

Episode: *Ethics Talk: How to Fight BMI-Based Denials of Payment*

Guests: Astrid Floegel-Shetty, MA, Kratika Mishra, and Ragen Chastain

Host: Tim Hoff

Transcript by: Cheryl Green

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[mellow theme music]

TIM HOFF: Welcome to *Ethics Talk*, the *American Medical Association Journal of Ethics* podcast on ethics in health and health care. I'm your host, Tim Hoff. On August 17th, 2019, Becky Hill injured her knees while working. After physical therapy, medication, injections, and activity limitation failed to improve her range of motion, activity tolerance, and pain, Becky was referred to an orthopedic surgeon who recommended a total knee arthroplasty. You might think—and hope—that the story ends here. A person experienced an injury, found a clinician and a treatment, and experienced relief of symptoms.

On February 19th, 2020, however, a utilization review company working for Becky's workers' compensation insurer recommended denying payment for her surgery. Payment of claims Becky would plan to file would be denied. Why? Becky's body mass index was higher than clinical guidelines suggested it should be to qualify for surgery. Faced with the prospect of paying out of pocket for needed and clinically indicated care, Becky began collecting literature supporting knee surgery in larger-bodied patients. Her surgeon provided additional documentation to her workers' compensation insurer, even speaking directly with the insurer's medical director to stress that, without this surgery, Becky would likely need to use a wheelchair within six months.

Becky's insurer insisted if Becky wanted surgery and wanted her insurer to pay, she would need to lose weight first. One might think that such a rigid stance would be supported by the clinical literature, but it's not. Losing weight prior to knee surgery does not lead to better outcomes for patients. Even if we assumed that it was in a patient's best interest to lose weight generally, research shows that for most people, weight loss is impermanent. Kratika Mishra, one of the editorial fellows who helped to curate this month's issue, explains.

KRATIKA MISHRA: When we dug into the research, it told us something very important and pretty sobering. One meta-analysis in particular that looked at 29 long-term weight loss studies showed that more than half of the weight loss was regained within two years, and by the five-year mark, most of the participants had regained 80 percent of the weight that they had initially lost.

HOFF: So, weight loss as an intervention falls well short of efficacy expectations that we have for interventions generally. For Becky specifically, suggesting losing weight posed risk because of her history of disordered eating. A weight loss surgeon Becky consulted during this time even indicated that weight loss was contraindicated for her. Like many people facing costly medical expenses, Becky couldn't finance her knee surgery herself, so she didn't have it. She got a cane, a walker, an electric scooter, and a disabled parking permit, and she lost the job at which she was injured.

Along with legal help and months of discussion involving the attorney general, Becky finally got her right knee surgery 680 days after her orthopedic surgeon's recommendation. After her left

knee surgery was similarly denied, she eventually received it 904 days after her surgeon's recommendation. Her insurer eventually paid for the parts of both surgeries they were contracted to cover. But because treatment guidelines suggested that Becky's BMI was too high for surgery, she was forced to wait nearly two years before receiving even part of the treatment she needed. Whatever harms BMI-based surgical candidacy guidelines were supposed to prevent, they didn't work.

Later in this episode, we'll be talking with weight stigma and weight-inclusive health care researcher Ragen Chastain about BMI-based denials of care. But first, the editorial fellows who helped develop this issue, Kratika Mishra and Astrid Floegel-Shetty, join us to discuss their work on this month's issue. Astrid and Kratika, thank you so much for being on the podcast with me.

MISHRA: Thank you for inviting us. So great to be here.

ASTRID FLOEGEL-SHETTY: Thanks for having us. [music fades]

HOFF: So, why did you choose medicine's overreliance on BMI as the topic for this month's theme issue?

