The prevalence of Eating Disorders Not Otherwise Specified

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Abstract

Objective: Eating Disorders Not Otherwise Specified (EDNOS) represent the most common eating disorder diagnosed in specialized treatment settings. The purpose of the current study is to assess the prevalence of EDNOS in a nationwide community sample. Method: Participants were 2028 female students, aged 12 to 23, attending public schools in the 9th to 12th grades in Portugal. Participants completed the Eating Disorder Examination Questionnaire in Stage 1 of the study. In Stage 2, we selected all the participants who met any of these criteria: (1) BMI = 17.5, (2) scores = 4 on any of the four EDE-Q Subscales, (3) a total EDE-Q score = 4, or, (4) the presence of dysfunctional eating behaviors. In Stage 2, eating disorder experts interviewed 901 participants using the Eating Disorder Examination. Results: The prevalence of all eating disorders was 3.06% among young females. Prevalence for anorexia nervosa was 0.39%, for bulimia nervosa 0.30%, EDNOS 2.37%. Conclusion: EDNOS is a very common eating disorder and accounts for three-quarters of all community cases with eating disorders

The prevalence of Eating Disorders Not Otherwise Specified

In spite of many epidemiological studies, there is still a considerable debate about the prevalence of eating disorders in the community. This is even more so in the case of Eating Disorders Not Otherwise Specified (EDNOS), due to the lack of epidemiological studies designed to detect and clinically diagnose EDNOS cases.

Community based two-stage epidemiological studies of eating disorders, conducted in North America and Western Europe, have revealed an average prevalence rate of 0.3% for anorexia nervosa (AN) in young females[1] Recent studies among female twins show high lifetime prevalence rates for anorexia nervosa of 1.2% in Sweden [2] and 1.9% with an additional 2.4% for partial anorexia nervosa (absence of amenorrhea) in Australia [3]. The generally accepted prevalence rate of bulimia nervosa from two-stage studies is about 1% among young females[4,5]. The few available epidemiological studies suggest a prevalence of at least 1% for Binge Eating Disorder in the general population[6,7].

The number of methodologically sound epidemiological studies of eating disorders is limited, as it has been pointed out in a series of reviews published along the years (e.g.[1,8-11]). Most of the two-stage studies also have considerable limitations. Mainly, the sample is usually drawn from a limited geographical area, relying mostly on urbanized areas and without carefully controlling for socio-economic status of participants. In addition if interviews in the second stage are not carried out by trained clinical staff there might be the risk of misdiagnosing cases.

Limiting samples to urbanized areas increases the sampling bias, as previous research reported a more than five-fold increase in the prevalence rates of bulimia nervosa in urban areas compared to rural areas[12] and we can speculate that the same might be true for EDNOS.

Although Anorexia Nervosa (AN) and Bulimia Nervosa (BN) are the most well known and best described eating disorders, most of the individuals who seek help do not meet the full diagnostic criteria for these disorders. Most cases would fall into the DSM-IV [13] category of "Eating Disorders – Not Otherwise Specified" (EDNOS), a diagnostic category used for eating disorders that do not meet the criteria for one of the specific eating disorders (i.e., AN or BN). In outpatient settings EDNOS cases account for an average of 60% of all cases, compared to 14.5% for AN, and 25.5% for BN[14]. While these patients are characterized by similar core cognitive psychopathology[15], they represent the least studied group in eating disorder patients.

Eating Disorders Not Otherwise Specified. are eating disorders that, according to the DSM-IV, feature behavior variants such as 1) for females, all symptoms of AN but amenorrhea, 2) all symptoms of AN except that current weight is in the normal range, 3) all the criteria for BN, but the frequency of binges or compensatory behaviors do not meet the frequency criterion, or last less than 3 months, 4) inappropriate compensatory behaviors by individuals of normal weight after eating small amounts of food, 5) repeated chewing and spitting out, but not swallowing large amounts of food, and 6) Binge Eating Disorder: recurrent episodes of binge eating in the absence of regular other inappropriate compensatory behaviors, characteristic of Bulimia Nervosa.

The purpose of the current project was to conduct a two-stage epidemiological study of Eating Disorders Not Otherwise Specified in a large community sample. Such a study would need: 1) a large sample; 2) drawn from different geographical areas; 3) use a two stage design; 4) guarantee a high response rate; 5) use lenient criteria for selecting cases for the second stage; 6) use strict DSM-IV diagnostic

criteria to define cases; and, 7) use clinically valid and tested procedures to analyze detect cases and diagnose them according to DSM-IV criteria.

