The (Un)Fleshiness of Existence An Autoethnographic Exploration of the Datafication of Eating Disorders


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THE (UN)FLESHINESS OF EXISTENCE
An Autoethnographic Exploration of the Datafication of Eating Disorders

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ABSTRACT: This paper seeks to understand how the datafication of health influences individuals' understanding of themselves and their bodies in the context of eating disorders, particularly anorexia nervosa. Using autoethnographic methods, I begin by extending Horrocks' (2019) concept of the Datafied Body Double (DBD) to examine how data and numbers, particularly weight, come to be the primary bearers of evidence for the claims of truth that Western biomedicine is invested in making. I identify a gap between the DBD and the lived experience of illness, resulting in a skewed perception of what eating disorders are and how to treat them. I explore how data come to discipline the body by limiting the possibilities of personhood and constraining the human condition to that which can be measured, quantified and controlled, before further identifying eating disorder treatment as an anticipatory project that depends on trends and trajectories, or what I call the narrative arcs of numbers. Finally, I reflect on the dictatorship of data—the way data come to structure behaviors, organize and, eventually, overtake thoughts. Ultimately, I call for an approach to eating disorders and eating disorders treatment that prioritizes meaning-making, situated knowledge, and ethical forms of engagement over the depersonalizing logic of data-driven health governance.

KEYWORDS: Anorexia Nervosa, Eating Disorders, Autoethnography, Datafication

> "You cannot feed the hungry on statistics."
> —Heinrich Heine

My therapist's face appears on my screen the second I click on the meeting link. I'm late logging into the call, as always. It's not that I had anything better to do; there's no reason for my lateness. I guess I was just trying to avoid the inevitable question.

"How's it going?" she asks, as soon as my audio connects. I fidget with the chain-link toy in my hand and look at my feet. I want to say "fine," the way I usually do. If she had asked me yesterday, it might have even been the truth. I had a good week (as good as it can get for someone who is in the throes of recovering from an eating disorder, at least). Today, though . . . Today is a whole different story. I weighed myself this morning.

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> I'm up half a pound. It doesn't sound like much, I know. But it changes everything.
>
> "It's probably just normal fluctuation," my therapist says, when I relay my fears. I've been trying to tell myself that all day—that it's just normal fluctuation—but it's no use. I don't believe it. The numbers suggest otherwise.
>
> "You said that last week already when my weight was up," I counter. "And the week before that. It's been 3 weeks in a row now," I say, and what I mean is: it's become a trend. The trajectory is clear. Up. Always up. If I don't take control now, it will be too late.
>
> I can feel the extra weight on my body. The way my hip bones are less prominent, my shoulder blades less protuberant, buried under a layer of fat cells that weren't there yesterday. Fat cells stacked like bricks, one atop the other, caging me in. Today, I am not fine. Today, my week was not good.

This paper is an attempt to understand how the datafication of health—what Ruckenstein and Schüll describe as "the conversion of qualitative aspects of life into quantified data" (2017, p. 262)—influences individuals' understanding of themselves and their own bodies in the context of eating disorders, particularly anorexia nervosa (AN) in the North American context. I come to this work from a place of lived experience, having been diagnosed with AN when I was 12 years old. For years, I cycled in and out of treatment centers across Canada and the United States without much success. Rather than getting better, I seemed to get worse with every admission, more entrenched in my eating disorder, falling "under the sway of older girls versed in the illness," as Rachel Aviv (2022) describes happening to herself when she was admitted to "the anorexia unit" at her local hospital. More than being influenced by older girls who were versed in the illness, however, I have come to understand the very structure and logic of eating disorders care to be at the root of the problem. In her book *Famished*, Rebecca Lester explains how:

> [T]he dominant logic of care forces eating disorders treatment to operate with an anorexic mentality of scarcity and deprivation that replicates the core dynamics of the very illnesses it purports to treat, catching patients in double binds that keep them unwell. (2019, p. xviii)

The dominant logic of care Lester is referring to here is one that demands quantification, prediction, and verification—one that rests on and reproduces the datafication of eating disorders.

In what follows, I demonstrate how the emphasis and dependence on quantifiable metrics produces what Stephen Horrocks calls "Datafied Body Doubles: numerical stand-ins for the body" (2019, p. 1) that fundamentally alter the conceptual and material experience of living with an illness. I begin by identifying and exploring the gap between disembodied, objective knowledge about eating disorders and the lived experience of eating disorders. I then examine how numbers and data create looping effects (Hacking, 2007) by virtue of them functioning as local terms of recognition in eating disorders treatment and argue that it is through this process that the Datafied Body Double (DBD) emerges. I demonstrate how the DBD functions to create "regimes of perceptibility" (Murphy, 2006) that render certain experiences legible, and I consider the implications of this for individuals living with eating disorders. In doing so, I draw attention to what I call the "narratives" behind numbers—the subjective nature of data and their interpretation, and the way numbers find meaning as trends and trajectories, creating a kind of narrative arc. Finally, I explore how datafication fundamentally alters the embodied experience of illness in ways that feed back into and fuel the illness itself.

Methods

Autoethnography is a qualitative research method that utilizes the researcher's personal experiences to analyze and critique cultural beliefs, practices, and experiences; it acknowledges the importance of the researcher's relationships with others and emphasizes deep self-reflection, or reflexivity, to explore the intersection between the individual and society, the personal and the political, and the specific and the universal (Adams, Jones, & Ellis, 2015). This approach captures people in the process of making sense of their choices, their ways of living, and the meaning of their struggles. It balances intellectual and methodological rigor with emotion and creativity, while striving for social justice to improve lives. Considering this definition of autoethnography, it could be argued that all anthropologists are doing autoethnography when they engage in participant observation, which involves using their own experiences of living with and listening to interlocutors as primary data. However, as Annelies Moors explains, what distinguishes autoethnography and participant observation, is the researcher's positionality and pre-existing relations:

> When one is a relative outsider to the lifeworld of one's interlocutors, participant observation involves developing relations of trust, forms of closeness and empathy by participating in their lifeworlds (even if this always remains limited). But if one starts off as relatively close to, or part of, a particular lifeworld, and already has acquired forms of experiential, embodied knowledge, one has a different point of departure. Then one moves from participating to reflecting upon one's experiences. The latter is what I would consider autoethnography. (2017, p. 387–388)

