# **Barriers to Treatment for Eating Disorders Among Ethnically Diverse Women**

Fary M. Cachelin, 1\* Ramona Rebeck, 1 Catherine Veisel, 1 and Ruth H. Striegel-Moore 2

California State University, Los Angeles, California
Wesleyan University, Middletown, Connecticut

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Abstract: Objective: This study examined barriers to treatment in an ethnically diverse community sample of women with eating disorders. Method: Participants were 61 women (22 Hispanics, 8 Asians, 12 Blacks, 19 Whites) with eating disorders. Diagnosis was determined using the Eating Disorder Examination. Treatment-seeking history, barriers to treatment seeking, ethnic identity, and acculturation were assessed. Results: Although 85% of the sample reported wanting help for an eating problem, only 57% had ever sought treatment for an eating or weight problem. Individuals who had sought treatment reported being significantly more distressed about their binge eating than those who had not sought treatment and having begun overeating at a younger age. Of those who had sought help, 86% had not received any treatment for their eating problems. The main barriers to treatment seeking were financial reasons. Conclusion: Women from minority groups who have eating disorders are underdiagnosed and typically not treated. © 2001 by John Wiley & Sons, Inc. Int J Eat Disord 30: 269–278, 2001.

**Key words:** barriers to treatment; eating disorders; ethnicity; treatment seeking

## **INTRODUCTION**

The general belief until recently had been that eating disorders afflict only White women. This conclusion was based largely on the fact that clinical samples are disproportionately White. The rate of minority women found in clinics is very low (3%–5%), even in cities with large minority populations (M. Strober, personal communication, June 20, 1999; D. Wilfley, personal communication, June 23, 1999). On the other hand, community studies reveal that eating disorders do exist among minority groups (Bruce & Agras, 1992; Cachelin et al., 1999; Cachelin, Veisel, Striegel-Moore, & Barzegarnazari,

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<sup>\*</sup>Correspondence to: Dr. Fary Cachelin, Department of Psychology, California State University at Los Angeles, 5151 State University Drive, Los Angeles, CA 90032-8227. E-mail: fcachel@calstatela.edu

2000; Fitzgibbon et al., 1998). Frequency of occurrence is similar to that reported for White populations (see review by Crago, Shisslak, & Estes, 1996) and symptomatology appears to be the same across ethnicities (Cachelin et al., 2000; Cachelin, Striegel-Moore, & Elder, 1998). One possibility is that women with eating disorders from minority groups do not seek treatment. Another is that they may seek treatment for their eating disorders, but do not receive an appropriate diagnosis.

A recent study by Cachelin et al. (2000) found that among an ethnically diverse sample, only 19% of individuals with disordered eating reported having sought treatment. This rate is consistent with rates reported by other investigators for treatment seeking for psychological problems in minority groups (O'Sullivan, Peterson, Cox, & Kirkeby, 1989; Ying & Miller, 1992). There has been growing recognition in the mental health care field that minority populations do suffer from mental health problems and that their underuse of the mental health care system is not a function of less need for such care (Bernal & Enchautegui-de-Jesus, 1994; O'Sullivan & Lasso, 1992). Compared with White samples, minority groups are much less likely to seek treatment (Dew, Dunn, Bromet, & Schulberg, 1988).

An important question that has not received adequate research attention is: Why do minority women with eating problems tend not to seek treatment? In the health care literature, various factors have been proposed as barriers against general mental health care utilization, although few empirical investigations have been conducted. These proposed barriers can be viewed from an "individual" or from a "system" perspective (Escovar & Kurtines, 1983). Individual or person variables include feelings of shame and fear of stigma (Kline, 1996); cultural perceptions of psychiatric disturbance (O'Sullivan et al., 1989), specifically, minimizing or interpreting differently problems that others would consider to be serious psychological problems or not identifying psychological problems as such (Acosta, 1979; Kline, 1996); the belief that seeing a therapist is a sign of character weakness and that one should be able to help oneself (Keefe, 1979; Poma, 1983); turning to family or other informal support systems in times of need (Escovar & Kurtines, 1983; Keefe, 1979; Poma, 1983); turning to alternative forms of therapy such as folk healers (Acosta, 1979; Poma, 1983); discomfort about being separated from one's family (Kline, 1996); not viewing counselors as credible sources of help (Buhrke & Jorge, 1992); expectation that counselors will be hostile or cold (Keefe, 1979); and unfamiliarity with mental health services (see review by Keefe & Casas, 1980). Examples of system barriers are language barriers (Acosta, 1979; Marin, Marin, Padilla, & de la Rocha, 1983); financial difficulties and lack of health insurance (Marin et al., 1983; Wells, Golding, Hough, Burnam, & Karno, 1988); inaccessible health care facilities, time conflicts and long waits (Marin et al., 1983); lack of transportation and lack of child care (Marin et al., 1983); and lack of ethnically representative professional staff (Acosta & Cristo, 1982). The present study is the first to examine such barriers to treatment seeking as they apply to a population with eating disorders.

