struggle with being a feminist and a scholar who is supportive of the field of fat studies and still being preoccupied about my body size.

The cultural rhetoric surrounding body size, fat, and obesity exacerbates that struggle. On the one hand, excess weight is related to all sorts of health problems. Obesity or excess weight is statistically associated with heart disease (Ghandehari, Le, Kamal-Bahl, Bassin, & Wong, 2009), cancer (Heron et al., 2009; Leitzmann et al., 2009), type II diabetes (Nguyen, Magno, Lane, Hinojosa, & Lane, 2008), esophageal reflux (Chung et al., 2008), diverticulitis and diverticular bleeding (Strate, Liu, Aldoori, Syngal, & Giovannucci, 2009), hypertension (Nguyen, Magno, Lane, Hinojosa, & Lane, 2008), kidney stones (Asplin, 2009), poor wound healing (Wilson & Clark, 2003), periodontal disease (Ylostalo, Suominen-Taipale, Reunanen, & Knuutila, 2008), and other chronic diseases (Field et al., 2001). However, research does not confirm that people's obesity is the *cause* of these disorders.

One explanation for the connection between weight and poor health is that, unrelated to any health implications of excess weight, people who are fat avoid or delay going to the doctor when they need healthcare or even routine screenings because of their past bad experiences and expectations of discrimination by healthcare providers,

and that may result in worse health outcomes (Creel, 2010; Fontaine, Heo, & Allison, 2001). People who are fat frequently report having difficulty finding doctors who will provide good healthcare without imparting value judgments on their size (Lupton, 2013), and this can prevent a patient who is fat from receiving decent healthcare (Puhl & Brownell, 2006). Researchers argue that doctors blame the patient for his/her excess weight and admit perceiving that patients who are fat are dishonest, hostile, unhygienic, indulgent, lacking in willpower, lazy, possessing emotional problems and unresolved anger, unsuccessful, worthless, bad, ugly, and awkward (Brownell, 2005; Epstein & Ogden, 2005; Fabricatore, Wadden, & Foster, 2005). Frequently, physicians ignore other physical symptoms and only focus on pushing patients who are fat to lose weight, as if all a patient's problems are related to his/her weight. Healthcare providers also blame people who are fat, if they are unable to lose weight, as if the inability to lose weight represents the patient doing something wrong (Thomas & Wilkerson, 2005).

[Insert HCIA 8.1: Loose-ing Weight]

We're not disputing that obesity is a pervasive phenomenon; almost seven out of ten adults in the U.S. over age 20 weigh more than the medical guidelines suggest they should, and almost half of them would be termed obese ("Prevalence of Overweight," 2006). However, research suggests that obesity is not increasing to the extent many people claim. Body Mass Index (BMI), determined by the Centers for Disease Control and Prevention (2009), is calculated based on a person's weight and height and indicates whether someone is overweight, obese, or morbidly obese. When authorities generate claims around obesity rates increasing, they do not acknowledge the fact that a great deal of this increase is due to the BMI categories arbitrarily changing, resulting in many more people being labeled as overweight, obese, or morbidly obese, without any changes at all to their body weight (Lupton, 2013).

Further, in perpetuating the claims that fatness places people at risk for various health and medical conditions, medical researchers are ignoring, misrepresenting, and misinterpreting the myriad of research that *disputes* that the weight is the cause of the medical problems and suggests that, instead, the medical problems might be the *cause* of the weight gain, or other phenomena may contribute to both excess weight and related health problems. They are confusing association with causality.

In this chapter, we discuss issues of fat talk, hegemony and medicalization of fat, social construction of body size, stigma, and the biomedical model, related to obesity primarily, but also to the body generally. We introduce you to the concept of fat studies and suggest a new way to view and interact with people who have more body fat than the "norm" or who live with other stigmatizing conditions.

■ Hegemony and Medicalization

I take the upcoming exit off the interstate. "Well, my sister certainly lives the fat body experience, so it will be interesting to see what she has to say about it."

"So, fill me in with a little background information," Maggie says.

"Kelli is my younger sister. She's in her early 50s. She's been overweight her entire life, ever

since she was a very small child. I can remember her being two years old and being picked on by other kids about her weight. When she was in her 20s and 30s, she was large but very strong. If you wanted something heavy lifted or moved, you'd ask Kelli. In the past 20 years she's had quite a few serious and chronic health problems that have made her pretty much obese. And now she's battling breast cancer too."

"I can't wait to meet her," says Maggie as I pull my Miata into the parking space at the Village Tavern.

I'm relieved that Kelli smiles as we walk in. She's already at the table and I know from her text messages she got there early and has been waiting for us for almost an hour.

"There you are!" Kelli says as we walk up and take our seats. I introduce her to Maggie.

"I ordered some food," Kelli says. "I hope you don't mind. My blood sugar was getting low. Diabetes," she explains to Maggie. "Help yourself." She passes a bowl of homemade potato chips to our side of the table.

Maggie helps herself to a chip as I set up the tape recorder and open my menu.

The waitress stops by our table.

"Water, no lemon," I order. "And an order of sweet potato fries as well," I add.

We turn to Kelli to begin our questions.

"How are you doing?" I ask.

Kelli shakes her head. "Fair." I'm going in for my pre-op on Wednesday." She turns to Maggie to explain. "I'm having a port put in to start chemotherapy."

"I'm so sorry to hear you're going through all that," Maggie says.

"Tell her about all your health issues," I prod.

Kelli frowns. "Let's see if I can remember them all." She recites. "Type 2 diabetes, osteoarthritis in both hips, degenerative disc disease, patellofemoral arthritis in both my knee caps, chronic venous insufficiency in both my legs, stasis dermatitis, pyoderma gangrenosum."

"An autoimmune skin disorder," I interrupt to explain to Maggie.

Kelli nods and continues. "Obstructive sleep apnea, psoriasis, rosacea, and a couple other skin disorders, whose names I can't remember and are a mile long. I also have a history of a rare reoccurring viral meningitis, which came back several times over the years, resulting in a total of nine spinal taps."

"And now breast cancer," I add.

"Wow," says Maggie. "Do you think of your weight as a health issue as well?"

"From my experience," says Kelli, "it is all related. My weight is related to my health conditions—going back as far as I can remember." She pauses. "Being overweight is a result of other issues, not a cause of them."

"Are you open to talking more about that?" I ask. "Give us the history?"

Kelli nods. "When I was in my early, mid-twenties, about 25 years ago, doctors discovered I have very severe obstructive sleep apnea. I was born with it and it was a birth defect. They told me then that my weight was probably a result of that. All of my health issues since have been a result of all those years of lack of sleep—causing all kinds of issues. When they did the sleep study, I stopped breathing over 500 times in six hours. As far back as I can remember, I had a long history of having severe out-of-body experiences during the night—probably from dying in my sleep over and over again. When the sleep apnea was discovered, I stopped having these experiences."

Kelli's numerous health issues are not uncommon. There is a plethora of research about the relationship between excess weight and sleep issues (e.g., sleep apnea)

(Carter & Watenpaugh, 2008; Hirshkowitz, 2008). However, while some medical researchers claim that obesity causes sleep apnea, others argue that studies like these conflate findings of association with causation. In Kelli's case, they may be related, but it is possible the sleep problems are causing the obesity rather than the other way around, as Kelli said was true for her. We also note that Maggie has sleep apnea as well, and she is at the low end of the BMI standards for her height and age.

"Let's talk about your weight," I say to Kelli. "When you think of your weight, what do you think?"

Kelli frowns. "I think I don't like it. I am not happy with it. And I need to keep trying harder to fix it."

"What do you mean by fix it?" Maggie asks.

"Lose it, get healthy," Kelli says.

"Do you think of yourself as overweight or fat?" I ask, searching for the terminology she uses to describe herself.

"Yes," Kelli says. "I think of myself as very overweight. Obese."

"Is that a term you use?" I ask.

"It's a term other people use," she answers. "It's a term I really do not like." She sits for a minute. "It is what it is. I don't like it because it is close to the truth."

"Is there a word you would prefer?" Maggie asks.

"No, not really." Kelli says. "I would prefer to not talk about it." She pauses. "It's not something you dive in and generally advertise."

