

From the Klarman Eating Disorders Center, McLean Hospital

Cognitive-Behavioral Treatment of Body Image Disturbance in a Congenitally Blind Patient With Anorexia Nervosa

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Fewer than 10 published case reports have described the development of anorexia nervosa (1–8) or bulimia nervosa (9) in blind persons, and some of these explicitly deemphasized the centrality of body image disturbance in the etiology and maintenance of eating disorders in the nonsighted (6, 9). In addition to these case data, a single study (10) has examined features of eating pathology in blind women. In that nonclinical sample, scores on the Body Shape Questionnaire and Eating Attitudes Test indicated significantly less pathology among congenitally blind women relative to both sighted women and women who became blind later in life. The investigators therefore concluded that “the ability to visualize oneself and others is integrally linked to the dissatisfaction of one’s own body shape” (10, p. 321).

In contrast, other investigators have posited that the inability to see oneself has the potential to exacerbate the development of poor body image, given that blind persons may be especially likely to misperceive body size (7), partly because of a lack of corrective visual feedback to challenge perceptual distortions (4). To augment the sparse literature on eating pathology in blind persons, and to examine further the novel window on etiologic questions that anorexia nervosa comorbid with blindness allows, we describe a case of anorexia nervosa in a 20-year-old woman with congenital blindness.

The following case presentation was drawn from the patient’s subjective report of her history and symptoms at treatment presentation; behavioral observations we made while providing standard care; a comprehensive review of the patient’s medical record; and the patient’s self-re-

ported symptoms 10 weeks and 20 weeks after discharge from our residential eating disorders treatment program. Because the patient was quite insightful about her illness, we also transcribed selected illustrative patient quotations from individual therapy sessions and posttreatment interviews. This procedure was reviewed by representatives of the institutional review boards at both McLean Hospital and Massachusetts General Hospital and exempted from formal review. The patient consented to use of her case data for publication in the scientific literature, and she read and approved the final manuscript.

Case Presentation

“Ms. A” was a single Caucasian woman who first presented to a residential eating disorder treatment unit at age 19 with a 10-year history of anorexia nervosa, restricting subtype. Ms. A also had congenital blindness associated with albinism. She described herself as having “3% of full vision”; she was able to detect only high contrast, some color, and large forms under optimal circumstances, and nothing at all under others. Despite her visual impairment, Ms. A was exceptionally high-functioning, articulate, and bright. In addition to receiving a mainstream education, she had attended a school for the blind, where she received occupational therapy that facilitated her ability to read and write with accommodation (e.g., via closed-circuit television reading machine) and mobility training that promoted her integration into the sighted world through techniques such as simulated eye contact and echolocation of nearby people and objects. Ms. A’s family history was notable for both mental illness (e.g., depression) and physical disabilities (e.g., visual impairment). Notably, per Ms. A’s report, she had a close relative with severe anorexia nervosa who had received treatment that included multiple psychiatric hospitalizations during Ms. A’s own childhood and whose illness was still active at the time Ms. A presented to the treatment facility.

History of the Presenting Illness

In the initial clinical interview, Ms. A provided a psychiatric history. She reported that her eating disorder symptoms had begun at age 9, although she did not receive formal treatment until she was 14. After onset, her eating disorder was characterized primarily by chronic food restriction, low weight, and irregular menses. She denied a history of binge eating, self-induced vomiting, or diuretic abuse, although she had taken laxatives to facilitate purging on a few occasions. Ms. A also presented with comorbid obsessive-compulsive disorder (OCD)—characterized by excessive hand washing and need for