Over the last two decades, there has been a significant increase of autoethnographic work in social science research and contemporary literature, particularly in the field of health, where it is gaining recognition as a powerful research tool (Chang, 2016).[1] This methodological approach is particularly useful for exploring stigmatized conditions as it amplifies marginalized voices and fosters dialogue that can lead to policy and practice changes. One key advantage of autoethnography is its ability to foster empathy and understanding by presenting illness experiences from the perspective of those who live them (Adams et al., 2015). Narratives, particularly those told from a first-person perspective, are powerful persuasive tools for reducing stigma (Zhuang & Guidry, 2022), and have been mobilized across clinical, political, educational, and social contexts to effect change in both policy and practice (Fadlallah et al., 2019).

Arthur Kleinman (1988) emphasizes the importance of illness narratives in understanding the personal and cultural dimensions of health and disease. He argues that illness is a deeply personal and social experience, shaped by cultural meanings, personal histories, and social interactions. Kleinman (1988) highlights how patients make sense of their suffering through storytelling and advocates for clinicians to engage with patients' narratives to provide more empathetic and effective care. His work underscores the need to move beyond purely biomedical models of disease and consider the subjective experiences of illness, which can reveal crucial insights into patient needs and health care practices. By centering the researcher's personal narrative, autoethnography similarly challenges dominant clinical and biomedical discourses, highlighting the complexities of mental health beyond diagnostic criteria and treatment protocols (Bochner & Ellis, 2016).

Engaging in this kind of autoethnographic writing is not without its risks. Although storytelling has many benefits, some of which I have outlined above, it also presents burdens. Narrative scholar Mark Leeman describes how "the disruption that makes stories interesting to the rest of us also tends to make them [the storytellers] vulnerable, exposed, and yes, even exploitable" (2011, p. 108). Similarly, April Chatham-Carpenter (2010) has written specifically about the ethical challenges and risks associated with the process of doing autoethnographic writing about a potentially ongoing disorder, such as AN. She describes how the research process may trigger previously disengaged unhealthy thinking patterns or behaviors and emphasizes how "writing about your experiences is so tied to your life course that you have to be in a certain space to feel comfortable to write" (Chatham-Carpenter 2010, p. 9). As one of the reviewers of Chatham-Carpenter's work pointed out, if you try to write a narrative before you have fully processed the experience you wish to convey, it ends up reading more like a personal journal and "does not yet have the ability to connect to larger ideas, theories, people and communities" (2010, p. 9).

Various risks—epistemic, ethical, political, and methodological—also arise in extrapolating one person's lived experience to a general population. First, there is a risk of false universality. A single experience can come to stand in for a whole population, erasing heterogeneity (e.g., class, race, gender, disability, culture, diagnosis, and temporality), and turning narrative coherence into epistemic authority. This is particularly dangerous when an experience *resonates* affectively, as resonance can be mistaken for representativeness. When one person's account is taken as generalizable, it risks silencing those whose experiences diverge and potentially reproducing power asymmetries. Methodologically, extrapolating a singular experience to a general population risks treating experience as self-interpreting data; the mediated nature of memory, language, genre and audience is minimized, as is the work of interpretation, framing and narrative construction. Fabry comments on the latter in relation to grief memoirs, arguing that "they should not be treated as if they were phenomenological evidence," but as "carefully crafted and curated literary artefacts" (2025, p. 3).

The autoethnographic vignettes I share here are narratives of poignant moments and memories that I have engaged with through deep and careful self-reflection, supported by the analysis of personal medical records. Although I portray the encounters with my therapist in present tense and as singular instances, these vignettes are the result of years of deep intra- and interpersonal emotional work. By weaving my personal story through this paper, I hope to breathe life into the concepts and ideas I discuss. In the words of Ralph Clare, I engage in this kind of autoethnography not "merely to deconstruct the self and fragment the 'I,' . . . but to self-consciously and practically construct an ethical or sincere self in a critical manner" (2020, pp. 85–86)—a self that transcends data. In doing so, however, I recognize that I am subjecting myself to yet another point of analysis, turning an anthropological gaze on myself to dissect the clinical gaze. It could be said that, just as the clinical gaze creates a DBD, the anthropological gaze creates a narrative body double. I inevitably had to make decisions about what details to include in the autoethnographic vignettes, where to focus my attention, and how much personal details I was willing and able to reveal. Although the stories I supply are raw, honest, and deeply vulnerable, they are nevertheless contained. What systems, structures, power dynamics, values, and norms guided the construction of these narratives? What kind of person materializes through them? And what is left unsaid? These questions must be asked and held top of mind when engaging with this text to understand that it, like all other texts and narratives, can only ever offer a limited representation of lived experience.

Mind the Gap

I haven't always cared about my weight. It hasn't always governed my thoughts, determined my behaviors, dictated my life like an oppressive regime.

"Can you remember when that started? When did you start to become fixated on your weight?" My therapist asks, curious. The question catches me off-guard.

"I've never thought about it before," I admit. But somewhere deep inside, I know. "Treatment," I say, without a doubt. "My first hospital admission."

My therapist looks at me quizzically, trying to make sense of my answer. It's probably not what she was expecting to hear. Treatment is typically seen as the solution to the problem, not the cause of it. "Tell me more," she encourages. And I do.

I was 12 years old when I was diagnosed with anorexia; 12 when I first went into treatment. More than half a lifetime ago now. Still, I remember it like it was yesterday. The way the doctor examined me. The way he tentatively held my legs in his hard, calloused hands, as if afraid to break them, it seemed. How he pressed his stethoscope to my chest—the sting of the cold metal—and turned his gaze to the Rolex watch on his wrist, brow furrowed in concentration, counting as I lay perfectly still. *One–one thousand, two–one thousand, three–one thousand, four*—there. A beat. The concern that flashed across his face for a second before he caught himself, cleared his throat, excused himself from the room for a moment.

