

Working with families of youth with eating disorders

Family members are essential allies when supporting a young person affected by an eating disorder.

ABSTRACT: Family involvement is an important component of the treatment of children and adolescents with eating disorders. Effective treatment means developing a strong therapeutic alliance not only with the youth but with the family. Family members can be a primary resource in recovery if they are assisted to cope during the crisis, to deal with the effects of the eating disorder, and to practise supportive parenting approaches.

Family involvement can make a difference in helping a child or adolescent recover from an eating disorder. Involving the family acknowledges that children and youth live within the context of a family rather than in isolation and includes the family as a resource in treatment.

Parents are naturally very distraught about the impact of the eating disorder on the life of their child and on the whole family. Families as well as patients need help to cope with the eating disorder. All of the health care professionals providing care to the child or youth can optimize care by involving the family to different degrees. In addition, care providers who take the time necessary to support family members when the eating disorder is first identified and family tension is elevated can prevent other problems later on.

Support strategies

A number of strategies may be used to promote the inclusion of families as partners in treatment.

Establishing a therapeutic alliance with the family

The most crucial step with family participation involves developing a strong therapeutic alliance.¹ This first contact with the family is the foundation for future relationships. If possi-

ble, meet all members involved in the care of the child so that you have the opportunity to develop a direct relationship. Even if you first meet with an older adolescent patient alone, with her consent, you also need to meet the patient with family members to review your recommendations. Including parents in the process helps build the trust necessary for engaging the child or youth and her family in treatment. When families trust the health care provider, the youth perceives this trust and can then establish a sense of trust as well. When one parent distrusts the care provider, even if the other parent trusts the provider, the youth can feel confusion and conflicted loyalties.

Listening to the family's needs

Most families feel desperate when attempting to find professional help for their child. They are trying to figure out the health care system related to eating disorders and secure what services are available. This search is often fraught with fear, helplessness, guilt, self-blame, and ambivalence. Listening with empathic responses, as described elsewhere in this issue (see "A new treatment approach to eating disorders in youth"), demonstrates to

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the family that you are aware of their struggle and needs. Fears need to be addressed regarding safety issues. If parents are worrying more than necessary, they will benefit from being reassured.

Avoiding blame

The family may previously have had challenging experiences with health care professionals. It is important to hear what those concerns have been without expressing judgments about the care. You can use this information to improve your working relationship with the family.

Families often fear being judged by health care professionals.² If family members feel blamed, they will be less likely to get involved in the treatment process, and their self-doubt can have detrimental effects on their confidence as parents.

Feelings of frustration and even helplessness may be aroused in practitioners who work with families, as described elsewhere in this issue (see “‘No, I can’t be your ...’: Boundary issues for health care professionals”). This countertransference with families can bring reactivity that can result in blaming. It is important to be aware that countertransference can interfere with successful work with families.

Demystifying eating disorders

Parents may worry that their child’s behavior is abnormal and that they must be suffering from a psychiatric problem requiring care that is beyond their control. You can help parents understand that the young person is trying to cope with something by not eating, and that the demands of this problem may be helping the youth focus away from other distress. You can provide information about the effects of malnutrition and how this perpetuates the habit of disordered eating. The parents can then start to



Artwork by patient Christina Van Veen

think about what their child might be using the eating disorder to cope with in life, rather than conceptualizing the disorder as an illness that they cannot influence.

Helping parents work together

The eating disorder can result in two parents blaming one another rather than working together against the problem. It is useful to meet with both parents and help them work as a team. This also helps to prevent secrecy, which is especially important if parents are separated or divorced. The young person feels relieved and valued when separated parents can put aside their differences in order to help. The more parents can agree on approaches, the more effective their parenting can be. If parents disagree significantly about approaches, then alliances can form between one parent

and a health care professional. Children and youth are then unable to experience the safety they need to feel from a cohesive parenting unit.

It is common for fear to push parents to “do anything” to get their child to eat. Some parents bargain around food in an attempt to keep the situation from getting worse, and they feel helpless when this does not work. Although setting rational limits may at first upset the youth, this can actually lead to a sense of control over the power of the eating disorder. Parents come with a variety of skills and levels of competence. Parents usually have thoughts about what they need to do, but fear and self-doubt can stop them from acting on those ideas. With support that tells them “It is okay to have expectations or set limits,” they may well be able to parent together more effectively.