symmetry—that had predated her eating disorder. Interestingly, despite her impaired vision, Ms. A's obsessive-compulsive need for symmetry manifested across multiple modalities, including tactile (physically sorting books, dishes, and clothing into symmetrical arrangements) and cognitive (requiring that the main events of her day be separated by symmetrical increments of time). At age 14, she was formally diagnosed with major depressive disorder and anorexia nervosa, and she began outpatient treatment, which included psychotherapy and pharmacologic management for her eating, mood, and OCD symptoms. For the next 5 years, she received non-specific supportive psychotherapy in weekly individual sessions with a psychiatrist who prescribed fluoxetine (adjusting the dosage up to 80 mg/day) to address depression and anxiety and encouraged Ms. A to develop insight into her eating, mood, and OCD symptoms without applying direct pressure for behavioral change. Ms. A retrospectively described her outpatient treatment as “unsuccessful,” noting that her weight dropped steadily to a low of 95 lb, representing a body mass index (BMI) of 15.1 for her height of 66.5 in. At age 19, she matriculated at a university in a region distant from her childhood home. During her first semester, she presented for treatment at the university's student mental health service, where she received weekly psychodynamic therapy for anorexia nervosa and depression. Because of concerns related to her low weight, Ms. A's university-based treatment team strongly encouraged her to participate in residential eating disorder treatment immediately after completing her first semester in order to facilitate her continued enrollment at the university.

On admission to the treatment facility, Ms. A was visibly underweight (100 lb, BMI=15.9), had missed several recent menstrual periods, and denied the seriousness of her low weight. Her treatment team diagnosed her with DSM-IV anorexia nervosa, even though she did not overtly endorse criterion B for the disorder (“intense fear of gaining weight or becoming fat”) at her first admission. On presentation, Ms. A was noted to have a total lack of pigmentation (pale skin, white hair), consistent with her report of albinism. Moreover, her hands appeared red and raw from repeated washing. Formal clinical evaluation confirmed her comorbid self-reported axis I diagnoses of current OCD and major depressive disorder and did not reveal any axis II diagnoses. She was highly cooperative and articulate and exhibited mood-congruent, bright affect. She did, however, report daytime fatigue and low energy, possibly secondary to depressed mood. Despite her low weight, she did not present with significant medical complications on axis III. Her Global Assessment of Functioning score was 45.

Course of Treatment

To facilitate weight restoration and to promote further insight into her symptoms, Ms. A was admitted to the residential eating disorders treatment program to participate in individual, group, and milieu therapy, along with pharmacologic management and nutritional rehabilitation. Over the course of 1 year, Ms. A presented for three separate episodes of care at the same treatment program: an initial 10-week admission at age 19 after her first semester of university; a 2-week readmission 1 month later to prevent imminent relapse during her second semester; and a 4-week readmission nearly 1 year

later at age 20, after a second relapse during her third semester. Treatment planning was arranged to minimize term time absences.

When Ms. A was first admitted, her treatment medication regimen, according to her outpatient psychiatrist, included fluoxetine (80 mg/day) for depressed mood and OCD, modafinil (200 mg/day) to augment the effects of fluoxetine and to enhance alertness, and risperidone (0.75 mg/day) to stabilize mood. Because of Ms. A's poor tolerance of side effects, the unit psychiatrist reduced her dosage of fluoxetine (to 20 mg/day) and replaced her risperidone with quetiapine (200 mg/day).

During her first two admissions, Ms. A provided multiple rationales for food refusal, none of which prominently featured shape and weight concerns. For example, she stated that she derived self-esteem from her ability to restrict her diet, which assuaged her “fear of exorbitance” by providing “containment, safety, and control.” Second, she endorsed prominent maturity fears and explained that her eating disorder helped her elicit the mothering behaviors she craved from caregivers (e.g., physical affection and emotional reassurance): “I have an overwhelming desire for the experience of childishness and care,” she said. By age 14, Ms. A explained, she had become “very private and independent” about her psychiatric symptoms in an effort to protect her parents, whom she worried were already overburdened by years of difficulty coping with the challenges of raising a blind daughter. Even when directly queried about shape and weight concerns during these first two treatment episodes (e.g., during individual therapy sessions and during body image therapy groups), Ms. A minimized their relevance to her long-standing pattern of restrictive eating.