When he returned—5, maybe 10 minutes later—it was with my growth chart in hand.

"Do you see here?" he said, tracing the points my family doctor had carelessly plotted over the years. "Until now, your weight and height have hovered around the 25th percentile."

"Leighton has always been on the smaller side," my mom said, somewhat defensively.

"That's fine," the doctor waved her off. "The problem is that your weight is here now." He pointed to a spot near the bottom of the chart, outside the lines that bounded normality. "You've fallen off the curve entirely."

My mom inhaled sharply. Laid out on the page like that—as points of data—there was no denying the deadly abyss I'd fallen into.

The doctor took out an angry red pen and started drawing a dotted line through the previous points, following the trajectory of the 25th percentile. "This here—" he explained, planting his pen on the page, "—is where you should be. This—" he pointed at the spot near the bottom of the chart again. "This is where your weight is." He paused. "Do you know what an eating disorder is, Leighton?"

I shook my head "no." I can't remember exactly how the doctor described it. Something about being underweight and malnourished, about being overly concerned about your appearance and afraid of becoming fat. I would have to be hospitalized, he explained, but the treatment was simple: food would be my medicine. All I had to do was eat. Gain weight.

The doctor pointed to the red dot he'd drawn on the trajectory of the 25th percentile again. "This is your ideal weight," he said. "Let's call it your goal weight. Our job is to get you from here—" he pointed at the spot on the chart indicating my current weight, "—to there," and shot an arrow straight up to my goal weight. "We need to close the gap. Does that make sense?"

It did; it was simple math. A numbers game. Like one of those word problems in the math workbooks my mom made me do each summer in preparation for the upcoming school year:

> Johnny currently weighs 80 lbs. Based on his age and height, Johnny's doctor thinks he should weigh 120 lbs.
>
> a) Express Johnny's current weight in relation to his goal weight as a percentage.
> b) How many pounds does Johnny need to gain to reach his goal weight?
> c) If Johnny's doctor wants him to be at 85% of his goal weight in 8 weeks, how many pounds does Johnny need to gain each week?

I nodded.

"Good," the doctor said, rising to his feet. "Hang tight while we get a room set up for you on the ward. And remember . . . " he tapped the growth chart with his pen like a teacher, looking for an answer.

"Close the gap," I said, obediently.

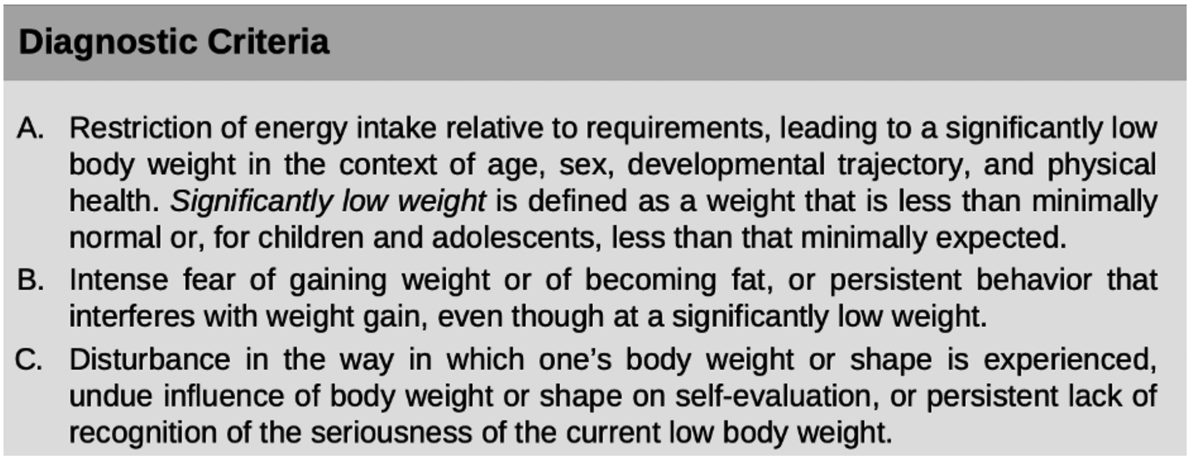
Capturing Suffering: The DBD

If anything became clear to me during those first few weeks of treatment it was that, as much as I did not know what an eating disorder was, neither did my doctors. Eating disorders are not about food or weight—not really. Contrary to what many people think, Lester explains that:

> [e]ating disorders are not diets that have gone "too far." Nor are they like cocaine or heroin addictions, where an addict can conceivably go cold turkey, detox for thirty days, and essentially be back to baseline as long as they avoid the drug. They are not juvenile temper tantrums, though they can be an expression of anger and rage. They are not "phases" someone goes through. They are not about superficial vanity or self-aggrandizement, though this is how they may look from the outside. (2019, p. 5)

Such a perspective is not new; feminist accounts of eating disorders have long emphasized that eating disorders are about more than just food and weight. Hilde Bruch (1978), for example, understands AN as a disorder of the self. Individuals with AN, she argues, experience a profound sense of inner emptiness, difficulty recognizing and trusting internal bodily signals, fear of adulthood, and a fragile or underdeveloped sense of personal agency. For Burch, the goal of AN is not starvation, but control.

These accounts of eating disorders are not recognized in the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5-TR), however, which broadly defines eating disorders as "a persistent disturbance of eating or eating-related behavior that results in the altered consumption or absorption of food and that significantly impairs physical health or psychosocial functioning" (American Psychiatric Association, 2022, p. 372). At the time of my diagnosis in 2012, the DSM was in its fourth edition (American Psychiatric Association, 1994). Importantly, it was the release of the previous edition of the DSM—the DSM III (American Psychiatric Association, 1980)—that marked a significant turning point in psychiatry. Namely, the move away from a psychoanalytic, etiologi-



Diagnostic Criteria

A. Restriction of energy intake relative to requirements, leading to a significantly low body weight in the context of age, sex, developmental trajectory, and physical health. *Significantly low weight* is defined as a weight that is less than minimally normal or, for children and adolescents, less than that minimally expected.

B. Intense fear of gaining weight or of becoming fat, or persistent behavior that interferes with weight gain, even though at a significantly low weight.

