The Promise of Music Therapy: Understanding and Treating Individuals With Comorbid Eating Disorders and Physical Disabilities

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Research has historically dismissed the prevalence of eating disorders in people with disabilities, yet studies and clinical observations suggest that individuals with physical disabilities are at increased risk for developing eating disorders. Due to this discrepancy, there is little awareness of how to treat eating disorders among this population. Self-understanding is a key component in treating both individuals with physical disabilities and individuals with eating disorders. With this finding, this article seeks to demonstrate that music therapy is an effective treatment option for those with both an eating disorder and a physical disability due to its focus on self-understanding.

Eating disorders have historically been characterized as an illness affecting adolescent, middle- to upper-class, able-bodied, white female individuals; thus, early academic research tended to dismiss the prevalence of eating disorders in people who fell outside these categories—such as people with disabilities (Striegel-Moore & Bulik, 2007; Striegel-Moore & Smolak, 2001; Tiggeman & Lynch, 2001). Although studies and clinical observations suggest that individuals with physical disabilities are actually at increased risk for developing eating disorders, there is little awareness of how to treat and prevent eating disorders among this population (Gross, Ireyes, & Kinsman, 2000). Unique stressors, such as body-image disturbances due to the disability, feelings of lack of control due to dependency on others, and an emphasis on weight maintenance to sustain mobility, make people with disabilities particularly vulnerable to eating disorders (Gross et al., 2000). Treatment and prevention, however, are particularly difficult due to accessibility issues, stigma, diagnosis errors, and physical and medical limitations.

Examining current therapeutic interventions, it is clear that there is a lack of available treatments for individuals with both an eating disorder and a physical disability. Music therapy shows promise as an intervention for these comorbid conditions (Heiderscheit, 2009; Hooper, 2007; Weiss, 2013). For both client groups, the most common goal is feeling more in control and improving self-understanding (McFerran, 2010). These goals align with one of the main purposes of music therapy: identity formation (McFerran, 2010). This article seeks to demonstrate that music therapy shows promise as a

valuable technique for treating individuals with both physical disabilities and eating disorders as it addresses goals common to both of these comorbid diagnoses.

Eating Disorders and People with Physical Disabilities

For the purposes of this article, physical disability is defined as "a congenital disease, acquired illness, or trauma that leaves a person with a physical limitation that lasts at least one year" (Tsan-Hon, Pi-Sunyer, & Laferrère, 2005, p. 321). The fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders* identifies three main types of eating disorders: anorexia nervosa, bulimia nervosa, and binge eating disorder (American Psychiatric Association, 2013). Having a physical disability is often stressful, chaotic, and unpredictable; as such, individuals with disabilities may use calorie restriction as a distraction, stress management tool, or means of control (Roosen & Mills, 2014). These behaviors are so common that having a physical disability is a higher risk factor for developing an eating disorder than having a mental illness such as depression or anxiety (Roosen & Mills, 2014). For example, in a survey of 71 women diagnosed with spina bifida or rheumatic illnesses, more than 20% of respondents showed symptomology of eating disorders (Gross et al., 2000). In comparison, 9.4% of the United States population suffers from an eating disorder (National Eating Disorders Association, 2014).[1]

Early feeding problems (e.g., difficulty consuming solid foods or liquids due to a physical impairment and/or behavioral issue) are common for those with disabilities and may constitute a risk factor for later eating disorders (Schwarz, Corredor, Fischer-Medina, Cohen, & Rabinowitz, 2001). Due to fears and limitations regarding food consumption, children feel isolated and misunderstood, which can have a detrimental impact on the child and may later lead to a diagnosed eating disorder (Chatoor, 2009; Natenshon, 2016).

Obesity rates for adults with physical disabilities are approximately 53% higher than for adults without physical disabilities (Tsan-Hon et al., 2005). More than 50% of adults with physical disabilities have concerns about their weight, often leading to unhealthy eating behaviors such as restricting food intake (Roosen & Mills, 2014). Silber, Shaer, and Atkins (1999) looked at five individuals diagnosed with spina bifida. They all were overweight prior to their diagnoses and had been advised by their health care professionals to lose weight in order to improve their mobility. Dieting and the resulting weight loss they experienced became a source of power for them that could compensate for their neurological limitations and deflect attention from

[1]According to the National Eating Disorders Association (2014), there are 30 million people in the United States with an eating disorder, out of a total population of 318.9 million as of 2014 (United States Census Bureau, 2014).

social problems associated with their spina bifida diagnoses (e.g., job losses, lack of independence, etc.). Eventually, all five individuals were diagnosed with an eating disorder.