Preliminary evidence indicates a relationship between level of acculturation and treatment seeking, suggesting that minority women who are less acculturated to U.S. society are less likely than more acculturated individuals to get treatment for their eating problems (Cachelin et al., 2000). This finding is in accord with research demonstrating that acculturation level has a significant effect on ratings of counselor trustworthiness and understanding among Hispanic students (Lopez, Lopez, & Fong, 1991; Pomales & Williams, 1989) and that acculturation is a predictor of attitude toward utility of mental health service among Chinese Americans (Ying & Miller, 1992).

In the only prior study that has examined systematically treatment seeking for eating

disorders among a community sample, Yager, Landsverk, and Edelstein (1989) investigated lifetime help-seeking patterns in a large sample of respondents to a national magazine survey. They found that between 61% and 93% of respondents in three diagnostic groups (anorexia nervosa [AN], bulimia nervosa [BN], and subdiagnostic eating disorders) had sought professional treatment; binge eating disorder (BED) was not included as a separate diagnostic category. Likelihood of help seeking increased with the severity of the eating disorder and significantly more respondents with bulimic anorexia nervosa had sought professional treatment than had the others. The researchers concluded that a large percentage of women with eating disorders seek professional help for their symptoms. This study, however, did not investigate characteristics of treatment nonseekers or barriers to treatment seeking and it did not examine different ethnic groups. Additionally, as the authors pointed out, a methodological limitation was that diagnoses were based on self-report questionnaires rather than on clinical interviews (Yager et al., 1989).

The purpose of our study was to explore barriers against treatment in an ethnically diverse community sample with eating disorders. We used a highly structured clinical interview (Fairburn & Cooper, 1993) to determine diagnostic status because survey instruments tend to result in false-positive cases (Striegel-Moore & Smolak, 1996). We compared individuals who had sought treatment with those who had not and predicted that: (1) White women would be more likely than the other ethnic groups to seek treatment, (2) treatment seekers would have higher socioeconomic status than nonseekers, (3) other sociodemographic characteristics such as marital status would be related to likelihood of treatment seeking (Gallo, Marino, Ford, & Anthony, 1995; Leaf et al., 1988), (4) individuals with earlier onset age and/or more severe symptoms would be more likely to seek treatment, and (5) more acculturated individuals would be more likely than the less acculturated to seek treatment. Additionally, we investigated whether or not treatment seekers had received treatment for their eating disorders.

#### **METHODS**

#### **Participants**

Participants were 61 women who fulfilled clinical criteria for an eating disorder as outlined in the Diagnostic and Statistical Manual of Mental Disorders, 4th ed. (DSM-IV; American Psychiatric Association, 1994). Participants were recruited from an urban community via flyers posted in local organizations and compensated monetarily for their time. They had been identified in a previous study as having a probable eating disorder (Cachelin et al., 2000) and were recontacted for the full clinical interview. The sample consisted of 33 individuals with BED, 17 with BN, 5 with AN, and 6 with eating disorder not otherwise specified (EDNOS). Average age for the group was 30.5 years old (range 19–43 years). Mean body mass index (BMI) was 30.2 (range 14.5–65.3) and mean level of education was some college. Of the sample, 22 (36%) were Hispanic, 12 (20%) were Black, 8 (13%) were Asian, and 19 (31%) were White.