Communicating openly and consistently

Ongoing direct communication between the health care professionals and family members is of utmost importance. Families need to be kept up-to-date on the process, progress, and plans during treatment. They need to be informed directly, not just through their child, in order to avoid misinterpretation and misunderstanding. When possible, talk with parents with the youth present to ensure that everyone hears the same message. Information provided to parents or by parents without the youth's knowledge leads to secrecy that can interfere with treatment. Openness and trust are promoted when notes or assessments are copied to the family or done in the form of letters.³ Receiving information in writing can also be therapeutic for the youth and family as it may promote further reflection later on.

Issues of power and control enter into the delicate balance of working with the child or youth and the family. It is vital to maintain confidentiality with young patients and to work with them to be comfortable about involving their family members. Family involvement in decision making depends upon the developmental age and stage of the child or youth. The younger the child, the more family involvement in decision making is necessary. Families need to be informed about what is confidential and to what degree they will be informed and involved so that expectations are clear from the start, especially regarding safety issues.

Building on parents' motivation

The motivation of parents has an undeniable impact on treatment. Parents may hope that their child will recover without parental involvement and may be reluctant to look at how

they may need to change to help their child. For parents who do not feel ready to embrace treatment approaches such as family therapy, discussing how their contribution can make a difference in recovery can be helpful. Their reluctance needs to be understood and addressed. They may not be convinced that their child has a serious eating disorder and may benefit from more education about its seriousness or how they can help.

Parents can be more motivated for change than their child is. This is very tough for parents if the young person does not want help with the eating disorder. Still, you can continue to build a therapeutic alliance with the family by listening, providing education, encouragement and feedback, and supporting parents to tolerate their child's ambivalence about change while helping parents to ensure the child or youth's safety.

Being aware of many risk factors

Trauma or abuse (physical, psychological, or sexual) is only one risk factor in the development of an eating disorder. Eating disorders are caused by a combination of risk factors rather than a single influence.⁴ It is important to remember that the majority of people with eating disorders have not experienced abuse. It is good clinical practice to screen for potential trauma to ensure that issues are not overlooked. Asking about abuse over time is important as children and youth are more likely to gradually give you hints about situations as they establish trust in you. There is no one symptom indicative of abuse and unless you have a disclosure, you cannot assume that it has occurred. If abuse is a factor for an individual, it may not be intra-familial.

More common forms of trauma experienced by children or youth in-

clude bullying, teasing, harassment, and peer exclusion. These distressing experiences are common precipitating factors for youth who develop eating disorders.⁵ When a young person is left out of a peer group, teased by peers or family members, or bullied, it is painful, embarrassing, and traumatizing. The youth or family may minimize these events and see them as insignificant. It is important to fully understand these experiences and assess if intervention involving parents or school staff may help stop bullying or teasing.

In very rare cases, parents may refuse to provide appropriate medical care for children with eating disorders, which can lead to serious physical and mental health consequences.⁶ When parents do not provide essential health care, this must be reported to the Ministry of Children and Family Development under Section 29 of the Child, Family and Community Service Act.⁷

Providing hope

Parents need to know that most youth with an eating disorder recover.⁸ As a care provider you too need to examine your beliefs about recovery. Only if you truly believe full recovery is possible will you be able to pass on this essential message of hope. Parents feel a sense of hope when they perceive competence in health care providers. In turn, parents feel reassured when they experience your trust in their competence and your belief that they will get through this problem.

Communicating with other health care professionals

In addition to communicating actively with family members, health care providers must communicate effectively with one another so that parents feel trust and can work well with all the professionals involved. If team members do not communicate or have

splits among them with respect to beliefs or approaches, it becomes readily apparent to the families, just as it does when the youth knows that two parents are not working together. A cohesive team of health care providers, who may even span various organizations in the community, allows the youth and family to see that everyone is on the same side working against the eating disorder.

Community resources

In British Columbia, a number of resources are available to help families deal with an eating disorder.

Family therapy or parental counseling

When suggesting a referral for family therapy, it is helpful to demystify therapy. You can explain that counseling is a process of building on family strengths, a way to help families cope with the eating disorder, and not a way to lay blame. How family therapy is described can have an influence on whether the family agrees to try this approach. Parents may not realize that they can help with recovery.

