

## “The part too often left out involves the perspectives of patients”: helping health-care providers understand the material reality of the every day for individuals with eating disorders

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**Abstract** I am in recovery from anorexia nervosa, and I have been struggling with this battle for almost 9 years. Nearly 10 million females, and one million males, in the USA are currently struggling with anorexia or bulimia as diagnosed by a physician, not even counting those exhibiting disordered eating behaviors undiagnosed (“Anorexia Nervosa” 2005). Estimates have shown that 80% of women in the USA are dissatisfied with their bodies (“Anorexia Nervosa” 2005). Suffice it to say that eating disorders are rampant in our country, and often remain a silent issue, as their effects make individuals feel ashamed and alone. While research has made leaps and bounds in eating disorder cause, treatment, and risk factors, unfortunately, the personal voice behind an eating disorder often gets lost in the midst of medicine aiming to find helpful approaches. This personal, layered account is an attempt to show that every patient’s individuality and personal experiences should be privileged throughout their diagnosis and care. Secondly, this research argues that an individual goes through a process of disease and recovery that are both complex and unpredictable. Having anorexia, and attempting to recover from it, is not as simple as a medical process resting only upon one’s motivation. I decided to write this research in an attempt to offer a voice for eating disorders, making the argument that although scientific research has been useful in particular treatment programs, perhaps it should only be used as a small supplement to eating disorder treatment programs, as personal experience shows that recovery from any life-threatening addiction

cannot be simplified in a way that ignores the agency of the patient and their experiences.

**Keywords** Eating disorders · Personal health narratives · Autoethnography · Eating disorder treatment · Doctor–patient relationship

### **Personal Calorie Log—September 14, 2009**

Went running for two hours, class for three hours, power-walked for 45 min, and ate one apple today, consumed 90 calories total—this means that 400 will be permissible tomorrow (490 calories in 2 days, round up, 500 calories—fine)

### **Journal—November 12, 2009**

I’m freaking out trying to get skinny, so I randomly just cry all of the time. I don’t know what to do. I read that there is something you can ask for at the pharmacy called Ipecac that makes you throw up (meant for infants that get poisoned), but I can only order it online from a different country. Why do I feel guilty?

### **Journal—March 8, 2010**

I feel numb. Like a shell. I think I need help. My boyfriend thinks that getting help might be over-the-top. I don’t have control over this anymore. I’m getting a little bit better with it though—only 24 diet pills today, I’ll try to cut back tomorrow.

### **Journal—March 18, 2010**

I’m so hungry and tired. I don’t care if I kill myself with this. I just want to be alone. But I feel like I’m drowning. I’m really, really scared.

Nearly one-fourth of my life has been lived while devoid of joy and self-acceptance, as I spent that portion of time incapable of being satisfied with physical aspects of my

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body that manifested into a more deep-seeded form of self-loathing. On many of my lowest days, I did not want to live anymore. This is not a tale of personal triumph, where I overcome all odds and rise to the top, beating anorexia mercilessly and never looking back. This is an experience that offers a glimpse into a terrifying disorder that countless individuals (including myself) will deal with for the rest of their lives. Now, I realize that the experiences I have had with anorexia matter, as my life and story may be able to serve as an example of the personal aspects of an eating disorder for medical professionals and patients.

Western medicine has allowed patriarchal constructions of the medical field to be viewed and understood as a site of domination, purely distinct from those that are “ill” [7]. Research has begun legitimizing patient voices by focusing on illness narratives that attempt to give voice to patients’ experiences. Storytelling provides an outlet for not only acknowledging these experiences, but also helps individuals to make sense of their everyday lives in the context of their health challenges [3, 7, 9, 17, 30, 35, 37]. Through auto- and narrative ethnography, methods of research grounded in the description of lived experience, the centrality of personal experience can be reestablished as a form of knowledge for health literature. Autoethnography is defined by Ellis and Bochner [11] as “an autobiographical genre of writing and research that displays multiple layers of consciousness, connecting the personal to the cultural,” oftentimes utilizing various storytelling techniques (i.e., short stories, plays). Narrative ethnography is used as an umbrella term covering all types of autoethnography and is characterized as a cross-disciplinary project aimed at emphasizing personal experience [18]. This account features autoethnography through the use of personal journal entries while simultaneously incorporating narrative ethnography via my shared experience [32].

