

Family-based treatment of children and adolescents with anorexia nervosa: Guidelines for the community physician



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Anorexia nervosa (AN) is a serious life-threatening illness that typically has its onset during the adolescent years. Evidence regarding the optimal treatment of AN in children and teenagers is growing; however, much remains unknown. Although current treatment approaches vary in Canada and elsewhere, the evidence to date indicates that family-based treatment (FBT) is the most effective treatment for children and teenagers with AN. A key component of the FBT model is that the parents are given the responsibility to return their child to physical health and ensure full weight restoration. An understanding of the basic principles and philosophy underlying FBT allows the physician to initiate elements of this evidence-based intervention to young patients with AN and their families.

Key Words: *Anorexia nervosa; Child and adolescent; Eating disorder; Family therapy; Outpatient*

Eating disorders are common in Canadian society, with up to 5% of young women having experienced an eating disorder before reaching adulthood (1). Anorexia nervosa (AN) typically has its onset in mid-adolescence; however, AN also occurs in younger children (2). AN entails severe morbidity among young people and is associated with increased mortality (1). The impact of AN on the parents and other family members can also be devastating. Less commonly, boys and young men also present for treatment of AN.

Evidence regarding the optimal treatment of AN in children and teenagers is growing; however, much remains unknown (3,4). Although current treatment approaches vary in Canada and elsewhere, the evidence to date suggests that family-based treatment (FBT) (5-8) is the most effective treatment for children and teenagers with AN. A key component of the FBT model is that the parents are given the responsibility to return their child to physical health and ensure full weight restoration. In this model, the patient is treated as an outpatient by an interdisciplinary team assisting the family in tackling the eating disorder and helping the child to make changes in his or her eating

Le traitement familial des enfants et des adolescents anorexiques : Des lignes directrices pour le médecin communautaire

L'anorexie mentale (AM) est une maladie grave qui met la vie en danger et qui fait généralement son apparition pendant l'adolescence. Les données probantes au sujet du traitement optimal de l'AM chez les enfants et les adolescents sont en croissance, mais il reste beaucoup à apprendre. Même si les démarches thérapeutiques actuelles varient au Canada et ailleurs, les données jusqu'à présent indiquent que le traitement familial (TF) est le plus efficace pour les enfants et les adolescents anorexiques. Un élément essentiel du modèle de TF, c'est que les parents sont investis de la responsabilité de rétablir la santé physique de leur enfant et de s'assurer de la reprise complète de son poids. Le médecin qui comprend les principes fondamentaux et la philosophie du TF peut mettre en place les éléments de cette intervention fondée sur des faits probants auprès des jeunes patients anorexiques et de leur famille.

behaviour. The potential advantages of this approach are numerous – the young person remains in his or her environment, which allows for ongoing connection with friends, family and activities – all of which are essential for long-term recovery. The family becomes empowered as they learn that they have the ability to help their child. Finally, scarce inpatient resources can be directed to young people whose eating disorder cannot be managed as an outpatient with FBT.

Although FBT is considered standard treatment in child- and adolescent-onset AN, it is unclear whether it is the best initial approach for all young patients and their families, or whether we can predict who is more likely to respond. This model has also not yet been studied in a community setting. Despite these limitations, however, a knowledge of the basic principles and philosophy underlying FBT allows the paediatrician or family physician to initiate elements of an evidence-based intervention to the young person with AN (9,10). Further, an understanding of FBT allows the physician to introduce components of this treatment should the patient and family be waiting for further consultation from specialized paediatric eating disorders services.

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The Canadian Paediatric Society statement “Eating disorders in adolescents: Principles of diagnosis and treatment” (11) provides a general introductory overview of eating disorders in adolescents. We refer readers to this and other papers (1,2,9,10,12-14) for information on diagnostic issues, indications for hospitalization, medical complications and monitoring of young people with eating disorders. The goals of the current paper are to describe the principles of FBT for children and adolescents with AN. It is beyond the scope of family physicians and paediatricians to provide long-term family therapy; however, the principles presented here are those that community physicians should be aware of and use as first-line interventions for young patients with AN and their families.