There is an area of academic scholarship called "fat studies," similar to cultural studies and gender studies in that they all are populated by critical scholars who examine *hegemonic* (i.e., influence or authority exerted by a dominant group) language and discourse within these areas of study (Rothblum & Solovay, 2009). Fat studies scholars analyze how society, supported by the biomedical model of medicine, communicates in hegemonic ways to marginalize people with differently sized bodies. Critical fat studies scholars have a lot in common with activists and critical scholars in LGBTQ (lesbian, gay, bisexual, transgender, questioning, queer), cultural, disability, aging, and gender studies in that they all are concerned with the way hegemonic (hidden) norms constrain, control, and marginalize bodies that are different from the dominant view.

The story of difference, stigma, discrimination, and marginalization is one we can relate to, as it touches all of us (Green, Davis, Karshmer, Marsh, & Straight, 2005). As we and our loved ones age, our bodies are less under our control, and we are all a few short steps from being older, larger, or less-abled than we would like to be. Other than fat bodies, many disabling conditions have their own specific social difficulties. Speech and hearing difficulties make interpersonal communication challenging, piling an additional awkwardness onto an already stigmatizing situation. Hearing impairments are socially isolating. Wheelchair users have the danger of being embarrassed by committing social transgressions such as tipping over, bumping into people, or knocking things over (Green et al., 2005). Many people with different appearing bodies (and behaviors)—people with mental illness or mental disorders, people with physical disabilities, people who are older, as well as people with larger bodies—often find themselves in social situations in which they are treated as being not quite human. This results in "nonperson" treatment, with people frequently either com-

pletely ignoring the person with a disability or larger body, mistreating him/her, or treating the person with civil inattention (a glance followed by the immediate withdrawal of visual attention) (Cahill & Eggleston, 1995; Goffman, 1963; Marks, 1999; Susman, 1994). Barnes (1996) suggests that the ideals of our Western society worship the perfect body, and a body that is less than perfect—older, larger, impaired in some way—tends to be stigmatized.

In addition, there is a relationship between thin bodies and gender, ethnicity, and socioeconomic status. Fat studies scholars claim that an insistence that all bodies must be thin ignores genetic differences and therefore marginalizes minorities such as females, nonwhites, and individuals with lower socioeconomic status who are more likely to be larger (Donaghue, 2014; Farrell, 2011).

Critical fat scholars pay a significant attention to language usage and tend to avoid using the terms *overweight* or *obese*, because these terms have diagnostic and medicalizing implications. Labeling people with larger bodies “obese” has connotations that a larger body size is always a medical issue, and that’s simply not true. These scholars often prefer to use the term *fat*, because that is more of a descriptive term. Although labeling someone else as “fat” has other cultural meanings, fat studies scholars reclaim that word and change the denotation to one that is less negative (LeBesco, 2004; Lupton, 2013). To *medicalize* means to turn something natural into a medical condition to be treated and fixed, like the way pregnancy, menopause, and aging are now medical conditions rather than just normal parts of the life span. The terms *overweight* and *underweight* imply there is a normal weight to be desired, and *obesity* implies abnormality, pathology, or a medical problem. Ironically, the term *obesity* comes from a Latin word that implies that larger people always consume more than thinner people, and that’s not necessarily true either. The words we use to describe others and ourselves have real implications (Lupton, 2013; Wann, 2009), as we further discuss in the next section.

■ Social Construction of Body Size

“Do you ever talk about your weight to people?” Maggie asks Kelli.

Kelli frowns. “Yes, I do have private conversations about my weight, with close friends. I don’t discuss it with people I’m not close to.”

“What do you talk about, when you talk about your weight?” I ask.

“I generally talk to people who have lost weight or can give me advice. Pointers or tips to lose weight,” Kelli says.

“Oh, it’s always about losing it?” I ask.

“Oh, yes,” Kelli says. “For instance, I’ve talked to people who have had gastric bypass surgery, about their adventures with that. And my best friend CJ is a professional bodybuilder and a fitness fanatic. I’ve talked to him about what to do in terms of exercising, fitness.”

“Do you have friends who are fat?” I ask.

Kelli nods.

“It’s interesting,” Maggie says. “Women like to sit around and talk about weight. It becomes a bonding thing, to one up each other, to ask each other ‘do I look fat in this,’ in dressing rooms.”

“I have not experienced that,” Kelli says. “Maybe I don’t because I am obese and it isn’t a conversation that comes up with me. Maybe that’s something that thin women discuss.”

Some health communication scholars suggest that obesity is a social construction (Campo & Mastin, 2007; Kim & Willis, 2007). When we interact socially with each other, through communication, we share our experiences and knowledge (Laing, Phillipson, & Lee, 1966). Our identities—how we see ourselves and how we think others see us—are constructed through those interactions with others. Cultural communication, especially via media outlets—TV shows, movies, books, magazines, the Internet, and so on—also affects our identity. All of us live within our socially constructed meanings (Davis, 2013). We all communicate with others to construct our meanings of health, illness, ability, obesity, and normal weight. Your body might be a certain size. That is a fixed reality. What that size *means* is a product of communication. The fact that people look down on others because of the size of their bodies is a social construction. For example, the BMI cutoffs that are used to classify people by the labels of overweight, obese, or morbidly obese were arbitrarily determined and based on population parameters rather than on any health conditions related to weight. In addition, BMI is an inaccurate guide for health, as it does not distinguish between fat and muscle, body frame, age, gender, good health, or ill health (Lupton, 2013). Several medical researchers (Campos, 2011; Gaesser, 2002; Oliver, 2006) claim that obesity is *not* increasing to the extent many people contend; that there is *no* evidence that obesity or fat shortens life spans or increases health risks; that there is some evidence that excess weight has some protective health benefits (doctors call this the “obesity paradox”); that research shows that attempts to lose weight, which result in weight cycling, are themselves detrimental to health and, ironically, frequently result in ultimately higher weight; and that fatness is often a *symptom* of health problems rather than their cause (Lupton, 2013).

The social construction of fat does not take into account how people’s weight is affecting their health; it is the *meaning* attached to the body size that creates a problematic situation, often through social stigma. The meaning is socially constructed, but it still has effects on people, both physically and socially (Freedman & Combs, 1996). An example of the physical effects of stigma is that while women in all cultures go through a period in their lives that we call menopause, women in cultures other than ours do not experience distress from the phenomenon. And American women today experience less menopausal distress than did our mothers and grandmothers, because the ability to bear children is not the identity-ending experience it was to them (Kleinman, 1988). In an example of the social effects of stigma, people with mental illness and disabilities, for example, are frequently perceived to have characteristics that others look down on and are treated differently as a result—often devalued, disrespected, or treated as if they are less than fully human (Green et al., 2005).

When we label and classify each other, we marginalize and create cultural narratives that depict certain groups of people as unwanted or undesirable, separate from their actual physical properties. Sometimes, for medical conditions or mental disorders, labeling is perceived as positive, because without the label (diagnosis), the person cannot be treated and possibly relieved of her/his symptoms. But, concurrently, labeling categorizes people into social hierarchies. As Foucault (1995) pointed out, labeling people as somehow “deviant” led to the long-term confinement of people with mental illness (labeled “the insane”) in mental hospitals, of people who were ill in hospitals, of people who were older-aged in nursing homes. Szasz (1987) noted that

“the primary function of the public mental hospital has always been, and still is, to provide room and board for society’s misérables—the homeless, the unskilled, the unemployed, those unable or unwilling to care for themselves and for whom no one else is willing to care” (p. 358). Separating out the deviant other makes us feel more “normal” (Szasz, 1970).

Space for deviant others is not only created by physical location, however. It is also created in language, by referring to people with illness or disability by their illness or disability, or by pointing out their difference through language, rendering people “less human, more a collection of body parts” (Marks, 1999, p. 57). Theorizing Practice 8.1 invites you to consider people-first language as a way of challenging dehumanizing references.

[Insert Theorizing Practice 8.1]

Labels reinforce the traditional medical hierarchy because the process of diagnosing privileges medical terminology and creates dependence on professionals. Labels are products of social practice and discourse. While there are advantages to medical labeling, as we’ve stated, all of these medical labels still construct the person as deviant (Davis, 2013). While impairment can be seen as a “real” physical fact, disability due to that impairment is believed by social constructionists to be a negative label used to enforce social marginalization (Barnes, 1996). As Cris observed in her research on children with mental illness, we blame people for their problems (poor people for their poverty, people with physical or mental impairments for their disabilities), rather than acknowledging the social issues that contribute to their situation (Davis, 2013).

