The Gluten-Free Family Ripple Effect: The Tides that Bond and the Tides that Divide

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What does it mean to “break bread” in a gluten-free household? In a culture where gluten is so engrained in our rituals, the gluten-free diet pervades every aspect of celiac disease patients’ lives. The biomedical approach to healthcare teaches physicians to recognize a diagnosis and offer a treatment without much consideration about the psychosocial implications. For some diseases, particularly those requiring dietary interventions, the psychosocial repercussions of treatment may be even more impactful than the physiologic effects. One study demonstrated that patient perception of the burden of celiac disease was second only to end-stage renal disease [1]. While physicians often focus on the individual patient during the course of celiac disease management, successful implementation of a gluten-free diet prescription requires commitment not only of the patient, but also their family and social networks. Thus, a gluten-free lifestyle constitutes a significant financial and psychosocial burden for families [2, 3]. Dining out, food preparation, and entertainment are all intimate aspects of patients’ home lives and the family dynamic. Consequently, celiac disease is one of the few conditions for which treatment may reasonably entail putting unaffected family members on a partial broad elimination diet. Parents may also feel a unique obligation to provide their children with celiac disease with safe and adequate nutrition for growth and development. As a strict dietary intervention, these gluten-free burdens impact parents and siblings, but the ripple effect of the gluten-free diet on the family is often overlooked [4].

In this issue of *Digestive Diseases and Sciences*, Carrie Russo and co-authors present their bidirectional model of celiac disease treatment as a family affair in their article

entitled “The Impact of a Child’s Celiac Disease Diagnosis and Management on the Family” [5]. This team is commended for conducting a comprehensive mixed-methods study that involved semi-structured interviews, standardized questionnaires, and tours of the family home, which were typically led by the reference child with celiac disease. This methodology is particularly important in celiac disease research since a gluten-free diet is a complex intervention and since quantitative measures are inherently limited in what they capture. The use of mixed methods with all members of the family unit as the focus generated a treasure trove of data that included 74 photographs, 1313 min of recordings and responses to modified standardized measures of gluten-free diet adherence (i.e., Celiac Diet Adherence Test [CDAT] and Biagi questionnaire), and of quality of life (i.e., Celiac Disease Pediatric Quality of Life [CDPQOL] and Ferretti Caregiver Questionnaire). Key findings included both negative and positive impacts which differed according to one’s position in the family. Notably, all family members consistently reported that the mother was primarily responsible for creating a safe gluten-free environment. The study is somewhat limited by inclusion of families with relatively high socioeconomic status who were from a specific geographic area and who self-reported high rates of gluten-free diet adherence; nevertheless, it is a major advance in understanding the psychosocial impact of a gluten-free diet since unlike prior studies that have relied upon quantitative measures and/or include only some family members, the team was able to construct a bidirectional model of the wave pattern of the gluten-free ripple effect.

As dining out, mealtime, and entertainment are intertwined with family socialization and structure, it follows that celiac disease management has significant psychosocial impacts on all family members; many of which were actually positive. Parents reported becoming more innovative with their culinary skills and more focused on preparing fresh, well-balanced meals. They transitioned to new family traditions in order to accommodate their dietary needs. Siblings

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without celiac disease felt that having a family member with celiac disease and observing these restrictions firsthand made them more empathetic to others. One sibling felt that “it opened her eyes to other people who have different diseases”.

Nevertheless, families did not view all gluten-free adjustments as positive. Parents noted the burden of shopping for gluten-free items and coordinating to ensure safe options at school and outside activities. Siblings with celiac disease found varying sensitivities to gluten exposures difficult, since they did not want to be as much of a risktaker as their sibling. Too often, this burden and worry translate into hypervigilance which should be addressed at all follow-up visits with patients with celiac disease [6]. Families also regretted the more limited dining options and loss of spontaneity and convenience when eating out. While families were able to get more creative together in the kitchen, the gluten-free lifestyle did impair their ability to dine out and socialize with others. One parent mourned this loss of convenience stating, “there’s no driving to Wendy’s, there’s no McDonald’s, there’s no quick anything ever, because it’s not an option.” Parents helped their children to cope with this by planning ahead and fostering independence and confidence when eating out. These findings highlight the need for family-based interventions to enhance coping skills and build resilience.

The profound and extensive psychosocial impact upon the family of a child with celiac disease on a gluten-free diet highlights the consequences of being diagnosed with a disease for which the only treatment is a strict and complex exclusion diet. It is also notoriously difficult to quantify and even harder to place a value upon psychosocial effects. This paper circumvents this barrier by elegantly describing how a gluten-free diet substitutes a disease understood in biologic terms with a treatment that is itself a psychosocial condition. For those with celiac disease, the gluten-free diet often becomes so interlaced with their identity that they would be unwilling to replace it with pharmacotherapies. How radically different would patient and family experiences of celiac disease be altered if a non-dietary treatment were available at diagnosis? Equally important—and yet to be answered—what does the impact of a gluten-free diet look like in families with fewer financial resources or in areas where access to gluten-free foods may be limited?

Family-based interventions can help address the ripple effect of the gluten-free diet for more meaningful effects on quality of life and adherence. As noted by Russo et al., other disease models use this bidirectional framework in order to help improve healthcare outcomes. While new pharmacotherapies may help mitigate some of the negative impacts of current celiac disease dietary treatment, patients—and their families—cannot wait for a new drug to cure the psychosocial tribulations of a gluten-free diet. Interventions to help support the entire family are desperately needed now and must be further explored and developed as a matter of priority.

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