#### **Procedure**

Each participant completed a phone interview lasting 90–120 min. as well as one questionnaire sent via mail. Several studies have found that telephone and face-to-face interviews generate comparable diagnostic information (Study Group on Anorexia Nervosa,

1995) and that telephone interviews result in higher participation rates than face-to-face interviews (Allgood-Merten, Lewinsohn, & Hops, 1990; Wells, Burnam, Leake, & Robins, 1988).

### **Demographics/Characteristics**

Each participant was asked to report her ethnicity/race, age, marital status, number of children, level of education, occupation, and height and weight. BMI (kg/m²) was calculated. Research has shown that self-reports are highly correlated with actual heights and weights and are sufficiently valid to use in epidemiological and survey studies (Davis & Gergen, 1994; Nieto-Garcia, Bush, & Keyl, 1990).

Socioeconomic status (SES) was calculated for each participant based on her education and occupation according to Hollingshead's two-factor index of social position (Hollingshead & Redlich, 1958; Miller, 1991).

Insurance coverage was assessed using questions from the Health Care Utilization Questionnaire (HCUQ; Striegel-Moore, Pike, & Wilfley, 1995): During the past year were you covered by any health insurance? For how many months out of the past 12 months were you covered by health insurance? During the past 12 months, were you unable to obtain certain medical or psychological treatments because you had no insurance for these services or because you had exceeded the amount of coverage your insurance policy allows for these services?

## The Eating Disorder Examination

The EDE (Fairburn & Cooper, 1993) was used to establish diagnostic status. Age when subject first met all criteria required for a diagnosis of the syndrome and age of onset for each behavioral symptom were determined. The EDE has been shown to have high discriminant and concurrent validity and reliability (Fairburn & Cooper, 1993).

#### **Treatment History and Barriers**

Participants were asked if they ever had a significant eating problem and if they ever believed that they needed help for an eating problem. Participants who responded "yes" to either of these questions were then asked if they had ever sought (lifetime) treatment from a doctor, counselor, or other health specialist for an eating or associated weight problem.

Participants who indicated that they had sought treatment were asked about their treatment experience: What comprised the treatment? What diagnosis, if any, were they given? At what age did they first seek treatment? What made them decide to seek treatment (Striegel-Moore et al., 2000)?

Participants who reported never having sought treatment were asked to endorse (yes/no format) the reasons for not seeking help: financial difficulties; lack of insurance; transportation difficulties; lack of knowledge about available resources; feelings of guilt or shame; belief that mental health care providers (i.e., others) would not really be able to help; fear of being discriminated against or treated unfairly; difficulties finding a mental health care provider with a similar ethnic/cultural background as oneself; turning to other sources for help (e.g., family, friends, or church); the belief that one's eating problems are not serious enough to warrant treatment; and fear of being labeled as having a disorder. An example question was: Did you not know where to seek treatment or what resources were available? These questions were based on the existing literature on barriers to mental health care utilization (see reviews by Keefe & Casas, 1980; Marin et al., 1983).

#### **Acculturation and Ethnic Identity**

The Multigroup Ethnic Identity Measure (MEIM; Phinney, 1992) is a widely used scale of ethnic identity for use with diverse groups. It has high reliability, with alphas above .80 across a wide range of ethnic groups and ages (Phinney, 1992). A mean score can be calculated for each individual, ranging from 1 to 4, with a higher score indicating stronger ethnic identity.

Acculturation was measured using several variables that are included in most instruments and are considered to be basic to the concept (Phinney, in press): country of birth (United States or other), parents' country of origin (United States or other), whether or not English is subject's primary language, and whether or not subject is bilingual (i.e., speaks a language other than English regularly).

#### **RESULTS**

Results indicated that 85.2% of the sample wanted treatment for an eating problem, 35 (57%) made treatment contact at some time, and 26 (43%) had never sought treatment. Of those who had sought treatment (n = 35), only 5 individuals (14%) had received treatment for eating problems. In other words, only 8% (5 of 61) of the sample had received treatment for their eating disorder. On the other hand, the majority (65.7%) of treatment seekers had been prescribed treatment for a weight problem. This pattern was particularly true of individuals with BED: 64.7% (11 of 17) of those who had made treatment contact had received treatment for obesity, but only 1 individual had received treatment for an eating disorder.