FLOEGEL-SHETTY: I originally was very interested in doing a journal issue, but obviously, you need to bring something new to the table. And what's exciting and also cumbersome about the AMA's long history is that they've covered almost every topic you can think of. However, I think it was back in 2013, the AMA did an issue about the ethics of obesity. And when I was discussing this topic with Kratika, we came to realize that this journal issue kind of came from the perspective that obesity is a clinical threat that we need to address, and it's part of our ethical duties as physicians or health care providers to kind of really go after it. And Kratika and I felt like some of the things that were discussed in those articles or recommended as ethically permissible seem to really ignore the lived experience of people who are diagnosed as obese or classified as obese by BMI.

When Kratika and I were really thinking about this topic, why this topic would actually be relevant, if there is something new to contribute to the conversation, something that made it immediate for the both of us was the conversation that was happening around COVID and kind of distribution of care, distribution of limited resources. And there was a really big conversation happening about whether or not fat people should be getting the resources that a lot of ICUs and emergency rooms found themselves incredibly short on, given that studies were showing that fat people have worse outcomes, etc., etc.

HOFF: Yeah, I remember the sheer volume of articles during the beginning stages of the pandemic that were asking those questions. Kratika?

MISHRA: All of these conversations about the distribution of resources were essential, but there was really no consideration of Health at Every Size or taking the weight normative approach, not just to distribution of resources, but also to the health care of fat people generally. And those perspectives of treating fat people equal to our quote-unquote "normal weight" patients seems like such a radical idea. And while we were reading this literature, both of us also did our family medicine clerkships, and we saw how this played out in clinical interactions where fat patients weren't asked really basic questions that would've been important to get to know more information about their health that could've changed the course of that clinical encounter. And I think that the combination of those two experiences, for us, really motivated us to delve into it

further and also directed us toward the people that we wanted to include in this issue. And I have to say we're very proud of the people that were willing to commit and write articles for us.

HOFF: Yeah, as you should be. I think this issue turned out really well. So, what's something you found during your research that surprised you or perhaps something that you think would be surprising to the audience who hasn't done as much of this research as you and the authors of this issue have?

FLOEGEL-SHETTY: I think something that shocked us was how often weight loss is recommended as a treatment for obesity or any kind of person who's perceived to have a higher-than-normal weight. And a lot of these weight loss recommendations involved either dieting or intensive exercise or medications or gastric bypass surgery. And we didn't really see a sophisticated conversation about what is inherent to weight loss is kind of diet culture. And a lot of that is, honestly, treating the body badly. And when Kratika and I were discussing about what does it mean to lose weight or diet culture of medicine, we kind of came upon this idea that treating the body badly in medicine to achieve an outcome is actually not an unfamiliar experience for a lot of health care professionals. We go through medical school, we go through residency, we stay up late studying, we do 36-hour shifts. We don't actually get the proper nutrition. I think there was even a study at one point that showed our telomeres unravel at a faster rate than the average population.

And so, it's not hard to fathom that when physicians are recommending all of these weight loss treatments that are, or even some, I mean, objectively terrible ways to treat the body like cutting into the body and making the stomach smaller, that for them, maybe their definition of what kind of harm can you inflict on the body in order to achieve a good outcome, right? Like, we do that in chemotherapy to treat the body for cancer. But the extent of that which can be justified against bodies of fat people probably the definition is a lot more permissive for health care professionals than the average person because of how we treat our own bodies and how that distorts our perception of what a body can tolerate in the pursuit of an outcome or health.

HOFF: Hmm. Yeah, that's, I'd never really thought about that. That's an interesting example of how health education prepares or perhaps prompts students to think about patients in a specific way, so thank you for sharing that. Sort of building off of that, how has your research into this topic changed the way that you approach health care in your own practice or perhaps approach your studies as a health professions student?

