

ADVANCES IN IBD

Current Developments in the Treatment of Inflammatory Bowel Disease

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Psychosocial and Behavioral Issues in Children and Adolescents with IBD: Clinical Implications



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G&H How does the emotional impact of a diagnosis of inflammatory bowel disease in a child or adolescent differ from that in an adult?

KH Receiving a diagnosis of inflammatory bowel disease (IBD) is challenging for both children/adolescents and adults. One factor that differentiates these 2 groups is the impact of an IBD diagnosis on parents and siblings of a pediatric patient. The parent may grieve the loss of normality for the child, have concerns about functional limitations resulting from the disease, and worry about the long-term health and psychosocial implications of IBD.

Another factor regarding the impact of IBD that differs between children/adolescents and their adult counterparts is the developmental stage at which the diagnosis is received. Whereas adulthood is characterized by relative emotional stability, adolescence is a period of rapid physical and emotional change. Adolescence is a period during which individuals learn to manage their emotions, build long-term relationships, develop skills for handling adversity, and cultivate lifelong interests and values. The diagnosis of a chronic illness, such as IBD, can impede these processes or, alternatively, adjustment to the illness may become a lower priority because of these competing processes. Consequently, patients may have more physical and emotional difficulty over the course of the illness.

G&H What unique psychosocial challenges affect children and adolescents with IBD?

KH There are several psychosocial challenges that are unique to children and adolescents with IBD. Given the sensitive nature of the symptoms of IBD (eg, diar-

rhea, bloody stool, and abdominal pain), it is common for pediatric patients to not disclose their diagnosis to others. I have often heard patients say that they have not told any of their friends or perhaps have told only their best friend. Children and adolescents who must use the bathroom multiple times per day, go to the nurse's office to take medication or use the toilet, and/or have special accommodations for an illness that they do not discuss with others are often targets of teasing by peers and are at particular risk for being targets for "potty humor."

In addition, a normal part of adolescence is learning to establish and maintain romantic relationships. In general, it takes a lot of trial and error during this developmental period to learn how to build these relationships. The addition of a sensitive chronic condition like IBD, which has specific implications for romantic relationships, makes it considerably more difficult to build the necessary skills to have healthy, functional relationships of this nature.

Self-management of treatment regimens is another set of particularly complex behavioral challenges for children and adolescents with IBD. Whereas adults are generally independent and self-sufficient, children and adolescents naturally require assistance from their parents or caregivers to manage their illness. A threat to effective self-management is adolescents' move toward increasing autonomy. Although adolescents' desire for more control in decision making and self-sufficiency are developmentally appropriate, the transition to autonomous disease management must be made gradually, whereby the adolescent increasingly demonstrates self-management mastery. Due to a lack of standard guidelines, parents may make arbitrary decisions to abruptly shift complete disease management responsibility to their teenager based on his or her chrono-

logic age rather than developmental maturity and competencies (eg, cleaning one's room and doing homework without being reminded). This can result in poor disease management, increased symptoms and disease severity, and damaged parent-child relationships.

An additional threat to self-management is adolescents' natural tendency to be more risk prone and perceive themselves as more invincible than adults perceive themselves to be. If patients take risks by not taking medication, skipping appointments, engaging in unhealthy behaviors, or denying the existence of their illness, they are likely to have a more difficult disease course.

G&H Are young patients with one form of IBD at greater risk than others?

KH I have not seen empiric evidence that would suggest that pediatric patients with one form of IBD are at greater behavioral or psychosocial risk than others. It is often assumed that children with more severe or pervasive disease are at greater risk for psychosocial dysfunction; however, this is not necessarily true. Many children with severe or pervasive IBD adapt well and maintain a very functional and psychosocially healthy life, and there are many children in remission who continue to have multiple psychosocial challenges and functional disability. In some cases, quality of life improves with disease remission; however, this relationship is also not linear. Deficits in quality of life may persist well beyond improvement in disease status.

G&H How informed are pediatric specialists about the psychosocial burden of IBD?

KH Many pediatric gastroenterologists who I have worked with have a good understanding of the psychosocial stressors that their patients with IBD experience. In general, specific focus on psychosocial issues is not integrated into routine clinical care, and, as a result, there may be a decreased understanding about how psychosocial factors impact IBD among clinicians. In addition, because psychosocial issues are not a primary focus of clinical attention, many clinicians are not comfortable addressing them except in critical situations, such as when there is suspicion of patient self-harm.

