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Ginger Nicol

Washington University School of Medicine

Elizabeth Worsham

University of Florida

Debra Haire-Joshu

Washington University School of Medicine

Alexis Duncan

Washington University School of Medicine

Julia Schweiger

Washington University School of Medicine

See next page for additional authors

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Authors

Ginger Nicol, Elizabeth Worsham, Debra Haire-Joshu, Alexis Duncan, Julia Schweiger, Michael Yingling, and Eric Lenze

Getting to More Effective Weight Management in Antipsychotic-Treated Youth: A Survey of Barriers and Preferences

Ginger Nicol, MD,¹ Elizabeth Worsham, MD,² Debra Haire-Joshu, PhD,³ Alexis Duncan, PhD,⁴ Julia Schweiger, CCRC,⁵ Michael Yingling, MS,⁶ and Eric Lenze, MD⁷

Abstract

Background: Mentally ill youth are at risk for developing obesity, especially when they require antipsychotic treatment; moreover, they may face unique challenges in adhering to behavioral weight loss interventions. The aims of this project were to characterize the challenges families of youth with psychiatric disorders face when engaging in weight loss treatment and to gather information on attitudes and preferences for weight management interventions in this population.

Methods: We devised a telephone survey to evaluate caregiver-perceived barriers/challenges to and preferences for behavioral weight loss treatment in overweight or obese mentally ill youth ages 6–18 treated with an antipsychotic agent in an outpatient setting.

Results: A total of 26 parents or primary caregivers completed the survey. The most commonly cited barriers to participation in physical activity (PA) and maintaining a healthy diet were child's dislike of PA and child's preference for energy-dense foods, respectively, which were impacted by psychiatric symptoms. Preferences for weight loss treatment included individualized, prescribed meal plans and shopping lists, and exercise support/demonstration, with a preference for Internet or cell phone applications to help with monitoring food intake and exercise.

Conclusions: These results suggest that targets for obesity treatment in this population include individualized, specific support that takes into account the child's motivation, which is effected by psychiatric symptoms. Tools for providing support may include the use of telehealth visits and mobile device applications for self-monitoring.

Introduction

Between 41% and 50% of individuals with serious mental illnesses are obese.¹ On average, mentally ill individuals lose 25–30 years of life as a result of obesity-related illnesses, including diabetes and cardiovascular disease (CVD).² Higher rates of obesity in this population are, in part, attributable to antipsychotic treatment, which has well-established effects on adiposity and glucose regulation.³ Thus, the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) has identified individuals with mental illness, including those treated with antipsychotic medications, as a “special pop-

ulation” at increased risk for the development of obesity, diabetes, and CVD.⁴ The prevalence of type 2 diabetes (T2D) among youth in the general population is 0.46 per 1000 youth,⁵ with the majority of new-onset cases explained by high weight.⁶ Youth who are treated with antipsychotic agents experience significant treatment-related weight gain⁷ and are 2–3 times more likely to develop T2D than youth in the general population.^{5,6,8–10} Antipsychotic medications are commonly used in youth to manage irritability and aggression across a range of psychiatric diagnoses, such as attention deficit hyperactivity disorder (ADHD), autism, and mood disorders.¹¹ Antipsychotic treatment in youth is associated with severe behavioral

¹Department of Psychiatry, Washington University School of Medicine in St. Louis, St. Louis, MO.

²Department of Psychiatry, Forensic Institute, University of Florida, Gainesville, FL.

³Joyce Wood Professor and Associate Dean for Research & Faculty, George Warren Brown School of Social Work Director, Center for Diabetes Translation Research and the Center for Obesity Prevention and Policy Research, Washington University, St. Louis, MO.

⁴Assistant Professor of Public Health, George Warren Brown School of Social Work, Washington University, St. Louis, MO and Department of Psychiatry, Washington University School of Medicine, St. Louis, MO.

