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Strategies for supporting youth with eating disorders when intensive treatment is needed

Inpatients and outpatients in the Eating Disorders Program at BC's Children's Hospital have benefited from an approach that allows them to gradually take on greater responsibility for monitoring their diet and physical activity.

ABSTRACT: Inpatient treatment of youth with eating disorders at BC's Children's Hospital has undergone several changes in the last 2 years, resulting in increased patient, staff, and family satisfaction. New strategies being used include thorough pre-care interviews, Meal Support Therapy, the Responsibility Level System, and a step-out option. Modified versions of the strategies may be applied to treating eating disorders in the community health care setting.

Major changes have occurred in the past 20 years in the treatment of eating disordered patients in the hospital setting, as described elsewhere in this issue (see "A new treatment approach to eating disorders in youth"). In the past, treatment involved physician-directed care with standard orders such as bed rest, nasogastric tube refeedings, and restricted visitations. These orders often resulted in noncompliance and left the patient feeling socially isolated, anxious, and powerless. Families also felt blamed, uninformed, and hopeless, as they were not included in the treatment plan. This left both patient and family frustrated and angry. Today's approach at BC's Children's Hospital (BCCH) is patient-centred and involves both the child and the family. Community health care professionals working with individuals with eating disorders can benefit from knowing about the assessment process and some practical strategies used by the Eating Disorders Program. These strategies might be modified for use in communities with different needs and more limited resources.

Assessment and criteria for treatment

All assessment referrals to the BCCH Eating Disorders Program are initiated by a community physician. The assessment usually involves a full day with the program's assessment team (clinical director, psychologist, psychiatrist, pediatrician, nurse, and sometimes a social worker). These assessments are used to determine the most appropriate services for the patient and family. Recommendations for treatment include the following: (1) continue with care in the community; (2) attend a BCCH Outpatient Service clinic either weekly, biweekly, or monthly, depending on the need; or (3) be admitted to BCCH Intensive

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Treatment Service (for either the day program or as an inpatient).

The decision to recommend admission to the Intensive Treatment Service is based on the following criteria:

- Significant weight loss.
- Bradycardia.
- Abnormal ECG or changes in ECG.
- Chest pain on exertion.
- Shortness of breath.
- Hypotension.
- Syncope.
- Hypothermia.
- Poor peripheral perfusion.
- Laboratory values indicating metabolic changes.
- Growth delay.
- Severity of compensatory behaviors (purging behaviors, restricting, use of laxatives or diuretics).
- Lengthy illness.
- Lack of progress on an outpatient basis.

Although the patient may meet the criteria for admission to the Intensive Treatment Service, the patient may not be ready to follow the recommendation. The patient is then advised to continue at least weekly visits to a physician or the BCCH Outpatient Service Clinic and to go to a local emergency clinic about symptoms such as chest pain, dizziness, or fainting. Although in our centre all admissions are preplanned, smaller community hospitals are often faced with having to admit critically ill patients who are resistant to treatment. In this situation, the physician may want to admit the seriously ill patient for a period just long enough to achieve medical stability, since longer hospitalizations may result in power struggles, deceitful behaviors, and frustration. Short, frequent hospitalizations, with clear goals involving input from the patient, will help the physician gain trust and establish a therapeutic alliance.

Physicians throughout BC are encouraged to contact the Eating Disorders Program intake coordinator for advice or consultation at any time. Referrals can be initiated when further assessment or more intensive treatment is indicated. Following an assessment, if a patient expresses interest in intensive treatment, a pre-care interview will be arranged.

The pre-care interview

The pre-care interview or meeting is set up shortly before admission to hospital to discuss what the treatment will involve. The patient, the family, and the key worker or clinical resource nurse are present at this interview. In the community, the coordinator of care may be a physician, nurse, social worker, or dietitian. Ideally, this meeting takes place in person, but it will occasionally occur via videoconference for out-of-towners.

The goals of the pre-care interview are as follows:

- To provide information about the program (guidelines and expectations).
- To answer questions and address concerns.
- To observe patient and family dynamics.
- To establish a therapeutic alliance.
- To assess readiness for treatment.

Generally, the pre-care interview is meant to minimize surprise and reduce fear of the proposed treatment. It is not designed to coerce the patient into joining the program, even if it is obvious that the patient needs treatment. Patients are encouraged to process the information and contact us within a week with their decision. They usually leave the meeting with a better understanding of the eating disorder and the treatment being offered, and greater awareness of their level of motivation for treatment. Should the patient choose to enter intensive treatment, future battles may be avoided by clearly outlining the expectations of the program during this early interview.