Lupton (2013) also reminds us that in other times and places, additional weight has been considered a sign of health and beauty. She reminds us that “in and of itself, fat has no meaning” (p. 3), and she asserts that the significance of differently sized bodies is culturally constructed. Not all people with excess weight are gluttons, or are unhealthy. Scholars such as Lupton (2013) and Wann (2009) argue that society needs to accept *biodiversity*—a diversity of sizes and shapes. For example, many of the difficulties that people who carry more weight have are not due to conditions inherent in their bodies but rather are the result of architectural and spatial decisions that render spaces too small, tight, and unmanageable for people of many body sizes (Lupton, 2013). Think of airplane seats and turnstiles. Being larger-sized would not matter if design engineers made spaces generously large. Fat studies researchers suggest the stigma against obesity has a lot to do with space issues. Fat bodies take up more space (Lupton, 2013), and as the population gets larger, people get increasingly concerned about who’s taking more than their share—of space, resources, or healthcare. Also, when a person is fat, his/her body size is a master status (Hiller, 1982), overpowering all other characteristics she/he may have and affecting his/her whole life (Macionis, 1995). People with fat bodies are constructed as being out of control, lazy, ugly, monstrous, and emotionally unstable (Lupton, 2013). We are in what Lupton (2013) terms a “fat-phobic society” (p. 3) in which if you are not fat, you are afraid of becoming fat.

■ Stigma

Kelli frowns. “I can see a size-12 woman in a dressing room whose weight is up from a size 10 being concerned about it. But at my size I would never ask anyone if this makes me fat because the answer will be, ‘Well, duh.’”

“What do you think are some people’s misconceptions about obesity?” Maggie asks.

Kelli nods her head. “The biggest one is that it’s my fault; it’s something I’ve deliberately done to myself. And people think it’s very easy to fix and I’m this size simply because I eat too much. None of that is true.”

Stigma, a social construct, is defined as an undesirable differentness, an adverse reaction to the perception of a negatively evaluated difference (Goffman, 1963). Of course, the experience of stigma is not only experienced by people with larger bodies. All sorts of differently appearing bodies, including older, larger, and injured bodies, and differently acting behaviors (as people with mental illness or cognitive disorders), are potentially implicated in socially constructed and stigmatizing meanings. It is not about the attribute of the person who is stigmatized but rather about the way other people evaluate whatever is different about her/him in negative terms (Goffman, 1963). In a society in which health, youth, and beauty are highly valued, people with bodies that look different in a variety of ways—various sizes, shapes, impairments, or imperfections—are seen as having negatively valued traits (Barnes, 1996). The stigma itself can have a negative effect on a person’s well-being and sense of self. In the conversation among Kelli, Cris, and Maggie, examples of stigma are pervasive.

Link and Phelan (2001) identify five components of stigma: labeling, stereotyping, separation, status loss and discrimination, and power differential. Stigma occurs when people with these differences believe that they are labeled, stereotyped, and separated from others. They feel a loss of status when the labeling, stereotyping, and separation interfere with their ability to participate fully in the social and economic life of their community. In qualitative research on people with disabilities, Green et al. (2005) heard distressing examples of Link and Phelan’s (2001) five components: social awkwardness resulting from labeling; pity resulting from stereotyping; violence, hostility, mistreatment, and shunning resulting from separation (“othering”); deterred social and economic participation related to status loss and discrimination; inequitable power relationships that marginalize people with disabilities; and subsequent lower self-worth, depression, and social isolation. Green et al. (2005) quoted one participant with a disability describing the experience of separation: “People have a preconception of [the individual] not being a whole person when they see somebody on crutches or in a wheelchair so you have to kind of overcome that. Show them that you are a person and not an object to be pitied” (p. 205). Stigma can have long lasting negative consequences on employment, quality of life, and self-esteem. Being stigmatized results in negative outcomes including shame, depression, and social isolation, as well as mistreatment and discrimination (Puhl & Heuer, 2009).

[Insert HCIA 8.2: Experiencing Transgender Microaggressions]

Fat stigma is prevalent across media. Even children’s television depicts people with larger bodies as evil, lazy, weak, unattractive, unfriendly, cruel, unimportant, stu-

pid, uneducated, unsophisticated, and unlikeable (Fouts & Burggraf, 2000; Fouts & Vaughan, 2002; Robinson, Callister, & Jankoski, 2008; Spinetta, 2013; Veverka, 2014). Scholars criticize the reality television show *The Biggest Loser* because it treats people like children and humiliates and punishes them as motivational techniques. It teaches us that people with excess weight are not “normal,” that it is justifiable to mistreat people who are large because it is for their own good, and that certain people, because of size, are not worthy of being loved, which perpetuates fat shaming and anti-fat attitudes (Domoff et al., 2012; Lupton, 2013). Also, shows like *The Biggest Loser* sustain the misconception that excess weight is a direct result of simply eating more calories than you burn, despite the fact that much research shows that body size is much more complex. In fact, many people mistakenly attribute obesity to lack of willpower (Veverka, 2014).

Another example is Michelle Obama’s “Let’s Move” campaign, which targets children. It has been criticized for its emphasis on weight loss rather than healthy eating and exercise, resulting in potential stigma against children who are larger sized and propagating eating disorders in youth. In addition, the “Let’s Move” campaign also communicates, again, that fat is always negative and people who are fat are inevitably less healthy and they are to blame for their overeating and lack of exercise. It constructs a war on fat and, by association, on people who are fat (Jette, Bhagat, & Andrews, 2014). Unfortunately, this kind of discrimination and stigma has been shown to result in the bullying of children (Doty, 2014). Many individuals who are fat experience depression, lower self-esteem, body dissatisfaction, eating disorders, negative social relationships, reduced physical activity, higher blood pressure, and suicidal behaviors (Matthews, Salomon, Kenyon, & Zhou, 2005; Puhl & Latner, 2007).

The concept of “deviance” is related to our social emphasis on productivity. Part of the reason for the stigmatization of people who have bodies that are ill, impaired, or different is the value placed on productivity in our society. If individuals’ bodies (or minds, or emotions) do not allow them to be productive, such as when they have mental illness, impairments, or disabilities (especially hidden disabilities, as Theorizing Practice 8.2 demonstrates), they are often blamed for their bodies. Of course, this is paradoxical because by stigmatizing them, these individuals are held back from jobs and earning money, which in turn makes them less productive, and frequently even more sick and differently abled. The medical model of care reinforces this dilemma through its emphasis on loss and inability rather than on ability (Barton, 1996; Foucault, 1973).

[Insert Theorizing Practice 8.2]

People cope with being stigmatized in many different ways. They may attempt to hide their differentness (Goffman, 1963), educate or manage the emotions of others in public encounters (Cahill & Eggleston, 1995), withdraw from others (Link, Struening, Cullen, & Shrout, 1989), or mostly associate with people they know understand what they’re going through (Goffman, 1963). Ironically, stigma against individuals who are fat makes them much more likely to become and remain fat (Smith, 2011), which is why the public health messages against being fat and public discrimination against fat people often backfire.

"In many ways, I'm strong and tough on the outside, but on the inside, of course, it does hurt when people say cruel things about me. I am an emotional eater and I swallow my depression and that is a problem. That has contributed a lot to this," Kelli says.

"Do you know where your depression started?" Maggie asks.

"It's a domino effect," Kelli says. "I'm depressed because I'm, fat, so I eat more because I'm depressed. Go figure. I'm depressed because I don't like myself so I'm going to self-sabotage it."

I nod sympathetically. "That's very, very common, when people try to get other people to lose weight; it just makes them eat more."

Maggie adds, "3–5 are my eating hours."

"This is what strikes me," I say. "All three of us do the same things. We sometimes eat what we shouldn't, when we shouldn't. We probably all do emotional eating sometimes. And we probably all beat ourselves up for it when we do it. But because Kelli's behaviors manifest visually, she gets social blame and Maggie and I don't."

"Well, I know I have been the recipient of a great deal of hatred, discrimination, and bullying because of my weight," says Kelli.

"Do you think there are other misconceptions people have about people with excess weight?" Maggie asks Kelli.

Kelli nods. "There are misconceptions about overweight people in general—there is a prejudice about overweight people. There are people who think they are superior to us."

"How do you know that?" Maggie asks.

"It's their attitude," Kelli says. "I have a very early childhood memory of being in nursery school and having this little girl actually whip me with her jump rope. Beat me up against a tree. That was when I was six years old. I still remember that. That memory has stayed with me all these years. Now that I'm older, I want to beat her up."

I laugh, feeling very big-sisterly protective. "Tell us her name and we'll do it."