TREATMENT PLANNING AND FBT

After establishing a diagnosis of AN, the physician has to determine treatment recommendations for the young person and his or her family. Often, the first question after diagnosis is, “Where should the patient and family get treatment?” Where available, referral to a specialized service should be initiated, but in many places in Canada, these services are not available or have lengthy waiting lists. Initial management often falls to the primary care provider, who can set up regular visits with the young person and the family. In locations where no specialized services are available, multidisciplinary care should still be the goal and referrals can be made to other professionals, such as a family therapist, psychiatrist or dietician.

Provided the patient is not critically ill, outpatient weight restoration using the principles of FBT should be initiated in preteenagers and teenagers with AN as soon as a diagnosis is made. Educating parents about the need to confront the eating disorder symptoms should begin with letting them know that the eating disorder is not their fault, and that they are not to blame for their child’s illness. It is, however, the parents’ responsibility to ensure that their child gets well. Dwelling on the cause of the symptoms is unlikely to be helpful, but the family can be informed that the eating disorder is currently believed to be caused by a combination of many different factors – both genetic and environmental – and that they are unlikely to find any specific cause in their child (1,9,15).

Parents should be taught that their child has become unable to care for him- or herself, because he or she is overwhelmed by a powerful illness. The parents should be instructed to be in charge of their child’s eating and exercise to ensure weight restoration. They are given permission to take a firm stand against the eating disorder and to insist on adequate nutrition, which should start slowly, but immediately. Parents are encouraged to interrupt all abnormal food- and exercise-related behaviour. It is helpful to provide anticipatory guidance to the parents that refeeding will be difficult, because their child may become angry and defiant. When both parents are available, they need to work together to ensure that the child consumes an adequate amount of nutrition to ensure health. For parents who are

interested, they can be referred to read *Help Your Teenager Beat an Eating Disorder* by Lock and Le Grange, which provides in-depth strategies for parents undertaking refeeding of their child. There is also an excellent parent-run Web site <www.maudsleyparents.org> that provides support and information.

Although the early management of AN in children and adolescents involves engaging the parents in making changes, it is also critical to establish rapport and a therapeutic relationship with the young person with AN. Initially, this can be difficult, because in most cases, the young person is brought to the doctor’s office unwillingly; often not acknowledging his or her eating habits. This ‘denial’ that patients with eating disorders so frequently project is one of the most challenging features of the illness for physicians. Patients can be mislabelled as stubborn or difficult when, in truth, they are affected by a psychiatric illness that has symptom denial as one of its most striking features. Although the patient may not be interested in making any changes to his or her eating habits, they are likely to have some symptoms that they are bothered by – such as hair thinning or falling out, or always feeling cold. Many patients are also able to agree that they do not like the preoccupation with weight and shape that has affected their ability to relax or think about other things. Trying to find those few things that are unpleasant for the patient may allow for early rapport building with the reluctant young person.

Because many young people with AN deny their symptoms, it is not uncommon for the patient to resist the plan for weight gain. Advising the parents to change the way they have been handling their child’s eating disorder does not require the young person to ‘agree’ with the planned changes in nutrition or exercise, because parents are well within their authority to impose behavioural consequences (such as a withdrawal of activities) to affect their child’s choices. Traditional behavioural modification strategies – rewarding desirable behaviours and providing consequences for undesirable behaviours – can be useful. For example, privileges such as exercising or going out with friends can be negotiated between parents and teenagers, depending on cooperation with eating and weight gain. The teenager needs to understand clearly that physical health and weight restoration are not negotiable, and that the grown-ups (ie, parents and doctors) are working together to ensure that this happens. However, it is always helpful to try to help the young person understand why the changes are necessary. They may be more likely to cooperate if the physician can suggest some changes on their behalf – such as asking the parents or siblings to do something fun after the meal to help the young person distract themselves from ‘feeling fat’.

OUTPATIENT FOLLOW-UP

Outpatient medical visits are of central importance to the early management plan of the child or teenager with AN (9,10). One of the most important aspects of the visits is the establishment of an open therapeutic relationship with the

child and family. After a diagnosis is made, and the parents have been supported to take charge of the patient's eating and exercise habits, follow-up medical visits should be very frequent and regular, up to once per week, depending on the severity of the illness and medical complications. The primary goal for the medical visits is to assist the family, who is assisting the patient in gaining weight. The goal of consistent weight gains (0.2 kg to 0.5 kg per week) should be discussed with the parents and child. Guidance on how to facilitate weight gain can vary: some families use nutritional supplements, others sharply curtail exercise, and some simply insist that the child eat more. For almost all patients, face-to-face parental support of the patient consuming three meals and two to three snacks per day is critical. Some families may benefit from working with a dietician who can provide suggestions, although most parents have a good sense of how much nutrition their child needs.