We use a standard pre-care checklist to ensure that we consistently discuss all the important aspects of future care. The first item on the checklist is the introduction. Here, the physician or the identified staff person acknowledges the youth's personal struggle. This helps to decrease anxiety and facilitate a therapeutic alliance. Providing information about the illness and listening to the youth's concerns and those of the family set the tone for treatment. The patient and family are told that accepting treatment is a major first step toward recovery, and that relapses are to be expected. They are informed that full recovery may involve a long and difficult process but is achievable.

Other topics included in the BCCH Eating Disorder Program pre-care interview are:

- The importance of open, honest communication with staff and family to avoid misunderstanding.
- The importance of individual and family therapy.
- The conduct of monthly reviews in the form of team-family meetings.
- The various therapeutic groups and outings available.
- The meetings with psychiatrist, school teacher, and dietitian that will be set up.
- The behavioral expectations of the program, such as respect for self and property.
- The physical symptoms to be expected (e.g., bloating, feeling full, headaches).
- The psychological effects to be expected (e.g., anxiety, fear of weight gain, loss of control).
- How staff will help with the youth's anxiety and phobic response to weight gain.

- How the Responsibility Level System works.
- How Meal Support Therapy works.
- How the step-out option works.

This list can, of course, be adapted according to the services available in the community. Some expectations such as the weekly kilogram gain and returning to a normal weight range can be overwhelming and difficult for patients to comprehend. These topics, although well outlined during the pre-care interview, may need to be revisited throughout the hospitalization. Various factors such as malnutrition, anxiety, and ambivalence will affect the patient's ability to process and retain the information. It may be helpful to reinforce the ideas presented during the interview in written form.

Some patients may realize they are not ready for change. In this case, they are encouraged to continue weekly appointments with the Outpatient Service until they are ready for intensive treatment or until they reach a medical crisis that requires involuntary admission. The community practitioner may be faced with admitting a patient who is medically compromised but who is refusing recommended hospitalization. There may be pressure from families to intervene and to take action. In this case the pre-care interview still plays an important role. The following scenario depicts a situation that might be encountered in the community.

Mary is a 15-year-old patient with anorexia nervosa restrictive type. She has lost 7 kg over the past 6 weeks and is continuing to lose weight. Her daily diet includes diet cola, one bran muffin, and water. Physical complaints include fatigue, hypothermia, dizziness, and headaches. Blood levels are abnormal and an ECG indicates cardiac abnormalities. It is evident that hospital intervention is crucial. In the pre-care interview, the physician expresses concern for Mary's safety. "Mary, it is now necessary for you to come into hospital. Your health is at risk and we are concerned. Although you have no choice about being admitted to hospital, we can discuss what your stay will be like." In this situation, what can be negotiated includes the goals of the hospitalization, the length of stay based on medical stability (e.g., normalization of blood work results, vital signs), and meal planning options to be discussed with a dietitian (e.g., mealtimes, supplementation for incompletion, and activity level). Although weight gain may not be put forth as a primary goal, it should be explained that some weight gain is inevitable with the correction of acute symptoms.

Inpatient treatment

Once the patient is in the hospital, we rely on a number of strategies designed to help eating disordered youth become responsible for their own treatment.

Dealing with suicidality and self-harm

Some patients coming into hospital have a history of suicidality or self-harm behaviors. During the pre-care interview we assess the risk of self-harm by discussing past behaviors. We also emphasize that the patient is ultimately responsible for her or his well-being, which includes working toward self-respect, dealing with self-esteem issues, and refraining from self-harm behaviors.

Staff working with these at-risk patients should be trained to use a modified Dawson approach to help the patient get through hospitalization with minimal harm.[1] Some patients who are asked to take responsibility for their own behavior may try to avoid responsibility by creating situations that lead to conflict.[2] In this way, patients can create externalized situations that detract from the internalized work they need to do and the responsibility they need to practice.

To avoid becoming embroiled and entangled in conflict, staff should ask patients what is helpful to them rather than imposing solutions on patients whose anxiety is escalating. If and when self-injurious behavior does occur, the behavior must be addressed in a matter-of-fact manner; later, staff can explore the emotions behind the action and discuss how the patient might avoid harming behaviors in future. If a patient's self-harming behavior escalates to a point where it is threatening the patient or others, transfer to a safer environment may be necessary so that the patient can re-evaluate her goals and motivation for treatment.

Meal Support Therapy

Meal Support Therapy (MST) is underappreciated, in spite of being a critical component of the nutritional rehabilitative process. Patient satisfaction surveys indicate that youth find MST one of the most helpful aspects of the program. It should be noted, however, that MST must be well explained during the pre-care interview. For example, patients must be advised that 100% meal completion is expected.

