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The Gluten-Free Zone: School Considerations for Childhood Celiac Disease

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Abstract

Celiac disease is a lifelong autoimmune disorder that effects nearly 1% of the United States' population. Largely undiagnosed or misdiagnosed, celiac disease can present as physiological, psychological, or behavioral symptoms in children. Triggered by the presence of gluten, an item traditionally found in various products (e.g., food, school supplies, etc.), celiac disease is somewhat neglected in counseling literature despite its implications for those working with school-age children. The following provides an overview of important things for school counselors to know about the disorder, its causes, and approaches to reducing its effects in the school environment.

Keywords: celiac disease, gluten, school counseling, adolescents

Several years ago, individuals in California began a dietary fad in which they eliminated gluten and gluten related products from their diet due to concerns about the short-term and long-term effects of gluten on the human body (Saner, 2015). While the rationale behind this increasing fad was due to a desire to eliminate the negative effects of gluten, a protein commonly found in foods and other household products, and to promote a healthy lifestyle, the importance of avoiding gluten is much more serious and necessary for individuals with celiac disease. According to the University of Chicago Celiac Disease Center (2013), individuals with celiac disease inherit genes that, when triggered by gluten, can cause serious physical and psychological symptoms in children and adults. A lifelong autoimmune disease, celiac disease can result in one or many of more than 300 potential symptoms, can mock psychiatric diagnoses, and can be difficult to diagnose despite its prevalence in an estimated 1% of the population (Flamez, Clark, & Sheperis, 2014). Given its prevalence, diversity of symptoms, and the fact that the disease often goes misdiagnosed, it has become increasingly important for counselors to become familiar with the disease and its effects especially on children.

First discovered in 1888, celiac disease is now regarded as one of the most common autoimmune disorders (Flamez et al., 2014). Outnumbering the rates of diabetes among juvenile and adolescents by a 4 to 1 ratio, celiac disease is likely even more prominent given its high rate of misdiagnosis (American Diabetes Association, 2014; University of Chicago Celiac Disease Center, 2013). Still, diabetes education and awareness has gained increasing press in recent years. In fact, government efforts to increase the nutritional value of children's lunches in schools are a direct result of the effort to combat childhood obesity and diabetes. According to the U.S. Department of Agriculture (2014), these changes require that half of all grains served by schools are whole grains. While this change is noted as an effort to increase the health of children and adolescents, whole grains often contain wheat or barley and therefore gluten.

Although the consumption of gluten is a major concern for children and adolescents with celiac disease, the potential implications of gluten exposure extend beyond food products into everyday household products and even the potential spread through cross contamination or hidden gluten. According to the National Foundation for Celiac Awareness (2014), even a minute amount of gluten can trigger a reaction in an individual with celiac disease. This becomes more of an issue because many products listed as gluten-free actually contain trace amounts of gluten (U.S. Food and Drug Administration, 2013). Although this may not be an issue for anyone on a gluten-free diet (GFD) due to the desire to follow the fad or a desire to increase their overall physical health, it is something extremely important to consider when working with children with celiac disease. Given these concerns and foundations, the following article will address medical and psychological aspects of celiac disease, prognosis, and ways for school counselors to address the apprehension caused by this disease. A case illustration is also provided to demonstrate how celiac disease may be integrated into a counselor's work within the school.

Medical Aspects of Celiac

With an estimated prevalence rate of 1 out of every 133 people in the United States or 3 million people, celiac disease is more prevalent than multiple sclerosis, Crohn's disease, cystic fibrosis, and Parkinson's disease combined (Eslick, 2008). Largely undiagnosed or misdiagnosed, research has indicated increasing prevalence of celiac disease in the population, including the potential of 5 million people being affected by celiac disease in 2020 (Greco et al., 2011). Consistently seen in various populations and population characteristics including across gender, ethnic, socioeconomic, and generational lines, celiac disease is one of the most diverse disorders with the potential for more than 300 signs and symptoms of the disorder. While some patients are asymptomatic, many others experience significant symptoms associated with the consumption of gluten including intestinal problems, growth impairment, infertility, dental enamel problems, along with a host of other physical, developmental, and psychological complaints (Olsson, Lyon, Hörnell, Ivarsson, & Sydner, 2009).

