

## Illness intrusiveness in anorexia nervosa

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### Abstract

**Objective:** “Illness intrusiveness” refers to illness-induced lifestyle disruptions. The primary aim of the current study was to compare the level of illness intrusiveness in anorexia nervosa (AN) to that reported in a variety of other chronic medical and psychiatric conditions. A secondary aim was to compare the two subtypes of AN (binge/purge vs. restricting) in terms of the nature and extent of illness intrusiveness. A final goal was to examine changes in the level of illness intrusiveness in AN following successful completion of specialized inpatient treatment. **Methods:** The participants were a consecutive series of 121 female inpatients with AN who were admitted to a specialized inpatient unit for treatment of the eating disorder. Assessments took place before and after inpatient treatment and at 3-month follow-up. **Results:** At

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baseline, illness intrusiveness scores for AN patients were significantly higher than those reported by women in the medical and psychiatric comparison groups. Overall, illness intrusiveness scores decreased (i.e., improved) significantly following successful completion of inpatient treatment. Among patients with the restricting subtype, scores continued to improve during follow-up, whereas this was not the case among patients with the binge–purge subtype of AN, whose scores did not change significantly during follow-up. **Conclusion:** Despite being notoriously ambivalent about change, these findings suggest that AN patients perceive their illness to be highly disruptive to a variety of life domains, even more so than patients with other chronic medical and psychiatric conditions.

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### Introduction

Anorexia nervosa (AN) is an eating disorder characterized by severe food restriction, maintenance of an abnormally low body weight, intense fear of weight gain, and body image disturbance [1]. In about half of cases, there is recurrent binge-eating and purging through self-induced vomiting or laxative misuse (i.e., binge–purge subtype). The disorder tends to run a chronic course and is associated with significant psychiatric comorbidity, serious medical complications, and considerable impairment in psychosocial functioning.

Some previous studies have found greater self-reported impairment in health-related quality of life among those with the binge–purge subtype (AN-BP), as compared with the restricting subtype (AN-R) of the disorder [2–5], while other studies have not [6,7]. Possible reasons for these contradictory findings include the use of different measures and different populations (e.g., patients vs. community samples). Most previous studies have used the Medical Outcomes Study Short Form 36-item Health Survey (SF-36) [8], a well-validated questionnaire that provides a global measure of health-related quality of life, by assessing physical, emotional, and social well-being. In the present study, we were interested in examining one particular aspect of health-related quality of life, namely, *illness intrusiveness*, which is defined as illness-induced lifestyle disruptions that interfere with continued involvement in valued activities and interests [9]. To measure illness intrusiveness, the Illness Intrusiveness

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Ratings Scale (IIRS) [9], which measures the extent to which an illness and/or its treatment interferes with 13 domains central to quality of life, has been developed [10]. Illness intrusiveness correlates significantly with a number of quality of life indicators, including life satisfaction, depressive symptoms, self-esteem, marital satisfaction, and global psychopathology, as well as social and occupational functioning [9,11,12].

Normative data is not available for the IIRS since the nature of the measure requires its testable population to be restricted to individuals with a medical illness, and norms would require extremely large numbers of participants stratified by their particular illness. However, there is an ongoing effort to determine how illness intrusiveness differs among different medically ill populations. Devins et al. have administered the IIRS to a number of medically ill populations, including patients with end-stage renal disease, multiple sclerosis, cancer, and rheumatoid arthritis [9,13–17], as well as patients with a variety of psychiatric disorders, including anxiety disorders, schizophrenia, bipolar disorder, and insomnia [18–21]. Thus, although standard norms are not available, there is a literature available to allow for comparisons between specific illnesses.

Although AN is widely recognized to be highly disruptive to patients' quality of life, the degree to which AN compromises quality of life as compared to other chronic physical and psychiatric conditions is unknown. The primary aim of the current study was to compare the level of illness intrusiveness in AN female patients with that reported by female patients with a variety of other serious medical and psychiatric illnesses. Data for the comparison groups were obtained from previous studies. A secondary aim was to compare the two subtypes of AN (i.e., AN-BP vs. AN-R) in terms of the nature and extent of illness intrusiveness. A final goal was to examine changes in illness intrusiveness in AN following successful completion of specialized inpatient treatment for the eating disorder and at 3-month follow-up.

## Method

### Participants

The participants were a consecutive series of female patients who were admitted to the Inpatient Eating Disorders Program (IEDP) of the Toronto General Hospital between 2000 and 2005. Originally, 149 patients were approached about participating in the study; however, 9 refused to participate, 13 agreed to participate but did not complete any of the questionnaire packages, and 6 dropped out of the program before they were approached about the study. Thus, the remaining sample comprised 121 participants. All participants met *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV)* criteria for AN at the time of admission to the program. The IEDP is an intensive

group therapy program that is primarily directed at symptom control, normalized eating, and the restoration of body weight to a body mass index [BMI (kg/m<sup>2</sup>)] of 20 [22].

At admission to the inpatient unit, the 121 participants had a mean age of 25.4 years (S.D.=7.4) and a mean BMI of 15.0 (S.D.=1.7). The mean duration of illness was 6.6 years (S.D.=7.0 years), and the mean age of onset of AN was 18.7 years (S.D.=5.0). The average length of stay in treatment was 12.5 weeks (S.D.=5.8), and the mean weight gain was 10.9 kg (S.D.=6.2). Eighty-four percent were single, 13% were married or living in common-law relationships, and 3% were separated or divorced. Most participants were students (49%); 13% were unemployed, and 38% were employed. With regard to racial background, 93% were Caucasian, 2% were Asian, and the remaining 5% were either African Canadian or East Indian. Fifty-two participants (43%) met *DSM-IV* criteria for the AN-BP subtype. The remaining 69 participants (57%) had AN-R.

### Comparison groups

IIRS means for the comparison groups were obtained from the studies cited in Table 1. In each case, the sample consisted of female outpatients attending university-affiliated clinics for the treatment of their illness. Scores from all patients in each comparison study were used. As we did not have access to the raw data from the previous studies, formal statistical comparisons could not be conducted between the AN patients and the comparison subjects in terms of demographics. The mean age appeared to be somewhat lower in the AN group as compared to the comparison groups, but otherwise, the groups were broadly similar demographically. The data from the comparison groups also were collected slightly earlier than the data from the group with AN. The data collection period for the comparison groups ranged from 1992 to 2004.

### Assessment instruments and protocol

The study was approved by the Institutional Research Ethics Board. Participants received a complete description of the study before written informed consent was obtained. Key eating disorder symptoms were assessed using the Eating Disorder Examination [23]. This is considered to be the "gold standard" interviewer-based measure of eating disorder psychopathology. It provides 28-day frequencies of key eating disorder behaviors and generates subscales that assess dietary restraint, eating concern, shape concern, and weight concern. The global score is the mean of the four subscales. Its reliability and validity have been established [24–28]. Weight and height were measured to calculate BMI (kg/m<sup>2</sup>).

The IIRS [9] assessed the degree to which AN and/or its treatment interferes with 13 diverse life domains that have been identified to be important to quality of life. This self-report instrument taps the extent to which one's "illness and/

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