MISHRA: For me, it kind of involves going a little off script. Like I mentioned before, weight loss is the first-line treatment. It's something that's discussed anytime somebody who's slightly overweight walks into the room. But I, very quickly after reading some of the stuff that we did researching this issue, became uncomfortable asking that directly about somebody's weight. And I began to focus more on health habits or diet or exercise. And I asked how patients feel about their relationship with food or if they're happy with the amount that they're exercising. It was obviously much longer. It was a longer conversation with every patient that I had, but I think it gave me a fantastic perspective. Because I saw that not everyone that appears to be thin has healthy habits, and not everyone that appears to be overweight or obese has unhealthy habits. And that's an assumption that a doctor can frequently miss in a 20-minute visit.

HOFF: Hmm. Mmhmm. Astrid, do you have anything to add?

FLOEGEL-SHETTY: I had two really practical things that changed for me, especially on my family medicine rotation, is that I no longer said, "What's your diet?" I said, "What's your eating

habits?" I think "diet" can feel very incendiary. And the other thing that I don't do anymore in patient encounters is I don't congratulate people on losing weight. And this particularly came from a patient interaction I had where I was meeting with the patient, and they told me that in college they had lost about 50 pounds from anxiety and depression and not being able to go eat in the dining hall because they were worried about people watching them while they ate. And when the physician came in with me afterwards, and they said, "Oh, congratulations. Whatever you're doing, keep it up" after the patient mentioned they had lost 50 pounds. And it was just...it just broke my heart seeing the look on that patient's face that most physicians would probably have approached this patient saying, "You're overweight, and you need to lose weight." But the second half to that story was that in her weight loss, she was just, it was a manifestation of the suffering she was going through. And to congratulate this person who had actually come for help to the doctor, for antidepressants or whatever, that really broke my heart.

HOFF: Mm. Yeah, that's awful, but a good example of why you shouldn't assume somebody's story before you've had a chance to talk to them. I appreciate you both giving sort of concrete things that you have done or changed in your own practice. And sort of building on that, what do you think are the three most important lessons for readers to take away from this issue?

FLOEGEL-SHETTY: The three most important lessons for clinicians we hope that they take away from this journal issue is that one, weight loss is not a proxy for curing obesity. Two, health and fatness aren't antagonistic. There can be health at every size. And three, there's no mandate to achieve what medicine thinks is healthy at the expense of the patient. I sometimes see parallels with physicians resisting Health at Every Size in favor of fighting obesity with weight loss and physicians who resist hospice for curative approaches. Both methods of hospice and Health at Every Size—which is like easing dying and not losing weight—challenge the idea of what the ultimate goal of medicine is, which is health care providers are geared to pursue cures and recommend weight loss as methods for achieving health.

MISHRA: I would also like to mention that we found certain books extremely helpful while we were researching our topic, and I just want to throw the titles out in case anyone is curious about further reading. The first one that was my personal favorite was *What We Don't Talk About When We Talk About Fat* by Aubrey Gordon. I believe Aubrey Gordon has a newer book out, and she also is featured on a podcast called *The Maintenance Phase*. Basically, all of the stuff that she's involved in was phenomenal. Also, *Fearing the Black Body: The Racial Origins of Fat Phobia* by Dr Sabrina Strings, *Fat Activism* by Dr Charlotte Cooper, *Health at Every Size* by Dr Linda Bacon, and *Against Health* by Jonathan Metzl and Anna Kirkland.

HOFF: Yeah, I appreciate you providing those resources. And I think it leads well into this last question of what do you think our listeners should know about the future of this topic? Is there any interesting research being done? You mentioned Aubrey Gordon's new book. What else should our listeners know about the direction that this field's heading?

FLOEGEL-SHETTY: A recent breakthrough that's related to our journal issue is the approval of weight loss medications like Wegovy and Ozempic. So, currently, there's a concerted media push to really emphasize the idea that obesity is a progressive, chronic condition needing continuous treatment. I think listeners should keep their ears open to the conversation happening around these weight loss pharmaceuticals from celebrities' usage to discussions about how the medications' popularity is causing shortages for diabetics. And we really hope that anyone who takes the time to peruse this issue of the AMA Journal will really pause before fully jumping in behind the idea that weight loss pharmacotherapy for obesity eradication is the future we want.

