



Family Matters

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Anorexia Nervosa: Patient and Family-Centered Care

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When children and teens are hospitalized with malnutrition secondary to cancer, cystic fibrosis, inflammatory bowel disease, HIV/AIDS, or other such illness, nurses engage in dynamic, reciprocal, therapeutic relationships that are extremely helpful to patients, as well as being caring toward and collaborative with their families. In contrast, when an equally malnourished patient with anorexia nervosa is hospitalized, a less open and less helpful attitude often greets patients and their families. Unfortunately, old theories and myths about this disease still undermine therapeutic relationships and a family-centered approach to care. A new paradigm is needed in the understanding of anorexia nervosa: an accurate, up-to-date, research-based perspective can inform patients and provide family-centered approaches to the nursing care of this population.

A Serious Disorder

According to the Renfrew Center Foundation for Eating Disorders (2003), "Up to 24 million people of all ages and genders suffer from an eating disorder (anorexia, bulimia, and binge eating disorder) in the United States." Regardless of the apparent lack of severity at any particular moment, symptoms of an eating disorder should always be considered serious and significant, and the affected individual must be understood to be at high risk. Anorexia kills at least 10% of its victims, and it has a negative impact on the lives of many more (Crow et al., 2009). Published numbers likely understate reality because many deaths may be listed instead as other diagnoses, including "heart failure" or "suicide" (National Association of Anorexia Nervosa and Associated Disorders, 2011). In fact, suicide is a leading killer of individuals with eating disorders (Snell, Crowe, & Jordan, 2010). Additionally, even patients who have recovered after prolonged malnutrition or purging suffer lifelong

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Anorexia nervosa is a serious disease. Outdated conceptions of anorexia nervosa and other eating disorders often lead to strained relationships between nurses, patients, and families, and to difficulty implementing a family-centered approach to care. Yet, research over the past decades has demonstrated the neurobiologic underpinnings of this mental illness. This understanding supports a new approach to treatment, for example, the Maudsley approach, that involves family members as collaborators in care.

health consequences, and 20% of individuals suffering from anorexia will die earlier than their peers (National Association of Anorexia Nervosa and Associated Disorders, 2011). The psychological impact of spending formative years under the influence of obsessive eating-disordered thinking is immeasurable as well – stealing the very person-ality of young people who were once on their way to normal lives. Howlader and colleagues (2011) emphasize that the disease poses as great a risk of harm as many cancers.

Neurobiologic Basis

From the outside, family members and even some health care practitioners may be inclined to see personal food restriction and excessive exercising as conscious choices, but clinical experience and patient accounts clearly indicate the opposite (Arnold & Walsh, 2007). Anorexia nervosa is not just about failing to eat enough. It is not a fad, it is not a capricious behavior, and it is not about vanity. What appears to be strength of will or stubbornness is actually the neurobiologic loss of ability to rationally weigh circumstances, make sensible decisions, and resist the anorexic compulsion. In addition to the known brain consequences of semi-starvation, such as brain atrophy and ventricular dilatation, research demonstrates both a brain-based predisposition to develop eating disorders (Kaye, 2008) and a primary brain-based phenomenon (Katzman et al., 1996) characterizing the disorder. Research has found a) specific neuropsychological deficits; b) specific neurotransmitter profiles; c) localized unilateral abnormalities on functional magnetic resonance imaging (fMRI), single-photon emission computed tomography (SPECT), and Positron emission tomography (PET) scans; and d) endophenotypes of similar findings in non-affected first-degree relatives

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(Jean et al., 2007; Kaye, 1997; Kaye, Gwartzman, George, & Ebert, 1991). None of these findings are seen in starvation by other causes.

Understanding the neurobiological nature of eating disorders, nurses can play an important role in educating parents that issues of “will,” “blame,” or “fault” are outmoded misconceptions. Anorexia nervosa is not a choice or decision, but actually, a brain-based mental illness.

Early Intervention Is Optimal

It is natural for a family to want to avoid over-reacting to behaviors that appear to be benign “healthy eating,” or at worst, peculiar, disordered eating. Additionally, eating disorders, especially anorexia, are “anosognosic” – the affected individual is unable to appreciate that he or she is ill, or how ill (Bruch, 1978; Snell et al., 2010). Therefore, families may understandably be slow to act on signs of eating disorders. However, research on the outcomes of treatment shows the majority of patients do quite well, especially if the disease is detected early and appropriate treatment provided (Treasure & Russell, 2011). Conversely, by the time an eating disorder has gained ground behaviorally and physically, it may sometimes be too late to prevent long-term damage and a prolonged detour from normal life (Treasure & Russell, 2011). An important role nurses can play is to encourage parents to pursue early, effective intervention for disordered eating.