Emergence of Body Image Disturbance

It was not until her third admission that Ms. A began to endorse body image disturbance actively. At this time, she requested a consultation with the unit body image specialist (J.J.T.) to discuss her emerging weight and shape concerns. Notably, the evolution of Ms. A's expressed shape and weight concerns from minimal to extreme resonates with contemporary debates (11) about whether body image concerns are intrinsic to anorexia nervosa or epiphenomenal to the disorder and merely co-constructed in the clinical encounter (12). Although we cannot be certain about what factor or factors precipitated the emergence of body image disturbance late in the course of Ms. A's illness, one or more of the following five contextual factors may have served as proximal triggers:

1. After returning to her family home after an extended absence during the academic year, Ms. A was reexposed to her relative's severe anorexia nervosa, which she reported was characterized by fat phobia and food restriction. Ms. A reported feeling highly “competitive” with this sighted female relative, whose recent dramatic weight loss Ms. A attempted to assess visually within the confines of her limited 3% vision and tactilely through embraces. During family gatherings, Ms. A reported feeling frustrated that she was encouraged to eat the balanced meal that was served, while her relative independently prepared and picked at a low-calorie alternative. Ms. A described her reexposure to this perceived rivalry as distressing and identified it as a major factor in promoting her relapse.

2. In contrast to her first admission, at which time Ms. A denied interest in dating because she was “blind and look[ed] different” (i.e., albino), when she presented for her third admission, she expressed a newfound interest in pursuing a romantic relationship. Notably, one of the main areas of body dissatisfaction that Ms. A newly endorsed was that she was too “flat-chested,” a complaint that, while uncommon in anorexia nervosa patients, who typically value extreme thinness, may have reflected Ms. A’s increased motivation to achieve the socially idealized feminine form.

3. After completing her first year at university, Ms. A placed greater emphasis on her autonomy and de-emphasized the need for significant others to provide caregiving behaviors. Before her third admission, Ms. A had placed herself on the waiting list for a guide dog that would afford her greater mobility and independence after discharge from the program. Moreover, she explained that she had begun to view food restriction as increasingly egodystonic, childish, and incongruous with her emerging academic, career, and social goals. It is therefore possible that Ms. A’s body image concerns became more salient as her maturity fears began to recede.

4. The social contagion of eating disorder psychopathology is well established (13), and Ms. A’s hospitalization on this unit was her first episode of inpatient or residential care. It cannot be ruled out that simply hearing other patients talk about their own poor body image or hearing clinicians target body image concerns in both group and individual therapy may have contributed to the initial development or increased salience of such concerns as legitimate rationales for food refusal (12).

5. Ms. A described herself as more motivated for change on her third admission. It is possible that her body image concerns were not new, but rather that she developed greater awareness, insight, or willingness to disclose and examine them than she had earlier in the course of her illness (14).

Cognitive-Behavioral Manifestations of Body Image Disturbance

Whatever the proximal trigger for Ms. A’s newly expressed body image disturbance, its presentation bore a striking similarity to that of her sighted peers. The following clinical data were collected during a series of three 60-minute cognitive-behavioral therapy (CBT) sessions that Ms. A requested specifically to address body image concerns during her third admission.

In the initial session, Ms. A disclosed myriad body checking behaviors. “I do all of the checking, but without the eyes,” she explained. As in two previous case reports of anorexia nervosa among blind patients (3, 5), Ms. A reported frequent tactile body checking, such as feeling for bony protrusions in her face, ribcage, spine, and hips, and assessing the perceived tightness of clothing. She anticipated that these tactile checking behaviors would be particularly difficult to relinquish because, she said, “touch is my primary sense.... As a child I was trained to feel instead of see.” Moreover, similar to the blind anorexia nervosa patient described by Yager and colleagues (3), Ms. A engaged in body avoidance, preferring during her admission to wear loose-fitting, dark-colored clothing that would disguise her body shape. Furthermore, in the years leading up to her admission, she reported eschewing jeans, fitted trousers, short-