MISHRA: I think the most exciting thing going forward is kind of idealistic, but I hope that this is the way that our practice changes. I hope that our definition of health is reconceptualized with more input from the fat community, more input from the BIPOC community, and also more input from the ethics community. Because now I know that interprofessional collaboration is the way to go in order to widen our perspective.

HOFF: Anything final before we wrap up here?

FLOEGEL-SHETTY: We would like to mention Dr Cat Pausé, who passed away during the development of this journal. She was one of the first professors who responded to us when we started this journey. And I remember Kratika and I were just over-the-moon excited with how warm her response was, and it was so emboldening because she really helped plug us into the whole community. [mellow music returns] We would also like to shout out Dr Angela Meadows, founder of the International Weight Stigma Conference, for her incredible work of amplifying important research around weight stigma, weight, weight loss, and obesity, as well as her kindness to us over the past year. Our journal would not have come to fruition without the mentorship, advice, guidance, connections, and just blatant kindness of so many of the people we interacted with.

HOFF: Kratika and Astrid, thank you so much for being on the podcast and for your work on the issue this month.

FLOEGEL-SHETTY: Thank you so much for having us. We really appreciate your taking the time to ask us all of these important questions.

MISHRA: Thank you.

HOFF: It's unknown how many BMI-based denials of payment for care happen in the US, but what is clear is that the overreliance of BMI in medicine has led to a pathologization of fatness that harms fat patients. Ragen Chastain joins us now to talk about BMI-based denials of care and payment for care, why they happen, how to fight them, and what health care professionals and insurers can do to create evidence-based practice about the role of body habitus in an intervention's success. Ragen, thank you so much for being on the podcast today.

RAGEN CHASTAIN: Thanks so much for having me, Tim.

HOFF: BMI-based denials of health services are often justified by research demonstrating poorer outcomes for people with a BMI above some cutoff. Obviously, that cutoff varies. You've written about some of the ways such denials increase these patients' risk of harm over the long term. So, what should our listeners know about this seeming contradiction?

CHASTAIN: Sure. So, the first thing is that often the research itself has flawed methodology, or the way that the risks are expressed is exaggerated. So, you'll hear that, for example, a higher-weight person has 100 percent greater risk. But what that actually means is that the risk increased from 1 percent to 2 percent. Or the picture's incomplete, and the research that doesn't show poorer outcomes is left out, right? So, there may be research that suggests that it's just as safe for higher-weight patients. But the thing that I want to concentrate on is that even if there are poorer outcomes, a denial of care can mean anything from a condition progressing to continued pain and suffering, lower quality of life, or sometimes even requiring an emergency procedure, which ends up being far more dangerous, or even the death of the patient. There is some research that I think is interesting around knee surgeries where higher-weight patients are

made to wait longer to get the surgery, and then their outcomes aren't as good. But instead of pointing out that they had to wait longer to get the surgery, they started the surgery more progressed, it just says, see? Higher-weight patients don't have outcomes that are as good as thinner patients. So, when I talk about flawed methodology, that's another example of that.

So, to me, the idea that if higher-weight patients don't have the same outcomes as thin patients, then they don't deserve care isn't ethically justifiable under any guise. And that ends up being made worse by the fact that most outcomes of weight loss attempts are actually weight regain. So, we don't actually know how to make people thin to comply with these BMI-based denials. And in fact, there's some research that shows that weight loss prior to surgery doesn't improve outcomes; it can even make them worse.

Also, if the risks are greater or the outcomes are more poor, we have to look into how much of that is because these outcomes are taking place in a system where the tools and the training and the pharmaceuticals and the best practices were typically created for thin bodies, and where levels of both implicit and explicit bias among practitioners is quite high. So, long term, I think what we have to do is get better at performing procedures and aftercare on fat patients starting with what exists now. For example, for weight loss surgery, often they'll use longer tools, but those tools may not be available to a general surgeon. And in the meantime, instead of these blanket-based denials based on a height/weight ratio, what we need to look at, I think, is a more shared decision-making process. Your risks may be higher, but here are the benefits of the surgery. Is that something that you want to continue with? And finally, I think we need systemic change in the way that surgeons' stats are measured so that surgeons and facilities don't end up incentivized to cherry pick their cases or punished for not doing so, then leading to denials of care for patients who may not have the best-case scenario.