METHOD

Design

This is a two-stage epidemiological study on the prevalence of eating disorders. In the first stage a large representative sample was screened. Individuals who met the criteria for "possible" cases were contacted and interviewed in the second stage of the study.

To ensure a wide participation in the study, we took several measures including: 1) we solicited permission for the study from the Portuguese Ministry of Education and the regional school authorities; 2) we then contacted the school directors to inform them about the project, and the fact that it had been approved by national and regional authorities; 3). the research team visited the schools to discuss in person the implementation, including discussing informed consent procedures ; 4). between this first visit to the school and the first-stage screening, we contacted each school's parents associations in order to increase consent from parents of students under the age of 18.

The current study was presented as a study on eating habits of adolescents. Informed consent was obtained from both students and in case of minors also from their parents. In most schools, the parents' association collected the informed consent for participation in both stages of the study prior to Stage 1. In two of the schools, consent was obtained for each stage of the study separately, in accordance with the preference of the parents association. All students were informed that participation in the study was voluntary.

Sample selection

We selected a nationally representative sample of women in the public school system. The target age range was 13 to 19 years, the expected age range of students between grades 9 and 12. To select which schools would participate in the study, school districts were aggregated in four geographical areas (North, Centre, Lisbon Metropolitan Area, and South). The North area, which includes the city of Porto (the second largest city in the country, has 37% of the population. The Lisbon metropolitan area, which includes the capital city, accounts for 36% of the population. The remaining is distributed in the Centre (18%) and South area of Portugal (9%).

To select the schools that would participate in the study, we first aggregated school councils in order to create a balance between urban and non-urban areas. The selection was then made in two stages. First, the council was selected, and then the school. Councils were selected in a weighted manner, considering the number of schools and population, and then schools were selected randomly (one per council). The sample was created in order to obtain a large sample of at least 2,000 women in the target age range, and 11 schools were selected to carry on the study.

Socioeconomic status (SES) of the participants was determined, at stage 1, using an adaptation of the Graffar schedule[16] on which scores range from 5 to 25 with higher scores indicating lower socioeconomic level. This schedule takes into account the years of formal education and profession of the parents, sources of income, type of housing and of neighborhood to assign the family to one of 5 SES categories. The information collected corresponds to data that students routinely provide to the school; in addition researchers were available to answer any questions students might have.

Measures

Eating Disorder Examination – Questionnaire (EDE-Q, 4th edition)[17]: This is a self-report questionnaire with 36 items that generates 4 subscale scores (restraint, eating concern, shape concern, and weight concern), as well as a global score which is the average of the four subscales. Respondents rate each item on a 7 point rating scale (i.e., 0-6) indicating the number of days out of the previous 28 in which particular behaviors, attitudes, or feelings occurred.

Eating Disorder Examination (EDE, 12th edition)[18]: This is a researcher conducted interview developed to measure a broad range of specific psychopathologies characteristic of eating disorders. For the current study we used the diagnostic items of the EDE, in order to determine DSM-IV diagnosis. The EDE diagnostic items assess the individual's state in the present and over the last three months, providing data on the frequency of key behaviors, such us binge eating and self-induced vomiting, and the severity of other features of eating disorders.

Procedure

In the first stage of the study, all female students attending school on the day the research team visited their particular school (Stage 1) were screened with the EDE-Q. For the second stage of the study, we selected all participants who met at least one the following criteria: (1) BMI = 17,5, (2) Scores = 4 on any of the four EDE-Q subscales; (3) a total EDE-Q score = 4, or, (4) the presence of dysfunctional eating behaviors (i.e., binge eating episodes, inappropriate weight control methods).

These very lenient criteria were used to ensure that every possible case of eating disorder (including EDNOS) would be identified. We preferred to have a large number of false positives rather than missing false negatives.

Additionally, approximately 20% of those not meeting any of the criteria above were randomly selected to participate in Stage 2.

In Stage 2, consenting participants were interviewed with the Eating Disorder Examination (EDE). All interviews were carried by clinical psychologists, with clinical experience and training in treating eating disorder patients, trained in the use of the standardized interview procedure by the principal developer of the procedure (CG Fairburn) who also served as a consultant to the project.

At the end of the interview, the researcher would answered any questions the participant had; participants diagnosed with eating disorders, and not currently in treatment, were referred to the school psychologist and/or the local health services. After the interview, responses were recorded on data sheets and all possible symptoms of eating disorder registered on a checklist. All diagnosed cases were reviewed by the research clinicians and the principal investigator of the project (PPM). All diagnostic decisions were reached in a consensus meeting. A case was considered EDNOS if it corresponded to one of the six examples presented by the DSM-IV[13], clinical severity was determined by clinically significant EDE scores on the relevant diagnostic items and by assessment of clinical impairment by the interviewer.

