

**University of Massachusetts Boston**

---

**From the Selected Works of Gonzalo Bacigalupe, EdD, MPH**

---

Winter January 12, 2015

# Celiac Is a Social Disease: Family Challenges and Strategies

Gonzalo Bacigalupe, *University of Massachusetts Boston*

Aleksandra Plocha, *University of Massachusetts Boston*



Available at: [https://works.bepress.com/gonzalo\\_bacigalupe/19/](https://works.bepress.com/gonzalo_bacigalupe/19/)

# Families, Systems, & Health

## **Celiac Is a Social Disease: Family Challenges and Strategies**

Gonzalo Bacigalupe and Aleksandra Plocha

Online First Publication, January 12, 2015. <http://dx.doi.org/10.1037/fsh0000099>

### CITATION

Bacigalupe, G., & Plocha, A. (2015, January 12). Celiac Is a Social Disease: Family Challenges and Strategies. *Families, Systems, & Health*. Advance online publication.

<http://dx.doi.org/10.1037/fsh0000099>

# Celiac Is a Social Disease: Family Challenges and Strategies

Gonzalo Bacigalupe, EdD, MPH and Aleksandra Plocha, MS  
University of Massachusetts Boston

Celiac disease is the most common autoimmune inherited disorder in the United States, affecting approximately 1% of the population. Little research exists on the impact of family processes on adherence to a gluten-free diet (GFD), the only treatment for celiac disease. The objective of this qualitative study was to examine the barriers that families with a celiac child face and the strategies they use to adhere to the recommended diet. In-depth interviews were conducted with 10 families with a child between the ages of 6 and 12 diagnosed with celiac disease. Grounded theory and narrative analysis were used to analyze interview transcripts. Social isolation and misunderstandings about celiac disease and the GFD emerged as the most significant barriers to diet adherence including the reproduction of traditional gender relations among parents. Diet adherence facilitators included various types of institutional and societal support and idiosyncratic family arrangements. Successful diet adherence strategies used by families included planning ahead and taking their own food to social functions. Family processes play a critical role in GFD adherence. Implications for health care clinicians working with families with a child with celiac disease are discussed.

*Keywords:* adherence, celiac disease, family rituals, gluten-free diet, social support

Celiac disease is the most common autoimmune inherited disorder in the United States, affecting approximately 1% of the population (National Digestive Diseases Information Clearing House, 2013). Research based on new serology and genetic testing suggests higher prevalence rates, as many as one in 86 men and 52 women (Anderson et al., 2013). Celiac disease is an autoimmune disorder that occurs in genetically predisposed individuals and is caused by the ingestion of gluten, a protein found in wheat, barley, and rye. The immune reaction of ingesting gluten in celiac patients can result in an array of symptoms. In addition

to its genetic and immunological components, celiac includes environmental, social, neurological, and clinical dimensions (Carrie & Chan, 2008; Jackson, Eaton, Cascella, Fasano, & Kelly, 2012; James, 2005). Strict adherence to a gluten-free diet (GFD) is the only treatment. As a result, how eating is organized in the patient's context is critical to the amelioration of the diseases' symptoms and long-term risks (Lionetti & Catassi, 2011; Tack, Verbeek, Schreurs, & Mulder, 2010). The gluten-free diet is complex because the elimination of gluten-containing food also requires avoidance of cross-contamination as trace amounts of gluten can cause intestinal damage (Black & Orfila, 2011).

Chronic illness forces families to confront difficult challenges that affect the most important family eating rituals and processes (Roslund, Heisler, & Piette, 2012; Santos, Crespo, Silva, & Canavaro, 2012). The preparation and exchange of food not only constitutes a biological necessity but involves deeply embedded relational and sociocultural experiences (Fiese, Hammons, & Grigsby-Toussaint, 2012). Choices about what food is purchased, prepared, and eaten have significant ramifications in the lives of families and children in particular.

---

Gonzalo Bacigalupe, EdD, MPH and Aleksandra Plocha, MS, Department of Counseling and School Psychology, College of Education and Human Development, University of Massachusetts Boston.

Professor Bacigalupe received financial support from the American Psychological Foundation Randy Gerson Memorial Grant. We are thankful for the collaboration of the New England Celiac Organization (NECON), formerly the Healthy Villi Boston Celiac Support Group.