This issue highlights the importance of multidisciplinary healthcare teams and comprehensive treatment that includes behavioral healthcare. Several examples already exist across the nation in which pediatric psychologists have been integrated into gastroenterologic clinical care. Here at Cincinnati Children's Hospital, a psychologist provides screening and clinical care for patients at the clinic and also by referral. Nationwide Children's Hospital in Columbus, Ohio and Children's Mercy Hospital in

Kansas City, Missouri are other examples of centers where children can receive integrated IBD care.

Although healthcare reform presents certain challenges and modifications to healthcare delivery, it also represents an opportunity for healthcare practitioners to adjust their clinical practice to attend to the complexities of psychosocial functioning. The lack of attention to psychosocial functioning often factors into reasons for increased healthcare utilization and costs.

G&H How can pediatric gastroenterologists and other clinicians assess for psychosocial challenges and behavioral dysfunction in their patients?

KH The best, most comprehensive approach would be to integrate a psychologist into the provision of care for each patient. However, this is not feasible for many institutions and clinical practices because of financial priorities and other barriers, such as access to pediatric psychologists. Nevertheless, several actions can be taken by clinical teams to better understand the psychosocial challenges of their patients.

Several screening tools that can be used on a regular basis include the Children's Depression Inventory and the Multidimensional Anxiety Scale for Children. Another resource is the PedsQL 4.0 quality-of-life questionnaire, which provides a brief assessment of overall functioning. Otherwise, clinicians should consider incorporating psychosocial concerns into every conversation they have with their patients. However, patients will often omit any real psychosocial challenges they are facing, so it is important to get parental or caregiver input on how they think their child is coping. Simple questions such as, "How often does Johnny seem to be sad or depressed?" or "How often does Sally seem to be nervous or anxious about things?" or inquiring about friendships, academics, boyfriends/girlfriends, and other issues can result in useful insights about the patient. Although time resources are the most common barrier to psychosocial assessment, regular assessment can save time by reducing patient phone calls and e-mails and unnecessary clinic visits for complaints that may be more related to somatization due to depression or anxiety.

G&H Do emotional health challenges in this population affect disease flare or progression?

KH Research in pediatric IBD, including our own research, suggests that rates of clinically significant depressive symptoms range from 18–25%, and there is evidence to suggest that rates of anxiety symptoms are elevated as well. In comparison, less than 10% of the general population demonstrates clinically significant

depression at any given time. This contrast represents a serious behavioral health issue for children and adolescents with IBD. Published data on the relationship between emotional well-being and IBD flares in the pediatric population are lacking, but there have been some reports in the literature that link IBD flares in adults to increased emotional stress. If you ask patients whether they perceive a relationship between their stress and IBD symptoms, many will tell you that they do. This can be a sensitive subject with patients, though. For a long time, a misperception persisted in the general public that IBD was caused by psychopathology. Plenty of evidence demonstrates that psychological factors are not causative, but the extent to which they contribute to disease fluctuation over the course of the illness remains unknown.

G&H When should mental health counseling be recommended?

KH Generally, any time a patient is demonstrating a negative change in emotional, behavioral, social, or academic/vocational aspects of his or her life, it is a good idea to refer the patient to a psychologist, particularly one who specializes in pediatric and/or child psychology. As previously mentioned, changes in psychosocial status might be revealed via standardized assessments or through conversations with patients and their caregivers. One important issue to keep in mind is that a stigma is still attached to receipt of mental healthcare. It is highly recommended that, early in the treatment process, all patients be introduced to the psychologist who works with the treating gastroenterologist's team. In instances where there is no such psychologist, the healthcare provider should discuss the potential need for psychological counseling to help cope with the disease. This could be done during a standardized new patient education visit, at which time other aspects of care are discussed.

It is very important to normalize the potential need for psychological intervention, stating clearly that it is common for patients to seek this type of support for comorbid behavioral health issues that can arise.

G&H What is the role of the family? When is family counseling of benefit?

KH Patients' families play a critical role in the adjustment to and management of IBD. Caregivers are often the managers of their child's illness. They may make and attend appointments, get prescriptions, make sure medications are taken, and check in with their children about how they are feeling physically and emotionally. As previously mentioned, caregiver and sibling functioning can be impaired in these families, and it is important to note that there is plenty of evidence in the literature on pediatric chronic illness that caregiver psychosocial functioning is correlated with patient functioning.

It is crucial to assess how other members of the family are coping, even if this is accomplished through simple conversation during visits. Resources and referrals should be made available when necessary. Whenever a member of the patient's family is exhibiting negative changes in emotional, behavioral, social, or academic/vocational functioning, a referral should be made even though the family member is not the patient per se. The referral might be for adult psychotherapy, couples/marital therapy, or family therapy. This type of intervention can be invaluable and help parents and siblings build the skills needed to adapt to the uncertainty that having a child, brother, or sister with IBD presents.

Suggested Reading

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