

The Canadian Eating Disorder Program Survey – Exploring Intensive Treatment Programs for Youth with Eating Disorders

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Abstract

Objective: To explore and describe philosophies and characteristics of intensive eating disorder (ED) treatment programs based in tertiary care institutions across Canada. **Method:** A ninety-item survey examining ED services for adolescents was developed, piloted, and completed by 11 programs across Canada. Information pertaining to program characteristics and components, governance, staffing, referrals, assessments, therapeutic modalities in place, nutritional practices, and treatment protocols were collected. **Results:** The results highlight the diversity of programming available but also the lack of a unified approach to intensive eating disorder treatment in youth. **Conclusions:** This report provides important baseline data that offers a framework that programs can use to come together to establish assessment and treatment protocols as well as a process for outcome evaluation. Continued collaboration will be essential moving forward to ensure Canadian youth, regardless of geographic location, receive the necessary treatment required to attain and sustain recovery.

Key Words: *eating disorder, survey, intensive treatment, anorexia nervosa, bulimia nervosa*

Résumé

Objectif: Explorer et décrire les philosophies et les caractéristiques des programmes de traitement intensif des troubles alimentaires (TA) menés dans des institutions de soins tertiaires au Canada. **Méthode:** Un questionnaire en 90 items examinant les services de TA pour adolescents a été mis au point, piloté et rempli par 11 programmes pancanadiens. L'information concernant les caractéristiques et les composantes des programmes, la gouvernance, la dotation en personnel, l'aiguillage, les évaluations, les modalités thérapeutiques instaurées, les pratiques nutritionnelles et les protocoles thérapeutiques a été recueillie. **Résultats:** Les résultats mettent en évidence la diversité des programmes offerts mais également, l'absence d'une approche unifiée du traitement intensif des troubles alimentaires chez les adolescents. **Conclusions:** Ce rapport offre d'importantes données de départ constituant un cadre que peuvent utiliser les programmes pour s'assembler et établir des protocoles d'évaluation et de traitement ainsi qu'un processus d'évaluation des résultats. La collaboration continue sera essentielle dorénavant pour faire en sorte que les adolescents canadiens, peu importe l'emplacement géographique, reçoivent le traitement nécessaire pour atteindre et faire durer le rétablissement.

Mots clés: *trouble alimentaire, sondage, traitement intensif, anorexie mentale, boulimie*

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Introduction

Eating disorders (ED) are the third most common chronic illness among adolescent females (Fisher et al., 1995) and are associated with the greatest mortality rate of all psychiatric disorders (Fisher, 2006). At present, the standard of care for patients with EDs encompasses a multidisciplinary approach, which draws upon medical and nutritional rehabilitation as well as psychological interventions (APA, 2008). Within Canada there are a number of ED treatment programs that operate out of tertiary care hospitals and offer care to adolescents. Although the focus of care within the majority of these settings has utilized outpatient services, many programs have also established more intensive services such as formalized inpatient treatment programs or partial hospitalization/day treatment programs.

Within Canada, health care is delivered through a publicly funded system and is guided by the Canada Health Act. Although the quality of healthcare is overseen by federal standards, delivery of service within most provinces is provided through Canada's largest healthcare program, Medicare (comprised of 10 provincial programs). The distribution of and budgetary allowances afforded to eating disorder programs varies tremendously depending on the province. Further, the variability and depth of programming and services that exist throughout the country has not necessarily been uniform or consistent in any one guiding treatment principle. Although Canadian sites offer quality treatment programs and demonstrate innovative research and treatment development, treatment practices and program structures differ across the country, and there is no consensus on best practice for medical and/or psychological treatment of adolescents with severe eating disorders in Canada.

Canadian experts in the field of adolescent eating disorders have recently been afforded a new national opportunity to liaise with each other and share information. The creation of The Eating Disorder Association of Canada in 2008 provided health care providers in the field with an opportunity to meet biannually in an attempt to establish better cross communication and collaboration as well as to solidify common ground relating to treatment approaches. It also provided a backbone whereby eating disorder researchers could begin to further explore the current state of practice on a national level. It was felt that a prudent initial step in helping to establish what Canadian practice guidelines should look like, would be to explore what was occurring across the country within established settings. As such, a small group of adolescent ED researchers assembled a working group with an aim to characterize and describe current practices using a comprehensive survey. Once informed about the range of treatment services provided nation-wide, experts could then start to look at developing a framework that could be used to guide best practices and measure outcomes across different treatment settings.