Correspondence concerning this article should be addressed to Gonzalo Bacigalupe, EdD, MPH, UMB-CEHD-CSP, 100 Morrissey Boulevard, Boston, MA 02125-3393. E-mail: [bacigalupe@gmail.com](mailto:bacigalupe@gmail.com)

Numerous studies highlight the impact of family dynamics on the treatment of food-related chronic illness such as diabetes (Ievers-Landis, Burant, & Hazen, 2011), cystic fibrosis (Grossoehme, Opiari-Arrigan, VanDyke, Thurmond, & Seid, 2012), sickle cell disease (Gold, Treadwell, Weissman, & Vichinsky, 2011), inflammatory bowel disease and Crohn's disease (Loga et al., 2012), phenylketonuria (Sharman, Mulgrew, & Katsikitis, 2013), and obesity (Fiese et al., 2012; Wansink & van Kleef, 2014). Similarly, the clinical literature in mental health and pediatrics has addressed the impact on family process of emotionally laden eating illnesses like anorexia and bulimia (Le Grange et al., 2012) and feeding disorders (Martin, Dovey, Coulthard, & Southall, 2013).

Studies indicate considerable variation in rates of GFD adherence. A systematic review of 38 studies of GFD adherence found that rates of adherence ranged from 41% to 91%, depending on the method of assessment and the definition of strict diet adherence (Hall, Rubin, & Charnock, 2009). Diet adherence has been strongly correlated with the child having professional parents, membership in celiac self-help organizations, the child's knowledge of the disease, confidence in the treatment information provided by the child's gastroenterologist, affluent background (Barratt, Leeds, & Sanders, 2011), university education (Treem, 2004), and age at which the child was diagnosed (Fabiani et al., 2000). The salience and severity of celiac symptoms have also been associated with higher rates of diet adherence (Sainsbury, Mullan, & Sharpe, 2013). Common strategies for managing the GFD include reading product ingredients, labeling all gluten-free flours, having snacks on hand at school or work, and bringing gluten-free food to social events (Zarkadas et al., 2013). Parents of children with chronic illness also describe a need for professional disease-related education and support (Byström et al., 2012).

The impact on quality of life in families with a child with a food allergy or intolerance has been widely studied in the past five years (Flokstra-de Blok et al., 2010; Lieberman & Sicherer, 2011; Resnick et al., 2010; Wassenberg et al., 2012), and a small body of this research is related to the impact of celiac disease on family processes (de Lorenzo, Xikota, Wayhs, Nassar, & de Souza Pires, 2012; Kurppa, Collin, Mäki,

& Kaukinen, 2011; Norström, Lindholm, Sandström, Nordyke, & Ivarsson, 2011). Families of children with celiac diseases report significant disruption around social activities such as family gatherings, school field trips, and eating out at restaurants (Cummings, Knibb, King, & Lucas, 2010). Some parents choose to avoid such events entirely in an attempt to reduce the risk of consuming gluten. Families have also reported feelings of alienation, shame, and fear of eating something that may contain gluten, while children with celiac have described feeling like a "nuisance" (Byström et al., 2012). Children also experience social stigma associated with their need to eat different foods (Bongiovanni, Clark, Garnett, Wojcicki, & Heyman, 2010), frustration and isolation (Zarkadas et al., 2013), and increased levels of anxiety compared with the general population (Häuser, Janke, Klump, Gregor, & Hinz, 2010).

The hypervigilance and daily management that are necessary when an individual has a food allergy can have a profound psychosocial impact on children, adolescents, and their families (Cummings et al., 2010). Close relatives of celiac patients have reported disease-related worries, guilt, changes in managing daily life (e.g., meal preparation, restricted freedom in meals, and changes in family members' power and control), and disturbances in social life as the most significant issues (Sverker et al., 2007). Lack of knowledge about the illness forces families to shift from being tolerant of others' carelessness around cross-contamination to advocating for food that is safe for the individual with celiac. Although some research has been published on the impact of the GFD on family rituals, a paucity of research exists on the impact that these factors have on diet adherence or the barriers parents of children with celiac disease face, and the successful strategies they employ in adhering to the GFD. Research on barriers to GFD adherence has focused on psychological dimensions (Sainsbury et al., 2013; Compas, Jaser, Dunn, & Rodriguez, 2012; Skjerning, Mahony, Husby, & DunnGalvin, 2014), rather than on family process.

Recent research specifically highlights the need for more insight into the impact of family process on GFD adherence (Flamez, Clark, & Sheperis, 2014). Increased awareness of the family processes that help or hinder GFD adherence has implications for the clinical prog-

nosis of celiac, as well as for the ability of physicians and other health care personnel to more effectively guide families in diet adherence. The objective of this qualitative study was to examine the family processes when a child has been diagnosed with celiac disease, with specific attention to the barriers these families face and the strategies they utilize to adhere to the GFD.

### Method

The study design used grounded theory and narrative analysis. Analysis of family history, which is common in evaluating other chronic diseases but has not been employed in the case of celiac disease, was also used (Yoon, Scheuner, & Khoury, 2003). Data were collected from a theoretical sample of 10 families. A theoretical or purposeful sample was used with the aim of selecting individuals who would provide a deeper understanding of a phenomenon that is partially known or understood (Glaser & Strauss, 2009). To increase the trustworthiness of the results, to triangulate the data analysis (Flick, 2008), qualitative findings were disseminated to participants for feedback that was then incorporated into the study results. The University's Institutional Review Board approved the study protocol.