"Bullying against larger sized children is a real problem," Maggie says. "There's been a lot of recent cases of kids being bullied over their weight, and some even committing suicide because of it" [Doty, 2014; Puhl, Luedicke, & Heuer, 2011].

"Unfortunately, it's not just children who are bullies," Kelli says. "I still get bullied today, as an adult. People look at me as an easy target. The prejudice against my body size has made me tougher growing up. I never dated a lot. The men I always wanted never wanted me," Kelli adds.

"I have a lot of friends," Kelli says. "I have been very blessed. In some ways, my weight and health issues have helped me be a little luckier. The friends I have are true friends. You find out who your friends are when you go through tough times. I have a handful of very close, very dear friends, and then I have a world of so-so friends. I have learned over the years to be more aware, more discriminating of people, as far as choosing my friends. I am not needy. I don't need to have a lot of friends. I think being overweight has strengthened me. You get a thick skin. I try not to think about things. I try not to let it get to me."

"Are there times when it does get to you?" Maggie asks.

"I'm sure there have been," Kelli pauses to think. "People can be cruel or ignorant. Recently, I went to a convention in New Orleans right after my initial cancer surgery and I was not well while I was there. I had just had the lumpectomy the week before."

"You got on a plane a week after the surgery?" Maggie interrupts to ask.

Kelli nods. "I barely survived it. It was very rough. I had a couple friends at the convention sit me down and let me have it about coming to the convention and being so far gone."

"What do you mean, far gone?" I ask.

“Being so sick. They told me it was my fault that I let myself go this far to get cancer. I didn’t know what to say to that.”

“Wow,” Maggie and I both say.

“I was sitting there minding my own business and this person came walking up. The day before, a couple friends and I had gone sightseeing and I was pretty well wiped out. I just couldn’t walk and I got a wheelchair, although it didn’t work on the cobblestone streets, so we ended up walking. But this woman came up to me and said ‘I heard you were in a wheelchair yesterday,’ and she just dove in. She said, ‘What do you think you’re doing? I don’t want to ever hear anything like that again. How can you do this to yourself?’” Kelli pauses. “She meant well.”

I grimace. “If that is someone meaning well, I’d hate to see someone who didn’t mean well. Why did she have to say anything at all?”

“Couldn’t she have said, ‘I’m sorry to hear you’re in a wheelchair; are you OK?’” Maggie says.

I frown. “What is it with people who think it’s OK to say things like that? Here’s how you want to respond: ‘Thank you for telling me I’ve put on some weight. Thank you for telling me my health is bad. I have been waiting and waiting for someone to tell me.’”

“Do strangers ever say anything to you about your weight?” I ask.

“Well,” says Kelli. “There are things I won’t do because of I’m afraid of reactions to my weight. Not that people usually say anything out loud, but I may get looks. I don’t go to public swimming pools or the beach.”

“That’s a shame,” I say. “Swimming would help your arthritis and would be great gentle exercise for you.”

“Yes, but I’m not going to a pool,” Kelli says.

“That’s such an example of weight stigma making it harder for people of size to get healthier,” I protest. “I remember when I was heavier, trying to exercise to lose weight; it was impossible to find workout clothes in my size.”

“But I do other stuff,” Kelli says.

“Like what?” Maggie and I ask.

“Well, at our convention, there was a party with a live band, and CJ and I got up on the dance floor and danced.”

I smile at the picture. “Flying itself, how was that?”

Kelli continues. “I have learned this last year, Southwest Airlines will give me a second seat for free. That is something special they do. I can be first on the plane and choose the seat I want. No one says a word. I have to ask for it, but I’ve never had a problem. On other airlines, I haven’t been able to have two seats without paying for both of them.”

“Do you have other space issues with your size?” I ask.

“When I go out to eat, I can’t sit at a booth so I always ask for a table. Sometimes, the table is fixed and I can’t move it to make more room for me.” She pauses thoughtfully. “Sometimes when I’m riding with someone, people try to let me sit in the front seat but I can’t use their seat belt. In my car, I have a seat belt extension. If I sit in the back seat, I can get away without a seat belt”

I nod, thinking about how that situation puts her at risk for injury in case of an accident.

“What about at work?” Maggie asks.

Kelli nods her head. “I have had suspicions that I have been turned down for jobs or promotions. When it goes to the younger, cuter looking girl with no experience, when I have years of experience, it makes you wonder. Things like that.”

Theorizing Practice 8.3 invites you to consider how the Americans with Disabili-

ties Act of 1990 (ADA) has afforded protection from discrimination in a variety of ways. Still, as Kelli demonstrates, weight stigma is one of the most pervasive types of stigma in our culture (Seacat, Dougal, & Roy, 2014). Puhl and Brownell (2006) report that if people think another's excess weight is due to a medical issue out of her/his control, then they have fewer negative opinions of the fat person, similar to reactions to breast versus lung cancer, for example, or differentiating causes of HIV, STIs, and so on. In interpersonal relationships, people who are fat are the recipients of discriminating behavior from family members and so-called friends (Puhl, Moss-Racusin, & Schwartz, 2007). Individuals who are fat have difficulty dating and are believed to be less warm and sexually attractive (Puhl et al., 2011). The discrimination individuals who are fat experience results in their being less likely to be hired, paid lower wages, given lower performance evaluations, less likely to be promoted, and more likely to be fired (Puhl & Heuer, 2009).

[Insert Theorizing Practice 8.3]

In addition, if individuals who are fat also have health problems, often society takes a moralistic standpoint, blaming their ill health on excess weight, when the health problem may be due to stress induced by the stigma against their weight. In fact, medical research has produced evidence that acute and chronic stress contributes to conditions such as cardiovascular disease, depression; lowered immune response; digestive, endocrine, circulatory, respiratory, gastrointestinal, genitourinary, and musculoskeletal disorders; and impaired brain structure and functioning (D'Andrea, Sharma, Zelechowski, & Spinazzola, 2011; Lupton, 2013; Schnurr & Green, 2004; Wann, 2009). In addition, research has shown that chronic stress from stigma and discrimination contributes to overeating as well as to lower metabolism, thus contributing to weight gain (Torres & Nowson, 2007).

■ Biomedical Model of Weight Loss

Maggie asks, "Do you think if obesity were talked about more as a disease that would change the way people think about it?"

Kelli shakes her head. "I actually read an article online where they were talking about that idea. The general consensus was that people with excess weight didn't want to think of it as a disease. I don't think of obesity as a disease. I think of it as an outcome, a result, a side effect of lots of other issues. I do think some people are fat because they do not take care of themselves; they don't eat right. But not all fat people."

Maggie and I nod as Kelli continues.

"People have different metabolisms. Food affects different people differently."

I nod as I think of friends I have who eat what we would call "fattening" foods regularly but don't gain weight as a result.

"But does that make obesity itself a disease?" Kelli asks. "For me, I think of it as a birth defect. Everyone is different. Some people can eat whatever they want and be as thin as a rail. Other people can eat lettuce and gain five pounds."

I nod. I'm one of those people.

Kelli continues. "The medical community doesn't really know why people are obese. And if it

takes calling it a disease to find out, maybe that's OK. But I don't think it's a disease. I think it is a result of something else, maybe different metabolisms or whatever. I don't think it's just because I eat too much. That is a very unfair generalization. It's especially unfair for someone with a size 2 body to sit with a bag of donuts in front of them and call me fat because they say I eat too much. I wish people would have more compassion in general."

"It's biodiversity," I say. "Whatever size we are is OK; we don't all have to be the same size. Get over it. My body is not anyone else's business."

"I am not healthy," Kelli says after a pause.

"Do you think your health problems are weight-related?" Maggie asks.

"I think to a certain extent they are, Kelli says. "They have proven some are weight-related. Like diabetes." She pauses. "But then there are thin people with diabetes as well."

I sit thoughtfully. "Lots of people in our family struggle with weight, but Dad was not obese. He had type 2 diabetes and he ate pretty healthy. Blood sugar issues run in our family. I don't think you can say excess weight always causes diabetes. And I don't think you can say eating unhealthy foods always causes excess weight. As I said, lots of thin people eat unhealthy also."

"What do you think your life would have been like if you had been thin?" Maggie asks.

"Would I still be working, not out on disability?" Kelli asks rhetorically. "Would I still have these health issues? I don't know how much my weight affects these health issues. Would I still have arthritis? Yes. Degenerative disk disease? Yes. Circulation problems? Yes."

"Moving forward," I ask, "if you were able to miraculously lose the weight, what would life look like for you?"