Furthermore, physical disability is often considered a burden, and people with disabilities may therefore feel that they are inconveniencing others (Silber et al., 1999). For these people, the pressure to become thinner goes beyond conforming to social norms: It affects whether or not somebody will take care of them (Roosen & Mills, 2014). Karin Hitselberger (2013) writes in her blog "Claiming Crip" that she has often been told to be thin in order to make it easier for others to care for her. She has restricted fluid intake for as long as she can remember because she worries about inconveniencing and feeling dependent upon others for survival. When she was younger, she would not drink fluids at school because she was afraid of untrained aides taking her to the bathroom. Today, she says she still restricts fluids, "usually because I'm not sure if the bathroom is going to be accessible, but also because I don't want to ask my friends for help" (Hitselberger, 2013, p. 40). When she started struggling with limiting food intake as well, her therapist dismissed her concerns, saying that as long as she was careful, it was fine. Hitselberger could not imagine anybody telling an able-bodied person not to eat or drink, but people such as her therapist often encourage her behavior. Because bodies with physical disabilities differ from what many consider mainstream, able-bodied people often have difficulty understanding that those with physical disabilities may also have body-image issues.

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Psycho-Social-Cultural Risk Factors

Individuals with disabilities often discuss two different areas of pressure from society: the culture of thinness, meaning that thin bodies are preferable to fat bodies, and the culture of ableism, meaning that able bodies are preferable to disabled bodies (Roosen & Mills, 2014). This double stigma often leads to restrictive dieting in order to try to fit in with society (Roosen & Mills, 2014). The media rarely highlights images and experiences of those with disabilities, and this shortcoming strongly influences body image (Minges, 2014). People with disabilities rarely receive positive feedback about their bodies and physical abilities, are aware that their bodies do not fit typical standards of physical ability, and commonly feel inadequacy, body

disconnection, fear, and shame (Minges, 2014). Hitselberger (2015) writes:

> I hated the way my body would jerk and spasm because of my cerebral palsy. I hated the scars left on my body from surgeries meant to fix me. Most of all, I hated going to the doctor and hearing what was still wrong with me, wrong with my body….I wanted to blend into the walls and disappear (p. 52).

In order to deal with these issues, a person with disabilities may develop an eating disorder or other unhealthy coping mechanisms as a means to gain control and punish the body for failing to function at the same level as an able-bodied individual (Minges, 2014).

Barriers Toward Diagnosis and Treatment

Most mental health professionals are not familiar with treating people with disabilities (Minges, 2014). Many individuals with disabilities fear judgment for discussing body image issues and have a history of feeling marginalized, which makes developing rapport a challenging task (Froehlich-Grobe, Nary, VanSciver, Washburn, & Aaronson, 2012; Minges, 2014). Health care professionals and caregivers must also navigate the individual's medical and physical limitations (e.g., balancing the disability-related need for an enema with a history of laxative abuse), avoid attendant service errors (e.g., making negative comments about the body), and ensure accessibility (e.g. making treatment centers wheelchair accessible) (Froehlich-Grobe et al., 2012). Many people with disabilities underutilize preventative health care due to such barriers as transportation and finances (Roosen and Mills, 2014).

Diagnosing eating disorders in people with disabilities is often difficult. Health care professionals often attribute all issues to the physical disability, including weight loss. One common way to diagnose an eating disorder is through Body Mass Index (BMI). However, a person with a physical disability may have bone or muscle loss or be of a short stature, making an accurate BMI reading nearly impossible (Roosen & Mills, 2014).

Stigmatization also plays a major role in diagnosing an eating disorder in a person with a physical disability. In accordance with Goffman's (1963) theory of social stigma, in which individuals with disabilities are classified as undesirable, rejected stereotypes, these people possess attributes that discount them from meeting mainstream, socially constructed standards of beauty (Roosen & Mills, 2014). The resulting false belief is that people with disabilities do not care about their appearance and would never restrict their diet to meet these standards.

Clinicians need to be aware that clients with physical disabilities may be at risk of developing an eating disorder. This knowledge must influence the quality of nutritional counseling such patients receive and the assessment

of any sudden weight loss they experience (Silber, Shaer, & Atkins, 1999). This author believes that having a physical disability coupled with an eating disorder presents additional challenges that traditional therapy may not effectively address.

Music Therapy for People With Physical Disabilities

Unlike an eating disorder, recovery from a physical disability is often impossible. With disability comes a social and political identity and a distinctive worldview and culture (Straus, 2014). Brown (2013) found that the culture of disability is characterized by "hope, endearment, [and] ability" (p. 1). Instead of seeking to normalize people with disabilities, music therapy may enhance their indigenous culture, acknowledge their struggles, and promote self-expression (Straus, 2014).

Music therapy is a successful therapeutic intervention allowing persons with physical disabilities to achieve physical, emotional, and social goals (Hooper, 2007). Scientific evidence increasingly indicates that rhythm stimulates and organizes muscle responses (Weiss, 2013). Music may also provide a distraction from pain or discomfort associated with some physical disabilities (Hooper, 2007). Since music therapy uses musical interaction as a conduit for nonverbal communication, it is a useful technique for individuals who are unable to communicate or verbally express their emotions (Gold, Voracek, & Wigram, 2004). Treatment requires empowering people with disabilities by shifting how they view the disability (Roosen & Mills, 2014). This author believes that an important step in reducing body image issues is to develop a sense of connection with one's own body.