A priori analyses revealed few significant differences between treatment seekers (n = 35) and nonseekers (n = 26). Compared with nonseekers, treatment seekers reported greater current levels of distress regarding their binge eating, t(49) = 2.43, p < .02. Treatment seekers had earlier first experiences with overeating (mean age = 13 vs. 17 years old), t(55) = 2.01, p < .05, and earlier onset of regular overeating (mean age = 16 vs. 20 years old), t(55) = 2.03, p < .05. There were no significant differences between the two groups on the remaining variables of interest: ethnicity, BMI, SES or insurance coverage, other so-ciodemographic variables, ethnic identity or acculturation, diagnostic category, or onset of full clinical syndrome (see Table 1).

Among the group of treatment seekers, mean onset age of eating disorder was 18.8 years old and mean age for first treatment contact was 22.4 years old, with an average delay of 3.6 years between onset of disorder and first treatment contact. Various reasons for seeking treatment were provided (Table 2). The qualitative responses provided most frequently were concern with body weight, feelings of depression and anxiety, being encouraged by friends or family to seek help, feeling physically uncomfortable, and being concerned about health problems.

The possible reasons for not seeking treatment are presented in Table 3. Treatment nonseekers endorsed most frequently financial difficulties and lack of insurance, followed by not believing others could help, fear of being labeled, not being aware of available resources, feelings of shame, and fear of discrimination.

#### **DISCUSSION**

We found that among a sample of ethnically diverse women with eating disorders, more than one half had made treatment contact, but the majority had not received treat-

Table 1. Characteristics of treatment seekers and nonseekers

	Seekers (N = 35)		Nonseekers $(N = 26)$	
	M	(SD)	M	(SD)
Age	30.5	(5.5)	30.5	(6.9)
Body mass index (BMI)	31.6	(9.9)	28.2	(9.0)
Socioeconomic status (SES)	2.6	(0.6)	3.0	(0.7)
Months of insurance coverage	8.9	(5.1)	7.6	(5.6)
Ethnic identity score	2.8	(0.5)	2.7	(0.5)
Onset age of clinical syndrome	18.8	(6.1)	20.8	(6.5)
,	n	(%)	n	(%)
English primary language	33	(94.3)	26	(100)
Bilingual	13	(37.1)	5	(19.2)
Born in the United States	30	(85.7)	24	(92.3)
Parents born in the United States	19	(54.3)	16	(61.5)
Ethnicity				
Hispanic	15	(42.9)	7	(26.9)
Asian	4	(11.4)	4	(15.4)
Black	7	(20.0)	5	(19.2)
White	9	(25.7)	10	(38.5)
Marital status				
Single	23	(65.7)	16	(61.5)
Married	8	(22.9)	7	(26.9)
Divorced	4	(11.4)	3	(11.5)
Diagnostic category				
AN	1	(2.9)	4	(15.4)
BN	10	(28.6)	7	(26.9)
BED	21	(60.0)	12	(46.2)
EDNOS	3	(8.6)	3	(11.5)

Note: SES based on Hollingshead's two-factor index of social position (Hollingshead & Redlich, 1958; Miller, 1991). AN = anorexia nervosa; BN = bulimia nervosa; BED = binge eating disorder; EDNOS = eating disorder not otherwise specified.

ment for their eating disturbance. Many of those who had sought treatment (particularly those with BED) had been treated for a weight problem. Similarly, Striegel-Moore et al. (2000) compared Black and White women with BED in a community-based study. They found that although treatment for eating disorders was uncommon in both groups, Black women were significantly less likely than White women to have received treatment. Treatment for a weight problem was much more common and there were no differences

Table 2. Reasons for having sought treatment provided by women with eating disorders

	Total $(n = 35)$
Concern with body weight	19 (54.3%)
Feelings of depression and anxiety	11 (31.4%)
Being encouraged by friends or family	8 (22.9%)
Feeling physically uncomfortable	4 (11.4%)
Being concerned about health problems	4 (11.4%)
Concern about overeating	3 (8.6%)
Believing one has an eating disorder	2 (5.7%)
Being teased by others	1 (2.9%)
Having access to free treatment	1 (2.9%)

Note: Individuals may have provided more than one response.