"I'm hoping it would make enough of a difference that I could get back to work, be less dependent, not so needy. I could make more money, support myself better, get back to my regular wages and achieve other goals like get a job I like. Get my own place, get a dog. Date." Kelli pauses. "I don't know. Be out of pain hopefully."

"There is a perception that people who receive disability benefits would choose that rather than a job," Maggie notes. "Talk to us about being on disability."

"Many days, I'm in a lot of pain. I have to keep my legs up, which means I sleep a lot. I can go days without even getting out of the house. When I'm feeling better, I can go to the gym and try to exercise. I can go maybe 15 minutes on a treadmill and play around with the equipment. But if I do too much then I am laid up for days. It is a vicious cycle. It is not really living. When I went on that trip to New Orleans I was so ill I didn't know if I could make it home. This is not living." Kelli thinks for a minute. "My income was cut by 40% when I went on disability. I am living on 60% of my pay and I don't know how much longer I'll be approved for that. I put in for an extension of my disability income. They may say OK or not. If I don't get approved for permanent disability, I'll have to find a job whether I can physically work or not. Or I'll be out on the street. I might be in big trouble. This is no way to live. If I lose my disability, I'll lose my health insurance and I'll really be in big trouble."

"But there's the Affordable Care Act, right?" I say.

Kelli nods. "As of right now, I don't qualify for it because I make too much money on disability. If I lose it all, I'll have to go on welfare and hope I qualify for Medicaid."

"North Carolina politicians chose not to expand Medicaid," I say. "That's the reason you don't qualify for the ACA now. The original intent of ACA was to care for people in your situation. Politicians playing with people's lives."

"You have a lot of health issues," Maggie notes. "Where does your weight fall in the list?"

"I think about it 24/7," Kelli says. "It's the number one thing in my subconscious that I'm

always thinking about. It's the one thing about myself that I hate the most."

"Why?" I ask.

"I know that if I can lose the weight it would help some of these other problems," Kelli says.

"And, it is an image thing. It is the elusive goal that I want to achieve the most. Of everything. I think about it more than other health issues. I'd like to lose weight; I can't."

"You haven't been able to?" Maggie asks.

"I haven't yet," Kelli says.

"What attempts have you made?" Maggie asks.

Kelli shrugs. "Not a lot."

"So you haven't done yo-yo dieting," Maggie clarifies.

Kelli shakes her head. "I consider myself a moral failure. I see myself doing it in my mind. But then the day goes by and I haven't done enough."

"I feel like a failure," Kelli says, grimacing. "I know what I'm supposed to eat and what I'm not supposed to eat. I know how much exercise I'm supposed to do. I know I'm supposed to get off my butt and go to the gym every day. I do it for a while and I'm doing great and wonderful, and then something happens. Lately it's been health-related. I threw my back out at the gym. Then something else happened. Now I have cancer."

I interrupt her. "You consider yourself a moral failure because health issues stopped your exercise? You have cancer, for goodness' sake!"

"You sound like you're struggling with being self-disciplined," Maggie says. "Nobody has 100% self-discipline 100% of the time!"

Kelli shakes her head. "My friend CJ is very disciplined. He doesn't care about food. He will have a little grilled chicken and a salad. He could eat that seven days a week. If he were here, that is what he would eat. He doesn't care about taste and flavor. And I am a foodie."

Maggie laughs. "I get up in the morning and the first thing I think about is what I am going to eat." Kelli and I laugh with her. "That actually sounds like CJ is the one with food issues."

"Yeah, well, maybe," Kelli says. "He has his moments, but for the most part he is not consumed with it. His food issues aren't hurting anyone."

"Yours aren't hurting anyone else, either," I say with a grimace. "What is it about our society that—for some people with certain body sizes only—it is considered a moral failing to like food?" I shake my head.

Maggie changes the subject. "So, you bring it up to friends? To doctors?"

Kelli nods. "My doctor and I talk about it a lot. A couple months ago I started the process to do gastric bypass surgery. As part of the prep with that I have to talk with my doctor once a month about my weight, because we have to document that I'm trying to lose weight. I was moving forward with that until I got the breast cancer diagnosis."

I turn to Maggie. "Now they won't talk to her until her cancer treatments are over with."

"I'm not sure I want to do it," Kelli says. "I keep changing my mind. Something inside me is telling me not to. I think it is too dangerous. I'm concerned with all my other health issues that it could be a serious problem doing surgery that drastic. I'm afraid it would do more harm than good." Kelli adds, "And there's no guarantee it's going to work. A lot of people have the surgery and it comes right back. You can still have problems."

Kelli is not alone in her efforts to lose weight. Fewer than 5% of the people losing weight through dieting have been able to maintain their weight loss (Bacon, 2012). Further, research suggests that gastric bypass surgery leads to health problems later,

such as regained weight, nutritional deficiencies, alcoholism, and substance abuse, even in people who never had those problems before the surgery (Hagedorn, Encarnacion, Brat, & Morton, 2007). Also, many people require additional surgeries to remove excess skin, which usually is not covered by insurance (Bishop, 2005).

The desire to medically fix weight is part of the biomedical model of illness. Excess weight is labeled as “unhealthy,” as a medical problem. Weight is discussed as a temporary biological condition that can be cured by medical intervention. This model stresses cure; a dominant, paternalistic physician role; and a passive patient role, rather than prevention (Mischler, 1984). Foucault (1995) said that, in this model, the body serves as an object and target of power in which professionals disempower and marginalize the patients. This creates a distance between people who are healthy and people who are ill, who are considered to be “deviant” in some way—in this case, in their body size.

We pause our conversation as the waitress brings our salads and refills our unsweetened iced tea.

Kelli takes a sip of her tea. “One thing I wanted to add about the surgery,” she says, as Maggie and I take a bite. “I don’t think I’ve tried hard enough on my own and I would feel like I was giving up. A cop-out. It goes back to I know what to do. I just seem to have a mental block. I try to eat better. Like bread; I should cut out bread. I have food sensitivities and allergies to wheat. I think I’m addicted to it.”

I nod. I know I feel much better all the way around when I am not eating wheat.

Kelli continues talking between bites of her salad. “When I first became a diabetic, giving up sugar was very easy. I’m fine with fake sweeteners. Giving up pasta, not a problem, I don’t like it anyway. I never eat rice or potatoes. I don’t bake potatoes. All of that was easy to give up. But it’s all those other carbs and sugars. Any form of bread, I cannot stop, and that is my biggest issue.”

“What’s the longest you’ve been successful in healthier eating?” I ask, purposefully avoiding the term “diet.”

“Four months,” Kelli says.

“What triggers you to stop eating healthier?” I ask.

“I eat one thing I shouldn’t, and it’s hard to stop,” Kelli says.

I make a mental note of her continued use of moralistic language (e.g., “shouldn’t”). I wonder if it would be easier to have a healthy lifestyle if stigmatizing, moralizing judgments were removed from the equation.

“What could doctors do to help patients?” Maggie asks.

“It would be nice if they could try harder to actually help. Just sitting and talking to the doctor isn’t doing anything. The local hospital does have a medical diet center, but my health insurance won’t pay for it. It costs \$2,500 out of pocket. If something like that was covered, I would be the first one in line.”

“Yet your insurance covers gastric bypass,” I say.

Maggie nods. “They want the quick fix.”

“They will pay \$25,000 for the surgery,” Kelli says. “But they won’t pay \$2,500 for the non-surgical route. To me that is crazy.”

“But we’re still talking about trying to fix fat,” I say in protest. “It’s still the medical model. Whether it’s The Biggest Loser, or gastric bypass surgery, or medical weight loss clinics, we’re using language that identifies excess body weight as a medical problem that needs medical intervention to fix.”

“And that language stigmatizes people,” says Maggie.

■ Addressing and Reducing Stigma

Just as language stigmatizes, it can also connect and heal. Sharing personal experiences through story—in various forms—is a great way to minimize stigma and encourage inclusivity and biodiversity. Providing space for people with stigmatizing conditions to be seen as fully human lessens their experiences of separation, othering, marginalization, discrimination, and negative stereotypes (Davis, 2013; Green et al., 2005). Hearing others’ stories, such as in this chapter, is an effective way to get to know someone as a person beyond his/her body size, shape, age, or ability. Cris’s work with poetry, drama, and fiction (see, for example, Davis, Delynko, & Cook 2010; Davis & Warren-Findlow, 2011, 2012) has shown the importance of providing opportunities for people, who are not frequently afforded a voice, to tell their story. Storytelling lets us reframe our versions of reality—either our own or someone else’s, and it helps us better understand someone else’s experience. Storytelling acts as resistance discourse because it lets us substitute our personal narratives for the canonical (official) narratives (Davis & Warren-Findlow, 2011, 2012).