Before admission, the dietitian helps patients understand that they will start off with small meals and gradually build up to larger meals, a plan that will promote a weight gain of 1 kg per week. The dietitian also explains that the patient is allowed two "dislike" foods but all other foods will be introduced to decrease fear of food categories such as fats. On occasion, patients will panic upon receiving this information, and may attempt to bargain and request special considerations. Staff then explain that this is non-negotiable. Patients are

encouraged to review the meal support guidelines and expectations before making a commitment, and are reminded that staff will support them through this difficult process. The first day after admission, a nurse is assigned to spend the day with the new patient to coach, support, and distract throughout the meals. On the second day, the patient is expected to join other patients for mealtimes.

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For MST to be effective, staff must be prepared to eat appropriate meals with the patients. Therefore, staff members who have food issues themselves are not suited to carry out this role. As well as eating with the patients, staff are responsible for planning and carrying out distraction techniques throughout the meals. In our program, there are three meals and three snacktimes at specific hours. Mealtimes are 30 minutes maximum and snacktimes are 20 minutes maximum.

Following meals, patients often experience psychological and physical discomfort. They may be preoccupied with thoughts of purging and feelings of guilt. A period of distraction (postmeal support) for 1 hour following meals and 30 minutes following snacks has been found to help delay these thoughts and urges. Distractions at this time may include movies, board games, and puzzles.

There are several points to keep in mind when planning Meal Support Therapy:

1. Provide an appropriate role model:
- Do not diet (i.e., no "diet," "light," or "low-fat" foods).
- Eat normal amounts of food.
- Eat a balanced meal (i.e., three to four food groups at a meal).
- Eat sufficient food at a snacktime (i.e., a minimum of one glass of juice).

2. Coach with empathy and provide positive feedback:
- Validate the patient's struggle by acknowledging how emotionally and physically challenging it is.
- If the patient is not able to complete the snack or meal, find out why and discuss ways to make completion possible the next time, setting achievable goals.
- In the beginning, be flexible (e.g., allow a few more minutes for the patient to finish a meal on the first day but explain that completion will be expected within time limits on the following day).

3. Address the disordered eating behaviors at the time:
- Encourage once and leave it at that.
- Avoid using a confrontational tone.
- Be nurturing and supportive.
- Deal with what you observe directly (not with hearsay).
- If there are others at the table, address a disordered eating behavior with the patient privately the first time (i.e., after the meal is finished). Explain that in future you will address the behavior at the table. Patients have indicated that they appreciate and expect these reminders.
- Do not let competitive and mimicking behaviors take over.

4. Distract during eating times:
- Be prepared.
- Be creative.
- Vary the distractions.
- Use a radio in the background to create a less tense atmosphere.

5. Be consistent:
- Be well acquainted with the guidelines.
- Do not bargain regarding the guidelines.
- Be clear about what is expected of everyone in the program in order to create an atmosphere of fairness.
- Provide a consistently safe environment (i.e., the dining area should be neutral, pleasant, and calming).

6. Use conversation that is nonemotional in tone during eating times:
- Refer to news items, word puzzles, mind games, horoscopes.
- Avoid conversations about food, diet, calories.
- Avoid talking about tube refeeding and the need for nutritional supplements.

- Avoid comparisons with other patients and staff.
- Avoid personal issues.

When patients are admitted it is common and expected that they will struggle at meals. Staff should acknowledge the struggle while at the same time setting limits with a firm, consistent approach. Patients have found certain phrases to be particularly helpful in allowing them to eat:

- "Your body really needs the fuel."
- "This is your medicine."
- "Take a few minutes to collect yourself, then start again. Try some relaxation and deep breathing."
- "You must be angry and scared, but you deserve to eat. You deserve to get better."
- "I see you are struggling. Right now it is important that you get through the meal. Let's take some time afterwards to talk about it."

Meal Support Therapy is anxiety-provoking but it gets easier over time. Staff who are positive role models and who consistently expect 100% completion of meals will see positive results. A training video and manual[3] for health care professionals and families is available from the Eating Disorders Resource Centre of BC (in the Lower Mainland, phone 604 875-2084; elsewhere in BC, phone toll free 1 800 665-1822). To purchase a video, e-mail Ms Margo Catamo at mcatamo@cw.bc.ca, write to her at Eating Disorders Program, BCCH, Room D409, 4480 Oak St., Vancouver, BC V6H 3V4, or fax 604 875-2271.