sleeved shirts, and bathing suits. In addition to tactile checking and body avoidance, Ms. A also reported several cognitive-behavioral manifestations of body image disturbance that have not previously been reported in the literature on blind patients with anorexia nervosa and bulimia nervosa, including attempted mirror checking. “I like to pretend I can see a form,” she explained, describing how she often stood very close to full-length mirrors in order to make out patterns of light and darkness that might provide insight into potential changes in her body shape. Ms. A explained that because she could typically only see “a blob,” mirror checking usually resulted in her concluding that her body was too large. She also reported that she engaged in frequent body comparisons between herself and others. Not only did she engage in tactile comparisons (e.g., feeling another person’s arm bones during an embrace), but she also compared herself to the imagined attributes of others’ bodies, despite her inability to see them. To facilitate navigation without sight, Ms. A had been trained to use echolocation to ascertain the approximate location of nearby people and objects. As she increasingly endorsed extreme body image disturbance, she began to describe applying these techniques to the assessment of others’ shape and weight. For example, during conversations, she paid close attention to others’ voice location and pitch, which she interpreted as clues to height and weight, respectively, with higher locations indicating taller height and lower pitch indicating greater abdominal girth. One study of 9- to 11-year-old blind children confirmed the use of auditory clues to ascertain others’ appearance as a common practice among the non-sighted; indeed, 43% reported using the sound of others’ voices to estimate their approximate body size (15). However, the accuracy of these auditory estimations remains unknown. Ms. A further estimated others’ body sizes through vigilance for changes in air pressure when standing near those individuals, interpreting greater pressure as indicative of larger body size.

Adaptation of CBT for Body Image Disturbance in a Nonsighted Patient

In the spirit of strong recommendations to adapt cognitive-behavioral interventions to the individual characteristics of the presenting patient (16), the unit body image therapist adapted Ms. A’s treatment plan from cognitive-behavioral interventions that had previously been shown to ameliorate body image disturbance in sighted individuals (16–19).

First, the therapist utilized self-monitoring and response prevention to reduce body checking and comparison behaviors (16, 17). Ms. A was receptive to psychoeducation highlighting how body checking may promote selective attention to perceived flaws and thereby maintain negative body image. She agreed to keep a detailed self-monitoring record of her body checking behaviors for 1 day, which revealed that she relied heavily on her sense of touch for self-care activities, such as dressing and showering. Collaborative examination of the self-monitoring results allowed Ms. A to identify and reduce extraneous movements that did not facilitate the completion of daily activities, such as feeling her hipbones while dressing, feeling her arm bones while showering, and hugging herself while sitting. To facilitate response prevention, Ms. A agreed to adhere to

a 2-minute time limit for dressing each morning. With regard to body comparison, Ms. A was steadfast in defending her ability to make reasonably accurate inferences about others' appearance from techniques in which she had been trained to manage her visual impairment (e.g., voice location and pitch, changes in air pressure). She did concede, however, that she "probably imagines the best of all possible worlds," such as "a slim figure and attractive proportions." Therefore, she agreed to complete homework exercises in which she imagined a variety of possible physical appearances that might plausibly be consistent with the location, pitch, and pressure data she had collected, not all of which were as attractive or idealized as the first images that she had envisioned.

Ms. A had also heard about the use of mirror exposure therapy to promote body acceptance (18) in this program, and she requested a trial for herself in order to determine the extent to which her mirror checking behaviors might be contributing to cognitive distortions. During the 15-minute exposure exercise, the therapist asked Ms. A to stand in front of a full-length mirror and describe only what she could objectively see within the limits of her 3% vision. She responded as follows: "I can't see my body because I'm wearing dark clothes.... I can't detect any contour.... I'm used to taking a lot more from it." Ms. A then compared these limited data to the broad-based conclusions that she typically drew from her mirror checking behaviors (e.g., that she had "large hips, large thighs, and strange coloring"). After completing the exposure exercise, Ms. A was able to discuss how, before the onset of her eating disorder, making inferences about her own physical appearance likely represented a helpful adaptation to her visual impairment. However, she admitted that in the setting of increasingly poor body image, such inferences often became extreme versions of the body-related cognitive distortions that are typical of sighted individuals with anorexia nervosa, such as all-or-nothing thinking, magnification, and discounting the positive (19). She was therefore receptive to the suggestion that she carefully evaluate the objective evidence for and against these body-related distortions as they occurred (19).