Table 3. Endorsement of reasons for not seeking treatment by women with eating disorders

	Total $(n = 29)^a$
Financial difficulties	17 (58.6%)
Lack of insurance	14 (48.3%)
Others can't help	11 (37.9%)
Fear of being labeled	10 (34.5%)
Not knowing about resources	10 (34.5%)
Feelings of shame	9 (31.0%)
Fear of discrimination	6 (20.7%)
Turning instead to other sources	6 (20.7%)
Don't think I have a problem	4 (13.8%)
Counselors not of same ethnic background	3 (10.3%)
Lack of transportation	3 (10.3%)

Note: Individuals may have endorsed more than one barrier.

between the two groups. It appears that among women who are being treated for obesity and who have therefore accessed care, the opportunity to offer treatment for their eating disturbance is being missed, particularly for minority women (Striegel-Moore, 2000).

Our finding that treatment-seeking subjects had an earlier onset age of the first symptom of disordered eating (i.e., overeating) is consistent with research demonstrating an inverse relationship between age of onset of psychiatric disorder and probability of treatment contact (Kessler, Olfson, & Berglund, 1998). We did not find, however, that treatment seekers had a significantly earlier onset age of the full clinical syndrome than nonseekers (although the mean onset ages were in the expected direction). The initiation of binge eating occurred during adolescence, a finding that has been reported as well by other researchers (Mussell et al., 1995).

Treatment-seeking subjects had more binge eating-related distress than nonseekers and reported seeking treatment due primarily to weight concern. The mean delay time between onset of eating disorder and first treatment contact was approximately 4 years, which is somewhat shorter than the average delay of 6–14 years reported for mood, anxiety, and addictive disorders (Kessler et al., 1998).

Surprisingly, there were no significant differences in treatment seeking between the ethnic groups and there was no effect of ethnic identity strength or acculturation. A possible explanation is that our sample was fairly acculturated because participants had to be fluent in English in order to complete the interview. Additionally, a number of the White women were Armenian or Middle Eastern in origin. Hence, this group may not have been representative of typical White samples. On the other hand, our results may indicate that among populations of women with eating disorders drawn from the community, ethnic or race differences in treatment seeking do not exist. Race differences (with Whites being predominant) may emerge in referral to clinics and inclusion in treatment trials. For example, treatment trials typically focus on BN and have vomiting as an inclusion criterion. Minority women, who generally are less likely to vomit as purging and more likely to use laxatives and diuretics (Cachelin et al., 2000; Story, French, Resnick, & Blum, 1995), would be excluded from such trials.

Likewise, there were no differences between treatment seekers and nonseekers on the remaining variables (e.g., age, marital status, BMI, SES, insurance coverage, or type of eating disorder). The lack of differences between groups in SES and insurance coverage

<sup>&</sup>lt;sup>a</sup>Responses of three individuals who expressed that initial treatment contact made them unwilling to seek further treatment are included in this sample.

suggests that self-reports of not seeking treatment due to finances and insurance may simply have been ready or convenient excuses. Other research also indicates that availability of health insurance does not necessarily promote greater contact with mental health services (Olfson, Kessler, Berglund, & Lin, 1998). Finances/insurance and other barriers to treatment seeking need to be further explored in future studies.

This study had several potential limitations. The sample was self-selected in nature; participants responded initially to a recruitment flyer and then agreed to be recontacted for a full interview. This self-selection resulted in a sample that was fairly acculturated and educated and that may have been composed of women who overall are more willing to seek treatment. Additionally, some of the groups were small, particularly those with AN and EDNOS. Asian women were not well represented. Therefore, sufficient statistical power to detect some differences may not have been present. Nevertheless, this study represents an important first step toward understanding barriers to treatment for eating disorders in women of minority groups, an issue that has not received empirical attention.

In conclusion, among a sample of ethnically diverse women with eating disorders, more than one half had made treatment contact, but the majority had not received treatment. Treatment-seeking subjects had more binge eating-related distress and reported seeking treatment due to weight concern. In fact, a majority of treatment seekers, in particular those with BED, had been treated for a weight problem. There appears to be a lack of recognition on the part of both health care providers and clients that women from ethnic minority groups can suffer from eating disorders such as BED, a key behavioral symptom of which is binge eating. More research and educational intervention are needed if women of ethnic minority groups who suffer from eating disorders are to receive adequate treatment.

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