Great progress has been seen in the area of meal support. Whereas we used to initiate refeeding with passive methods such as nasogastric tube refeeding, we now help the patients realize that, with support, they can eat normal meals. Nutritional supplements are only very rarely used as a replacement for "difficult" foods. This year, patients in the Eating Disorders Program have moved from eating meals served on hospital trays to serving their own portions. This change reflects our new philosophy of giving increasing levels of responsibility. Concurrently, a monthly restaurant outing with the dietitian and staff has been implemented to help with the transition from eating in an institutionalized setting to eating again in the community. In addition, a weekly cooking group has helped the patients challenge their fears about foods. Learning how to cook has given them an increased sense of self-sufficiency and an awareness that they are preparing for future independent living.

Refeeding syndrome

Refeeding syndrome can occur when a very low-weight patient is reintroduced to regular meals (see "Medical complications in children and adolescents affected by eating disorders," elsewhere in this issue). Nutrition management of patients at risk for refeeding syndrome involves close monitoring of their symptoms and electrolyte status, particularly their phosphate and magnesium levels.[4] The pediatrician in our program orders blood work every 2 days for the first week and then as needed while the dietitian reintroduces food gradually. The recommended initial daily caloric intake usually ranges from 800 to 1200 calories, but may need to be set at only 100 to 300 calories above the patient's preadmission daily intake to reduce the risk of refeeding syndrome and to support adherence. For the first 3 to 4 weeks in an inpatient setting, patients with anorexia nervosa are weighed biweekly. Caloric increases ranging from 300 to 500 calories per week are given to achieve the expected weight gain of 1 kg. The dietitian bases the caloric increase on the patient's weight as well as on laboratory test results. The increases are usually implemented on weighing days. Laboratory tests are ordered and reviewed for the first 3 to 4 weeks but become less important as the patient becomes used to eating. The pediatrician may order supplements such as calcium or phosphorous, but most nutritional requirements are met through diet.

Patients with bulimia are normally weighed only monthly to minimize the psychological effect of weighing. Blood work may have to be continued weekly if patients report or are suspected of ongoing purging.

In the BCCH Eating Disorders Program there has been no incidence of refeeding syndrome consequences such as heart or kidney failure. Close monitoring and very gradual reintroduction of regular meals have contributed to this. In community hospitals, nutritional needs may have to be met by nasogastric tube refeeding or intravenous restoration of fluids. However, it is always better to negotiate a meal plan with the patient prior to a short hospitalization if possible.

The Responsibility Level System

The Responsibility Level System was constructed by Eating Disorders Program staff in collaboration with patients. Feedback in satisfaction surveys indicated that patients were looking for a consistent and fair way to have their progress acknowledged in the form of increased responsibility and autonomy.[5] They asked for gradual and predictable challenges. In response, we eventually developed the Responsibility Level System. Today, the system consists of guidelines for activity and nutrition. Meetings with the psychiatrist, key worker, and the patient are held weekly to review the patient's progress in both areas. Changes in the assigned levels are requested by the patient and are then negotiated based on the patient's progress (weight gain, decrease in

Table 1. The Responsibility Level System: Activity

Level	Activity Guidelines
Admission	• Medical status determines activities.
A	• Stretch/relaxation sessions only. • Patient may ambulate around unit at staff discretion. • Passes allowed in exceptional circumstances. (After 1 week in the program, patient will automatically move up to activity level B unless medically contraindicated.)
B	• Daily physical activity sessions. • Patient may go on outings with staff. • Progressive passes negotiated weekly at review meetings. • Patient may go out for 5-minute unsupervised breaks (after parental approval is obtained) before breakfast, lunch, and once at 6:30 p.m. after postmeal support is finished.
C	• Physical activity sessions as in level B. • Patient may walk on hospital grounds, but must sign out and specify destination. • Obtaining weekend passes is encouraged. • Other passes can be obtained for activities outside of scheduled therapies or activities, with parental approval.
D	• Physical activity sessions as in level B. • Obtaining weekend passes is encouraged. • Passes can be obtained for activities outside of scheduled therapies or activities, with parental approval. • Patient may leave hospital grounds unaccompanied, with parental approval.
Note	• Postmeal support should be completed before passes are obtained. • Nutrition levels take precedence over activity levels. • Individual modifications may be made at the team's discretion.

binging and purging), as well as on feedback from the team about the patient's involvement in other therapeutic activities.