In seeking treatment, nurses should encourage parents to act on their children's behalf. Because of the neurobiology and resultant mind-set, an individual with an eating disorder cannot be reached by logical explanations of consequences of the illness, and they will commonly resist treatment (Lock & LeGrange, 2005). Nurses can model for parents and support them in the difficult challenge of sympathizing (but not colluding) with the child's demands, and tolerating the child's fury commonly triggered by the idea of treatment. Parents may be relieved to know at least one study found that two weeks into hospitalization, many patients who initially were reluctant or opposed to treatment already recognized it was needed (Guarda et al., 2007).

Beliefs about Families

Outmoded beliefs about families and eating disorders are reflected in the following statement by the parent of a teen with anorexia nervosa: “I felt like the doctors and nurses were blaming *me* for my daughter's eating disorder. Instead, I was truly trying everything I knew to help her.”

Some professionals have not overcome the belief that parents/families cause eating disorders. The idea that eating disorders are a sign of a dysfunctional and pathological family has had a long history. The English doctor credited with naming anorexia nervosa, William Gull, spoke in the 1800s of “relations and friends being generally the worst attendants” (Acland, 1894, p. 311). In the 1970s, Hilde Bruch (1978), believed by many to be the originator of modern eating disorder treatment, brought the issue of eating disorders to public attention, emphasizing societal and parental expectations as causative. Salvador Minuchin, a prominent family therapist, also portrayed anorexia nervosa as the symptomatic expression of dysfunctional family relationships (Minuchin, Rosman, & Baker, 1978). Unfortunately, even experienced health care providers may be unfamiliar with the latest science, and thus, rely on these outmoded understandings.

Fortunately, as an understanding of anorexia nervosa as a neurobiologically based mental illness has grown over the

past decade, past practices involving automatic and misguided blaming of parents have begun to decrease (Academy for Eating Disorders, 2009). Rather than blaming families, an increasing number of professionals in the field are now coming to appreciate the importance of family members in the treatment of eating disorders. Rather than conveying a subtle (or not so subtle) sense of blame or responsibility on parents, professionals who embrace the current understanding of anorexia nervosa, involving neuro-circuitry and neurotransmitter regulation, can better collaborate with and support parents and families as a whole.

Parents as Partners in Treatment

In addition to helping families understand the realities of anorexia nervosa and relieving them of blame, clinicians, including nurses, can take key steps to positively engage families as partners in treatment.

The Maudsley Hospital in London has successfully developed a family-based approach to treating patients with anorexia nervosa. The “Maudsley Method” is based on empowering parents to help their children recover their lost weight (Alexander & Treasure, 2011; Collins, 2005; Lock & LeGrange, 2005; Treasure, Smith, & Crane 2007). The Maudsley method has three phases. The first is “weight restoration.” As the individuals responsible for the growth and development of their children, parents are responsible for preventing starvation. Yet given the difficulties faced in addressing re-feeding with this diagnosis, parents may need education and support in the hospital setting to take on this task. Nurses and hospital staff can both explain to and model for parents the balance between being positive and empathetic with their children while remaining firm in the stance that starvation is not an option, and consequently, proceeding with a prescribed eating disorder protocol. The second and third phases of the Maudsley approach (“handing control of eating over to the adolescent” and “establishing a healthy adolescent identity”) can typically be accomplished at home (<http://www.maudsleyparents.org/whatismaudsley.html>). The guiding motto of the Maudsley approach clearly conveys a new perspective: parents are not the problem; they are the solution.

Nurses can advocate for acceptance and implementation of the “Maudsley Method” in their own settings. Nurses can also share information, as well as the Maudsley approach and Web site (<http://www.maudsleyparents.org/>) with families. Families may also find support and information about managing eating disorders and a 24/7 online forum of “Families Empowered and Treating Eating Disorders” (<http://www.feast-ed.org>). Additionally, James Lock and Daniel LeGrange have written an excellent family-oriented book that can be recommended or provided to families: *Helping Your Teenagers Beat an Eating Disorder* (2005).

Conclusion

As parents and nurses work together to restore a patient's weight, this demonstration of a united front against the *disease*, not the patient, is therapeutically beneficial. When nurses share the belief that the disease is not the fault of the parent nor the result of a child's “stubbornness,” their therapeutic presence helps to empower parents and alleviate parental – and patient – feelings of guilt. In turn, empowered parents can better learn how to manage the disease and share their own thoughts and experiences with the treating clinicians. As one parent of a child hospitalized with anorexia nervosa shared: “When the Eating Disorders team gave me some actual strategies to use, I felt, finally,

like I was actually doing something to help my child!" Viewing parents as members of the treatment team will enable family-centered, parent-nurse partnerships that are more effective in both treating the child and restoring a positive sense of family. ■■■

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