This article chronologically looks at my own process of trying to make sense of an eating disorder, emerging through various visits with counselors, doctors, and treatment professionals. By writing from an autobiographical standpoint while fusing my experience with academic literature, I offer a layered account [28] which is defined as “a narrative form designed to loosely represent to, as well as produce for, the reader, a continuous dialectic of experience, emerging from the multitude of reflexive voices...” (p. 396). Yet, to write of just my experience is to also provide a voice for a larger population of individuals that have faced eating disorders. Modern medicine has given priority to treatments that allow a medical narrative emphasizing an objective, scientific story of disease to be understood and perpetuated [13]. In doing so, the body has become estranged from society. As medicine has assumed a privileged position in society as the source for all answers regarding the body, my narrative account is an attempt to

flip the script. It is my goal to write about a humbling experience that while unique to me is one that has on some level been lived by millions of others. As Frank has written on the common experiences of illness, “the disease that sets the body apart from others becomes, in the story, the common bond of suffering that joins bodies in their shared vulnerability” [13]. The method of storytelling, particularly in regard to experiences with illness, offers a therapeutic effect whereby a person can find some level of healing through reaffirmation or validation of a transformation made [13]. For those reading about another’s identification with illness and their journey, this alternative type of representation can “offer a way of seeing beyond social scientific conventions and discursive practices and therefore might be of interest to those concerned with epistemological issues and challenges” [27]. Previous autoethnographic health research focusing on eating disorders has successfully pulled readers away from the abstractions of academic jargon and toward the experience of how something feels in an effort to go beyond the manuscript and show how these forms of addiction are lived not just within the context of a writing, but throughout an everyday reality which continues for the person sharing their story [10, 25, 33]. There is a material reality for an individual with an eating disorder—while the condition is unfortunately common and much is known about its devastating effects, only part of the story of anorexia is being told. The part too often left out involves the perspectives of patients. I cannot speak for an entire group, but I can offer one perspective that can help health-care providers take a peek behind the curtain at what it *feels* like to receive the label of an eating-disordered patient.

Furthermore, my experience can serve as an example as to why it is so vital for health-care providers to acknowledge an individual’s process of experiential learning during their illness and subsequent recovery. Beginning in the 1980s, experiential learning became widely used in education, stressing that the foundation of learning lies in the ways individuals process their experiences, emphasizing the process of critical reflection [12, 15, 21, 22, 36]. The process of writing this manuscript has proven to be a form of education, not just for myself, but more importantly for the health-care community. Boud, Cohen, and Walker [4] explain that one’s experience can be the catalyst for an active process of learning in a holistic sense, meaning that by practicing reflection in the socially and culturally constructed context one has the ability to not only achieve self-growth, but the application of experiential learning can be more widespread, influencing effects on social education and community consciousness [8]. The quality of the learning is possibly dependent upon the degree of involvement of the individual, meaning that, in health care,

patients must be involved with their health-care providers in making sense of their experiences [12]. However, beyond merely experiencing something and reflecting upon it, experiential learning takes place when an individual has the opportunity to have a meaningful interaction by overlapping these two components, suggesting that it would be helpful for health-care providers to give their patients the time to make these connections when discussing their condition, thereby increasing the strength of the doctor–patient relationship [5, 20, 24].

I have had anorexia for 9 years, and at more times than I would like to admit, it was an exclusive representation of my self-identity. One question my family always asked was why I felt compelled to control my weight. Traumatic experiences can result in someone becoming more likely to develop an eating disorder, as pivotal moments that life throws our way often cause us to reevaluate who it is we think we are. For me, there was one moment that turned my life upside down, and I know it contributed to my feelings of inadequacy. At the age of 13, I fell off a trampoline and was seriously injured. Prior to this experience I had always been an active, confident individual. As medical problems persisted, I discovered I had developed a condition called Chiari malformation, which required me to have brain surgery. After going through that experience at a relatively young age, I felt as though my identity had shifted. I no longer knew exactly who I was and had to adjust to the changes life had thrown my way. I can recall that my medical experiences made me feel as though I was abnormal on the inside, so once I went away to college and had the ability to function more independently, I became fixated on making myself correct again (as perfect as possible) on the outside. My eating disorder stemmed from a traumatic accident that made me feel out of control of myself, and as a result I sought ways to regain control of my body. By refocusing one's attention on weight and eating, individuals that have previously had a traumatic experience impacting their identity can regain some type of emotional control [26]. Research has shown that eating disorder patients report significantly higher levels of dissociative experiences than normal subjects, showing a relationship between overwhelming trauma and a dissociative reaction [34]. Eating disorders are often attributed to a need for gaining a sense of control; for individuals who are already struggling with conceptions of their identity, managing eating habits aids in combatting these emotional struggles [29]. For me, this meant restricting my nutritional intake to the point of obsession. While my progression toward anorexia was gradual, it eventually caught up with me as I realized the self-induced pressure and incessant analysis of my body in the mirror had taken over my ability to care about anything else in my life. Controlling my image became my hobby, the one area that no one else

could question or touch. It proved I had strength. At least I thought it did.