⁵Clinical Lab Manager, ⁶Senior Data Analyst, ⁷Professor of Psychiatry, Department of Psychiatry, Washington University School of Medicine, St. Louis, MO.

symptoms and more frequent acute psychiatric care episodes than are experienced by non-antipsychotic-treated mentally ill youth, suggesting that antipsychotic treatment may be an indicator of illness severity.¹² Although discontinuation of antipsychotic medications can lead to weight loss, this may occur at the expense of disabling symptom recurrence.¹³ Given that antipsychotic discontinuation may not be a feasible option for many youth taking these medications, methods to mitigate treatment-related weight gain are necessary.

Lifestyle interventions to promote healthy behaviors are a first-line treatment recommendation for pediatric obesity.¹⁴ Therefore, it follows that behavioral intervention should also be the starting point for addressing high weight in youth treated with antipsychotic medications. However, rates of treatment nonadherence in behavioral weight loss interventions can be as high as 50% in non-mentally ill individuals.¹⁵ Reasons for attrition in behavioral weight loss treatment studies include psychosocial and socioeconomic factors,¹⁶ which may be more prevalent in mentally ill individuals. Nonetheless, adult weight management programs located within community mental health clinic settings have been successfully implemented.^{17–19} Although the available evidence base in this area is limited, a small number of studies suggest that factors specifically related to psychiatric illness, including behavioral symptoms (e.g., social anxiety, paranoia, and lack of initiative), medication effects (sedation and excessive weight gain preventing physical mobility), and lack of transportation or social support often prevent mentally ill adults from engaging in weight loss treatment.^{20,21} Programming that increases health knowledge and that offers social engagement and daily structure is cited as promoting engagement in behavioral weight loss programs.²²

There have been no published reports of behavioral weight loss interventions in antipsychotic treated youth, and no data are available regarding the preferences for and barriers to participating in behavioral weight loss interventions in this uniquely at-risk population. However, studies of barriers to participation in and preferences for weight loss treatment in non-mentally ill obese youth can offer useful information. Pediatric behavioral weight loss interventions that focus only on parents and parent behaviors have been shown to be at least as successful as family-based interventions,²³ suggesting that caregiver preferences for weight loss treatment are an important aspect of treatment adherence in non-mentally ill youth. Parents report that a child's lack of internal motivation is a primary reason for treatment nonadherence.²⁴ Parent-level barriers include pragmatic issues, such as cost, transportation, and appointment availability; parents also cite a lack of alignment with the provider regarding the goals of treatment as a barrier.^{16,25} Predictors of treatment nonadherence in pediatric behavioral weight loss studies include lack of intrinsic motivation to change health behaviors and pragmatic challenges preventing families from attending visits.^{16,26} Taken together, these points might suggest that obese youth

with psychiatric disorders have more innate barriers to treatment adherence than do their non-mentally ill counterparts. Information regarding preferences and barriers specific to this population is needed in order to determine whether a modified approach is needed to enhance treatment participation in this population.

To characterize the most common self-reported barriers to participating in a behavioral weight management program for families of children with a psychiatric illness, we interviewed parents or adult caregivers of youth who were treated with antipsychotic agents and had a documented BMI in the overweight or obese range (≥ 85 th percentile for sex and age). A secondary aim was to obtain descriptive information on attitudes and preferences toward weight management interventions in parents or adult caregivers of youth treated with antipsychotic agents. Our ultimate goal was to describe barriers to and preferences for behavioral weight loss treatment in families of youth treated with antipsychotic medications.

Methods

Participants

Eligible participants were parents or legal guardians of (1) patients attending the university outpatient child psychiatry clinic or (2) participants in psychiatric clinical research at the university ages 6–18 who were continuously treated with antipsychotic medications between December 1, 2012 and December 31, 2013, and who had a documented BMI percentile >85 for age and sex, calculated using the Epi Info software that was developed by the CDC.²⁷ BMI percentile was taken from the most recent appointment in the medical record, and BMI trend over the defined study period was assessed to confirm that weight gain occurred during antipsychotic treatment. Contact information for the primary adult caregiver, listed as the guarantor of health insurance, was also obtained from the medical record. The listed guarantor was contacted by phone and provided verbal informed consent to participate in the study. If another adult caregiver was determined to be the primary caregiver for the child, that individual was contacted by phone and provided verbal informed consent to participate in the study.