The practicalities of this time-consuming intervention present very real challenges to most families. Some families are very busy, and if they do not make some changes, refeeding can be nearly impossible. For many parents, a leave of absence or reduced hours at work is necessary to ensure adequate supervision of nutrition. Physicians can offer to write letters to employers if parents need support. For most patients, schooling should continue, although the parents may need to bring the child home for lunch if there is reason to believe the entire lunch will not be consumed. For most patients, stopping physical activity as the refeeding process gets started is necessary, but other activities can continue provided they do not interfere with adequate nutrition and weight gain. Once weight gain is steadily occurring at each visit, physical activity can be slowly restarted while monitoring further gains. Families can be advised that the time commitment and intense supervision required at the beginning of treatment is time well spent, and offers the child or adolescent the best chance of complete recovery.

Many families express doubt at the effectiveness of this strategy, believing that they have done 'everything' to get their child to eat. In reality, explaining to the parents that it is their right and responsibility to ensure that their child eats, and having the parents present a united front to the child, can change things tremendously. In families with two involved parents (even if living in separate houses), it is recommended that both parents participate actively in the 'hands-on' work of renourishing their child; this is a powerful message to the child that both parents are working together to fight the AN. It is often necessary to give parents frequent reminders that the illness has affected the child or teenager's ability to adequately care for themselves, and that without the parents continuing to take charge, recovery will not occur.

Depending on the age of the patient, the visits should almost always begin with the teenager alone. Visits should begin in an open-ended and friendly manner, with the teenager free to ask questions on any new issues that he or she would like to discuss. Given the high frequency of visits, the

physician has the opportunity to inquire about other areas of life (eg, school, friends or sports) to reinforce that not everything is about his or her weight. Although this may, at first, feel like small talk, it delivers the message that you are interested in him or her as a person, and that he or she is important – a message many patients with AN struggle to believe.

For many patients, being checked regularly may have a positive impact on the eating disorder behaviours. They may be less likely to restrict food intake, exercise excessively or purge, knowing that eating disorder behaviours will be discussed and that they will be weighed and examined each week. For their part, parents may be less tolerant of these same behaviours in their child, knowing that they are responsible for curtailing them on their child's behalf. Going to the doctor to be weighed provokes a lot of anxiety; thus, visits should be as predictable as possible so that the teenager and family know what is coming next.

The physician will want to find out about core eating disorder behaviours – eating, exercise and purging – at each visit. Although teenagers with eating disorders have a reputation for being deceptive, this is not usually the case. Most patients are honest with their struggles, when asked in an empathic, nonjudgmental manner. They need to know that you will not be mad or disappointed if they are struggling. It may be helpful to discuss how hard it is for the teenager to give up control of eating and exercise to his or her parents, and how hard it is to tolerate weight gain. Reminding the patient that the parents and physician are working together to fight the eating disorder, not to fight him or her, can be helpful. The physician can also educate the patient about the need for weight restoration, discuss the short- and long-term risks of malnutrition, and offer encouragement to make changes to their current eating and exercise patterns.

Information that the patient discloses during individual visits should be considered confidential; however, it is important to let the patient know about the limits of confidentiality. Certain eating disorder behaviours or symptoms pose immediate and long-term safety issues for the teenager, and cannot necessarily be kept private from parents. Some examples include a recent fainting episode, hypokalemia, hematemesis or suicidal intent.

Following the initial time alone with the teenager, the physician should leave the room and allow the teenager to change into a gown, leaving on only the undergarments. Wherever possible, the same scale should be used at each visit, and the teen should be asked to provide a urine sample and completely empty the bladder. This allows the weight to be measured in a consistent manner each time. Intermittently checking the patient's height and sexual maturation is important for children and teenagers who are still growing and developing. Orthostatic heart rate and blood pressure should be checked at each visit. Extreme self-consciousness and, at times, frank loathing of the body are common in eating disorders, and physical examinations can be excruciating for the patient. Special attention needs to be paid to the teenager's need for privacy.