Maggie is interested in the ways in which numerous forms of aesthetic storytelling, including dance, can do the work of social movements (Quinlan, 2010a, 2010b; Quinlan & Harter, 2010). For example, she conducted an in-depth case study of Dancing Wheels—the first modern dance company to integrate professional stand-up (able-bodied) and sit-down (wheelchair) dancers, based in Cleveland, Ohio. She is interested in the ways in which the performing arts, particularly dance, have a history of engaging only the “physically elite” (i.e., able-bodied) as performers. She has explored how Dancing Wheels positions performance as artistic vocation, individual expression, and social change. Dance offers employment but also allows individuals to creatively express themselves, connect with others, and challenge stereotypes and enlarge possibilities for individuals marked as disabled (Quinlan, 2010a, 2010b; Quinlan & Bates, 2015; Quinlan & Harter, 2010).

[Insert HCIA 8.3: Communicating Disability and Health]

Taking an active role in our own care can also reduce stigma (Davis, 2013). Puhl (2015) suggests that people with stigmatizing conditions can address bias by educating others, challenging negative attitudes, obtaining social support, participating more fully in enjoyable activities even when it is challenging to do so, practicing self-talk and self-acceptance, being vocal and assertive about needs, responding assertively to people who make unkind or hurtful remarks, participating in advocacy groups, and getting professional help from a therapist.

Puhl (2015) has several suggestions for healthcare providers to address the bias that comes with stigmatizing conditions. Healthcare providers should: (1) directly address stigma with their patients by encouraging them to share their experiences, offering social support, and helping them identify ways they can cope; (2) address stigma within themselves by identifying their own biases; (3) better support patients by improving their own environments and making sure they are accessible to and

appropriate for people of all sizes and abilities; and (4) improve their interpersonal skills to better communicate with patients in a nonjudgmental supportive manner. Given that communication research demonstrates the prevalence of stigma and the harm it creates (Smith, 2011), it is ultimately the responsibility of all of us to recognize and eliminate stigmatizing attitudes, messages, and behaviors.

■ Epilogue

“Bottom line—what do you want us to know?” Maggie asks Kelli.

“Get the insurance companies to pay for better treatment—preventative treatment. Know that we are all different and there are many factors that enter into it.” Kelli pauses thoughtfully for a minute, “We need to quit playing naming and blaming games and be compassionate to each other.” Kelli takes a deep breath. “I need to stay hopeful that all my health problems will be OK.”

■ Conclusion

Although attempts to encourage others to lose weight may be well intentioned, they are based on questionable science and are ill-advised in many ways. The medicalization of fat—the assumption that people’s fat is an inherent medical problem that is entirely under their control to fix—results in stigma, hate, prejudice, and in treating fat people like they are not human and do not have rights (Cooper, 1998). As Wann (2009) reminds us, “It is not possible to hate a group of people for their own good” (p. xiv). Interpersonal and mediated communicative attempts to persuade people to lose weight result directly in stigma and marginalization of people who are fat, and indirectly in stress-related medical problems, and ironically, related weight gain. One exception to this is a relatively new social movement called Health at Every Size, which focuses attention on healthy eating and physical fitness for everyone rather than reducing body size for people who are larger sized or assuming that thin automatically equates with health. Health at Every Size also supports biodiversity and acceptance of people of many different body sizes and shapes (Thomas & Wilkerson, 2005).

Discussion Questions

1. This chapter focuses on the stigma associated with body size. Why do you think this stigma, perhaps more than others, is so prevalent in our society?
2. How can stigma affect our health in negative ways? What communicative strategies can help to resist the stigma?
3. Have you experienced a stigmatizing condition? How were your experiences similar to Kelli’s? How were they different?
4. Think of a natural process (e.g., aging, childbirth, or weight gain) that has been medicalized in our society. What are the consequences? How have people taken back control? How might we develop strategies for taking back control?

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Theorizing Practice 8.1
People First Language

“Sticks and stones will break my bones, but words will never hurt me.” Chances are you’ve heard this childhood chant, and chances are you know it’s not true. Words *do* hurt. They can also stigmatize, stereotype, and dehumanize, whether as purposeful insults or as thoughtless labels. “People First Language” is one way to avoid prejudicial and hurtful terms, particularly when communicating about disabilities. While many champion this terminology, believing it eliminates generalizations and assumptions by focusing on the person rather than the disability, some critics reject it (e.g., autism activists who argue that “person with autism” suggests that autism can be separated from the person). Regardless, thoughtful word usage communicated with sensitivity and respect should always be the rule. Some suggestions include:

- Refer to the person before the disability (e.g., girl with Down syndrome or boy with epilepsy).
- Avoid terms and phrases that equate the person with the disability (e.g., the disabled or autistic) or that carry negative connotations (e.g., she *suffers* from mental illness or he’s *confined* to a wheelchair).
- Emphasize abilities rather than limitations (e.g., he walks with crutches).
- Consider whether the disability is relevant and necessary to mention when referring to or describing individuals.

Conduct a search of stories about individuals with disabilities in a variety of media formats. Note the use of appropriate and inappropriate terminology. Did anything in your findings surprise you? Why or why not?

Theorizing Practice 8.2 **“People Think I Look Fine, So I Am Not Sick”**

Consider the following Facebook post by Julie McGovern, who hopes to raise compassion and awareness for people like herself with hidden disabilities. After reading Julie’s story, formulate your response to the following questions:

- Have you ever questioned someone’s abilities based solely on their appearance?
- Do you think people with hidden disabilities or illnesses have a responsibility to announce their condition? Would you want your hidden disability or illness known to strangers or casual acquaintances?
- Julie says, “It is up to us to share our story and to raise awareness.” What stories of discrimination could you tell? What do you take away from hers?

My name is Julie. My entire life I have been an athlete. I have excelled in all things athletic. I was on the track team in high school and college, as well as a cheerleader in high school and college. In the summer of 2005 I was diagnosed with mononucleosis. I was unaware of this and continued to train hard in my collegiate sports. I thought my excessive fatigue, sore throat, headache, and overall sickness was due to being a freshman living in the dorms. It is not uncommon to get sick in that environment. However, my symptoms progressed and I went to the doctor. As soon as I learned about the mono, I immediately stopped these activities.

Six months later I began fainting, my heart would race, I was nauseous, had migraines, along with other debilitating symptoms. I knew something was wrong when I could no longer walk to my mailbox without being short of breath and having to sit down for several minutes before I made my way back to my house. I went to the doctor and they told me it was nothing. They said if I had anything, it was anxiety. I knew they were wrong. I knew my body and I knew something was very wrong. After many months searching for answers, I finally found a doctor who changed my life with a few simple words, “I believe you.” Together he and I began the journey to find out why my quality of life had decreased in such drastic ways. After many tests, I was diagnosed with Postural Orthostatic Tachycardia Syndrome (POTS). My physician believed because of the mono and my continued activity, the mono destroyed my autonomic system, which controls all things in the body that are automatic. This illness affects literally every organ in the body.

It causes my blood pressure to be dangerously low and my heart rate critically high. I have GI issues and my body cannot withstand the pull of gravity, so the blood drops to my feet, which can cause a loss of consciousness. Due to this, I am unable to stand for long periods of time or walk long distances. Being a young person with an invisible chronic illness is one of the hardest things I’ve ever dealt with. People think I look fine, so I am not sick. It isn’t that I’m looking for sympathy, but respect and compassion. It has been an incredible odyssey going from a vibrantly healthy person to someone living with a chronic illness. My life before I was sick is much different now that I am.

I am unable to keep up with my friends and my pride often keeps me from asking for help. Sadly, the disbelief of others around me has caused me to remain silent about my illness. It is like I am being punished for being sick. They think if I just eat better or sleep more, I would be cured, but that couldn’t be further from the truth. POTS symptoms are always changing, they come and go, and appear in many different combinations. No one POTS patient is treated medically the same. The symptoms I have today, I may not have tomorrow. I can be fine one minute and on the floor the next. It is very hard to make plans due to the unpredictability of this horrible syndrome.

My doctor issued me a handicap parking tag. I have always been afraid of what others would say and I often sit in my car until I feel no one is around so that they won’t judge

me or accuse me of using the system. I am sick. I didn't choose this and it isn't my fault. I would give anything to be healthy again. I would give anything to have one day of freedom. Just because a person looks fine does not mean they are. There are many illnesses that go unnoticed to the untrained eye. Being handicapped isn't always a wheelchair or crutches. Some illnesses manifest themselves internally and destroy the body from within. I have one of those illnesses.