Barriers and Preferences Survey

We created a semistructured survey instrument to evaluate parent or caregiver barriers/challenges to and preferences for behavioral weight management treatment in obese youth treated with an antipsychotic medication. Questions were generated based on a review of existing research regarding adult or parent/caregiver preferences and barriers to participation in weight loss programs^{15,16,28} and in mental health treatment,²⁹ the research team's previous experience working with obesity and metabolic disorders in mentally ill populations, and consultation with experts in community behavioral obesity treatment and in dissemination-implementation research methodology.

Open-ended questions were based on prompts developed during pilot testing (*e.g.*, for reported barriers, examples included “too difficult to participate based on psychiatric symptoms such as irritability or anxiety” or “too difficult to participate based on logistic challenges such as appointment time availability or transportation”) or “other.” The survey addressed several domains related to behavioral weight loss treatment experiences and utilization and was pilot tested (for feasibility and clarity) with families who were currently participating in a behavioral weight loss intervention study funded by the National Institute of Mental Health (NIMH).

The final instrument was comprised of 37 questions divided into three domains: demographics¹¹; barriers to participation in behavioral weight management treatment¹⁹; and preferences for behavioral weight management treatment.⁷ Questions were presented in several forms, including open ended, yes/no, multiple choice, and Likert rating scales. The survey was administered as a one-time, 30-minute telephone interview.

The Washington University School of Medicine Institutional Review Board (St. Louis, MO) approved this study. Verbal consent was obtained before the start of the phone interview. To accommodate scheduling, the option of completing the survey by phone outside of business hours was offered.

Statistical Analyses

Data were analyzed using SPSS software (v.22; IBM Corp., Armonk, NY). All available data from all participants were used. Descriptive statistics (mean, frequencies, and proportions) were generated for survey responses. Likert scale items were converted from severity to numeric rating (*e.g.*, 1 = not at all; 3 = very much). Responses to each survey question are reported as number (*n*) and percentage of caregivers with a response in each category for a given question.

Results

Population Characteristics

A total of 91 youth were identified as being eligible for the study, and the legal guardian documented in the medical records for the child was contacted. After initial phone contact, 26 adult caregivers agreed to participate (response rate, 28.6%). Forty-eight adult caregivers were unable to be contacted (*n* = 9 had numbers that were not in service or were disconnected; *n* = 39 did not respond to multiple voice messages). Seven adult caregivers declined to participate (*n* = 4 reported they were “not interested” and gave no other reason for declining; *n* = 3 declined because of time constraints). Ten adult caregivers consented to participate and began the survey, but were unable to complete within the first contact and were unable to be contacted thereafter. Demographic data were not obtained from adult caregivers who were unable to be contacted or consented for participation. Table 1 provides detailed information

Table 1. Respondent Characteristics

| | |
|---|------------|
| Primary diagnosis (<i>n</i> , %) | |
| Autism spectrum disorder | 13 (50.0) |
| ADHD | 7 (26.9) |
| Mood disorder | 2 (7.7) |
| Anxiety disorder | 2 (7.7) |
| Disruptive behavior disorder | 1 (3.8) |
| Other | 1 (3.8) |
| Respondent's relationship to child (<i>n</i> , %) | |
| Mother | 21 (80.8) |
| Other | 5 (19.2) |
| Child's race (<i>n</i> , %) | |
| Caucasian | 22 (84.6) |
| African-American | 4 (15.4) |
| Child's age (mean years, SD) | |
| | 13.7 (4.4) |
| Weight status before starting antipsychotic (<i>n</i> , %) | |
| Normal weight | 15 (57.6) |
| Overweight or obese | 11 (42.3) |
| Primary caregiver's highest level of education (<i>n</i> , %) | |
| High school/some college | 8 (30.8) |
| College graduate/some graduate school | 12 (46.1) |
| Graduate degree | 6 (23.1) |
| Child's principal residence (<i>n</i> , %) | |
| Mother | 15 (57.7) |
| Equally with mother and father | 8 (30.8) |
| Father | 1 (3.8) |
| Aunt/legal guardian | 1 (3.8) |
| Supportive community | 1 (3.8) |
| ADHD, attention deficit hyperactivity disorder; SD, standard deviation. | |