TABLE 1
Practical elements of family-based treatment that the physician can initiate when treating children and adolescents with anorexia nervosa

Parents:

- Do not cause eating disorders and should not be blamed
- Can be angry at the eating disorder, not at their child who is suffering with an eating disorder. A child or teenager with an eating disorder is not doing it on purpose or for attention
- Need to understand that anorexia nervosa is a serious condition that probably would not improve without treatment
- Need to be responsible for their child's weight gain. Weight restoration is the first step in treatment
- Must be in charge of eating and exercise until the child has returned to health
- Should support and supervise their child's meals and snacks
- Must appreciate that eating disorders affect a child's ability to make reasonable decisions about food and exercise; parents must temporarily manage these areas of the child's life

Medical visits:

- Should be frequent at first, such as weekly or biweekly
- Should include checking the patient's weight and vital signs at each visit
- Should include meeting with the patient alone to review his or her eating attitudes, behaviours and challenges at each visit
- Should include feedback about weight and vitals to both the parents and patient at each visit
- Should include frequent reminders and encouragement to the parents about the need to insist on adequate nutrition and limit setting

Behavioural management:

- Encourages parents to use 'natural consequences' for food refusal. For example, do not allow the teenager to attend a sports practice until a proper dinner is eaten
- Involves a gradual return of the responsibility from the parents back to the child once the refeeding is going well
- Includes slowly integrating exercise back into the child's life once weight is steadily increasing

The remainder of the visit should include meeting with the parents who accompanied the patient to the appointment. Given that this initial phase of managing the AN involves putting the parents in charge of the child's eating, they will need regular feedback on how their child's weight is progressing. If weight gain has not occurred, it is important to discuss with the parents and teenager together what the problem seems to be, and what changes can be made to ensure adequate nutrition. Parents can struggle with providing adequate meal support or insisting on reduced exercise in an effort to avoid unpleasant conflict with their child. The physician can remind the parents that the conflict that arises is part of the process of helping their child get healthy, and avoiding the conflict may prolong the eating disorder.

The combination of individual visits with the young person followed by meetings with the patient and parents is an initial intervention that can be offered to all children and teenagers presenting with AN. In some less severe cases of AN, this intervention, coupled with some general family counselling, may be adequate to resolve the symptoms. For patients who are awaiting more specialized services, this initial intervention may prevent deterioration and hospitalization, or may reduce the need for more intensive treatments, such as day hospital or residential treatment. Slow weight restoration is the initial treatment goal of FBT. Improvement in eating attitudes and body image are often slower to return to normal. If outpatient FBT does not result in weight gain, then referral to specialized eating disorder services is warranted.

CONCLUSIONS

AN is a serious life-threatening eating disorder that usually presents in the adolescent age group, but is increasingly recognized in prepubertal children. The physician caring for

young people with AN must be in a position to intervene as soon as the diagnosis is made. In the initial management, the physician should empower and support the parents to take a firm stand against the eating disorder behaviours (restricting, purging and over-exercising) and bring the patient to regular medical appointments. See Table 1 for a summary of the key points of using FBT for AN.

RECOMMENDATIONS

- After a diagnosis of AN is made, physicians should provide initial counselling to the parents, asking them to take charge of the child's eating and exercise. Both parents (when available) should work in unison to ensure that all meals and snacks are supervised, that exercise is not excessive and that the patient attends regular visits.
- Where available, referral should be made to a specialized paediatric eating disorder service.
- Medical visits should occur regularly (ie, weekly or biweekly) with the patient and family. These visits should include an interview with the child or teenager alone, followed by a physical examination and laboratory evaluation (when indicated) to assess the patient's physical status.
- Parents should receive feedback at every visit. If weight is not increasing, the physician, together with the parents and patient, should try to ascertain why weight is not increasing. Any excessive activity may need to be stopped or any unsupervised eating may need to be supervised.
- For patients and families who do not respond to outpatient interventions, the physician should advocate for intensive paediatric eating disorder treatment, which may include inpatient or day hospital services.

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SUGGESTED READINGS FOR PARENTS

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