I could not bring myself to sticking my fingers down my throat to vomit. After I made myself throw up just one time in the shower of my dorm during my sophomore year of college, I remember thinking that starving myself would have to be the way to do it—vomiting seemed too drastic to me. I remember thinking that if I purged, it would have meant I had a problem. Instead, dieting was part of the culture in college. Restricting your food intake was normal, accepted, and even encouraged. If I just wrote down every calorie consumed, swallowed enough of the dark green diet pills, ran just one more mile, refused another dinner invitation, I felt I was one step closer to being good enough. What started as a form of willpower quickly turned into a perpetual battle with myself. There was a constant conversation in my mind and I would always wind up being not good enough, not beautiful enough, and not the perfect version of myself I wanted so desperately to be.

As many as 61 % of college-aged women have some type of disordered eating, often attributed to culturally mediated pressures in Western societies to have thin, perfect bodies [23]. I certainly felt that pressure, and still struggle with mediated images of what it means to be attractive. While research cannot prove that the media causes eating disorders, it does show that the type of exposure, not the amount, correlates with higher rates of body dissatisfaction and an increased drive for thinness [31]. Specifically, exposure to soap operas, movies, music videos, and magazines are associated with higher rates of negative body image [31]. Perhaps, one of the strongest examples of the media's influence on body image is Becker's study comparing rates of eating disorders before and after the arrival of television in Fiji in 1995. Prior to the introduction of television, Fijians were traditionally healthy with rotund body types, serving as a form of cultural significance by exemplifying that an individual was wealthy and able to provide for their family [1]. In 1998, 3 years after television had been introduced in Fiji, rates of dieting increased from 0 to 69 %, with young women attributing their change in eating behaviors to the appearance of the actors on television shows such as "Beverly Hills 90210" and "Melrose Place," serving as inspiration for their weight loss [2]. My experience with anorexia involved a desire to be perfect, and I defined perfection based on the images I saw in the media. I can still recall believing that the only way my body would look acceptable in a bathing suit would be if my hip bones were visible like the models in the *Victoria's Secret* catalog. I could not flip through a magazine without thinking, "My hips are so much wider, her thighs are so much thinner, I want my ribs to show that way, I look nothing like that..."

For someone not experiencing an eating disorder, it can be difficult to understand its effects. There were psychological, social, and physical effects associated with my being underweight. My thinking was impacted since the brain requires energy (in the form of calories) to properly function. By becoming malnourished, my brain could not work logically or quickly. When I would restrict (a common term used to delicately describe the points at which I starve myself, with my longest stretch lasting 3 days), I struggled trying to find the right words when speaking to a friend, fought to get the simplest of tasks accomplished, and could not think clearly. I became obsessive in my daily routines, almost as if my sanity depended on my ability to control my life. I can recall physically feeling my heart ache in my chest, almost as if it were straining to pump blood. My blood pressure became significantly low at points, I often got dizzy when standing up, and I knew I had inflicted a great amount of stress on my body once my period had stopped. My hair fell out, I was constantly cold and wrapped in blankets, and I developed insomnia. You know how it feels when you get the flu, and your entire body aches? It just hurts, all the time, and you feel as if you will never feel healthy again? That is what it feels like to have anorexia. I had to experience these feelings to realize just what I was doing to myself. Aside from the physical aspects, having to deal with the emotional impact surrounding the self-inflicted trauma you have put on your body is much harder to grasp.