Family therapy and parental counseling can contribute to the recovery of young people with eating disorders and are a necessary component of a comprehensive biopsychosocial approach to the treatment of eating disorders.⁹ Family therapy may have more impact for youth with eating disorders than for adults and needs to be considered whenever possible, especially for youth still living with parents.^{10,11} In addition to the considerations already discussed, family therapy can help to:

- Balance power and control.
- Increase the voice of the youth.
- Deal with conflict.
- Promote family connection.
- Examine parents' own issues that may affect the eating disorder.

Anorexia, getting here

Anorexia is a cocoon that someone who is crying out for help wraps themselves in.

It is a hell they put their bodies through when their voices are not strong enough to say that their soul is crying and sad.

Anorexia is a dark blanket that will wrap around you.

Anorexia is also a cradle that will hold the broken body to wait for help. The cradle will tell someone that the person needs care, care that is missing.

Anorexia is a cloud that thunders on your mind until it breaks your spirit, and it makes a voice in your head that is telling you to run faster, longer, harder and beat what you did from yesterday and eat less and less and less and less...

And anorexia will not let go of you.

The cocoon and the dark blanket and the cradle and the thundering cloud and horrible hell will not go away from your body and spirit and mind and soul. It will stay until somebody comes.

Until someone comes to fill in the spaces.

The spaces that were missing, lost and wandering somewhere else.

Maybe love.

Maybe hope.

Maybe control.

I'm not sure.

Or maybe it will stay until someone comes to care.

The care you couldn't give yourself.

And so you cried out.

—Gemma
13 years old

- Help parents care for themselves as individuals and as a couple.

Siblings also feel the impact of the eating disorder on family life and relationships. Sometimes there are significant family issues that involve siblings, such as competition, conflict, teasing, or distress at how much power the eating disorder has in the family. It is important to help parents realize that other children in the family are affected and can benefit from being included in family therapy.

In rare situations, there may be intense family dynamics that include sexual, physical, or emotional abuse or neglect. If family interaction continues to be destructive after attempts with family therapy, continuing family therapy may not be indicated.

Sometimes families live a long distance from the location where treatment is being provided. In these cases, technical advances in the form of telemedicine may help. Videoconferencing can be used to enable family

therapy sessions in many rural communities.^{12,13} Videoconferencing can also be used for meetings when health care professionals and family members are at different sites. Speaker phones and conference calls can be used for this purpose as well.

Parent support groups

Parent support groups draw on the resources of those who are struggling with youth in various stages of recovery from eating disorders. Support is provided through the group facilitators and other parents who share experiences and offer possible solutions.¹⁴ Parents who share stories of recovery demonstrate hope. Parents may choose to be connected with other parents outside of the group for support. They often naturally develop their own network of informal support after attending a group meeting.

Eating Disorders Resource Centre of BC

This provincial resource provides educational materials and information about eating disorders for youth and their families. The centre maintains information about treatment programs and support groups, as well as individual and family therapists who work in the field of eating disorders. This is a free service located at Children's and Women's Health Centre, Room E200, 4500 Oak Street, Vancouver. Health care professionals, patients, and families can contact the resource centre directly by phone (in the Lower Mainland: 604 875-2084; toll-free elsewhere in BC: 1 800 665-1822) or by e-mail (edrcbc@direct.ca) for educational or referral information.

Summary

Families can contribute a great deal to the recovery of a youth affected by an eating disorder. Developing a therapeutic alliance with family members

and involving families in treatment is worth the effort as it results in more comprehensive and effective treatment.

When you see families at a time of crisis you do not necessarily gain an accurate impression of their strength. Even individuals with strong parenting ability feel helpless when their child is struggling with a potentially life-threatening eating disorder. It is important to remember that the majority of families are caring, supportive, capable, and resourceful.

Working with families of children and youth with eating disorders can be challenging and yet extremely rewarding. You are being given an opportunity to help families withstand a crisis and sometimes years of hardship, and to help family members rally together in spite of the stress. You are able to see how they rebuild and eventually reconnect with one another as they reach recovery. Families need professionals who will stick by them through the often lengthy process. You can help them most by offering your compassion, respect, hope, and belief in their ability to get through this challenge.

Competing interests

None declared.

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