### Participants

Participants were recruited from an annual conference hosted by a large celiac support group in the Northeast United States. Families with children between the ages of 6 and 12 who had been formally diagnosed with celiac disease—either through blood work and/or an endoscopy—were invited to participate in the study. After an initial list was collected, we e-mailed all respondents inviting them to confirm their interest. The first families interviewed were those who responded to this e-mail; follow-up e-mails were sent to all remaining families. Because qualitative data analysis and data collection are iterative processes, we capped the sample ( $n = 10$ ) when data no longer presented new information—or when data saturation was achieved. Ten participating families consisted of two heterosexual parents and one to four children ( $M = 2.5$ ;  $Mdn = 2.5$ ;  $SD = 0.85$ ). With the exception of one family in which the

father was Indian, all participants were Caucasian. In half of the families, both parents worked full-time outside the home. In four of the families the mother stayed home either full-time or nearly full-time. The parents' occupations varied and included two researchers, three medical professionals, three engineers, and two trade-workers. All families had the financial means to attend the conference at which recruiting took place. The age at which the celiac child was diagnosed ranged from 5 to 10 years old ( $M = 7.1$ ;  $Mdn = 7$ ;  $SD = 1.75$ ), and the amount of time since the diagnosis was between 1 and 7 years ( $M = 3.1$ ;  $Mdn = 3$ ;  $SD = 1.75$ ). In seven of the families, the child diagnosed with celiac received an endoscopy; in the other three, the doctors determined that the results of the blood work were conclusive enough to make the diagnosis without the endoscopy. Families varied in the amount of support they received around the celiac diagnosis, with only one parent participating in a regular support group.

### Procedure

Interviews, which ranged in length from 60 to 90 minutes, took place either in the family's home or a place of their choosing, including a coffee shop and a restaurant. In nine of the interviews, only the mother was present; in one interview, both the mother and father were present. In seven of the interviews, the child with celiac was present. The second author was present for all the interviews, with the first author attending four of them. Written consent for participation in the study and for audio recording of the interviews was obtained. The interviews followed a semistructured interview format, with interviewees being asked a series of open-ended questions about the history of the diagnosis and the gluten-free diet.

### Data Analysis

Grounded theory and narrative analysis were used to systematically analyze the families' personal accounts of their experiences managing the GFD (Bryant & Charmaz, 2007; Glaser & Strauss, 2009). We collected narrative data via interviews and verbatim were produced of audio-recordings (Bryant & Charmaz, 2007). The transcripts and qualitative results of the assessment measures were entered into the qualitative research software data analysis package NVivo

9 for coding (QSR International, 2010). Case and line numbers were added to each transcript to cite quotations. For example, 04:414–417 indicates a quote from the fourth interview beginning at line 417 of the transcript. Consistent with analytical triangulation procedures (Flick, 2008), both authors collaborated on theoretical memo writing reflecting the coded data from each family case. A summary of the findings was e-mailed to study participants for their input. Their feedback aided in the triangulation and was integrated into the results.

## Results

Barriers to diet adherence were clearly identified by families and under three primary categories: social isolation, gender inequity, and misunderstandings about celiac disease (see Table 1).

Social support was identified as a primary facilitator of diet adherence. Four forms of social support were identified: accommodation by family and friends, school and community support, group support, and having acquaintances who are also under the gluten-free diet (see Table 2).

Strategies that aid in diet adherence include continuous planning and carrying food to social functions (see Table 3).

## Discussion

This study examined the family processes that impact adherence to the GFD, with specific attention to the barriers families face and the strategies they utilize. Social isolation was identified as a significant barrier by nearly all participants. Tables 1, 2, and 3 summarize the findings and provide representative quotes from