According to Hooper (2007), music therapy incorporates different musical formats to achieve individualized treatment goals. Musical instruments develop range of motion, hand grasp strength, and nonverbal self-expression. Singing improves oral motor skills, pulmonary functioning, breath control, rate of speech, articulation, and pronunciation. Analyzing music and lyrics provides opportunities to share personal thoughts and experiences. For a person with disabilities, music therapy is an important way to increase independence, self-confidence, and self-esteem (Peters, 1987).

Music Therapy for People With Eating Disorders

Just as music therapy is beneficial for individuals with physical disabilities, it is also a useful treatment for eating disorders. Eating disorder symptoms are typically a means of coping with stressful or anxious feelings, and music therapy provides new adaptive coping skills (Robarts & Sloboda, 1994). Listening, relaxation, guided imagery, songwriting, music analysis, and active music making are all musical ways of coping. Music provides a way for the

individual to discuss emotions and access repressed feelings or experiences while examining his or her sense of self (Robarts and Sloboda, 1994).

Heiderscheit (2009) describes several types of music therapy treatment for eating disorders. Song analysis helps clients share their stories by listening attentively to a song's lyrics, tonality, rhythm, instrumentation, and form. Another approach, song autobiography, asks clients to select important moments in their lives and identify songs that express these moments, thereby obtaining a better understanding of their lives. In addition, songwriting brings many issues—such as the challenges of an eating disorder, resistance to treatment, and acceptance—to the surface. Finally, guided imagery in music helps explore underlying issues. As the music begins, clinicians lead clients through a brief relaxation and then ask what they are experiencing. Clinicians then move into imagery, which often includes metaphors that allow clients to feel their emotions and begin to recover.

Music Therapy for People With a Physical Disability and an Eating Disorder

Given the research, music therapy holds intriguing possibilities for individuals struggling with eating disorders and individuals with physical disabilities. As there are no current evidence-based practices addressing treating individuals with both conditions, music therapy seems to be the most promising intervention for this comorbidity at present. The viability of music as a treatment in such cases is even more evident in the following clinical case study of a man diagnosed with both cerebral palsy and anorexia nervosa.

Case Example

Ryan B. is a 24-year-old graduate student (Ryan B., personal communication, July 14, 2015). Ryan was diagnosed with cerebral palsy at age 3 and used a walker-frame or scooter to move around. At school, people imitated his walking and called him "crip." He had no real friends and felt excluded and lonely. As a result, he became very depressed. He dreaded going to school every day and wanted to "disappear." Thinking that if he lost weight his peers would no longer make fun of him, Ryan developed an intense fear of eating and getting fat. At age 17, he was diagnosed with anorexia nervosa and soon after was admitted to an inpatient eating disorder treatment center. During his stay, he had regular therapy sessions, but as the

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only patient with a physical disability, it was difficult for him to talk about the root causes of his eating disorder. After his release from treatment, he continued to struggle and relapsed at age 22.

Ryan was eventually referred to a music therapist. He attributes his recovery to music therapy because it gave him a way to tell his story. By sharing songs in sessions, he recognized that his cerebral palsy had made him feel out of control of his body, but as he began to lose weight, it felt as if he was somehow reclaiming control. This concept was something he had never been able to verbalize. Through continued music therapy sessions, Ryan learned new coping skills and now feels that his eating disorder and cerebral palsy have been blessings in disguise. Both make him different, which he now realizes is a strength.

Conclusion

Individuals with physical disabilities are at an increased risk of developing eating disorders (Roosen & Mills, 2014). With regard to people with both an eating disorder and a disability, there must be more representation in research, greater competency among health care professionals, and treatment options that better address their experiences. Music therapy is an effective treatment option in treating those with both an eating disorder and a physical disability due to its focus on self-understanding, a key component in treating those with this comorbidity (Heiderscheit, 2009; Weiss, 2013). It is therefore likely that music therapy is a useful intervention for people with a comorbid diagnosis.

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to the Junior Board of the National Eating Disorders Association and served as a mentor at Mentor Connect, the first global eating disorder mentoring community to women in recovery from an eating disorder. In 2015, Kimberly was elected as Mentor Connect's Executive Board Chair. Music will always remain a passion for Kimberly, but helping those with addiction issues is her life mission. Kimberly will graduate in May 2016 from the Columbia School of Social Work's 16-month program. She is currently President of the Substance Abuse and Recovery Caucus and recently organized a standing-room-only speaking engagement featuring author, Iron Chef America winner, and recovered substance user Jesse Schenker. Her greatest pride is being a wife to her amazing husband, Evan, and a mother to her 1.5-year-old daughter, Atara.