C. Disturbance in the way in which one's body weight or shape is experienced, undue influence of body weight or shape on self-evaluation, or persistent lack of recognition of the seriousness of the current low body weight.

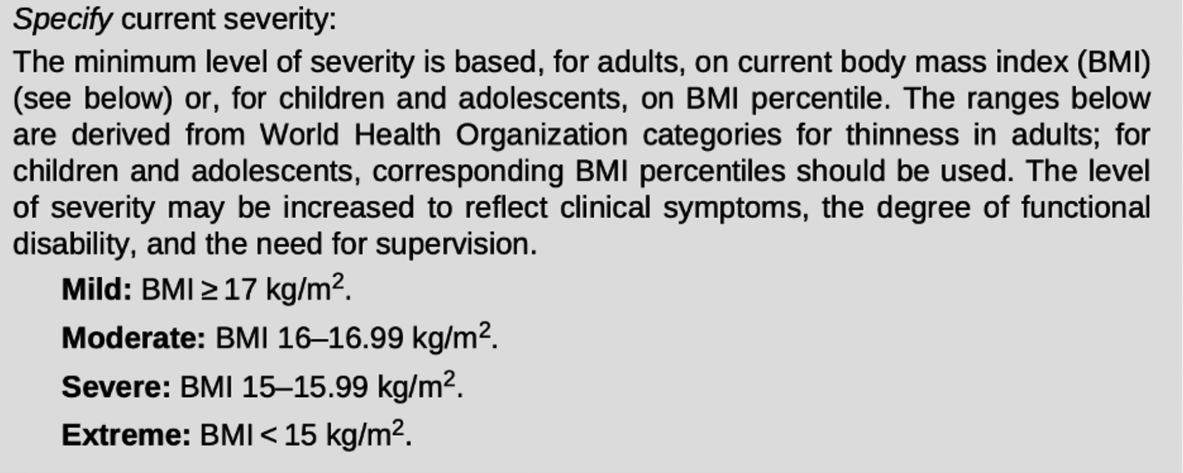
Figure 1. DSM-5-TR Diagnostic Criteria for Anorexia Nervosa, as presented on p. 382.

cal, and interpretive approach to psychiatric diagnosis toward a more descriptive one in which psychiatric distress was classified according to a specific pattern of objectively quantifiable cognitive, behavioral, and/or biological symptoms that could be measured and tracked (Harrington, 2019; Shorter, 2015). Heralded for improving diagnostic reliability (Spitzer, Williams, & Skodol, 1980), this symptom-based, checklist-driven approach continues today.

Consider, for example, the DSM-5-TR criteria for AN, shown in Figure 1.

That the low weight criterion is listed first is not a coincidence. In fact, the *International Classification of Diseases*, 11th edition, another diagnostic system that serves as the global standard for diagnostic health information, specifically identifies the low weight criterion as an "essential feature" for diagnoses of AN, further quantifying "low weight" as a body mass index of less than 18.5 kg/m^2 in adults and body mass index-for-age under the 5th percentile in children and adolescents. Alternatively, rapid weight loss, defined as more than 20% of total body weight within 6 months, may replace the low body weight criterion if other diagnostic requirements are met (World Health Organization, 2022). Previous editions of the DSM (American Psychiatric Association, 1994) also quantified the low weight criterion, arbitrarily setting the threshold as 85% of the expected body weight for one's age and height. Weight continues to be used today as an indicator for illness severity, as shown in Figure 2. This is to say that, in Western biomedicine, body weight has become *the* distinguishing feature of AN—a proxy not only for the severity of illness but also the extent of suffering.

Reflecting on the experiences of people living with contested illnesses in the United States, American anthropologist Joseph Dumit identifies the Western biomedical system as one where patients must "'prove' their illnesses and suffering through mobilizing facts" (2006, p. 577). Until and unless patients can use biomedically recognized markers to demonstrate that their disease is "real," they are met with skepticism, suspicion, and even scorn. As Dumit explains, "one must suffer in code in order to be suffering in fact, or one does not suffer at all" (2006, p. 580). The code, for eating disorders, is data, numbers, things that can be measured, tracked, charted and made sense of. Weight, primarily, but other measurements as well: heart rate and blood pressure, body temperature, blood glucose, sodium, potassium, phosphate and magnesium levels, liver enzymes, calories consumed, kilometers walked, and so on and so forth. Measurement and quantification of the material body's processes become numerical stand-ins for the body, recreating the body as both usable and controllable in the form of what Horrocks (2019) calls a DBD. This DBD becomes the primary bearer of evidence for the claims to truth that biomedicine is invested in making.



Specify current severity:

The minimum level of severity is based, for adults, on current body mass index (BMI) (see below) or, for children and adolescents, on BMI percentile. The ranges below are derived from World Health Organization categories for thinness in adults; for children and adolescents, corresponding BMI percentiles should be used. The level of severity may be increased to reflect clinical symptoms, the degree of functional disability, and the need for supervision.

Mild: BMI ≥ 17 kg/m^2.

Moderate: BMI 16–16.99 kg/m^2.

Severe: BMI 15–15.99 kg/m^2.

Extreme: BMI < 15 kg/m^2.

Figure 2. DSM-5-TR Anorexia Nervosa Illness Severity Specifier, as presented on p. 382.

For eating disorders, it is important to note that it is not the illness itself that is contested, but the extent to which "a given patient is thought to be *suffering appropriately* from an eating disorder and is therefore deemed worthy of care" (Lester, 2019, p. 12, emphasis original).