Methods

Study approval was provided by the hospital's Research Ethics Board. The survey was piloted and revisions made where indicated prior to the survey's national distribution.

Participants

Contacts from eleven programs were established prior to the survey distribution. We asked that Clinical Directors and Program Coordinators complete the survey with input from senior clinicians. One survey was completed per program site. The inclusion criteria for treatment centres were provincially recognized and/or hospital funded programs operating out of a tertiary or quaternary level hospital.

Procedure

A 90-item questionnaire was developed with the input of physicians and researchers on the Researching Eating Disorders in Adolescents (REDA) Working Group (2008). This working group was made up of members from five of the participating sites and was multi-disciplinary in nature. The survey included several questions on each centre's program, including inpatient, day treatment, and outpatient services as well as treatment philosophies. Feedback from REDA committee members prompted multiple revisions. The survey was piloted in February 2010 and made available online via Survey Monkey in July 1, 2010.

Statistical Analysis

Data was analyzed using simple descriptive statistics.

Results

All eleven sites completed the survey. Responses were collected within three months of survey distribution.

Program Characteristics

Every program surveyed reported treating patients with diagnoses of anorexia nervosa (AN), bulimia nervosa (BN), and eating disorder Not Otherwise Specified. Only four (36%) programs assessed and offered treatment to patients struggling with binge eating disorder. Each site acknowledged using the DSM IV-TR diagnostic classification system at assessment and for treatment purposes. Each site provides inpatient and outpatient services. Just over half of the programs surveyed (55%) also provide day or partial hospitalization treatment services. Almost all of the sites (91%) provide consultation services within the hospital to patients not under the care of the ED program.

With respect to program leadership, six programs are governed by the Department of Psychiatry or a larger hospital-based mental health operational framework; two programs are housed within and directed by members of the Paediatrics Department; and three program sites share leadership and operational organization between Psychiatry/Mental Health and Paediatrics/Paediatric Medicine. Six of 11

Table 1. Percentage (%) of inpatient program sites (n=10) that provide each professional service; and mean total full time equivalent (FTE) of each professional's allocation to the entire program per program site (n=11).

Professional	% of inpatient program sites (n=10)	Mean total FTE per program site (n=11)
Physician (non-psychiatrist)	80	1.4 (SD=0.90)
Psychiatrist	80	1.4 (SD=1.3)
Psychologist	90	1.5 (SD=1.2)
Social worker	90	1.5 (SD=1.3)
Nurse	90	6.9 (SD=7.7)
Occupational therapist	20	0.21 (SD=0.38)
Dietician	100	0.7 (SD=0.96)
Child and youth counsellor	60	2.1 (SD=2.8)
Teacher	90	0.85 (SD=0.84)
Recreational therapist	50	0.22 (SD=0.34)
Administrative support	70	0.97 (SD=0.83)
SD= standard deviation		

program sites have a precise program budget which is used to guide treatment and resource planning specific to EDs, whereas the other five programs did not identify a budget separate from a global departmental budget. All sites provide ED treatment to adolescents aged 12-18 and three quarters of programs (eight of 11) do so using services that are distinct and separated from adult care. Nine sites (82%) offer ED treatment to children under 12 years of age and in one case, such patients remain eligible for treatment using a day hospital approach.

Table 1 provides an overview of the professional services provided at the ten inpatient program sites. One program site does not have an inpatient ED program that is separate from a general medical inpatient unit, which accounts for the sample size of only 10. Table 1 also shows the mean full time equivalent of each professional service at the 11 program sites.

Referrals and Assessments

There was a wide discrepancy between the number of stated referrals received and completed in 2009 by each of the eleven programs (Table 2). Similarly, the variance in number of patients treated by programs was large, and could not be easily explained by catchment area size or by the depth of program resources. When asked specifically about treatment indicators and length of treatment, the average time given for treatment of patients within a program (i.e. point at which first assessment takes place to point at which discharged back to primary care provider) in years was found to be 2.0 (SD=1.1, min=0.67, max=3.5), although it was

unclear what measures programs used to delineate these results.

