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The Burden of Eating: Misconceptions About Eating Disorders

I knocked on the door and saw a woman who was more fashionably dressed than would have been expected for a trip to the cardiologist's office. Ronnie* was in a program at a nearby facility dedicated to the treatment of women with eating disorders. The facility sent Ronnie to see me for cardiac evaluation, to ensure she was medically stable to continue with her treatment there. My office was conveniently located. But the staff also included female cardiologists, not common as men greatly outnumber women in the subspecialty. The assumption, or perhaps the hope, was that as a woman I better understood eating disorders. But I did not. My medical training had not included even rudimentary education regarding eating disorders. I had learned mainly from treating patients like Ronnie.

Like the general public, medical professionals have misconceptions about these patients. For many, "eating disorder" is synonymous with anorexia nervosa. Although she had been anorexic in the past, Ronnie was currently bulimic. Although both share an intense fear of gaining weight, bulimia is characterized by periods of overeating followed by purging, often in the form of vomiting or laxative abuse, both of which Ronnie had done from time to time. However, unlike anorexics, Ronnie maintained a normal body weight. All eating disorders, including anorexia and bulimia, are classified as psychiatric conditions. Anorexia nervosa was originally labelled a neurosis in 1952 by the American Society of Psychiatry in the first edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM), the authoritative index of psychiatric diagnoses. The term bulimia nervosa was coined by psychiatrist Gerald F.M. Russell and more recently added in 1987 to the DSM.

Despite entering the medical lexicon, awareness of disordered eating was largely non-existent when Ronnie was growing up. In the United States, eating disorders entered public consciousness in the 1970s with Karen Carpenter, lead singer of the Grammy award winning band, The Carpenters. She was anorexic and as her popularity soared, her weight plummeted. At one point she weighed less than 80 pounds. She died in 1983 with the official cause of death listed as "Emetine Cardiotoxicity due to Anorexia Nervosa," implying she regularly ingested emetine. It was the active ingredient in ipecac syrup, a substance toxic to the heart. Its official indication was to induce vomiting in cases of accidental poisoning. At a time when eating disorders were unacknowledged, it had not occurred to medical professionals that ipecac would be misused.

Karen Carpenter's death at the age of thirty-two raised awareness of eating disorders. Since then, others have been more forthcoming about their struggles. Jane Fonda recounted the impact of disordered eating and poor body image on her health. Princess Diana laid all bare in a 1995 BBC interview when discussing her bulimia. She likened the temporary comfort it gave her to "having a pair of arms around you." Twenty-five years later another icon, Taylor Swift, revealed she sometimes had an unhealthy relationship with food. In her 2020 documentary *Miss Americana,* she spoke of how a picture of her or a comment about her appearance could

trigger her "to just starve a little bit — just stop eating." Clearly, material success and fame do not ensure a sense of self or safeguard one's confidence.

Ronnie did not have fame or fortune. She worked a humdrum job, stressed not by popularity but by anonymity. Feeling invisible at work and in life, the eating disorder was her coping mechanism. Like many with disordered eating, she was smart and functional. Yet she struggled with an eating disorder for most of her life, at a time when recognition of and treatment for eating disorders were essentially non-existent. It felt like a secret to her even though National Association of Anorexia Nervosa and Associated Disorders (ANAD) estimates disordered eating will affect approximately 70 million worldwide (approximately 10-15% of those affected are men), and 30 million in the United States during their lifetime. Diagnosis of an eating disorder confers a higher likelihood of depression, substance abuse and death. Of all categories of mental illness, those with eating disorders have the highest likelihood of dying, with up to one-third of deaths in this population attributed to cardiac dysfunction.

This explained Ronnie's visit to a cardiologist. I started with my usual questions. At one point I asked, "When did your eating disorder start?" She paused. Despite giving her medical history to many others before me, she did not have a ready answer. Perhaps no one had asked this question, or maybe she had tried to forget how it started.

"I can't remember an exact date, but it started decades ago. School was tough for me in so many ways. I was always concerned about my weight and how I looked. One night I was really upset about something, maybe a boy. I talked to my mother, sobbing, trying to explain what was wrong. She listened and told me not to worry. She told me I could just---" And then she pointed her finger into her mouth and motioned she was gagging.

