Supporting Caregivers' Critical Role in Treating Eating Disorders

Family & Community Health

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For parents, having a sick child is always difficult. We as medical and psychological professionals want nothing more than for these children to feel better, to be able to return to school and activities, and for them to seem like themselves again. When a child has a cold or stomach bug, this return to health can happen very quickly. While stressful for everyone, families bounce back and get back to life. Things aren't always so straightforward when we discuss severe pediatric illnesses that threaten the very life of a child. Parents of children with a chronic or severe illness experience more parenting stress than those with healthy children. Emotionally supporting the child, managing treatment regimens and personal distress about invasive procedures can all negatively impact parent stress. In fact, simply having a child hospitalized for something mild or acute can lead to significant short-term stress on families.

Recognizing Unique Challenges for Parents of Children with Eating Disorders

This week is National Eating Disorder Awareness Week. Eating disorders are severe, biologically based illnesses that can have significant medical and psychosocial effects on an individual and, by extension, their family. Eating disorders can have serious medical complications including significant weight loss, heart arrhythmias associated with malnutrition, bone loss, loss of brain volume and imbalanced electrolytes. Many children and adolescents with eating disorders need to be hospitalized for a brief period in order to stabilize medically. Currently, the only evidence-based treatment for adolescents with eating disorders is Family-Based Treatment (FBT). In this approach, parents are charged with nourishing their child, facilitating exposure to new foods and helping to reduce other eating disorder behaviors like over exercising. The FBT model empowers parents to take back responsibility to renourish their sick child. In this family-based model, parents are on the front lines of their child's eating disorder care and the stress of having a child with an eating disorder is not

always appreciated.

One study highlights that the burden and stress for these families is greater than that observed in caregivers of individuals with schizophrenia, a severe psychological disorder with an extremely high caretaker burnout rate. In addition to treatment requirements and medical care, the stigma around eating disorders can also increase parental stress and burden. During my time as a behavioral health clinician, many parents have told me that stigma around this illness was one of the hardest things for them to cope with and that it often played a role in the family receiving less perceived or actual support from their community. This was particularly true of parents of boys or adolescents who did not fit the stereotype (e.g., due to size, shape, or ethnicity) of someone with an eating disorder.

Engaging Parents to Improve Family Outcomes

A very small body of literature exists on how we can support parents of individuals with eating disorders. We know that providing education and support to families can help reduce burden and stress which in turn can improve outcomes for their child. But most of the research in this area has been on caregivers of adults with eating disorders and has focused primarily on mothers. Parents of teens may encounter different stressors and may need different types of support. Organizations for parents exist, such as F.E.A.S.T., but as parents are key agents in their child's fight against eating disorders, it is essential that we find more ways to support them in this space.

Ideally, this involvement begins with parent engagement in research. This can be in the form of advisory boards or participatory research where family members are key partners and part of the research team. At CHOP, we are working to include parents in research by asking what type and frequency of support they might need between treatment sessions, whether or not various apps may be helpful to them and what else they feel they need from us to help them be successful in their fight against this illness.

During National Eating Disorder Awareness week, we need to ensure that we don't forget the tireless work of parents and the key role they play in a child's battle with eating disorders. By expanding our research and bringing caregivers into the process, we can better support families and improve outcomes for children and adolescents.

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