Nine programs (82%) utilize patient and/or parent psychological measures at the time of assessment. At the time the survey was completed, the most commonly reported measures used at assessment were the eating disorder inventory-3 (64%), the children's depression inventory (CDI) (45%), and a motivational-based scale (the specific scale used varied by site) (36%). Seven sites (64%) collect measures when a patient enters or leaves a component of the program (i.e. day treatment) and as well at the point of clinical discharge from the program. Three sites attempt to also administer measures at time points after the patient has been formally discharged from the program. Almost all programs (91%) collect data using an eating disorder specific database, although the range of variables collected is diverse (medical, psychological and family-related variables) and inconsistent.

Treatment

All programs provide patients with medical stabilization as well as nutritional restoration and employ a variety of therapeutic milieus. The majority of programs use family based therapy (91%) as indicated, either in the form of traditional Maudsley therapy or formalized family-based therapy as outlined by Lock & LeGrange (2001), for the treatment of AN. Depending on the specific diagnosis of patients and context of treatment (i.e. group vs. individual therapy), other treatment modalities including cognitive-behavioural approaches (100%), readiness motivational models (55%) narrative approaches (45%), interpersonal and psychodynamic

Table 2. Mean number of patient referrals and assessments performed in 2009, and mean number of patients enrolled at 11 Canadian eating disorder treatment program sites in July 2010

	Mean (n=11)
Number of referrals in 2009	119.1 (SD=53.2)
Number of assessments in 2009	98.7 (SD=56.7)
Number of patients currently enrolled (July 2010)	105.2 (SD=59.9)

approaches (36%) and multi-family therapy (27%) are utilized. Given the geographical challenges faced by multiple programs, seven sites (64%) utilize telehealth to offer care outside of local programming/therapy.

Nutrition

Regarding food and food choices, the majority of programs (92%) allow vegetarianism during treatment although the timing of onset helps guide treatment. Seven sites (64%) allow vegetarianism to continue only if it predated the eating disorder; three sites (27%) allow patients to continue as vegetarians regardless of timing. One site reported not allowing patients to be vegetarians during the acute treatment phase. Fewer sites support veganism (37%), and all of these sites support it only if veganism predated the eating disorder.

Ten programs (91%) provide pre-packaged/ plated meals for patients over the course of admission and every program offers meal support during the inpatient stay. Persons providing meal support are trained for this task at 10 sites (91%). Staff members eat with patients during meal support at five sites (45%). If required, liquid supplementation is used at all 11 inpatient program sites, at all six day program sites, and at 7/11 (64%) outpatient programs. Five inpatient sites (45%) give patients the option of initiating nutrition as liquid supplement at the time of admission. Nasogastric (NG) tubes are used by all inpatient programs as necessary, but they are used in only two thirds of day treatment programs and in just four of 11 outpatient program settings.

Inpatient Treatment

Eight sites (73%) reported having regular wait lists for inpatient beds (average wait 6.5 weeks). The majority of sites (82%) have a pre-determined heart rate cut off at which point admission is recommended (range 40-50 beats per minute (bpm)), whereas much fewer programs (27%) use a pre-determined weight cut off at which point admission would be recommended (<80% healthy body weight in all cases). The most common discharge criteria utilized in inpatient settings include: stable vital signs (100%); demonstration of successful passes outside of hospital (55%); minimum percentage of ideal body weight reached (64%); and weight restoration (55%).

Four out of six sites that have day treatment programs transition patients from an inpatient setting into a partial hospitalization setting as a means of facilitating discharge and continuing intensive hospital-based treatment.

Discussion

The results of the survey provide an overview of the diverse treatment programming currently operating across Canada. We were unable to identify any other study that has looked at similar program and treatment variables.

All program sites report a multi-disciplinary team-based approach to the care of adolescents with EDs. Not surprisingly, all teams provide assessments to patients struggling with DSM-IV-TR diagnosed eating disorders, although interestingly only one third of programs provide treatment for binge eating disorders. Although not clearly asked in this survey, it is possible that patients with binge eating disorder are assessed and treated by other multidisciplinary teams (i.e. obesity teams). Regarding treatment intensity, all programs acknowledge the need for an inpatient setting. Admission and discharge criteria used to guide treatment principles were outside the scope of this survey, yet clearly varied among sites.

Professional services were fairly standard across program sites, with most centres offering physician, dietician, nursing, psychiatry, psychology, social work, and teaching services. Fewer sites have occupational therapists, recreational therapists, and child and youth counsellors, which may reflect resource limitations.