In general, the things that cause the most suffering and debility in eating disorders—the deep, abiding shame and self-negation, the self-loathing and suffocating anxiety, the paralyzing fear and sense of being trapped in one's body, the relentless perfectionism and intrusive obsessive thoughts, the challenges with intimacy and inadequacy—are not captured in official diagnostic criteria. These "halo features," as Lester calls them (2019, p. 12), hover around the edges of official diagnostic criteria and resist quantification. While they feature prominently in the lived experience of illness, they form no part of the DBD. Simply put, the DBD is abstracted from lived experience. There is a gap between what is quantifiable and measured (the data) and what is lived and experienced (the reality) resulting in a skewed perception of what eating disorders are and how to treat them.[2]

Numbers Don't Lie

> I say I was 12 when I first went into treatment because, in the years that followed, there were countless admissions. Inpatient, outpatient, day patient, residential—you name it, I did it. I became accustomed to being woken up at six in the morning by the night nurse to check my weight, to stumbling bleary-eyed out of bed to use the bathroom and change into a hospital gown, to being patted down and asked to turn around before stepping backwards onto the scale. I would stand there, frozen, suspended in time as I waited for the scale to calibrate, my thoughts swirling. *Heavier today. Yes, heavier for sure. Two pounds at least. Maybe three. I can feel it. I'm sure of it.* I would wait there for the beep, for the nurse to lift the sticky note covering the display and scribble down the number on a scrap piece of paper they'd casually stuff into their pocket before letting me step off the scale again, change back into my pajamas, and crawl back into bed to ruminate about my weight until breakfast. That number—my weight—determined everything in treatment: how many calories I had to eat, what privileges I was permitted, how rational my reasoning was deemed to be, and when I would be discharged, no longer considered "sick enough" to require treatment.
>
> Between admissions, I saw my pediatrician once a week. Every visit, like every day in the hospital, started the same: with a weigh-in. In this way, my weight became information—a point of data—that overshadowed every encounter. In many ways, it didn't matter what I reported; the numbers presumably said it all. They spoke for me, over me, stealing my voice in exchange for a disembodied, objective, capital "t" Truth. If I said I'd had a good week but my weight was down, then clearly, I was lying. If, on the other hand, I'd had a tough week but my weight was

> stable, then surely things couldn't have been *that* bad. There were times when I asked for help only to be told I wasn't sick enough; that my weight was "too high" to be worthy of care. And so, I did what any logical kid would do: I ate less, exercised more, tried to lose weight. Not because I particularly wanted to lose weight, but because I needed the numbers to speak of an experience I was otherwise denied.

Learning to Speak in Numbers: Looping Effects and Legibility

In her essay *A call for our language: Anorexia from within*, the Japanese scholar Takayo Mukai describes entering what she calls a "digitalized world" when she was struggling with AN, "where everything was understood in terms of meters, centimeters, kilograms, calories, times, and so forth" (1989, p. 634). This digitalized world and our modern-day fascination with the quantified self can be traced back to the nineteenth century when new scientific methods and technology-enabled mass quantification of the individual for the first time, which led to "the constitution of the individual as a describable, analyzable object and his or her placing within a comparative system" (Gere, 2008, p. 40).

In health care in particular, the construction of disembodied, objective knowledge presents bodily processes as fully knowable and subject to action. The DBD is interpreted as one's "authentic identity" (Stepanchuk, 2017, p. 30); an "atemporal 'permanent' digital personality" emerges from the data that enacts "a moral and societal imperative: to be what algorithms tell you to be" (Stepanchuk, 2017, p. 30). Put differently, data construct, rather than reflect, lived experiences. Individuals become trapped in data, unable to exist outside the stories that algorithms tell, to speak truth to anything other than what the numbers seem to say. As Stepanchuk explains, "quantified datasets become Latourian actors, integral parts of our inner networks of the self. They serve as mediators, transferring our emotional, social, and digital acts into something different, thus influencing our understanding of ourselves and others" (2017, p. 31). In this way, data disciplines the body; it limits the possibilities of personhood, constraining the human condition to that which can be measured, quantified, and controlled.

Understanding data as disciplinary measures illuminates how datafication forces eating disorders treatment to operate with an anorexic mentality that replicates and reinforces the very thoughts, ideas, beliefs, and behaviors it intends to treat. Like eating disorders themselves, treatment for eating disorders operates in a state of "constant precarity, coupled with imperatives for certainty and demands for quantification, predication, and verification that provide illusions of control" (Lester, 2019, p. xviii). The datafication of eating disorders is, at once, a way of accessing care and inflicting harm, of both illuminating and imposing suffering.

It did not take long for me to learn how to speak in numbers; to become fluent in a language of logic and enumeration. My diagnosis of AN created a very narrow realm of possibility within which my suffering could be understood. The label had a limiting effect that not only restricted the *kind* of person I could be, but also the way I could communicate, namely through numbers and data. Although perhaps unconsciously, I made adjustments according to the way I had been classified. I ate less and exercised more, trying to unbalance the energy equation, driving it into a deficit in order to lose weight. I fixated on kilograms and calories because that's what counted and, over time, this willed pattern of behavior became increasingly involuntary and ingrained.

The philosopher Ian Hacking (2007) uses the concept of looping effects to describe the way scientific classifications and people interact to shape each other. He suggests that a new classification, such as a psychiatric diagnosis, changes the space for personhood, creating a new *kind* of person who it is possible to be; individual people, in turn, change their behaviors as they are recognized to be part of that classification, thereby reinforcing what it means to be a certain *kind* of person. "We make ourselves in our own scientific image of the kinds of people it is possible to be," Hacking writes (2007, p. 305). And yet, the kind of person made possible through the classification of eating disorders is not a person at all, but a numerical stand-in for the body—a DBD. Here, data provide the scaffold for a destructive looping effect that brings the DBD into being. The datafication of eating disorders leads individuals to first understand and then express themselves, their bodies, and their experiences through data, reducing lived experience to that which can be measured.[3]

Moreover, the specific techniques of measuring suffering—diagnostic criteria, questionnaire screening scores, biometric data—create "regimes of perceptibility" (Murphy, 2006) in which particular aspects of an illness become more or less visible. The politics of knowledge production and the process of materialization involves obscuring awareness of certain things and experiences to make others more apparent, intelligible, and, ultimately, controllable. In eating disorders, the DBD is what falls within the regime of perceptibility. This numerical stand-in for the body is considered a reflection of the absolute truth, which not only fails to recognize the gap between the DBD and the lived illness experience, as outlined in the previous section, but also disregards the subjective, interpretive nature of data analysis, which I turn to next.