This study was reviewed and approved by the granting institution review board, and conformed to both National and European regulations on conducting research with human participants and on the management of personal data.

RESULTS

The sample

At stage one, 2028 students from the 11 public schools selected that were attending a class at the time the research team visited the school completed the questionnaires. 194 participants did not complete all questionnaires properly, producing

missing or unusable data. This corresponds to an attrition rate of 9.5% at this stage. At stage two from the remaining 1834, 1094 were selected based on our previously defined criteria. We were able to interview 996 participants at stage two, 836 based on the selection criteria, and 130 randomly selected from those not meeting any selection criteria to identify possible false negative cases. At stage two, 258 of those selected based on selection criteria, missed the scheduled interview by either refusing to participate in the interview, failure to obtain consent, or because they missed school that particular day. This corresponds to an attrition rate of 23.5%, at this particular point of the study, representing 13% of the initial sample. Figure 1 presents the number of participants on each stage of the study, as well as the number of missing data at stage one and the number of participants that were interviewed at stage 2.

Insert figure 1

The age of the 2028 participants, at stage 1, ranged from 12 to 23 years; the mean age was 16.19 (SD = 1.33) years, and mean BMI was 20.92 (SD = 3.80). Participants from the Northern region of Portugal – the region first studied - were slightly, but significantly younger (*Scheffè test* Mean = 15.85, SD = 1.36) than those from other areas; all other differences were non-significant. There was no significant difference on BMI amongst regions.

The social economic status distribution (SES) of the sample was: 1) high SES, 21%; 2) medium high SES, 22%; 3) medium SES, 32%; 4) medium low SES,24%; and, 5) and low SES, 1%.

EDE-Q mean, global and subscale, scores for the 1834 participants who were screened in Stage 1 of the study, and produced useable data, were: EDE-Q Restraint,

Mean = .92 (SD = 1.26); EDE-Q Eating Concern, Mean = 1.83 (SD =1.62); EDE-Q Shape Concern, Mean =.65 (SD = .96); EDE-Q Weight Concern, Mean =1.89 (SD =.67); and, EDE-Q Global, Mean = 1.31 (SD = 1.23).

Table 1 shows the number participants that met each of selection criteria for being selected for the stage 2 of the study.

Insert Table 1

In Stage 2, using DSM-IV[13] diagnostic criteria, we detected 62 cases of eating disorders. Of these, 48 cases were of cases of "Eating Disorders – Not Otherwise Specified" corresponding to a prevalence rate of 2.37%. Fourteen cases (0.69%) were either anorexia nervosa (N=8; 0.39%) or bulimia nervosa (N=6; 0.30%). None of the participants that were randomly selected to participate on the stage 2 of the project were diagnosed with an eating disorder. The age of the 62 cases ranged from 14 to 19 years; the mean age was 16.12 (SD = 1.18) years.

Of the 48 cases of EDNOS, 5 were sub-threshold clinical cases of AN (all DSM-IV AN criteria but amenorrhea), 19 were sub-threshold clinical cases of BN (all BN symptoms present but the weekly frequency was lower than the DSM-IV criterion), 2 were Binge Eating Disorder (BED), and 22 corresponded to other possible EDNOS, sometimes called mixed cases. Of these 22 other EDNOS cases, 3 met all of the criteria for AN except that, despite significant weight loss, the individuals' current BMI was over 17.5; the remaining 19 cases indicated the regular use of inappropriate compensatory behaviors in the absence of regular binges and most (N=13) of these cases would be best classified as what some authors call purging disorder[19].

Based on the observed rates using the total sample (2028) as a denominator we also computed the extrapolated prevalence assuming that the observed prevalence would be observed in the missing cases at each stage of the study (i.e., missing data at stage 1, and non-interviewed at stage 2). Table 2 shows the prevalence rates (observed and extrapolated) and confidence intervals of eating disorder diagnosis in the studied sample as well as the distribution EDNOS cases based on DSM-IV[13] example categories.

Insert Table 2

Table 3 presents the clinical features of the EDNOS cases with the number of participants that endorsed each key ED behaviors such as purging, dietary restriction, excessive exercise, and binge eating, during the 3 months prior to the clinical interview.