HOFF: Mmhm. Do you know of any models of surgeon quality evaluation that would help avoid that?

CHASTAIN: So, I think if we do believe that there are higher risks or poorer outcomes among higher-weight patients, then we may need to change the model of how we look at the plausible risks and outcomes based on patient BMI if that's what's believed. Instead of just saying, "We think this patient group has higher risks, and so we're going to deny care," we say, "we think this patient group has higher risk. And so, if they end up having higher complication rates or poorer outcomes, then that's as expected." But again, I still think it's so important that we get better at doing these surgeries on higher-weight patients to make sure that we're having parity of outcomes. But I think that is a start.

HOFF: What should patients experiencing a BMI-based denial of a health care service or perhaps a delay of health care service do to get indicated standard of care that they're seeking?

CHASTAIN: Yeah. First, I want those patients to remember that while this is becoming your problem, this is not your fault, and you deserve health care in the body you have now. So, typically, the first step is to find out where the denial is coming from. It's going to usually be the surgeon, anesthesiologist, facility, or insurance. So, once you know that and collect as much information as you can about where the denial is coming from and the exact nature of the denial—like, do they expect anesthesia complications, are they concerned about outcomes—then you can look to first, try to find a different provider or facility or insurance coverage or cash pay if that's something that's available to you, though, of course, that's incredibly difficult. You can also try to fight the denial. So, you can find out the path to dispute it. You can collect research, get any support you can. For example, oftentimes a surgeon will be willing, but a

facility will have a denial, or insurance will have a denial. And so, you can get the surgeon on your side to help advocate for your care. And then any other support that you can get from friends, family, community, even legal support, if that's available to you to fight the denial.

HOFF: You're currently working on a study about weight stigma and iatrogenic harm for the highest-weight patients. So, what should our listeners know about potential shortcomings of current weight stigma research, and what do you hope that your research will help us understand?

CHASTAIN: A lot of the research on weight stigma still comes from a place of inherent weight stigma. And that happens when the researchers are still philosophically invested in, and sometimes even funded by, the weight loss paradigm. So, the message becomes, "Well, we don't want to stigmatize higher-weight people, but we do want to eradicate them from the Earth and prevent any more from existing," which is an inherently stigmatizing message. It also comes through when the research focuses on the idea that weight stigma is bad because it might make people gain weight, or it might make them less likely to participate in weight loss interventions, or it might make insurance less likely to pay for those interventions. Or when it suggests that the solution to weight stigma is weight loss, right? Whatever someone thinks about weight and health, the idea that an oppressed group should have to change themselves to suit their oppressor is always wrong.

So, I wanted to point out the reason that Dr Owen and I are undertaking this study of weight stigma experiences and iatrogenic harm in the highest-weight patients is that first of all, weight stigma research often leaves out the experiences of the highest-weight people, either by just excluding them outright or just lumping all the experiences together. And that's significant because intrinsic and extrinsic and structural bias—which is when the things that patients need simply don't exist in a size that accommodates them—all tend to increase as the patient size increases. And then the negative outcomes that are driven by that bias tend to be captured in correlational research on weight in health and then blamed on the patient's size rather than the experience of stigma. And so, we really wanted to capture those experiences of stigma and look at how are they doing real harm to these patients?