regarding the characteristics of the respondents. In all cases, the respondent was the youth's legal guardian; 21 of 26 respondents who completed the survey were the youth's biological mother. The population was primarily privately insured (*n* = 20) and mostly white (*n* = 22). There was a high degree of parental educational attainment, with 18 of the 26 adult caregiver respondents having completed at least some college and 6 respondents reporting graduate-level education. Mean age of youth in question was 13.7 (standard deviation [SD], 4.4) years. The youths' primary psychiatric diagnoses were autism spectrum disorder (*n* = 13), ADHD (*n* = 7), mood disorder (*n* = 2), anxiety disorder (*n* = 2), or disruptive behavior disorder (*n* = 2). The majority of youth in question achieved overweight or obese status (by BMI percentile) during antipsychotic treatment (*n* = 15; 57.6%),

whereas the remainder of the population was overweight or obese before starting antipsychotic medications ($n = 11$; 42.3%).

Identification of Weight Problems and Treatment Referral

Of the 26 participating families, the majority of caregivers recalled a healthcare provider initiating a discussion about their child's weight (81%; $n = 21$) and reported that weight loss treatment was recommended (58%; $n = 15$); half of caregivers ($n = 13$) reported receiving counseling from a primary care provider (PCP). Additionally, 4 reported being referred to a dietitian, 6 were referred to a specific behavioral weight loss program available in the

community, 2 reported that their psychiatrist recommended a medication change to decrease side effect of weight gain related to medication, 1 reported being referred to an endocrinologist, and 1 reported being referred to see a therapist. Families who received weight loss counseling from their PCP indicated they were given recommendations to decrease foods high in sugar and fat, increase consumption of fruits and vegetables, and increase physical activity (PA).

Of the 15 families who were referred for behavioral weight loss treatment, 13 adult caregivers indicated their level of motivation for participating in a weight loss program with their child; the majority of respondents reported high (61.5%; $n = 8$) or moderate (23.1%; $n = 3$) motivation for weight loss. Despite this high reported initial rate of

Table 2. Reported Barriers to Participation in Weight Loss Treatment

| What is the biggest barrier to participation in physical activity (N = 22)? | | |
|---|-----------|---|
| Barrier | n (%) | Representative quote |
| Child's dislike of physical activity | 9 (40.9) | "It's like world war three trying to get the iPad away from [him]." |
| Symptoms of a physical or mental diagnosis preventing child from participating in physical activity | 8 (36.4) | "[Her] weight makes it hard for her to be active." "[He] doesn't get along with the other kids at recess because of the autism." |
| Respondent's lack of knowledge about safe/effective physical activities for their child | 4 (18.2) | "I just wish someone would show me what to do. Is weight lifting OK for kids who haven't even gone through puberty yet?" |
| Financial barriers limiting access to treatment program | 1 (4.5) | "We just don't have the money to join a gym right now, and it isn't safe for the kids to play outside in our neighborhood." |
| What is the biggest barrier to maintaining a healthy diet for your child (N = 26)? | | |
| Barrier | n (%) | Representative quote |
| Excessive food intake | 11 (42.3) | "[He'll] drink 60 oz of regular soda at a time." |
| Child's preference for energy-dense or fast foods | 8 (30.8) | "Every time we pass a Taco Bell we have to stop." |
| Restrictive food preferences | 2 (7.7) | "I've tried all the tricks to hide veggies in things and [he] always knows." |
| Difficulty meal planning | 1 (3.8) | "Everyone in the family wants something different so it's hard to plan." |
| Financial barriers | 1 (3.8) | "[Fresh produce] is so expensive. I could spend my whole paycheck and it'll go bad before anyone eats it." |
| None | 3 (11.5) | |
| What is the biggest reason for not starting, or starting but not completing a weight loss program (N = 21)? | | |
| Barrier | n (%) | Representative quote |
| Child's physical or emotional health interfering with participation | 8 (38.1) | "It's just so stressful to talk about it. I don't want [my son] to feel deprived or ashamed." |
| Difficulty doing treatment related "homework" (e.g., logging foods, planning meals) | 7 (33.3) | "Homework for school was a battle already, so by the time we got to the therapy homework everyone was too exhausted." |
| Financial barriers | 4 (19.0) | "My insurance doesn't pay for 'weight loss' treatment. We tried to see a dietitian but that wasn't covered either." |
| Transportation difficulties | 1 (4.8) | "We have one car and [my husband] needs it to go to work." |
| Time commitment | 1 (4.8) | "We both work, and the other kids have activities after school so we always missed appointments." |