I knew I needed help the moment my family came to visit me and I saw the looks on their faces. My mom just had tears in her eyes, and I could tell something was wrong. It was not until that moment, where I was forced to be removed from myself and to realize the impact my disease was having on those that I loved, that I understood I had a problem. While scholarship continues to address possible causes of eating disorders, focusing on physical symptoms, the media, childhood trauma, and personality types, one aspect that is often missing is someone's voice—a story, an experience, and the feelings that accompany the most deadly form of mental disease in the USA. Rather than emphasizing individual facets of eating disorders, my experience can shed light on why emphasizing a holistic model of patient care is so important during an individual's eating disorder recovery. Holistic patient care refers to viewing a patient as a whole person, “as an individual with physiological, psychological, and spiritual needs who is part of and is influenced by family and other social cultures” [16]. Rather than identifying a person as an eating-disordered patient, I can attest to how vital it is that a patient feels that medical providers are attempting to understand the individual behind the disorder in the context of their everyday life. In my case, I wanted to be seen as more than just a patient with an eating disorder. It was

important to me that my medical team understood that I was also a daughter, sister, friend, and graduate student. Thus, by medical professional emphasizing wellness and promotion while addressing the whole person within their familial and cultural context, eating disorder recovery can seem like more of a possibility for an individual that is facing such a significant challenge.

#### **Worksheet on first day of treatment in Pittsburgh—May 17, 2010**

**Prompt provided: “I want to be perfect at the following things or in the following ways...”**

4.00 GPA, do everything asked of me, always be ahead in school, be a skinny/pretty daughter that others can be proud of, following exercise routines or meal advice from boyfriends as best as I can, have it all together, fix everything for everyone, size 0 or 00, hip bones visible, thin face, thin arms, no belly, bones, thin legs, small thighs, be the perfect package  
**Treatment Journal—June 3, 2010**

I'll never get discharged from this place. I'm so tired of hearing “we know what we're doing. You're driven, Janelle, but is this you or your eating disorder talking?” It's me. Just because I have an eating disorder doesn't mean I'm lost forever. I'm still here.

It is important for research to begin looking at the concept of social identity in association with the recovery process. Family and friends have been identified as great tools for relapse prevention for those recently recovered from eating disorders, but perhaps research could more specifically identify the social identities that would be deemed most helpful for those recovered as a form of relapse prevention. Furthermore, and this cannot be stressed enough, health-care providers must involve support systems in the recovery process and point them to resources for help. My loved ones were often at a loss for how to help me, and I think a great part of that comes from the inability for research to extend dialog to offering individuals helpful suggestions. There is no right or wrong way to help someone with an eating disorder, but there are certainly ways that support team members can become positively involved in the process of recovery, as these individuals are seen as components of the holistic person discussed earlier [16].

#### **Worksheet from treatment in State College—October 26, 2011**

**“Ways I Have Made Progress So Far in Recovery...”**

I accepted that I have anorexia, go to counseling twice a week no matter what, in a recovery program, I have a great support team, trying to sleep more, not lying or hiding about where I am at with my disorder,

haven't taken diet pills in almost two years, I'm excited to eat Thanksgiving dinner with my family (that's a huge deal!), and I can go grocery shopping now.

#### **Journal—February 11, 2012**

At some point, I think everyone in their own story, their own life, has to do something. In my story, and in who I am, I've been thinking a lot lately about recovery, about really taking the next step forward. My "doing" something might just be living a normal life. I've been medically cleared to enter into a step-down recovery group if I choose, which means I'll be graduating from the intensive outpatient program I've been in for the past five months. I want to move forward and focus on happiness. Instead of remaining stagnant or comfortable, I feel like I'm ready to take the next leap of faith, not for recovery this time, but more for my life. I've decided to continue my individual counseling sessions and to have bi-monthly visits with my physician for accountability. My job right now is to remain happy, healthy, and excited about life. I'd like the chance to apply all that I've learned.

#### **Art Therapy Workbook—February 26, 2012**

**Prompt: "In this task, create a series of tools for mastering the discomforts of change. What is it like to approach the discomfort of healing by first laying a foundation of tools to help you move upward? How do you think these resources will be helpful? Write about how some of these new tools you identified might be useful in your current situation."**

(Jacobson and Foy-Tornay [19], p. 125).

My tools for recovery: Getting medical help, putting a support team in place, speaking honestly about where I'm at in recovery, slowing down more to enjoy life, admitting lapses to get back on track, having more fun, and eating with others. It felt really, really good to formulate these tools because it reminds me of the steps I've already taken to stay healthy. I can't believe how far I've come. Keeping myself in-check medically is crucial, but I've also learned how important it is for me to take the lead. It's my journey, my road to being fully recovered. And I've already put all of these tools in place. These pieces will be part of my trajectory toward a successful, forever-lasting recovery. How exciting!