Fact or Fiction? The Narratives Behind Numbers

According to Deborah Lupton, "*numbers* alone tell us nothing. It is the *contexts* in which numbers (or any form of data about the self) are created that are important" (2016, p. 66, emphasis original). In contrast to dominant discourses, which represent data as being generated almost in the absence of human intervention (Boyd & Crawford, 2012; Helles & Jensen, 2013), data production and interpretation must be viewed as an active, purposeful, and human-driven process. "Accounting for illnesses under biomedicine requires attending to both the ways in which scientific facts are circulated and used, and the ways in which the same facts are socially and economically controlled, contained, and exploited" (Dumit, 2006, p. 579).

In eating disorders treatment, data and the DBD are largely mobilized for economic reasons and motivated by a scarcity mindset in the context of managed care (Lester, 2019). Broadly, the managed care framework constructs a narrative about the kind of patients deemed worthy of care. "Good" patients, or patients who are the "right" kind of sick, are typically health-seeking patients who follow recommendations and are active in their recovery. Their illnesses follow a relatively coherent, predictable course. In short, they *want* to get better and *can* get well. Such patients are considered good investments of health care dollars. "Bad" or "difficult" patients, on the other hand—patients who are noncompliant, who present in unexpected ways, or who may even do things to exacerbate their conditions—are the "wrong" kind of sick and are identified as "poor economic investments" on whom scarce health care resources should not be "wasted" (Lester, 2019, p. 16). Patients with psychiatric disorders are, almost by definition, the "wrong" kind of sick. Eating disorders perhaps especially so:

> [U]nlike other serious mental illnesses like schizophrenia or depression, eating disorders continue to occupy a space in the popular imagination as a choice—a manifestation of vanity, manipulation, or childish rebellion. Managed care case managers are as susceptible to these erroneous stereotypes as anyone else, and they often have little sympathy for the struggles of clients with 'self-inflicted illnesses' (as one case manager characterized anorexia to me [Lester] when denying a client further [insurance] benefits. (Lester, 2019, pp. 16–17)

Writing from within the American health care system, Lester's argument may, at first glance, only seem applicable to private, for-profit health care systems, where insurance companies hold the upper hand in deciding what services to fund. Yet the principles of managed care—attempting to reduce health care expenditures by encouraging the provision of only necessary and appropriate care—are pervasive. In public health care systems, the onus simply falls on the health care provider, rather than the insurance provider, to manage care.

So, what does that mean for patients? I still remember the day when my mom dragged me, kicking and screaming, to the emergency department because I had not eaten in days. I can practically see the pediatrician rolling his eyes when he saw my name on the screen—*them again*. I can picture him wrinkling his nose in disgust and huffing in annoyance before pulling my mom aside and telling her (in only slightly kinder terms) to get lost. Having spent the better part of 3 years in treatment by then, the doctor clearly felt that I had "wasted" too much of the hospital resources and felt confident concluding that I was not worth investing any more money or time into. From then on, he said, they would no longer admit me, no matter how bad things got.

In a certain sense, it is the trends and trajectories of data, or what I will call their narrative arc, not the numbers themselves that matter. An individual's weight only takes on meaning in relation to the past and projected future. Treatment decisions—meal plan changes, activity restrictions, the granting of privileges and passes, assessments of progress and predicted prognoses—depend on the pattern of weight gain (or loss) relative to an anticipated ideal. With time, these trends coalesce to tell a broader narrative of either recovery or chronicity, the two possible end points of an eating disorder. Eating disorders treatment is what Lester calls "an *anticipatory project*; that is, it is structured not only in response to here-and-now concerns . . . but also in relation to a range of imagined possible future outcomes" (2019, p. 145, emphasis original). The treatment path taken depends on which possible future outcome is deemed most likely. The risks are weighed (organ failure, cardiac arrest, brittle bones breaking), the outcomes are considered (a life spent incapacitated and ill or, alternatively, a life in recovery, filled with joy and promise), the data are consulted (duration of illness, number of past hospital admissions, lowest body weight, physical and psychiatric comorbidities, the number of people in one's support network, suicide attempts), and a calculation is made, a future predicted, an outcome—recovery or chronicity—constructed through the trends and trajectories of data. "Eating disorders treatment is structured by such practices of prediction and anticipation" (Lester, 2019, p. 148) that rely on, and therefore necessitate, datafication. Notably, as my own experiences exemplify, the designation of "chronic" in eating disorders typically results in a *withdrawal* of support and denial of further care. Algorithms have social power; they generate narratives about individuals (Jacobsen, 2022) that, in the case of eating disorders, have life-threatening consequences. More than shaping the view of health care workers, these narratives become internalized, resulting in what Miyahara and Tanaka call "*narrative imprisonment*: the phenomenon whereby a self-narrative becomes detrimental to a person's well-being by constraining their identity and agency within its boundaries" (2025, p. 1, emphasis original). For too many years, I believed the narrative—one of hopelessness, chronicity, and premature death—that the numbers, algorithms, and data generated about me. As such, it is important to acknowledge that, by generating data about us, digital devices "work as powerful narrative devices, shaping and propagating the kinds of narratives that we self-ascribe and act in accordance with" (Osler, 2025, p. 379). Our narrative agency is constrained through a process of "narrative railroading" (Osler, 2025).

Horrocks' description of how trends and trajectories of glucose measurements for people with type 1 diabetes "construct positive and negative connotations around an imagined *future* numbers' proximity to the same" (2019, p. 5, emphasis original) similarly applies to measures of weight for people with eating disorders. Rather than having stable meanings, however, the connotations certain values take on—whether an increase in body weight is regarded positively or negatively, for instance—fundamentally depends on the motivations of the person interpreting the data. Different people may tell different stories about the same data, or the same person may tell different stories at different times. For individuals with eating disorders, for instance, restoration of one's "ideal weight" may take on increasingly positive connotations as they become more recovery oriented. Moreover, the *context* in which numbers, trends, and trajectories are interpreted matters: fluctuations or deviations from the ideal course hold more or less value depending on where on the trajectory they occur and the future they anticipate. From the clinician's perspective, minor downward fluctuations in weight may be critical when an individual is at a dangerously low weight, but those same fluctuations may hold little, if any, value for someone who is considered "weight restored," unless it becomes a trend. This change in significance of the value of numbers as they move from being independent measures to supposedly reliable trends that predict a seemingly certain future also animates patients' relationships with data. The vignette I use to open this paper, for example, reveals how a half-pound increase in weight takes on different values—emotionally and psychologically—depending on the narrative arc it emerges within.