Table 3. Reported Preferences for Weight Loss Treatment Programming

| Preferences for weight loss treatment (N = 26) | | |
|---|------------|---|
| What do you think would most likely make participation in a behavioral weight management program easier for you and your child? | | |
| Characteristics | n (%) | Representative quote |
| Individualized, prescribed meal plans and shopping lists | 10 (38.46) | "Is there a way to eat what you like, not starve and still lose weight?" |
| Exercise support/demonstration alone | 5 (19.23) | "Maybe if some of the sessions included physical activity [my son] would be more likely to try it." |
| Option for video conference appointments with provider | 3 (11.54) | "It would be so much easier to participate if we could Skype." |
| Access to weight loss education by an electronic interface such as a website or smartphone application | 3 (11.54) | "Can't someone figure out how to make an app that will help get [my son] motivated to try new foods?" |
| Food preparation assistance and support to try new foods | 1 (3.85) | "If you showed [my daughter] how to try new foods at an appointment, maybe she would do it." |
| Group therapy sessions | 1 (3.85) | "I would like to know how other parents deal with this." |
| Flexible scheduling | 1 (3.85) | "Weekend appointments would be better." |
| None or missing | 2 (7.69) | |

motivation, only 5 of the 15 completed the weight loss program to which they were referred. Two of the 11 families who were not referred to a weight loss program by a healthcare provider sought weight loss treatment for their child on their own; however, neither family completed the treatment.

Perceived Barriers to Participation in Weight Loss Treatment

Most (22 of 26) respondents indicated that it was either moderately (36.4%; $n = 8$) or very (63.6%; $n = 14$) difficult to ensure that their children engage in 60 minutes of PA per day (Table 2).³⁰ The primary reported barriers to participation in PA included child's dislike of PA, followed closely by concerns that symptoms of a physical or mental diagnosis would prevent the child from participating in PA. Specifically, adult caregivers reported difficulty introducing new, healthier foods and activities because of extreme irritability, sensory problems limiting taste and PA preferences, and social integration challenges preventing participation in group physical activities. Less commonly cited barriers included lack of knowledge about age-appropriate and safe PAs for youth as well as financial barriers limiting access to a treatment program. Perceived barriers to maintaining a healthy diet included excessive food intake, followed by preference for energy-dense, low-nutrition foods and extreme resistance to the introduction of healthier options. Difficulty planning ahead for shopping and meal preparation and financial barriers limiting access to healthy foods were also reported as barriers.

The 21 families who either did not start or did not complete a weight loss program indicated that the most pressing reason for this was concern that the child's physical or emotional health would interfere with partici-

pation in the program or increase the stress of participation. The second most pressing reason for not starting or completing a program was related to concerns about the difficulty of completing treatment-related homework, such as keeping a daily food and activity log.

Reported Preferences for Weight Loss Treatment

Preferences for weight loss programming included individualized, prescribed plans for both meal planning and for PA (Table 3). Caregivers noted that in-session examples and exposures to exercise and trying new foods would be helpful, as would access to weight loss education and support by an electronic interface, such as a website or smartphone application. Caregivers also noted a preference for adult support groups and/or group therapy sessions in order to provide emotional and practical resources for caregivers to implement behavioral changes in the home.

Discussion and Conclusions

This study is the first, to our knowledge, to report on preferences for behavioral weight loss treatment in the uniquely vulnerable population of children with psychiatric illnesses who are treated with antipsychotic medications. An understanding of patient preferences for treatment, as well as perceived barriers (including past negative treatment experiences or failures) in at-risk populations is necessary for facilitating shared decision making between healthcare providers and their patients. This, in turn, can further inform the development of effective and targeted behavioral interventions to improve health outcomes.