In summary, Ms. A's receptiveness to and active engagement with this series of adapted cognitive-behavioral interventions indicated early therapeutic promise for a CBT approach. Although the clinical team encouraged Ms. A to remain in residential care until she had fully restored her body weight, the patient and her outpatient team negotiated an early discharge to allow her to return to university at the beginning of the new term to resume her studies. As a result, formal follow-up data to ascertain long-term treatment effectiveness are unavailable. However, in the short term, Ms. A did complete all in-session exercises and homework assignments during the three-session course of her body image treatment, and at program discharge she reported reductions in body checking, comparison, and avoidance behaviors.

When we met with Ms. A 10 weeks after discharge from her last program admission to assess her progress and obtain permission to write up her case, she reported that her menses had fully resumed and that her weight had increased to 111 lbs (BMI=17.6). When we spoke with her again by telephone 20 weeks after discharge, Ms. A reported that she was continuing to menstruate and was maintaining her weight at 110 lbs and that, despite the

brevity of her body image treatment, she had incorporated many of the prescribed CBT exercises into her daily routine. "I get dressed very quickly now, and I've been able to avoid body checking in the shower," she said. "I don't really use mirrors much at all anymore. Sometimes I'll ask my roommates, 'You be my mirror,'" in order to obtain a more objective point of view. With regard to body comparison, she said, "I've been trying to be more analytical about what people might look like." Consistent with the program's discharge recommendations, on both occasions, Ms. A was continuing to pursue intensive outpatient treatment, including individual therapy, group therapy, nutritional counseling, and pharmacotherapy. "It's a work in progress," she said. "I'm trying very hard."

Discussion

The finding that a nonsighted eating disorder patient exhibited such great preoccupation with body image is unexpected given previous case reports suggesting that body image concerns may not be central to eating pathology among blind individuals (6, 9). Nonetheless, our findings are consistent with a small number of case reports that have reported cognitive-behavioral manifestations of body image disturbance, such as body checking (3, 5) and avoidance (3) in nonsighted patients, and build on previous reports by identifying additional theoretically observable signs, such as attempted mirror checking, and self-reported symptoms, such as body-related comparisons. Our case findings suggest that with the need to rely frequently on assumptions about the physical appearance of self and others to compensate for visual impairment, coupled with a lack of corrective visual feedback, body-related cognitive distortions may have the potential to become severe in the nonsighted, as observed in this case. We have so far described Ms. A's visual impairment as it influenced her body image disturbance within the wider context of anorexia nervosa. However, just as Ms. A's visual impairment became a distinctive peculiarity of her eating disorder, it is possible that her eating disorder itself stemmed from the broader struggle to define herself as a blind person in a sighted world.

To our knowledge, this is the first description of the adaptation of CBT for body image disturbance in a blind patient with an eating disorder. Although the clinical significance of our findings is limited by being based on observations from a single case and by limited follow-up data, they support the idea that CBT, when adapted to address the impact of visual impairment on body image concerns, may be relevant and acceptable to at least some nonsighted patients. Of course, more research is needed to clarify the characteristics and severity of body image disturbance in individuals with visual impairment; the ways in which interventions for body image disturbance may be most strategically adapted for nonsighted patients; and the extent to which body image concerns are intrinsic to anorexia nervosa as opposed to being anchored in a particular social and personal context that enhances their relevance.

Received April 16, 2010; revision received June 20, 2010; accepted Aug. 23, 2010 (doi: 10.1176/appi.ajp.2010.10040555). From the Klarman Eating Disorders Center, McLean Hospital, Belmont, Mass.; Eating Disorders Clinical and Research Program, Massachusetts General Hospital, Boston; Department of Psychiatry and Department of Global Health and Social Medicine, Harvard Medical School, Boston. Address correspondence to Dr. Thomas (jjthomas@partners.org).

The authors report no financial relationships with commercial interests.

Supported by a Klarman Foundation Fellowship to Dr. Thomas.

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