Table 1  
*Barriers to Diet Adherence*

Social isolation	Traditional gender arrangements	Misunderstandings about celiac
Feeling left out/different because of diet <i>Birthday parties are hard because my daughter doesn't like to be the person with a different food. She doesn't want people talking about what she's eating.</i> (01:414–417)	Maternal assumption of dietary responsibilities <i>I'm the one. I don't know if my husband's been to any doctor's appointments.</i> (07:1313–1314)	Cross-contamination <i>[The pizza shop manager] said, 'On those pizzas everything is gluten free—I'll show you.' And then he took the gluten free pizza out and showed it to us, getting flour and dough all over the crust.</i> (04:604–618)
Social exclusion <i>You get more and more isolated because food is very social . . . Celiac is a social disease.</i> (08:1008–1009, 720)	Unequal impact of diagnosis <i>My husband doesn't really get caught up in the drama of it. In some ways it hasn't impacted him as much as it has me, because he hasn't had to leave work . . . And he doesn't research the products; he doesn't make sure all the things are safe.</i> (08:1486–1508)	Severity of consequences of eating gluten <i>I wasn't worried about my daughter eating [the Play Doh], just playing with it. And people look at you like you're crazy because they're like, 'What's the big deal? If she's not eating it, then there's no reason she can't play with it.' And it's like no, that's just not true.</i> (09:369–372)
Lack of social spontaneity <i>[Socializing] needs more planning and is less spontaneous now. [My husband and I] have fewer parties at our home. When there are potlucks or things down the street and people invite us, I feel more hesitant to say I'll come, because I feel like I have to plan much more.</i> (04:1036–1050)	Hindrance to going gluten-free in the home <i>If it weren't for [my husband], I would have gotten rid of gluten in the whole house</i> (04:1186).	Need to educate others <i>Depending on your personality, you feel more or less comfortable about it when you get annoying, ask five times, make a fuss, and send stuff back when you're not sure [if it's safe].</i> (04:1520–1525)

Table 2  
*Primary Facilitators to Diet Adherence: Social Support*

Accommodating friends/family	School/community support	Group support	Knowing others who require dietary accommodations
<i>My sister is really good about making sure that we have a variety of dishes to choose from. She'll take a certain color plate and say, 'Anything on a red platter is safe to eat.' So it isn't noticeable to anybody else, it's just part of what she does. (03:296–305)</i>	<i>[My daughter's teacher] went all out to make sure she was included. It makes me feel like crying for someone to go that length to include your child in an activity, just incredible, moved by that. (08:693–699)</i>	<i>I've posted a ton on Facebook since the diagnosis, and the mom's of all my daughter's friends read it, comment, and ask questions. They're super supportive. (09:562–563)</i>	<i>Sending children to celiac camp to meet peers with celiac, knowing another family with a child with a food allergy</i>

participants. Consistent with other studies, we found that children often felt isolated or different on account of their need to eat different food (Bongiovanni et al., 2010; Byström et al., 2012; Zarkadas et al., 2013). The social disruption caused by the GFD was also similar to cases of other food allergies, with a repercussion on family rituals (Cummings et al., 2010). Our participants' accounts revealed the additional impact of this isolation on family processes including shifts in marital dynamics and patterns of socializing, exclusion from family celebrations, altering vacation destinations, and changes in the nature and frequency of social interactions to accommodate the GFD. Therefore, celiac disease has an impact not only at the individual but on a family systems level as well.

This finding supports other research that draws attention to the social impact that having a child with a food allergy has on the family, particularly related to isolation (Rouf, White, & Evans, 2012).

A critical and unexplored dimension in past celiac disease research is that mothers, not fathers, appear to assume the majority of the responsibilities associated with managing the GFD, including educating others. In nearly all of the interviews, the gender differences associated with overseeing all aspects of the child's GFD adherence were salient. This finding is congruent with literature on families with a chronically ill child, in which mothers have been shown to assume primary caregiving responsibilities (August & Sorkin, 2010; Rosland

Table 3  
*Strategies for Maintaining the Gluten-Free Diet*

Planning ahead	Bringing own food to social functions
<p>Calling manufacturers</p> <p><i>I call every company—a huge time commitment. I check out every art supply. Even things like [my daughter] is in a play and she needs make-up. I research and I make sure I order make-up that's gluten free and safe. Everything has to be checked. (08:182–189)</i></p>	<p>Matching gluten-free food with what will be served at social functions</p> <p><i>If we go to a child's party, we'll usually try to find out what the menu is and we bring our own food. But try to make it something similar to what they're eating. (03:286–288)</i></p>
<p>Finding out what will be served at a party or available at a restaurant</p>	<p>Sending children with gluten free food to sleepovers, camps, and other situations involving multiple meals; keeping gluten-free food at school</p>
<p>Calling friends to see what would be served at a birthday party, looking at restaurant menus to ensure that there will be gluten free options, choosing vacation destinations where it would be easiest to access gluten-free food (e.g., a place with a kitchen)</p>	<p><i>I tell [my daughter] that she needs to bring extra food. If she doesn't eat it all, fine, but just to have in case. (02:626–627)</i></p>

et al., 2012). Some researchers have assessed this using psychopathological assessment and concluding that these parents in some cases exhibit a tendency to be overbearing, controlling, and/or vigilant (Sparud-Lundin, Hallström, & Erlandsson, 2013). We believe the adaptation and urgency that the illness poses may explain the anxiety and pushes mothers to respond accordingly. Mothers who care for a chronically ill child have also displayed high rates of depressive symptoms, burnout, reported higher burden, family stress, and role strain (Berge et al., 2006; Lindström, Aman, & Norberg, 2010; Pinquart & Sörensen, 2006). In contrast, in families in which the mother considers the father to be involved, supportive, and helpful, both parents have reported higher marital satisfaction and more optimal levels of family functioning and adjustment (Gavin & Wysocki, 2006).