The results of this study are consistent with other reports of parental preferences and perceived barriers to health behavior change,^{15,16,26} and additionally provide insight

into the factors that may enable versus hinder participation in behavioral weight loss treatments in the population of youth who are high weight and treated with antipsychotic medications. First, we found that families reported a high level of motivation to participate in a weight loss program, but only a minority of families had completed treatment recommended by a healthcare provider. Nonetheless, physician referral to weight management treatment appeared to increase treatment enrollment compared to families who self-referred, which is also consistent with reports that healthcare provider recommendation to engage in weight loss treatment is associated with greater motivation to participate in treatment³¹ and increases the likelihood that patients will engage in health behavior change.³² Second, families indicated that primary barriers to participation in or completion of a behavioral weight loss program were mostly related to psychiatric diagnosis or symptoms, as has been reported in adult mentally ill populations.^{20,21,33} Caregivers also frequently cited a preference for in-session support to expose the child to new foods and PAs. Finally, pragmatic challenges with time management, costs, and transportation were cited as common barriers to participating in treatment.

These results support the current recommendations that weight loss counseling be initiated by a healthcare provider.¹⁴ But perhaps more important, these results suggest that psychiatric symptom severity contributes substantially to caregiver perception of ability to successfully make behavior changes in the home. Thus, an important future topic of research in this area might include adaptation of existing parent-focused pediatric weight loss interventions,³⁴ which have the potential to increase parent confidence and ability to initiate health behavior changes. Additionally, a substantial minority of psychiatrically ill youth were overweight or obese before beginning antipsychotic treatment, suggesting that future behavioral weight loss interventions may be relevantly applied to the broader population of youth with psychiatric illness, not only to those treated with antipsychotic medications. Finally, many caregivers noted pragmatic barriers to participation, such as appointment availability and time constraints, as well as the time and difficulty related to the homework involved in most behavioral weight loss interventions (*e.g.*, logging of food intake and PA). These results are similar to those reported in non-mentally ill obese pediatric populations,^{15,26} and suggest that potential strategies to decrease pragmatic barriers to participation in the general population might also be useful in the population of obese youth with psychiatric conditions. These might include the use of telemedicine for remote access to providers and use of mobile device applications to simplify treatment-related homework.

This study was subject to limitations. Specifically, this was a small, single-site study of a primarily white and privately insured population and does not include youth self-report of barriers to and preferences for healthy eating and PA programming from youth. Additionally, the survey did not assess for disordered eating habits, such as binge eating, or body shape and weight concerns, which are commonly comorbid

with psychiatric disorders.³⁵ The presence of an undiagnosed eating disorder (ED) could confound the results, given that presence of an ED may impact preferences for and participation in behavioral weight loss treatment. Although this study advances our knowledge regarding parental preferences for weight loss interventions in mentally ill youth, the findings should be replicated and extended in a larger, more nationally representative sample, with both youth and parent reports. Future studies should also assess for EDs and feeding behaviors as potential barriers to participation in behavioral weight loss interventions. Finally, results of the study may have been subject to selection bias, which may have skewed results of survey responses, given that adult caregivers willing to participate in such a study may report different preferences and barriers than parents who were not willing to participate or who were unreachable. Survey nonresponse was also a limitation in the present study; further research in this area would optimally employ methods to improve survey response rate, as well as obtain descriptive information on survey nonresponders. These goals may best be accomplished by mobile technology-based research assessment, given that this methodology is readily accessible and commonly accepted in demographically heterogeneous samples. Such research is critical to clarify the targets and barriers for obesity treatment and prevention efforts in mentally ill youth.

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Address correspondence to:

Ginger Nicol, MD

Assistant Professor of Psychiatry

Healthy Mind Lab

Department of Psychiatry

Washington University School of Medicine in St. Louis

660 South Euclid Avenue

Campus Box 8134

St. Louis, MO 63110

E-mail: nicolg@psychiatry.wustl.edu