HOFF: In preparation for this interview, I was reading through some of the AMA's decisions about language to use when talking about obesity and fat patients and things like that, like their decision to label obesity a disease in 2014, the language around obesity, quote, "epidemics," things like that. I'm sure you have some well-developed thoughts about the language we use when talking with and to and about fat patients, especially if our goal is to reduce stigma in a truly helpful—that is, not additionally stigmatizing, like you were just talking about—in a truly helpful way. So, how do you see the language around this topic evolving or needing to evolve in order to approach patients in a helpful way?

CHASTAIN: Yeah, languages can be a really complicated thing. So, for me personally, I prefer the term "fat." It's a reclaiming term for me. It kind of lets my bullies know they can't have my lunch money anymore. And also, it doesn't pathologize or medicalize my body like the terms "obese" and "overweight" do. And these are terms that were literally made up to pathologize bodies based on size rather than symptomology or cardiometabolic profile. And so, "overweight" is inherently stigmatizing. It says there's a right weight, and you're not it. "Obese" actually comes from a Latin root that means to eat oneself fat.

HOFF: Hmm. Really?

CHASTAIN: Yeah. Yeah. So, more stereotype than science there. And so, now what we're seeing is this push for person-first language, the idea that we should be saying "person with obesity" or "person with overweight." And it's really important to know that is not coming from weight-neutral health community or fat activist community. That is coming from the diet industry. And it's part of a bigger push to have simply existing in a higher-weight body be seen as a chronic, lifelong health condition requiring chronic, lifelong treatment from their products. And it ends up being more stigmatizing because it means that we're talking about higher-weight bodies in different ways than we talk about other bodies, right? There's no push to say, "The person with thinness got on the bus." No one in my life has ever said, "Oh my gosh, don't call yourself brunette. You're just a person with brown hair." And so, this person-first language was actually co-opted by the diet industry from disability community, where it's quite controversial. And I highly recommend people reading authors in disability community to understand more about that. But in general, the idea that describing your body is so terrible that we have to find a semantic workaround becomes a stigmatizing message. And rather than reducing stigma, it simply increases the diet industry's marketing language in the world. And that's done by a lot of unsuspecting people who really mean well and want to reduce stigma and are being told, "Oh, this person-first language is the way to do it." And in fact, it's really not.

HOFF: So, speaking of people who likely mean well, but are inundated with messaging that is unhelpful to fat patients, what should health professions students and trainees know about caring for fat patients?

CHASTAIN: Mmhmm. I think the first thing I want to point out is that weight stigma in itself, the BMI specifically, these things are rooted in and inextricable from racism and anti-blackness in ways that still are disproportionately harming those communities. And so, highly recommend Sabrina Strings' *Fearing the Black Body* and Da'Shaun Harrison's *Belly of the Beast* to really understand how these things are not just rooted in racism and anti-blackness but continue to harm those communities. I think it's important to understand that the notion that simply existing in a higher-weight body is a disease was actually architected by the weight loss industry, and then they sort of pushed it really insidiously into the medical and health care community. It's deeply flawed, this idea, and it does serious disservice to patients and to providers. And again, with the most harm happening to those at the highest weights and patients with multiple marginalized identities.

I think it's important to know that the research shows that a weight-neutral approach, where we work to increase access and decrease barriers to care and support health rather than trying to manipulate body size, shows greater benefits with fewer risks than the current weight-centric paradigm. [mellow music returns] And I think it's important to know that if the current system and its tools and training make it more difficult to care for higher-weight patients, it's important for practitioners to realize that it's you and your patient against a system that's failing you both. It's not you against your patient.

HOFF: Ragen, thank you so much for being on the podcast today.

CHASTAIN: Oh, thank you again so much for having me.

HOFF: That's all for this episode of *Ethics Talk*. Thanks to Kratika Mishra, Astrid Floegel-Shetty, and Ragen Chastain for joining us. Music was by the Blue Dot Sessions. Thanks also to Becky Hill for agreeing to share her story with us. To read it in her own words, head to Ragen's newsletter at weightandhealthcare.substack.com. And to read our full issue on medicine's overreliance on BMI, visit our site, journalofethics.org. For all of our latest news and updates,

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