Research often discusses the recovery process, but little attention has been given to the process of change experienced once an individual becomes physically healthy and is discharged from treatment. Maintaining change once it has been achieved can be very difficult, and is a very important

topic, considering only 44 % to 76 % of individuals maintain their recovery after discharge (over a period of 56-59 months) [14]. Data suggest that one-third of patients with anorexia fully recover, one-third retain some symptoms, and one-third maintain a chronic eating disorder [14]. That statistic is alarming to me because as a researcher I find strength in numbers, yet what is behind those numbers resonates with me so much more. I do not want to be a statistic. I do not want to be another quantitative measure. Anorexia is the most deadly disorder recognized by the American Psychiatric Association, with up to 20 % of those with anorexia dying, primarily as a result of cardiac arrest or suicide [14]. Read that sentence again. It is important and it is what I have to remind myself of every day. Reasons for change need to be revisited often for individuals to remember why they are in recovery. While there are certainly a number of helpful sources individuals can reach out to during recovery, the fact remains that the process is heavily, if not all, influenced by one person's desire to be healthy. My desire also includes what I want for my future. I want children, and I want the opportunity to act as a healthy advocate for their lives.

Today, I am in recovery from anorexia. I regularly visit with my counselor, follow strict meal plans prepared by a nutritionist, and avoid anything that I know would be triggering against my recovery process. As I reflect on what I have been through, I can feel a sense of pride, but I am also excited for the challenge ahead. Many of the negative opinions I have of my body are still present in my mind, and that means I am still in the process of recovery, as I have some work to do. The silver lining is that, 1 day, I know I will be able to say "I am recovered" as opposed to "I am in recovery." The difference between those two sentences may seem minimal to someone else that has not experienced an eating disorder, but for me the meaning behind putting recovery in the past tense is everything—my everyday experience involves constantly reminding myself that the only way I can have a healthy future is if I keep going, fighting, and eating.

This narrative has given a small glimpse into my life through some of its worst moments that eventually led me back to a place where I regained hope. In association with literature already present in the field, it is my hope that my experience helps medical professionals, social workers, counselors, families, and friends to understand eating disorders better. Part of having an eating disorder means you lose yourself temporarily, maybe forever, oftentimes without realizing it. It is oppressive, uncertain, and lonely. I spent so many hours of my life counting calories, avoiding others, and pushing myself harder and harder, rather than enjoying my life. I hope that my story inspires not only academia to conduct future research in this field, but also



health-care practitioners to take a more personalized approach to medicine. This means that practitioners should enter into a partnership with patients whereby they medically evaluate their bodies while simultaneously listening to their concerns in moving forward with treatment. Eating disorders are all the more complicated because they are centered so much on the body, and what matters here is that patients are not thought of as just a body, but rather a holistic being with hopes, dreams, opinions, and fears.

By opening up to patients and showing that you are hearing their concerns, practitioners can better understand the lived experience of having an eating disorder, not only relying on medical research that has been provided for the field. In this way, practitioners have an increased ability to connect with their patients and act as a source of encouragement throughout health maintenance and recovery stages. Health-care practitioners can effectively achieve this style of narrative medicine by addressing three areas with their patients: attention, representation, and affiliation [6]. By enabling health-care professionals to “recognize more fully what their patients endure and to examine explicitly their own journeys through medicine,” a dialogue can begin that permits patients to feel they are being heard, thereby giving medical professionals the chance to be more receptive to their patients [6].

Individuals with eating disorders are more than the label assigned to their medical charts. We are all sisters, brothers, daughters, sons, friends, and spouses. We are all significant to someone, even if we may not believe we are. If you think someone you are close to may be struggling with an eating disorder, it is not my place to tell you to try to get him or her help. One thing you can do is let that person know they are loved, they are valuable, and that you care. The family and friends that loved me were my bridge back home. I am still taking the journey, but I know that I am closer than I have ever been before.

#### Journal—October 26, 2011

##### **Prompt: “One day, this is how I’ll define freedom from my eating disorder...”**

Freedom from an eating disorder means life. It means not restricting, and following the intuitive hunger I can feel in my belly. Freedom is nourishing my body, and not thinking twice about that. Freedom means loving my body and being confident about who I am. It involves caring for myself so that I can love others to the best of my ability. Freedom from an eating disorder means I fought death, and that I succeeded. It means I see myself for the true woman I am, inside and out. It means that someday I’ll raise confident, healthy children. Freedom means love, grace, support, and achievement. My freedom means everything to me.

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