I was confused. "Your mom told you to make yourself vomit?" Other patients have said things that have surprised or upset me, but I found Ronnie's admission particularly disturbing. A parent intentionally encouraged their child's self-destructive behavior.

"Yes." Ronnie said, "She taught me how to purge." Then Ronnie threw her hands up as if to say, "What can you do?" With a single gesture she simultaneously signaled a fait accompli, transgenerational pathology and her mother's denial of the disease. More importantly, her mother had passed on a mindset, one that values the opinions of others over your own. She spoke to a reality, the correlation of body image to self-worth, that women learn early in life even if it does not result in an eating disorder. Ronnie's mother conveyed this truth to her daughter in a devastating manner. But Ronnie was not upset with her mother. She felt her mother had genuinely tried to help.

"Did your mother purge, Ronnie?"

"I don't know for sure, but I think she probably did." She did not elaborate, and I did not probe further.

Patients often realized they had family members with eating disorders.

Their own disease made them look back at a relative's behavior and recognize it for what it was, even when it had no name. Eating disorders are thought to have a genetic predisposition. Research from the Price Foundation and the National Institute of Mental Health suggests certain genes may be linked to anorexia and bulimia, increasing a person's vulnerability to these conditions. Yet genetic predisposition does not fully explain eating disorders. Eating disorders are complex traits thought to result from an intertwining of genetic, psychological, and sociocultural factors, which often collide during adolescence. No single factor has been shown to be necessary or sufficient for causing eating disorders.

Although no clear cause for eating disorders has been identified, the effects of decreased consumption are known. In the 1944 University of Minnesota Starvation Experiment, the caloric intake of thirty-six male participants was reduced in half (semi starvation) for twenty-four weeks. Along with multiple physical changes, prolonged semi starvation induced depression, emotional distress, poor judgment, and decreased concentration-qualities present in those with disordered eating.

Why then would anyone choose not to eat, especially with the associated morbidity and mortality? Perhaps the greatest misconception is that it is a choice. Research from Dr Walter Kaye, director of the Eating Disorders Program at the University of California San Diego, indicates there is an underlying biochemical process. Neurobiology studies suggest the brain and appetite systems of patients with anorexia and bulimia function differently, so that eating is stressful, not pleasurable. It is unclear whether eating disorders reflect a primary disturbance of the brain systems that regulate appetite, or whether changes in appetite are caused first by factors such as anxiety or preoccupation with weight gain. This explains the most recent criteria change for defining anorexia. When last updated, the DSM removed the word "refusal" (as in refusal to eat or maintain weight) because it implied intention on the part of the patient. Hopefully, more accurate description of these behaviors will increase the likelihood of timely diagnosis and treatment.

Ronnie had been diagnosed later in life but always knew something was wrong. She was not alone. I thought of the young woman who worked in a fast-food restaurant. She could barely make eye contact, because her eating disorder caused her heart rate and blood pressure to be so low. It was hard to believe she could function, let alone work. There was the Ivy League educated professional who ran marathons in her spare time. Her reticence was not due to lack of energy, but rather a surplus of shame. She went in early to her office to binge and purge, away from the scrutiny of her children. Her colleagues found her unconscious on the bathroom floor. Another patient knew she had a problem as a teenager, but doctors would not formally name her condition until two decades later. She was forced to take medical leave from work after a precipitous decrease in weight. She insisted she ate in abundance, but also exercised for hours on end. Her discipline rivaled that of any professional athlete.

Ronnie, like these women, did not control her eating disorder but did her best to manage it.

Despite years of shunning food, Ronnie's eating disorder had not caused cardiac dysfunction. Others are not as fortunate. Regardless of outcome, these patients all share a certain ambivalence and work to create a world in which they coexist with their omnipresent eating disorder; a world that most, including medical professionals, do not understand. Even for those without a formal diagnosis of an eating disorder, the relationship with food can be complicated. It echoes larger issues such as the perception of beauty, self-acceptance, and control. A better understanding of disordered eating will hopefully lead to less judgement and more treatment options. Moreover, perhaps fewer will feel forced, as Ronnie and her mother had, to make peace with their eating disorder and accept it as the natural state of things.

*Names have been changed to protect patient privacy