Research also suggests that given a conflict between work and family, heterosexual couples often return to traditional gender roles in which men are the financial breadwinners and women assume responsibilities in the home, including caring for the children (Coontz, 2011). The reasons for this shift include sociopolitical factors such as gender inequity in financial compensation across all jobs and educational levels. From this standpoint, it is possible that the multifaceted burden of the celiac diagnosis might be connected to the tendency for mothers, and not fathers, to assume the majority of caregiving responsibilities. The parallel between our findings and the existing literature elucidates the need for further investigation into how traditional gender inequity impacts diet management responsibilities in families with a celiac disease child. No studies to date have explored how gender roles have been adaptive for, or a hindrance to, diet adherence in families with a child with a food-related chronic illness.

The general public's lack of knowledge about what it means to have celiac emerged as another significant barrier to diet adherence. This is consistent with other studies that highlight educating others about celiac disease and the GFD as necessary components of diet management (Byström et al., 2012; Sverker et al., 2007). Our inquiry revealed the need for increased education and support for parents that include advocating strongly for their children with celiac disease and prevent burn out. The identification of support as a facilitator of GFD adherence was

another significant finding. Although the benefits individuals derive from celiac support groups has been previously documented (Barratt et al., 2011), our results revealed that support can take many other forms. Participants drew attention to the tremendous impact of having even a few friends and/or family members who make an effort to understand the disease and accommodate the celiac child's GFD. Knowing other families with a child with celiac disease or other allergies that necessitate a specific diet was found to be a significant facilitator to diet adherence, as was using social media to both educate and garner support from others. These results indicate that looking beyond traditional, established sources of support (e.g., support groups) could be beneficial for families who have a child diagnosed with celiac disease.

The primary strategies cited by participants in this study for managing the GFD included planning ahead and bringing food to social functions. These findings are also consistent with previous research on managing the GFD (Zarkadas et al., 2013). Participants reported doing research on the foods that would be available in various situations and providing their children with gluten-free food options at school, birthday parties, sleepovers, and summer camp. The results also shed light on the familial processes that impact the level of preparation associated both with planning ahead and providing gluten-free food for social functions. This was most apparent in the mothers who go to great lengths to plan ahead and prepare. This is particularly important given our findings that all 10 families felt initially overwhelmed by the diagnosis and the transition to the gluten-free diet.

There are several limitations of this study. All participants were heterosexual; with the exception of one parent, all participants were Caucasian. Most participants had the financial means to purchase and prepare gluten-free food and were able to make other accommodations that facilitate diet adherence. Future studies should consider the inclusion of a more diverse sample and explore how to reach families who are not participating in celiac support activities.

This study highlights the need for clinicians to identify sources of support that the family can employ considering (a) the amount of time that has elapsed since the diagnosis; (b) the type(s) of support that will be most beneficial for the



family (e.g., support groups, online communities, etc.); and (c) the familial processes that may promote or hinder support. It is core not to assess social isolation as only a barrier but also an adaptive strategy for responding to others' misunderstandings about the disease and the dangers of cross-contamination. Finally, exploring and addressing proactively the distribution of caregiving tasks among parents may present an opportunity for family clinicians to address gender inequity in parenting.

### References

Anderson, R. P., Henry, M. J., Taylor, R., Duncan, E. L., Danoy, P., Costa, M. J., . . . Pasco, J. A. (2013). A novel serogenetic approach determines the community prevalence of celiac disease and informs improved diagnostic pathways. *BMC Medicine*, *11*, 188. <http://dx.doi.org/10.1186/1741-7015-11-188>

August, K. J., & Sorkin, D. H. (2010). Marital status and gender differences in managing a chronic illness: The function of health-related social control. *Social Science & Medicine*, *71*, 1831–1838. <http://dx.doi.org/10.1016/j.socscimed.2010.08.022>

Barratt, S. M., Leeds, J. S., & Sanders, D. S. (2011). Quality of life in coeliac disease is determined by perceived degree of difficulty adhering to a gluten-free diet, not the level of dietary adherence ultimately achieved. *Journal of Gastrointestinal and Liver Diseases*, *20*(3), 241–245.