Activity responsibility levels. Activity responsibility levels (see **Table 1**) set the stage for increased physical activity with less supervision. The levels provide opportunities for a range of physical activities, from level A (stretch/relaxation sessions only) to level D (various activities). Daily physical activity is promoted in our program as a way to experience the benefits of health and fitness. A weekly Fitness for Fun program gives patients accurate knowledge and an understanding of fitness concepts and appropriate activities needed for a physically active lifestyle. This program includes a psychoeducation component and supervised activities ranging from walking and recreational sports to strength training in a community recreation centre. Within 1 or 2 weeks of admission, most patients are allowed to participate in supervised physical activity. Eventually, patients progress to a level where they can leave the hospital grounds for unsupervised physical activity. Patients must have parental permission for this and must inform staff of their destination and anticipated return time. If a patient disregards the rules or has failed to gain weight, that patient may be assigned to a lower level of activity responsibility (e.g., level B rather than level D).

Nutrition responsibility levels. Nutrition responsibility levels (see **Table 2**) prepare patients for monitoring their own nutrition with less supervision. The levels provide opportunities for more self-monitoring and a range of nutritional experiences, from level 1 (eating with close supervision) to level 5 (eating in the cafeteria with peers). One hundred percent completion is expected for all snacks and meals at all levels. Proper, respectful eating behavior is also expected at meals and snacks. If a patient cannot carry out responsibilities at the assigned level, a more appropriate level is considered at the weekly review meeting. For example, a patient who is observed hiding food during a meal or who fails to gain sufficient weight (i.e., less than 1 kg) may need to have more supervision at meals and might be assigned to a lower level of nutrition responsibility (e.g., level 2 rather than level 4).

The step-out option

Motivation for recovery during a long hospitalization can fluctuate. Sometimes patients feel that they can't stay any longer and they may make comments such as "I know I can do it on my own" or "I have come as far as I can." If possible, and depending on local hospital policies, the patient and family can be offered a few days to try out recovery at home. In our program, this is done after a family meeting with specific goals for the step-out. During this time the patient's bed is kept available. Most often patients and family realize, after a couple of days of trying to eat on their own, that a discharge would be premature. For some patients, this can increase the motivation to continue. Other patients may choose not to return and may then relapse.

Others may find that they can continue their progress on an outpatient basis. If a patient opts to leave, it is crucial that follow-up outpatient visits continue in order to monitor progress.

Conclusions

Working with youth with eating disorders is a difficult task. Frustration and anger can soon lead to burnout or feelings of inadequacy. This can be avoided with a regular consultation process or debriefing with other members of the care team as described elsewhere in this issue (see "'No, I can't be your …': Boundary issues for health care professionals"). The staff assigned to work with patients with eating disorders can be from any of several disciplines but they must be competent, compassionate, and consistent. Patients' commitment to recovery can fluctuate; therefore, consistency will help the staff to know what to expect and what to watch for. Consistency of care will also instill a sense of confidence in the patient.

At the BCCH Eating Disorders Program we have found that a number of interventions, including Meal Support Therapy, have allowed patients to be increasingly responsible for their own treatment. This has led to a remarkable decrease in the use of coercive methods and a marked increase in patient, family, and staff satisfaction.

Table 2. The Responsibility Level System: Nutrition.

Level	Nutrition Guidelines
Admission	• Patient has 1:1 meal support with staff.
1	• Dietitian chooses meals. • Patient chooses snacks. • Staff set up trays (open all containers). • Staff supervise all meals and snacks at dining room table and check for completion. • Patient may require replacement (Resource Plus) for not completing meals or snacks. • Postmeal support: 1 hour after meals and 30 minutes after snack.
2	• Patient chooses meals and snacks. • Patient sets up own tray with staff support. • Staff supervise all meals and snacks at dining room table and check for completion. • Parents do occasional meal support. • Replacements (Resource Plus) are allowed but not encouraged. • Postmeal support: 1 hour after meals and 30 minutes after snacks.
3	• Patient serves own meals. • Patient may get up after 15 minutes for meals and 10 minutes for snacks. • Patient can take own meal or snack to eat in cafeteria with staff, progressing to dining with family and then friends (at staff discretion). • Patient may substitute snacks on outings (e.g., buy a muffin to have instead of the hospital snack, as long as it is an equal exchange). • If patient is missing an item on tray, may substitute with an equal item from the fridge, but replacements (Resource Plus) are not allowed. • Postmeal support is negotiated individually, as needed.
4	• Dietitian checks menus. • Patient can eat meals and snacks unsupervised off-unit or in room 10 during Eating Disorders Inpatient Service hours but not in the lounge or bedrooms. • One meal per day must be eaten on the unit. • Postmeal support is negotiated individually, as needed.
5	• Dietitian spot checks menus. • Patient may go to cafeteria to eat on own except for breakfast, which must be eaten on the unit. • No postmeal support is required. • Food vouchers are available Monday to Friday.

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Competing interests

None declared.

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