Today my fear came true. So many emotions flooded my mind. I was hurt, I was angry, I wanted my voice to be heard, but this person is a coward and could not tell me what he/she thought to my face. This person incorrectly perceived my situation, because it is impossible for someone my age to have an illness. This person doesn't know me or my struggles. They don't know what this illness has taken from me. They don't see the countless nights I cry myself to sleep, soaking my pillow with tears, pleading—praying for God to heal me. They don't see the weakness, the pain, the symptoms that are very real, but only I can feel. They don't understand, and until it happens to them they never will.

However, it is up to us to tell our story and to raise awareness. As I said, not all things are visible. The person who wrote me such a hateful note is also handicapped. This person has a mental handicap disguised as ignorance. And even though I am sick, I don't always park in the handicapped parking. I only do so on my bad days. And sometimes even on my bad days I won't park there because someone else might be having a worse day. And other times, I am just too afraid to be attacked, ridiculed, and judged like I was today.

To the person who wrote me that note. Shame on you! I pray you are never faced with the struggles I am every minute of every day. I pray that someone you love who is ill is never treated the way you have treated me. I pray you open your eyes and your heart to the people around you and exercise compassion, as you abandon your need to hurt others. You are obviously a very angry and unhappy soul. I pray you find peace and love in your life. And finally, I hope you are never a victim to a life-altering illness and experience the cruelty I experienced today because of you.

Insert Photo 8.1

Theorizing Practice 8.3
Equal Opportunity for Persons with Disabilities

The Americans with Disabilities Act of 1990 (ADA) prohibits discrimination and ensures equal opportunity for persons with disabilities in employment, state and local government services, public accommodations, commercial facilities, and transportation. Spend a day committed to noticing ADA provisions in your usual environment and regular routine. What taken-for-granted accommodations exist? What resources are available? What, if anything, surprised you?



HCIA 8.1

Loose-ing Weight

Bonnie Creel

One year, early in my teaching career, I got a student evaluation that has stuck with me. There was a question on the form that asked, “What could this instructor do to improve his or her teaching?” And this student wrote: “Loose weight.” Of course, it was a misspelling. But really, isn’t that the problem? “Loose” weight?

Out of my own personal experience as well as revelations over many years from other women affected by overweight and obesity, I became concerned that the healthcare needs of women who struggle with weight issues are not being adequately met. I wondered if avoidance or postponement of medical care might well contribute to the poor health outcomes often reported for overweight patients. The central research questions of my dissertation were: How is an overweight/obese (OW/O) woman’s weight implicated in her self-identity? How does she make sense of the experience of being overweight? What role does her identity and her understanding of her weight play in her health-seeking behaviors and interactions with physicians and other health professionals?

I employed multiple methods of analysis and multiple genres of representation of the data I collected, an approach described by Laura Ellingson as “crystallization.” I used auto-ethnography, in-depth interviews, narrative analysis, and grounded theory. I learned that the pernicious effects of social bias against OW/O people do, indeed, play a role in personal identity and in health-seeking behaviors of affected patients and that the attitudes communicated by many medical practitioners contribute to a vicious cycle of reinforcing negative identity and avoidance/postponement of healthcare.

As a final chapter to my dissertation, I developed a performance script capturing the voices of several of my informants. The excerpt below is an example of stories that were represented in the script.

So I went to the appointment and, of course, first the nurse comes in and takes your history and does your blood pressure and all of that sort of preliminary thing. And when she was taking my blood pressure she came up with a higher reading than was typical for me. And I was kind of surprised by that, so she took it another time or two, and then the whole time she was acting very frustrated, kind of “h h h h,” making little sounds that made me think that she was really kind of distressed. And she left the room for a few minutes, and then she came back and she said, “Well, we’re just going to have to go with the reading that we’ve got because I can’t find the blood pressure cuff that we have—we don’t use it very often so I’m not sure where it is, but it’s especially designed for large women. So I think maybe the reading is because this blood pressure cuff that we’re using for you is really too small, and maybe it’s because you’re nervous since you haven’t seen a doctor in some time.”

And I remember thinking that I felt like a freak. I was heavy, there’s no question about that. But I had never felt freakishly heavy. But I did at that moment. I was so big that a normal blood pressure cuff would not fit around my arm!

So then the doctor came into the room and she was performing the exam. And the whole time she was performing it she was kind of—I don’t know how to describe it. She wasn’t rude. But there came a point during the exam where I had the sense from the kind of sounds she was making—the kind of sounds that people make when they’re doing something physical that requires a lot of effort, so they have these little kind of “un h h h, un h h h,” little exhaled breath that you do when you’re exerting a lot of effort on

something? And then she said, "I'm afraid I'm not going to be able to do a very good exam on you because it's very difficult to palpate fat."

And I remember, when she said that, that I felt so terribly sorry that I was putting her through that. I realized that touching me was disgusting to her. I felt like I was an unpleasant object that she had to deal with. And that she was doing her best to be nice about it, but really, deep down, she was just terribly disgusted to have to be touching me. And I don't really know that it was anything that she did. I couldn't even say that I think now that she necessarily was. But that's how I felt at the time. I felt like she was disgusted with me. Or not disgusted with me, but disgusted with having to touch me.

So, the next time I had a well-woman check was five years later in the summer of 2000. My general practitioner's nurse practitioner did my well-woman check, and she was very good. But it came back with a suspicious result on my Pap smear. So I had to take some medication for several months and then go back for a follow-up Pap smear, and this time I had to have another doctor because of insurance carrier issues. And I really couldn't stand him. And I had a very definite impression when I left his office that he was very worried. There were things that he said and things that he didn't say that made it sound like he was very deeply concerned.

So for several weeks while I waited for the results of that Pap smear—that follow-up Pap smear—I remember thinking, "It's my own fault. I didn't get a well-woman check for so many years, and if this Pap smear comes back bad it's my own fault, because I didn't go to the doctor." But then I thought, "It's so hard to go to the doctor. Because you feel like you're so disgusting."

But the Pap smear came back OK.

QUESTIONS TO PONDER

1. What do you think is the basis of the narrator's perception of her doctor's response to her? Is it because of the way the doctor communicated with her? Or is it more related to her self-identity as an overweight/obese woman? Based on your answer, discuss what you might advise clinicians to consider when interacting with patients affected by overweight or obesity.
2. Do you think that men affected by overweight/obesity have similar stories to tell about their interactions with healthcare providers?
3. All other factors being equal (e.g., access to healthcare, financial ability to pay for healthcare, etc.), do you think that avoiding or postponing medical screenings and other preventive care is more likely to be a problem for people affected by overweight/obesity than it is for people of normal weight? What other physical conditions do you think might create the same sort of health-seeking or health-avoiding behaviors?

Source: Creel, B. (2010). *Suffering, hoping, resisting and accepting: Perceptions of overweight women about personal identity and medical care*. Unpublished dissertation: Texas A & M University, College Station, TX.



HCIA 8.2

Experiencing Transgender Microaggressions

Lucy J. Miller

As a graduate student, I once visited the campus health clinic for treatment of a sinus infection. The doctor began the examination and then paused, looked up at me, and asked, “You do know your body is male, right?” I froze and mumbled a quiet “yes.” The rest of the examination proceeded normally, but I still left the clinic in shock at the doctor’s inappropriate and irrelevant question. While one would hope for more sensitivity from a healthcare provider, such microaggressions are unfortunately not uncommon for me as a transgender woman.

Microaggressions are brief, interpersonal expressions of disgust, distrust, or dislike of the identity of another person, usually along the lines of race, gender, class, sexual orientation, religion, or other individual characteristics. While interpersonal in nature, microaggressions are part of societal systems whose master narratives force the individual to conform to commonly held norms. These experiences often place a great deal of physical stress and psychological discomfort on people. I have an abundance of personal experience with microaggressions as a transgender woman, and they have certainly affected my health—I feel self-conscious, disembodied, and stigmatized every day.

The microaggressions directed at me are intended to force me to conform to the expectations of the gender binary in order to fit with societal expectations of what it means to be male or female. Microaggressions are often intended to make me feel self-conscious about my gender performance. For example, I stopped once at a fast-food restaurant in a small Texas town in the early stages of my transition. The cashier, noticing my short hair, commented that I would look better with long hair; her microaggression was performed for an audience of her coworkers who chuckled behind her the entire time. While the comment was not overtly aggressive, its intention was to make me feel nervous and self-conscious about my appearance and, along with other comments, make me second-guess my perceived “choice” to violate social gender norms.