Insert Table 3

CONCLUSION

In a nationwide study in Portugal we have found that the prevalence of eating disorders among schoolgirls was 3.06%. The prevalence for anorexia nervosa was 0.39%, for bulimia nervosa 0.30% and for EDNOS 2.37%. EDNOS accounted for 77.4 % of all diagnosed cases of eating disorders in the community as compared to only 13% for AN and 10% for BN. Our findings support previous research in clinical settings that shows that most individuals that seek help, have neither AN nor BN according to the current diagnostic criteria.

Our point prevalence rate for anorexia nervosa of 0.39% is similar to the average prevalence rate found in Europe and North America[1]. The prevalence rate of bulimia nervosa was lower than that found in most other studies. This might reflect a possible decrease in the occurrence of bulimia nervosa, which is supported by some recent findings in the UK[20] and the USA[21].

The relatively high frequency of sub-threshold cases of AN and BN might reflect early stages of full syndrome development if we consider the young age of the population under study. Future longitudinal studies should evaluate the course of these cases in order to identify if they become full cases or remain EDNOS, or even remit. Our study shows that EDNOS is the most frequent eating disorder in young females, even if we partial out the sub-threshold cases of AN and BN. The remaining EDNOS (mixed) cases would still account for a third of all eating disorder diagnosed. The finding that Binge Eating Disorder (BED) was rare in this young population was expected as it is most commonly found in adulthood.

The high observed prevalence rate of EDNOS may be very significant in public health terms. Previous research has estimated that only about one third of anorexia nervosa patients in the community and 6% of those with bulimia nervosa receive mental health care[1]. This might reflect both the secrecy usually associated with eating disorder behaviors and the difficulty health care professionals experience detecting eating disorder cases, especially bulimia nervosa. It seems likely that this is even more the case in EDNOS patients, making the proportion of EDNOS cases in clinical settings a poor estimator of the number of cases in the community.

This study was designed to evaluate the prevalence of EDNOS in a community sample. With it we tried to address some of the methodological problems of previous studies, such as small sample size of a limited regional area and the use of self-reported

data only. We examined a nationwide representative sample, and used a standard, reliable instrument to collect our interview data by trained eating disorder experts. In the second stage of the study we also interviewed 20% of the non-selected cases in order to detect possible false negative cases. None was detected, probably because of the lenient selection criteria for Stage 2 inclusion.

As in all epidemiological studies, the current one has its limitations, namely, the attrition rate between the two stages of the study. It might be that some of the missing cases in stage 2 were actually clinical cases. We tried to circumvent this limitation by extrapolating the number of possible cases, assuming that clinical cases would have the same distribution amongst the ones that missed the clinical interview at stage 2.

In summary, EDNOS are the most common eating disorders diagnosed in the community. The cases present the same core psychopathology, as assessed by trained clinicians and standard measurements, as other ED cases. Some of them fail to meet the frequency of behavioral symptoms of Bulimia Nervosa or the amenorrhea criteria for Anorexia Nervosa; others are characterized by mixed features of eating disorders. However, the distribution of clinical cases in the community does not map the current diagnostic categories; in fact the vast majority of cases diagnosed fall into what should only be a residual category.

References

1. Hoek HW, Van Hoeken D. Review of the prevalence and incidence of eating disorders. International Journal of Eating Disorders 2003;34(4):383.

2. Bulik CM SP, Tozzi F, Furberg H, Lichtenstein P, Pedersen NL. Prevalence, heritability, and prospective risk factors for anorexia nervosa. Archives of General Psychiatry 2006;63:305.

3. Wade TD, Bergin JL, Tiggemann M, et al. Prevalence and long-term course of lifetime eating disorders in an adult Australian twin cohort. Australian and New Zealand Journal of Psychiatry 2006;40(2):121.

4. Fairburn CG, Beglin SJ. Studies of the epidemiology of bulimia nervosa. American Journal of Psychiatry 1990;147:401.

5. Hoek HW. Review of the epidemiological studies of eating disorders. International Review of Psychiatry 1993;5:61.

6. Hay P. The epidemiology of eating disorder behaviors: an Australian community-based survey. International Journal of Eating Disorder 1998;23:371.

7. Striegel-Moore RH, Franko DL. Epidemiology of binge eating disorder. International Journal of Eating Disorders 2003;34(S1):S19.

8. Fombonne E. Anorexia nervosa. No evidence of an increase. British Journal of Psychiatry 1995;166(4):462.

9. Hsu L. Epidemiology of the eating disorders. The Psychiatric clinics of North America 1996;19(4):681.

10. Keel PK, Klump KL. Are eating disorders culture-bound syndromes? Implications for conceptualizing their etiology. Psychological Bulletin 2003;129(5):747.