Berge, J. M., Patterson, J. M., & Rueter, M. (2006). Marital satisfaction and mental health of couples with children with chronic health conditions. *Families, Systems, & Health*, *24*, 267–285. <http://dx.doi.org/10.1037/1091-7527.24.3.267>

Black, J. L., & Orfila, C. (2011). Impact of coeliac disease on dietary habits and quality of life. *Journal of Human Nutrition and Dietetics*, *24*, 582–587. <http://dx.doi.org/10.1111/j.1365-277X.2011.01170.x>

Bongiovanni, T. R., Clark, A. L., Garnett, E. A., Wojcicki, J. M., & Heyman, M. B. (2010). Impact of gluten-free camp on quality of life of children and adolescents with celiac disease. *Pediatrics*, *125*, e525–e529. <http://dx.doi.org/10.1542/peds.2009-1862>

Bryant, A., & Charmaz, K. (2007). Grounded theory research: Methods and practice. In A. Bryant & K. Charmaz (Eds.), *The Sage handbook of grounded theory* (pp. 1–28). Thousand Oaks, CA: Sage Publications.

Byström, I. M., Hollén, E., Fälth-Magnusson, K., & Johansson, A. (2012). Health-related quality of life in children and adolescents with celiac disease:

From the perspectives of children and parents. *Gastroenterology Research and Practice*, *2012*, 986475. <http://dx.doi.org/10.1155/2012/986475>

Carrie, D. M., & Chan, N. K. C. (2008). Celiac disease in North America: The disabling experience. *Disability & Society*, *23*, 89–96. <http://dx.doi.org/10.1080/09687590701725799>

Compas, B. E., Jaser, S. S., Dunn, M. J., & Rodriguez, E. M. (2012). Coping with chronic illness in childhood and adolescence. *Annual Review of Clinical Psychology*, *8*, 455–480. <http://dx.doi.org/10.1146/annurev-clinpsy-032511-143108>

Coontz, S. (2011). *A strange stirring: The feminine mystique and American women at the dawn of the 1960s*. New York, NY: Basic Books.

Cummings, A. J., Knibb, R. C., King, R. M., & Lucas, J. S. (2010). The psychosocial impact of food allergy and food hypersensitivity in children, adolescents and their families: A review. *Allergy*, *65*, 933–945. <http://dx.doi.org/10.1111/j.1398-9995.2010.02342.x>

de Lorenzo, C. M., Xikota, J. C., Wayhs, M. C., Nassar, S. M., & de Souza Pires, M. M. (2012). Evaluation of the quality of life of children with celiac disease and their parents: A case-control study. *Quality of Life Research: An International Journal of Quality of Life Aspects of Treatment, Care & Rehabilitation*, *21*, 77–85. <http://dx.doi.org/10.1007/s11136-011-9930-7>

Fabiani, E., Taccari, L. M., Rätsch, I. M., Di Giuseppe, S., Valentino Coppa, G., & Catassi, C. (2000). Compliance with gluten-free diet in adolescents with screening-detected celiac disease: A 5-year follow-up study. *The Journal of Pediatrics*, *136*(6), 841–843. [http://dx.doi.org/10.1016/S0022-3476\(00\)35904-2](http://dx.doi.org/10.1016/S0022-3476(00)35904-2)

Fiese, B. H., Hammons, A., & Grigsby-Toussaint, D. (2012). Family mealtimes: A contextual approach to understanding childhood obesity. *Economics and Human Biology*, *10*, 365–374. <http://dx.doi.org/10.1016/j.ehb.2012.04.004>

Flamez, B., Clark, A. A., & Sheperis, C. J. (2014). Celiac disease: Psychosocial, developmental, and family counseling issues. *The Family Journal*, *22*, 226–230. <http://dx.doi.org/10.1177/1066480713515407>

Flick, U. (2008). *Designing qualitative research*. Thousand Oaks, CA: Sage.

Flokstra-de Blok, B. M. J., Dubois, A. E. J., Vlieg-Boerstra, B. J., Oude Elberink, J. N. G., Raat, H., DunnGalvin, A., . . . Duiverman, E. J. (2010). Health-related quality of life of food allergic patients: Comparison with the general population and other diseases. *Allergy*, *65*, 238–244. <http://dx.doi.org/10.1111/j.1398-9995.2009.02121.x>

Gavin, L., & Wysocki, T. (2006). Associations of paternal involvement in disease management with maternal and family outcomes in families with