Microaggressions are also directed at transgender people by treating them as exotic. Doing so attaches a stigma to the individual’s identity by bringing attention to the way she or he differs from the norm. When I am in public spaces, people often do double takes as they pass by, stopping to look over their shoulder to verify what they have seen. Some people are not discreet and openly gawk at me as I walk through a store or across a college campus. In all of these situations, I am treated as if I am a novelty, almost as if I were on display in a zoo or museum and must be stared at in order to be understood. People frequently take my picture without my consent in public. I have been followed through stores by people attempting to get a clear shot, and even had a man get verbally upset with me when I denied his request to take my picture in a supermarket. These actions clearly communicate that others see transgender people are bizarre, like mythical creatures whose presence must be documented. This kind of attention can be devastating for someone just trying to go about her or his daily routine. After experiences like these, I am often anxious in public spaces, looking over my shoulder constantly for any sign of unwanted attention.

Disapproval and discomfort represent the most common types of microaggressions experienced by transgender people. While shopping in a discount store, a mother said, “That’s just wrong!” under her breath as I walked by, and a cashier at a fast-food drive-thru laughed and exclaimed, “Ah, hell no!” when I pulled up to get my food. Expressions like these make it clear that some people are not comfortable with my presence in public spaces and cannot constrain themselves as they communicate their aggression. Even something as

simple as calling me by my correct name can be a clear indicator of whether or not someone approves of or is comfortable with my identity as a transgender woman. I have had to accept food orders for “Lucian” or “Lucius” many times because cashiers were unwilling to call me by my (rather uncomplicated) name.

What can be done about microaggressions? Personally, I often just avoid people who engage in this behavior, and I try to exit the situation as quickly as possible. I wish I could address these issues more directly, but the anxiety I feel in those situations is already high enough without confronting the perpetrator directly. I think sometimes people have just never encountered a transgender person before and would regret their actions if they were made aware of my perception of them. I know I would feel better if I witnessed people sincerely trying to understand me, but I am not yet able to take that risk, fearing increased mental stress or even physical violence. Victims often experience microaggressions similarly to abuse and require active coping strategies to deal with the negative psychological effects. What I believe is really needed is a way for people to understand that gender identities exist outside of the male/female binary. This could help reduce the negative reactions to transgender people because everyone wouldn't be expected to express their gender identities in the same way.

QUESTIONS TO PONDER

1. Do you know any transgender people personally? How have these personal relationships helped you reconsider any assumptions held about these individuals?
2. How would treating microaggressions as a health crisis instead of an interpersonal conflict open up new possibilities for addressing the issue?
3. Focusing on the serious health effects of microaggressions, how might you design a media campaign intended to raise public awareness of these negative impacts?

Source: Miller, L. J. (2015). Disciplining the transgender body: Transgender microaggressions in a transitional era. In A. R. Martinez & L. J. Miller (Eds.), *Gender in a transitional era: Changes and challenges* (pp. 133–149). Lanham, MD: Lexington Books.



HCIA 8.3

Communicating Disability and Health through Wheelchair Rugby

Kurt Lindemann

I grew up communicating with physically and mentally disabled people. My father was paralyzed from the waist down in a motorcycle accident when I was seven. While he still had to go through physical therapy during his time at the spinal cord rehabilitation center, an equal part of his recovery had to do with the mental adjustments he had to make. His doctors recommended sports and hobbies as ways he might learn that he could, indeed, live what could be considered by most accounts a “normal” life. So, while growing up in a culture of disability, I also came of age in a world of sport participation: first wheelchair basketball, then wheelchair road racing competing in marathons. I eventually realized that, while all these activities were just a way of life for me, most able-bodied people were shocked that people in wheelchairs could accomplish such demanding physical feats.

Years later, I came across an article in a Phoenix-area newspaper about wheelchair rugby and read the words of the athletes interviewed. I knew this was a subject I wanted to research. The sport, sometimes called Murderball (as popularized in the 2005 Oscar-nominated documentary of the same name), is played on a basketball court and consists of players strapped into tank-like wheelchairs smashing into each other and knocking each other over as they try to get the ball past a goal line. Using my in-group status as someone who had grown up around athletes in wheelchairs, I was granted access by the athletes on several teams to observe and interview them. I also talked to referees, coaches, and physical trainers who work with the athletes. In total, I spent about two-and-a-half years traveling the country to tournaments, attending practices, and hanging out with the athletes.

Being so immersed in the culture, I became privy to a lot of communication interaction: on the sidelines, during practices, at parties, in hotels, in bars, and waiting to board planes. It occurred to me that athletes’ communication was as much about health practices as it was about playing the game. Players took pride in the rough, aggressive, and dangerous aspects of the game; they appeared to relish shattering people’s perceptions about what those in wheelchairs are capable of. The ways the players talked about their play on the court seemed to frame their bodies as invulnerable. I heard players say, over and over, “What’s the worst that can happen? I break my neck again?” This phrase illustrates what my coauthor and I call a “daredevil masculinity,” which pushes some players to downplay the potential injuries that may arise from playing the sport. Considering many of the players I interviewed told me that their doctors recommended the sport as a form of physical therapy and rehabilitation, the way players talked about the potential for injury is ironic. Nonetheless, such talk illustrates the power of communication to frame health experiences.

One of the most interesting insights into health communication we found is the ways new players are taught to live the quad rugby “lifestyle.” Veteran players on the teams also have experienced living life in a wheelchair with quadriplegia, or impairment in all four limbs of the body. As such, the experienced players not only teach new players the ins and outs of the game, they also teach the newly disabled players how to live life with a disability. This may include transferring themselves from their wheelchairs to the bathtub and back, getting into bed, and other everyday activities most people take for granted. These shortcuts taught by veteran players often contradict the “safe” way doctors recommend to do such things. These shortcuts aren’t potentially hazardous to players’ health like the attitude of “daredevil masculinity.” But it still seemed ironic to us that a sport recommended by doc-

tors to help quadriplegic persons regain some of the strength, mobility, and self-confidence they might have lost due to their disability would be at odds with what was communicated in that very same sport.

Sex and communication about sex is an important part of understanding health. The athletes in the sport, who are mostly male (there is a small percentage of females playing the sport), definitely talked about sex; most of us probably know the term “locker room talk” as a phrase that refers to sometimes graphic, crude, humorous, and often sexist language. These players told stories that sometimes involved tales of sexual conquests. The difference in Murderball athletes’ talk is that these athletes more or less admitted in their storytelling that they weren’t able to “perform” like a “normal” able-bodied man. However, they made sure to emphasize other sexual abilities. For example, when I was waiting to board a plane after one tournament, some players and I were passing around a bag of Starburst candy. While I could unwrap one easily with my fully functioning hands and fingers, the same task was considerably more difficult for some players with hardly any dexterity. They explained that they had to do the same task with their mouths, and that this skill translated into the ability to please a woman with a good oral sex technique.

We concluded that quad rugby athletes’ off-court talk and on-court displays communicate to the able-bodied world that they can not only do the same things “normal” men can do but in some cases can do them better. In the process, however, they sometimes reaffirm somewhat narrow versions of what it means to be “healthy,” including an emphasis on the aggressive athletic prowess of the male athlete whose body is invulnerable to pain, and the sexual prowess of the heterosexual male. In both cases, society is likely to imagine an able-bodied male at the center, making the wheelchair athletes’ communication doubly ironic.

QUESTIONS TO PONDER

1. Do a Google search for a video clip of the film *Murderball*. What are your first reactions? Where do those reactions come from? Stereotypes? Personal experience? Can you think of any other portrayals in television and film of people in wheelchairs? How would you describe them?
2. What are your perceptions about the health of people in wheelchairs? Do you imagine them to be any less healthy than able-bodied people? In what ways? How might the concept of “health” be fluid and dependent on a person’s situation?
3. There have been a lot of news stories about NFL athletes dying young from complications related to head trauma, including concussions. Many of us would imagine most professional athletes to be the epitome of health in terms of physical fitness. In what ways might sport participation lead to unhealthy personal choices?

Source: Lindemann, K., & Cherney, J. L. (2008). Communicating in and through “Murderball”: Masculinity and disability in wheelchair rugby. *Western Journal of Communication*, 72, 107–125.