Numbers morph and metastasize; they take on a life of their own, tell their own kind of story—one that is regarded as more trustworthy and truer than any lived experience can be.

On the Matter of Millimeters: Becoming Data

> There's something unnerving about the sterility of the room I'm in. It's a small room with blindingly white walls, bare but for the clock hanging on the wall across from the door. The *tick, tick, tick* of its second-hand echoes through the silence, ominously counting down the minutes until the next meal, like a bomb about to explode. The room is bright, despite not having any windows. Too bright. I feel exposed, standing there, barefoot under the fluorescent lights in an oversized hospital gown that does little to protect my dignity. I shiver. The tiles are cold beneath my feet, hard and unforgiving. I am alone in the room, waiting. For what, I'm not entirely sure. Something about meeting with the dietician. Something about her needing to take a few measurements and make a few calculations.
>
> There's a knock on the door. Three knocks, actually, in quick succession—*tap, tap, tap*—like a woodpecker drilling into a tree.
>
> "Can I come in?" a voice asks, but the door is already creaking open before I can answer. Someone (the dietician, I assume) wheels a rickety metal cart into the room. I see the instruments before I see her. Calipers. Calculator. Measuring tape. A blank page. A black pen. Fear crawls under my skin. *What are they going to do to me?* I wonder, oblivious, still, to the ensuing demise. Innocent. Ignorant. Almost blissfully so.
>
> The dietician skips the usual exchange of pleasantries and jumps straight into a technical explanation of what she will be doing with me (to me?) in the next 30 minutes or so, most of which passes straight over my head. From what I manage to understand, she will be doing a "skinfold test" to calculate my body fat composition, which involves her clamping a pair of calipers around my skin at seven different locations. She will take 3 measurements at each location, 21 measurements in total.
>
> "I'm going to start by marking the spots where I need to take a measurement with a pen, okay?" The dietician steps behind me and undoes my gown, peeling it open like a curtain. She takes the pen from the cart and starts marking my body like a treasure map, drawing tiny "x's" on my chest, my abdomen, my triceps and thighs—all the places she will pinch between the calipers, again and again, until I'm certain I'm not dreaming.
>
> "Lift your gown. Lower it. Lift your arm. Lower it. Bend over. Stand up. Turn around. Good, now face me again." She orders me around like a servant with simple, assertive commands, pulling the skin from my bones as if I were a chicken carcass, teaching me where to pinch myself to determine how fat I am, the places to obsess over. In that moment, my fingers became calipers. My body, simply a thing to measure. A sac of bones. Something to constrict, constrain, contain. Something to control. To surrender. An uninhabitable space.

As Horrocks suggests, the re-imagining or translation of the body as a number has become normalized "by the reiterated act of overlaying those numbers onto users' sensory experiences with their own bodies" (2019, p. 11). In doing so, "one's embodied knowledge of how a particular state *feels* merges with a system of quantification with which to categorize it" (Horrocks, 2019, p. 11, emphasis original).

In the book *Hi, It's Me*, Fawn Parker writes about her experiences with numbers as someone living with AN: "I want to know the number," she says, commenting on the practice of weighing herself. "There have been times, in the past, where I've seen something in the mirror, checked the number, and returned to the mirror to see something else entirely. A number is the only thing I can trust about a body" (2024, p. 100). Parker poignantly articulates how systems of quantification become embodied. The number she sees on the scale fundamentally changes what she sees in the mirror—how she feels about her body. It is interpreted as more truthful and trustworthy than any inherent sense of being. The number overrides—and later becomes—her embodied knowledge. In the same way, the skin-fold test marked a pivotal moment when I began to internalize and embody systems of measurement. Whether I felt fat—or, rather, *how* fat I felt—was governed by a simple measurement: a pinch here, a pinch there, an estimate of the thickness of the roll of skin beneath my fingers, the outcome of which not only determined how I felt about my body, but also my social and emotional capacity to show up in my everyday life. The measurements I took of my body through body checking behaviors—no matter how biased and unfounded (see Slade & Brodie, 1994)—changed my experiences in and of my body. Numbers began to order and eventually override my embodied knowledge, creating a form of dictatorship in which the DBD thrived.

This process of disembodiment, or rather of embodying data, is further evident in linguistic acts wherein individuals equate their bodies/selves with biomedicalized re-creations thereof. Rather than telling my therapist that my *weight* is up or down a certain number of pounds when I log into our sessions together, for example, I tend to say that *I* am up or down a certain number of pounds. I *have* anorexia becomes I *am* anorexic becomes I *am* my weight. "The number *is* as much as one's own body *is*" (Horrocks, 2019, p. 11, emphasis original); years of reiteration materialize the number as one's body in and of itself (Butler, 1993).

At the top of each page of my medical records is a sticker with my patient identification. My full name is listed, along with my age, sex, date of birth, and hospital number. Beside the sticker is a hand-written number (often in big font and written in a bold marker or pen) indicating my weight that day. Typically, this is followed by an upward or downward arrow and another number indicating the change in my weight relative to the previous day. The positioning of this information and its relative emphasis on the page presents my weight as a critical piece of identifying information—something fundamental to *who I am* as a person. The body, here, is made to be understood as and through a number. More than *merging* with a system of quantification, as Horrocks (2019) describes, the embodied knowledge of how a particular state feels is subsumed by and succumbs to the system of quantification. There is a process of objectification happening here—of reducing the bodily subject to its physical dimension, thereby diminishing or silencing characteristics such as autonomy, agency, uniqueness, boundedness, feelings, and mental life, which are representative of subjectivity (Legrand, 2010).