- children with chronic illness. *Journal of Pediatric Psychology*, 31(5), 481–489. [http://dx.doi.org/10.1093/jpepsy/31\(5\)481](http://dx.doi.org/10.1093/jpepsy/31(5)481)
- Glaser, B. G., & Strauss, A. L. (2009). *The discovery of grounded theory: Strategies for qualitative research*. New York, NY: Transaction Books.
- Gold, J. I., Treadwell, M., Weissman, L., & Vichinsky, E. (2011). The mediating effects of family functioning on psychosocial outcomes in healthy siblings of children with sickle cell disease. *Pediatric Blood & Cancer*, 57, 1055–1061. <http://dx.doi.org/10.1002/pbc.22933>
- Grossoehme, D. H., Oipari-Arrigan, L., VanDyke, R., Thurmond, S., & Seid, M. (2012). Relationship of adherence determinants and parental spirituality in cystic fibrosis. *Pediatric Pulmonology*, 47, 558–566. <http://dx.doi.org/10.1002/ppul.21614>
- Hall, N. J., Rubin, G., & Charnock, A. (2009). Systematic review: Adherence to a gluten-free diet in adult patients with celiac disease. *Alimentary Pharmacology & Therapeutics*, 30, 315–330. <http://dx.doi.org/10.1111/j.1365-2036.2009.04053.x>
- Häuser, W., Janke, K. H., Klump, B., Gregor, M., & Hinz, A. (2010). Anxiety and depression in adult patients with celiac disease on a gluten-free diet. *World Journal of Gastroenterology*, 16, 2780–2787. <http://dx.doi.org/10.3748/wjg.v16.i22.2780>
- Ievers-Landis, C. E., Burant, C. J., & Hazen, R. (2011). The concept of bootstrapping of structural equation models with smaller samples: An illustration using mealtime rituals in diabetes management. *Journal of Developmental and Behavioral Pediatrics*, 32, 619–626. <http://dx.doi.org/10.1097/DBP.0b013e31822bc74f>
- Jackson, J. R., Eaton, W. W., Cascella, N. G., Fasano, A., & Kelly, D. L. (2012). Neurologic and psychiatric manifestations of celiac disease and gluten sensitivity. *Psychiatric Quarterly*, 83, 91–102. <http://dx.doi.org/10.1007/s11126-011-9186-y>
- James, S. P. (2005). National Institutes of Health consensus development conference statement on celiac disease, June 28–30, 2004. *Gastroenterology*, 128, S1–S9. <http://dx.doi.org/10.1053/j.gastro.2005.02.007>
- Kurppa, K., Collin, P., Mäki, M., & Kaukinen, K. (2011). Celiac disease and health-related quality of life. *Expert Review of Gastroenterology & Hepatology*, 5, 83–90. <http://dx.doi.org/10.1586/egh.10.81>
- Le Grange, D., Lock, J., Agras, W. S., Moye, A., Bryson, S. W., Jo, B., & Kraemer, H. C. (2012). Moderators and mediators of remission in family-based treatment and adolescent focused therapy for anorexia nervosa. *Behaviour Research and Therapy*, 50, 85–92. <http://dx.doi.org/10.1016/j.brat.2011.11.003>
- Lieberman, J. A., & Sicherer, S. H. (2011). Quality of life in food allergy. *Current Opinion in Allergy and Clinical Immunology*, 11, 236–242. <http://dx.doi.org/10.1097/ACI.0b013e3283464cf0>
- Lindström, C., Åman, J., & Norberg, A. L. (2010). Increased prevalence of burnout symptoms in parents of chronically ill children. *Acta Paediatrica (Oslo, Norway)*, 99, 427–432. <http://dx.doi.org/10.1111/j.1651-2227.2009.01586.x>
- Lionetti, E., & Catassi, C. (2011). New clues in celiac disease epidemiology, pathogenesis, clinical manifestations, and treatment. *International Reviews of Immunology*, 30, 219–231. <http://dx.doi.org/10.3109/08830185.2011.602443>
- Loga, S., Sošić, B., Kulenović, A. D., Švraka, E., Bosankić, N., Kučukalić, A., . . . Hadžić, A. (2012). Chronic illness and family: Impact of schizophrenia and Crohn's disease on the family quality of life. *Psychiatria Danubina*, 24, 359–366.
- Martin, C. I., Dovey, T. M., Coulthard, H., & Southall, A. M. (2013). Maternal stress and problem-solving skills in a sample of children with nonorganic feeding disorders. *Infant Mental Health Journal*, 34, 202–210. <http://dx.doi.org/10.1002/imhj.21378>
- National Digestive Diseases Information Clearing House. (2013). Retrieved December 17, 2013, from <http://digestive.niddk.nih.gov/ddiseases/pubs/celiac/index.aspx>
- Norström, F., Lindholm, L., Sandström, O., Nordyke, K., & Ivarsson, A. (2011). Delay to celiac disease diagnosis and its implications for health-related quality of life. *BMC Gastroenterology*, 11, 118. <http://www.biomedcentral.com/1471-230X/11/118>
- Pinquart, M., & Sörensen, S. (2006). Gender differences in caregiver stressors, social resources, and health: An updated meta-analysis. *The Journals of Gerontology: Series B: Psychological Sciences and Social Sciences*, 61, 33–45. <http://dx.doi.org/10.1093/geronb/61.1.P33>
- QSR International. (2010). NVivo 9 [Computer software]. Melbourne, Australia: QSR International.
- Resnick, E. S., Pieretti, M. M., Maloney, J., Noone, S., Muñoz-Furlong, A., & Sicherer, S. H. (2010). Development of a questionnaire to measure quality of life in adolescents with food allergy: The FAQL-teen. *Annals of Allergy, Asthma & Immunology*, 105, 364–368. <http://dx.doi.org/10.1016/j.anai.2010.09.006>
- Rosland, A. M., Heisler, M., & Piette, J. D. (2012). The impact of family behaviors and communication patterns on chronic illness outcomes: A systematic review. *Journal of Behavioral Medicine*, 35, 221–239. <http://dx.doi.org/10.1007/s10865-011-9354-4>