Inpatient and outpatient services are recognized as essential components of ED programming as all program sites surveyed had these two core branches. In contrast, day programs are currently operating at just over half of the program sites surveyed. This is less likely related to programs seeing day hospital programs as “less useful” but more reflective of budgetary constraints. Relative to in- and outpatient ED treatment approaches, case descriptions and outcome-linked studies using day hospital programming as the primary ED treatment variable have only appeared in the literature more recently (Piran et al., 1989; Zipfel et al., 2002). Day and partial-day hospitalization programs around the world have been found to have similar overall structure with common goals of weight and health restoration

and normalization of eating (Lammers et al., 2007). They offer a viable alternative to the traditional inpatient-outpatient model, offering cost-effectiveness while at the same time increased treatment intensity, serving as a bridge for patients transitioning out of inpatient care (Piran et al., 1989). Patient success as determined by sustained weight restoration and improved psychological outcomes requires patient motivation as well as a demonstration in readiness to change, which in turn creates a more wellness-focused environment in day programs as compared to the inpatient setting (Zipfel et al., 2002). Although many advantages of day treatment programs have been reported, Canada's geography may limit the feasibility of this model. Some centres have addressed these challenges using partnerships with subsidized and not-for profit organizations (i.e. Ronald McDonald Houses) and the establishment of host families. As well, despite the fact that partial hospitalization models have shown promise as it relates to outcomes, the organizational framework can be limiting given that the number of spots associated with such programs are limited and length of treatment can be extended.

Despite the fact that this survey had clearly identified questions relating to the referral process and waiting times associated with different program sites, there were large discrepancies in the manner by which programs reported this data. This may partly be related to the fact that programs do not track such variables. As a result of these discrepancies, we were unable to draw any correlations between the number of patients assessed in a given year to the number of patients treated. In hindsight, our survey could have been more specific in attempting to ascertain the pathways involved from point of assessment to time of discharge from programs. Further, our questions were likely too vague (i.e. "How many patients were treated...") as treatment can entail any number of different modalities. Not surprisingly, we found that patients tend to require extended treatment courses (regardless of how it was defined) as outlined by the fact that most programs followed patients for at least one year from the time of first assessment before transitioning back to primary care providers. Although completed in England, Gowers et al.'s multicenter randomized trial which explored different treatment modalities for adolescent AN found that just 33% of patients were in complete remission at the two year period, underlying the fact that most patients do require extended treatment courses (Gowers 2010). In keeping with the discrepancies observed with respect to referrals and triage, it was notable that the number of patients assessed was quite variable ranging from just 35 assessments per year to 235. Again, this could not be explained by catchment areas alone and was likely due to other factors, such as what the assessment day involved, the age of patients served by the treating team, and the size of the ED team and their capacity to complete regular assessments.

The majority of programs reported collecting baseline data at assessment and the Eating Disorder Inventory-3 (EDI-3)

was the most common measure used (64%). The results suggested that programs in general were using a host of different measures and the observed overlap outside of the EDI-3 and the children's depression inventory (CDI, used by 45% of sites) was very low. In the twenty-four months since this survey was completed, there has been a greater concerted effort to amalgamate the measures that are being used by adolescent eating disorder teams.

Family-based therapy is very popular at ED treatment sites across Canada. This reflects literature that gives empiric support for family therapy methods in the treatment of children and adolescents with EDs (Russell et al., 1987; Eisler et al., 1997; Le Grange et al., 1992; Eisler et al., 2000; Lock and LeGrange 2001; Lock et al., 2005; Lock et al., 2006). Designed to improve patient outcomes and reduce readmission rates, the Maudsley model of family therapy (developed in London, England) applies to patients under 19 years with AN with duration of less than two years (Dare, 1985). Although most trials involve individuals with AN, the Maudsley Model has also demonstrated success in the treatment of adolescents with BN (Russell et al., 1987). The majority of program sites across Canada offer stand-alone treatment for children and adolescents and utilize a family-based focus, although a multitude of models appear to have shaped programs' treatment philosophies. This variation may be due, in part, to different demographic and geographic needs or funding arrangements across program sites. It may also reflect the lack of standardized, best practice guidelines in this country and as well the historical frame in which programs developed.

Our study also revealed that Canadian centres have different approaches and philosophies pertaining to nutritional practices and provision (i.e. vegetarianism and veganism). Some programs allowed patients to continue with a vegetarian diet throughout treatment, while others, only if vegetarianism predated the eating disorder. Regardless of the nutritional belief, it is important for providers to understand the reasons that youth shift their belief patterns and/or practices as it relates to nutrition. It is clear that a percentage of adolescents who adopt a vegetarian diet do so in order to increase their control relating to weight or body shape (Perry et al., 2001; Kadambari et al., 1986; Gilbody et al., 1999). Robinson-O'Brien et al. (2009) reported higher rates of restriction, fasting, purging, and use of diet pills and laxatives among adolescent vegetarians compared to those who were not vegetarians.

