Commentary: Psychological and Behavioral Challenges for Families of Children with Eosinophilic Gastrointestinal Disorders

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Received March 12, 2012; revisions received March 17, 2012; accepted March 18, 2012

The current issue of the Journal of Pediatric Psychology includes two papers about children and adolescents with eosinophilic gastrointestinal diseases, or EGIDs. Each paper addresses key behavioral and psychological aspects of pediatric EGIDs. The first paper, by Taft and colleagues, characterizes caregiver stress in the parents of children with EGIDs and describes the relationships between the caregivers’ pediatric illness stress experiences and their own psychological functioning, as well as their children’s behavioral adjustment (Taft, Ballou, & Keefer, 2012). The second paper, by Hommel and colleagues, examines treatment adherence rates for children with EGIDs and their families (Hommel, Franciosi, Hente, Ahrens, & Rothenberg, 2011). Together, the papers provide an initial look at this recently recognized disease in terms of the challenges posed for the caregivers of the children with EGIDs, and to some extent for the children themselves, as they strive to cope with the illnesses and follow the recommended treatments aimed at disease management. The goal here is to underscore the importance of certain aspects of the initial findings from the papers and to further describe disease characteristics and related impacts that must be considered in future research regarding behavioral and psychological aspects of pediatric EGIDs.

The paper by Taft and colleagues focuses on caregiver stress that is experienced by mothers of children with EGIDs, mostly with eosinophilic esophagitis (EoE). In comparison with parent stress levels measured with the same instrument in other studies of pediatric illness (e.g., Hilliard, Monaghan, Cogen, & Streisand, 2010), stress levels for caregivers in this study were extraordinarily high. Demographic correlates of the high caregiver stress levels, low socioeconomic status and single parenting, may reflect reduced resources and support for meeting medical care demands for these children. Caregiver stress was also associated with disease variables including symptoms and disease management burden. In the Taft study, symptom burden was measured using mothers’ ratings of “recent flare severity.” For EoE, the maternal response to a “recent flare” not only includes an assessment of severity of the child’s symptoms, but also an attempt to determine how the symptom might be associated with a particular food exposure. This determination is especially challenging because most eosinophilic inflammation results from non-immunoglobulin E (IgE)-mediated allergic processes, with delayed responses that evolve over hours and days following food allergen exposure (Atkins, Kramer, Capocelli, Lovell, & Furuta, 2009), clouding the identification of culprit foods. Many children with EoE also have IgE-mediated food allergies, with symptoms that occur immediately after ingestion and have potential for life-threatening anaphylaxis. Distinguishing between IgE-mediated and non-IgE-mediated food allergies may be critical for understanding caregiver anxiety and children’s distress regarding dietary restrictions and accidental food exposure.

Certain qualitative aspects of EGID symptoms also can be associated with heightened caregiver stress. For EoE, the most commonly diagnosed of the EGIDs, presenting symptoms vary according to patient age. For example, feeding dysfunction is the most common primary presenting symptom for very young children (Mukkada et al., 2010). Epidemiological studies have shown that as many as a third of children diagnosed with EoE are less than 3–5 years of age, so studies of pediatric patients that encompass the entire age range from 0 to 18 years likely include a substantial proportion of young children with feeding problems. Having a young child with food refusal or vomiting, often resulting in poor weight gain or failure to thrive, elicits high anxiety, and is extraordinarily distressing for parents. Abdominal pain is the most common presenting symptom for older children; the ambiguity of this complaint, often lacking validating external evidence (unlike...
the typical fever rule for school attendance for healthy children), presents another type of management challenge for mothers. It is not surprising that the Taft study showed clinically significant levels of anxiety for 46% and of depression for 28% of the maternal caregivers, considering the dilemmas raised by the occurrence of symptom flares for children with EoE.

Besides symptom assessment and response, central features of disease management for pediatric EGIDs involve adherence with treatment recommendations. As emphasized in both the Taft and Hommel papers, current EGID treatments are complex, intensive, and demanding, and require significant parental monitoring. Hommel and colleagues assessed treatment adherence amidst this complexity, enlisting fathers as well as mothers as informants. The investigators found 30% of families were nonadherent, that is, did not meet criteria for dispensing medication, enforcing dietary restrictions, or providing tube feedings. In addition to presenting this clinically important information, these investigators characterized families in terms of the allocation of treatment responsibility for medical or dietary treatments. Although fathers consistently reported taking more responsibility than their wives said they did, overall most fathers apparently played a significant role in most aspects of providing treatment. Children and adolescents had only small proportions of responsibility allocated to them. Overall, the data suggested that children with EGIDs play a relatively small role in managing their disease, fathers have a substantial role, but mothers bear the primary responsibility. This pattern is consistent with the extremely high maternal-caregiver stress levels reported in the Taft study.

In addition to treatment adherence and symptom assessment, parent-caregivers face other multifaceted challenges. Many of the concerns and burdens for parents of children with EoE are similar to those that occur among other pediatric chronic conditions, for example, communicating with medical personnel or helping children endure diagnostic procedures. However, parents of children with EoE have multiple illness-specific concerns as well. The majority of pediatric patients with EoE have concurrent allergic diseases including atopic dermatitis, allergic rhinitis, asthma, and/or IgE-mediated food allergies (Straumann et al., 2012), compounding the disease burden for children and the management burden for caregivers. Because a primary treatment approach for EoE involves dietary restrictions, parents have concerns about the adequacy of the quantity, nutritional value, and palatability of their children’s nutritional intake, and how best to manage the dietary restrictions of the child with EoE within the larger family context. Finally, the fact that EGIDs has been recognized only recently may itself contribute to parents’ high illness-related stress levels. The medical community is still learning about EGIDs and evaluating optimal treatment approaches and, as a result, families may receive differing medical recommendations. Also, important members of children’s social networks, such as school personnel and extended family, often have no knowledge of EoE or eosinophilic gastroenteritis, and they require education about the disease above and beyond the collaborative planning with alternate caregivers that is typically required of parents of children with chronic illness. Thus, recent recognition of these illnesses may be a unique factor contributing to extraordinarily high levels of maternal-caregivers’ illness-related stress for pediatric EGIDs.

The two papers discussed here have made important inroads into an initial understanding of behavioral and psychosocial issues related to pediatric EoE. Together, the papers provide complementary views of current disease management for these children. Treatment regimens are complex and non-adherence is prevalent, yet treatment demands are among the many emotional burdens and responsibilities that underlie extremely high maternal-caregiver stress levels. Caregivers reported increased emotional and social problems for their children, although the extent to which these concerns reflect parental bias related to their own stress is unknown. Regardless, further research is urgently needed to better understand the specific demands and challenges associated with high levels of caregiver stress and psychological distress among parents of children with EGIDs. Research is also needed to define the impact of disease specific factors on children’s emotional and social development, to determine ways for children to participate in their disease management, and to explore optimal strategies for coping with the challenges they face. With a better understanding of specific challenges encountered by the children with EoE and by their parents, it will be possible to develop interventions focused on helping children and their families cope with the immense challenges posed by these diseases.

Conflict of interest: None declared.

References