- Rouf, K., White, L., & Evans, K. (2012). A qualitative investigation into the maternal experience of having a young child with severe food allergy. *Clinical Child Psychology and Psychiatry, 17*, 49–64. <http://dx.doi.org/10.1177/1359104511415636>
- Sainsbury, K., Mullan, B., & Sharpe, L. (2013). Gluten free diet adherence in coeliac disease. The role of psychological symptoms in bridging the intention-behaviour gap. *Appetite, 61*, 52–58. <http://dx.doi.org/10.1016/j.appet.2012.11.001>
- Santos, S., Crespo, C., Silva, N., & Canavarro, M. C. (2012). Quality of life and adjustment in youths with asthma: The contributions of family rituals and the family environment. *Family Process, 51*, 557–569. <http://dx.doi.org/10.1111/j.1545-5300.2012.01416.x>
- Sharman, R., Mulgrew, K., & Katsikitis, M. (2013). Qualitative analysis of factors affecting adherence to the phenylketonuria diet in adolescents. *Clinical Nurse Specialist CNS, 27*, 205–210. <http://dx.doi.org/10.1097/NUR.0b013e31829555d5>
- Skjerning, H., Mahony, R. O., Husby, S., & DunnGalvin, A. (2014). Health-related quality of life in children and adolescents with celiac disease: Patient-driven data from focus group interviews. *Quality of Life Research: An International Journal of Quality of Life Aspects of Treatment, Care & Rehabilitation, 23*, 1883–1894. <http://dx.doi.org/10.1007/s11136-014-0623-x>
- Sparud-Lundin, C., Hallström, I., & Erlandsson, L. K. (2013). Challenges, strategies, and gender relations among parents of children recently diagnosed with type 1 diabetes. *Journal of Family Nursing, 19*, 249–273. <http://dx.doi.org/10.1177/1074840713484386>
- Sverker, A., Östlund, G., Hallert, C., & Hensing, G. (2007). Sharing life with a gluten-intolerant person—The perspective of close relatives. *Journal of Human Nutrition and Dietetics, 20*, 412–422. <http://dx.doi.org/10.1111/j.1365-277X.2007.00815.x>
- Tack, G. J., Verbeek, W. H., Schreurs, M. W., & Mulder, C. J. (2010). The spectrum of celiac disease: Epidemiology, clinical aspects and treatment. *Nature Reviews Gastroenterology and Hepatology, 7*, 204–213. <http://dx.doi.org/10.1038/nrgastro.2010.23>
- Treem, W. R. (2004). Emerging concepts in celiac disease. *Current Opinion in Pediatrics, 16*, 552–559. <http://dx.doi.org/10.1097/01.mop.0000142347.74135.73>
- Wansink, B., & van Kleef, E. (2014). Dinner rituals that correlate with child and adult BMI. *Obesity, 22*, E91–E95. <http://dx.doi.org/10.1002/oby.20629>
- Wassenberg, J., Cochard, M. M., Dungalvin, A., Ballabeni, P., Flokstra-de Blok, B. M., Newman, C. J., . . . Eigenmann, P. A. (2012). Parent perceived quality of life is age-dependent in children with food allergy. *Pediatric Allergy and Immunology, 23*, 412–419. <http://dx.doi.org/10.1111/j.1399-3038.2012.01310.x>
- Yoon, P. W., Scheuner, M. T., & Khoury, M. J. (2003). Research priorities for evaluating family history in the prevention of common chronic diseases. *American Journal of Preventive Medicine, 24*, 128–135. [http://dx.doi.org/10.1016/S0749-3797\(02\)00585-8](http://dx.doi.org/10.1016/S0749-3797(02)00585-8)
- Zarkadas, M., Dubois, S., MacIsaac, K., Cantin, I., Rashid, M., Roberts, K. C., . . . Pulido, O. M. (2013). Living with coeliac disease and a gluten-free diet: A Canadian perspective. *Journal of Human Nutrition and Dietetics, 26*, 10–23. <http://dx.doi.org/10.1111/j.1365-277X.2012.01288.x>

Received July 2, 2014

Revision received November 10, 2014

Accepted November 13, 2014 ■