High caloric liquid supplements were used, if required, at all inpatient and day programs, however four sites did not use supplementation for outpatients. The specific circumstances under which liquid supplementation was used was not explored, but less than half of the program sites gave inpatients the options of using liquid supplements upon admission, indicating that protocols for supplementation are not uniform across the country. High calorie supplements

can facilitate weight gain in individuals with AN. Arii et al. (1996) demonstrated that compared to AN inpatients on a regular diet, those started on drink supplementation before initiating a regular diet had fewer gastrointestinal complaints and had greater weight gain. In another study, weight gain in a group of inpatients with AN on a regular diet plus supplement gained weight more rapidly, experienced a shorter duration of treatment, and weighed more on discharge compared to those on a regular diet without liquid supplement (Imbierowicz et al., 2002). Enteric feeding through nasogastric tubes was used at all programs surveyed. Although re-feeding through regular meal and snacks is the preferred method of weight gain in patients with EDs (Andersen, Bowers and Evans, 1997), intensive enteric feeding is warranted in urgent cases where patients are severely malnourished or when oral intake is refused (Neiderman et al., 2000). This is usually accomplished via nasogastric tube (Kennedy and Shapiro, 1993). Due to the potential psychological consequences of involuntary nasogastric tube feeding, this method is typically only used in urgent cases where oral intake has failed or been refused (American Psychiatric Association, 2006). Evidence from a retrospective chart review suggests that meal support therapy, whereby staff members enforce rules on eating behaviour and food consumption while providing emotional support to patients during meal times, can reduce the need for nasogastric tube feeding in adolescent inpatients with AN (Couturier and Mahmood, 2009). All program sites surveyed in our study employed meal support therapy, which may help to limit the number of patients requiring intensive enteric feeding and improve outcomes in general. A recently published study examining the effect of meal supervision on weight gain found that those supervised were more likely to gain greater amounts of weight than those not supervised (Kells 2012).

Regarding admission and discharge practices, the survey demonstrated variability in the threshold by which patients are both admitted to inpatient units and discharged. Survey questions examining these factors were adapted from previously published treatment guidelines made available by the American Academy of Pediatrics (2003) and the American Psychiatric Association (2000, 2006). Similar variability has been demonstrated by our American counterparts, and likely reflects the fact that treatment guidelines have been shaped by expert opinion as opposed to evidence-base data, which in turn has resulted in a variety of different treatment practices across the continent (Schwartz et al., 2008).

Future Directions

This survey is the first that we are aware of that begins to try and understand how national ED programs can come together to learn from each other's experiences in hopes of building a framework that would best suit all patients' needs. Clearly, there are a number of challenges associated with this task. For one, the funds allocated to eating disorder

programs vary tremendously from province to province. Three provinces could not even be included in this survey given the lack of stratified intensive ED treatment available to youth. Further still, the fact that all programs continue to have waiting lists, some of which last over one year, intertwined with the fact that these illnesses often result in severe medical and psychiatric co-morbidity, implies that a proportion of youth continue to get sicker while they await assessment and treatment. Funding agencies need to come to terms with the fact that the illness requires intensive psychological treatment and that early intervention is essential to stave off the chronicity that these illnesses all too frequently breed. Innovative solutions must be sought in order to serve as many patients as possible using the dollars that have been made available. As we build capacity, it will also be also important to examine the relationship between secondary and tertiary/quaternary services within provinces given the fact that early aggressive interventions should help decrease overall chronicity, morbidity, and mortality. To this end, it behoves programs to work collaboratively to ensure that outcomes are being tracked and reported on. The recent establishment of the CanPed working group (a national collaboration of ED researchers invested in streamlining assessment and program evaluation) provides the necessary first step in this journey. As well, as a national group of professionals invested in best practice, further work on exploring treatment guidelines that will address the unique challenges of the Canadian landscape should formally begin. Given the devastating effects of the illness when left inadequately treated, it is critical that those involved in clinical care, health policy, and funding decisions come together to ensure that the best possible care is delivered to all Canadian eating disordered youth, regardless of where they live.

Acknowledgements/Conflicts of Interest

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