11. Hoek HW. The incidence, prevalence and mortality of anorexia nervosa and other eating disorders. Current Opinion in Psychiatry 2006;19:389.

12. Hoek H, Bartelds A, Bosveld J, et al. Impact of urbanization on detection rates of eating disorders. American Journal of Psychiatry 1995;152(9):1272.

13. American Psychiatric Association. Diagnostic and statistical manual of mental disorders (4th edition). Washington, DC: APA; 1994.

14. Fairburn CG, Bohn K. Eating disorder NOS (EDNOS): an example of the troublesome "not otherwise specified" (NOS) category in DSM-IV. Behaviour Research and Therapy 2005;43(6):691.

15. Turner H, Bryant-Waugh R. Eating disorder not otherwise specified (EDNOS): profiles of clients presenting at a community eating disorder service. European Eating Disorders Review 2004;12:18.

16. Graffar M, Corbier J. Contribucion a l'étude de l'influence des conditions socio-economiques sur la croissance et le développement de l'enfant. Courrier CIE 1996;16(1):1.

17. Fairburn CG, Beglin SJ. Assessment of eating disorders: Interview or self-report questionnaire? International Journal of Eating Disorders 1994;16(4):363.

18. Fairburn CG, Cooper Z. The Eating Disorder Examination (12th ed.). In: Fairburn CG, Wilson GT, editors. Binge eating: Nature, assessment and treatment. New York: Guilford; 1993. p 317.

19. Keel PK, Haedt A, Edler C. Purging disorder: An ominous variant of bulimia nervosa? International Journal of Eating Disorders 2005;38:191.

20. Currin L, Schmidt U, Treasure J, et al. Time trends in eating disorder incidence. British Journal of Psychiatry 2005; 186(2):132.

21. Keel P, Heatherton T, Dorer D, et al. Point prevalence of bulimia nervosa in 1982, 1992, and 2002. Psychological Medicine 2006;36:119.

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Table 1. Numbers and percentage of participants that met each criteria for inclusion in Stage 2 as self-reported on EDE-Q

	(2028) N (%)
BMI <17.5	155 (7.6%)
EDE-Q Global Score	125 (6.2%)
Restraint	132 (6.5%)
Eating Concern	353 (17.4%)
Shape Concern	47 (2.3%)
Weight Concern	350 (17.3%)
Objective Bulimic episodes	517 (25.5%)
Subjective Bulimic episodes	499 (24.6%)
Self-induced vomiting	59 (2.9%)
Laxative misuse	33 (1.6%)
Diuretics use	37 (1.8%)
Excessive exercise	254 (12.5%)

Table 2. Eating Disorders frequency, observed, and extrapolated prevalence rates, and 95% confidence intervals (C.I.)

	N	Observed prevalence % (95% C.I.)	Extrapolated prevalence % (95% C.I.)
EDNOS	48	2.37 (1.70 – 3.04)	3.13 (2.36 – 3.90)
Sub-threshold AN	*5*	*0.25 (0.03 –0.46)*	*0.33 (0.08 –0.57)*
Sub-threshold BN	*19*	*0.94 (0.52 - 1.36)*	*1.24 (0.75 – 1.72)*
BED	*2*	*0.10 (0.00 - 0.24)*	*0.13 (0.00 - 0.29)*
AN "normal weight"	*3*	*0.15 (0.00 – 0.32)*	*0.20 (0.00 – 0.39)*
Regular use of compensatory methods	*19*	*0.94 (0.52 - 1.36)*	*1.24 (0.75 – 1.72)*
Anorexia Nervosa	8	0.39 (0.12 – 0.67)	0.52 (0.21 – 0.84)
Bulimia Nervosa	6	0.30 (0.06 - 0.53)	0.39 (0.12 - 0.66)
Total cases	62	3.06 (2.30 – 3.82)	4.04 (3.17 – 4.92)

Table 3 – Number of participants that endorsed each of the clinical features characteristic of the EDNOS cases (N=48)

	N	%
Objective Binge Eating	24	50.00
Subjective Binge Eating	5	10.42
Purging	38	79.17
Vomit	*19*	*39.58*
Laxative Abuse	*7*	*14.58*
Diuretic Abuse	*12*	*25.00*
Non-Purging	26	54.17
Dietary restriction	*18*	*37.50*
Excessive exercise	*8*	*16.67*
Currently in treatment for ED	6	12.50

Figure 1. Participants at Stages 1 and 2