One of the "core features" of eating disorders Lester identifies in her research is "extreme ambivalence about embodiment and difficulty being in one's body—that is, feeling oneself as grounded in the fleshiness of existence" (2019, p. 244). More than physically starving their bodies, Lester suggests that eating disorders also allow individuals "to starve or purge out their feelings, leaving no room for them" (2019, p. 247). This disembodiment, which is so characteristic of eating disorders, is replicated and reinforced by datafication practices in eating disorders treatment. Here, the DBD comes to provide a means of escape from the agonizing, unbearable fleshiness of existence.

CONCLUSION

> "I think you're missing a 'next steps' section, or something like that. You know, like, future directions and what can be done differently," my therapist says. It's the first time we've spoken since I shared (an earlier version of) this paper with her for feedback. "You make a very convincing argument about the risks associated with the datafication of eating disorders and I would agree with you; I think the focus on numbers—weight, in particular—in eating disorders treatment is probably not the best, but what's the alternative? What do you want to see instead?"
>
> We sit in silence together, an ocean between us and, for a second, I think she is frozen on the screen. But then I see her cock her head to the side and settle into her chair, waiting for me to reply. She's good at this—waiting me out.
>
> "I don't know," I say finally. "I guess that's why I didn't include next steps or future directions or anything like that in the paper because I don't know what they would be."
>
> My therapist nods. She knows that I know that this is a classic case of avoidance. "Can I ask you to think about it? In an ideal world, what would treatment look like? How can we move away from datafication?"
>
> I shrug. "Sure."
>
> "Sure?" she repeats, picking up on my noncommittal tone. "Is that a yes or a no?"

> "Yes, I can think about it," I sigh.
>
> "Good. Let's plan to check in about it next week, okay?"

I did not have an answer for my therapist when she checked in with me the following week. I still do not have an answer, probably because there is not one—at least not a single one. There is no one-size-fits-all approach to eating disorders treatment that will magically work for everyone. Treatment must be personalized and specific.

The call for more personalized approaches to eating disorders care is not new. For decades, research has shown that more individualized, integrative approaches to treatment and counseling that are tailored to the patient's unique sociocultural and personal experiences lead to greater reductions in eating disorder symptoms and overall improvements in well-being (Freudenberg et al., 2016; Ghaderi, 2006; Tone, Chelius, & Miller, 2022). It is essential to move beyond standardized protocols to address the complex and varied factors that contribute to eating disorders. I therefore hesitate to suggest a different approach, lest it be adopted as a new standard.

It is not my intention for people to turn to this paper with questions and walk away with answers. I do not want my voice to become *the* voice for all people with eating disorders, or for my story and lived experience to be projected onto others. Rather, I hope readers will walk away from this paper with a deeper understanding of how clinical metrics and quantification practices produce reductive understandings of eating disorders that obscure the complexities of lived experience; with the capacity to critically reflect on, engage with, and complicate the datafication of eating disorders; to ask questions like: what gets lost in the gaps between quantifiable metrics and lived experience? Who do those gaps serve? And how are those gaps straddled? The answers to which I have begun to explore in this paper.

By foregrounding my own narrative through autoethnographic vignettes, I resist the epistemic violence of numerical abstraction and instead emphasize the intersubjective, relational, and embodied dimensions of care. In doing so, I call for an approach that prioritizes meaning-making, situated knowledge, and ethical forms of engagement over the depersonalizing logic of data-driven health governance.

I began this paper by considering how the symptom-based approach to psychiatric diagnosis has contributed to the conceptualization of eating disorders as being about food and weight, which has, in turn, resulted in patients, clinicians, researchers, and insurance providers focusing on quantifiable metrics, like caloric intake and weight, despite these not being where the core of the issue lies. I engaged with Horrocks' (2019) concept of the DBD, demonstrating how the dependence and emphasis on quantifiable metrics in eating disorders treatment creates numerical stand-ins for the body that fundamentally alter the conceptual and material experience of living with an eating disorder, and further revealed how this DBD is abstracted from the lived experience of illness. I have argued that the gap between what is quantified and measured (the data) and what is lived and experienced (the reality) leads to a skewed perception of what eating disorders are and how to treat them.

Having identified these gaps, I turned my attention to what gets lost in them. I explored how data disciplines the body and limits the possibilities of personhood by constraining the human condition to that which can be measured, quantified, and controlled. Not only is the DBD taken as one's authentic identity, but it also creates a "regime of perceptibility" (Murphy, 2006) in which patients must learn to express themselves appropriately, adapting their behaviors to express their distress in ways that are locally recognized as legitimate—as quantifiable measures. In this way, the DBD emerges from an unfettered looping effect (Hacking, 2007).

But it is not only numbers that count. Rather, it is the contexts in which numbers are created, the way in which they come together as trends and trajectories, and the narratives they tell—the arc they follow—that ultimately render them meaningful. Eating disorders treatment is an anticipatory project that clinicians use numbers to navigate. Treatment is structured by practices of prediction and anticipation that necessitate the datafication of eating disorders. In many ways, it is algorithms and data that drive a patient down a path to recovery or chronicity, always already having determined the future from the past, unless something is changed in the present. The turn toward algorithmic structures as measures of suffering renders visible how "[i]nstead of human beings with body, history, and flesh, big data and statistical inferences are all that count" (Mbembe, 2021, p. 18).

Finally, I reflect on the dictatorship of data—the way it comes to structure behaviors, organize and, eventually, overtake thoughts. Ultimately, it is the DBD that fuels (dare I say feeds?) the eating disorder by providing a means of escape from the agonizing, unbearable fleshiness of existence.

Notes

1. Other research approaches, such as engaged phenomenology (see Stanier, 2022), which align with autoethnography in important ways—valuing first-person and experiential knowledge, rejecting objectivist distance, and considering the ethics of representation, including whose experience counts as knowledge, how experience is translated into academic form, and the risks of epistemic violence when lived experience is misrepresented—are also relevant here.

2. The outcomes of many psychosocial therapies, for example, are often difficult to measure; there may be 'low evidence' for their implementation, not because they do not work, but because their outcomes are not easily quantified. Focus is therefore put on quantifiable markers, like weight, which can be tracked, measured, and controlled.

3. For further exploration of *Hacking's work in relation to AN, see Bowden (2012).

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