Correlated with other mental and physical disorders, such as attention deficit hyperactivity disorder (ADHD), autism spectrum disorder, depression, seizures, irritable bowel syndrome, and migraines, seen in children, approximately 95% of individuals with celiac disease go undiagnosed (U.S. Department of Health and Human Services, 2012) with an average time of 6 years between the initial symptoms and diagnosis in those who are diagnosed (National Foundation for Celiac Awareness, 2014). While these symptoms vary in type, severity, and age of onset, the National Foundation for Celiac Awareness (2014) noted that symptoms commonly seen in children include diarrhea or constipation, bloating and gas, iron deficiencies, loss of tooth enamel, fatigue, skin rash, and vomiting. Behavioral issues, irritability, delayed growth or puberty, and abdominal pain have also been noted (Celiac Disease Foundation, 2014).

Because individuals with a family history of celiac disease are at a high risk of having celiac disease, the University of Chicago Celiac Disease Center (2013) recommends screenings for those individuals where a family member has been diagnosed with the autoimmune disease. Other individuals who experience symptoms associated with celiac disease should immediately seek medical consultation. In addition to the symptoms described above, recent studies have revealed increased prevalence of celiac disease among adolescents diagnosed with irritable bowel syndrome, making this another population that should seek evaluation for celiac disease. Specifically, Cristofori et al. (2014) found that adolescents diagnosed with irritable bowel syndrome were four times more likely than individuals without abdominal related problems to be diagnosed with celiac disease. While blood tests are available as a preliminary test for celiac disease, they are often inaccurate. Therefore, the only accurate diagnosis for celiac disease to date involves a biopsy of the small intestine (Silvester & Duerksen, 2013).

Prognosis

Despite a poor prognosis for individuals who fail to obtain proper diagnosis and treatment, a positive prognosis accompanies those who appropriately address the triggers associated with celiac disease. While there is no cure, individuals who adhere to a gluten-free diet and a gluten-free lifestyle can reverse many of the problems associated with their disease. For example, Flamez et al. (2014) noted that individuals who make changes to their lifestyle by adopting a gluten-free diet often reverse the damage to their intestines within 18 months. Although some symptoms can be reversed as a result of adopting a gluten-free diet, others such as growth impairment may be irreversible.

Adoption of a gluten-free diet involves more than just eating foods that are identified as being gluten-free. As de Lorenzo, Xikota, Wayhs, Nassar, and de Souza Pires (2012) noted, appropriate storing and processing of foods and avoidance of gluten containing products is also instrumental in avoiding the introduction of gluten into the body. Unfortunately, the financial costs and time associated with buying gluten-free foods and preventing cross-contamination are difficult for many individuals and families and can lead to noncompliance (Singh & Whelan, 2011).

Individual Dynamics

Celiac disease, when left undiagnosed or untreated, can cause significant health conditions and even result in death. Present in numerous foods and household products and subject to cross-contamination, gluten, a common protein, serves as a trigger for potential damage to an individual's intestines even when introduced in small amounts (University of Chicago Celiac Disease Center, 2013). Without adherence to a strict gluten-free lifestyle, symptoms such as depression, irritability, inattention, and behavioral outbursts have the potential to cause significant limitations in various areas of an individual's life. While these symptoms are well documented in medical literature (e.g., Rodrigo, Blanco, Bobes, & de Serres, 2013) the effects of living a gluten-free lifestyle are predominantly neglected.

According to Salmon (2013), adolescents experiencing physical disabilities are likely to self-exclude themselves from participation in activities with students without disabilities, even when the disability is not visible. This tendency to self-exclude one's self may serve as a defense mechanism from the notable challenges that face individuals with disabilities, including increased bullying victimization and reduced social inclusion (Kramer, Olsen, Mermelstein, Balcells, & Laljenquist, 2012). While the potential for bullying self-exclusion, bullying, and social isolation may occur due to the presence of a disability, the lifestyle adaptations and limitations associated with adherence to a gluten-free diet or gluten-free lifestyle may also result in social stigmas (Olsson et al., 2009).

Research has demonstrated the negative effects of social alienation on individuals' self-esteem and sense of belonging (Lindsay, Mcpherson, Aslam, McKeever, & Wright, 2013). Given the presence of gluten in many everyday products, participation in some social activities may be difficult. For example, a child with celiac disease who attends a friend's party will likely be limited on the types of food he may consume, including not eating a piece of the cake. While the American Celiac Disease Alliance (2014) recommends parents support their child's inclusion in these activities, they caution that both parents and children be aware of the possible dangers of cross-contamination. In effect, even if the child does not consume the cake, the presence of crumbs on the table or in the area can pose a significant risk to the child. Although the University of Chicago Celiac Disease Center (2013) noted that such risks of airborne gluten are often minimal in most environments, individuals with celiac disease should still proceed with caution.

Beyond the implications of the inability of children and adolescents with celiac disease to consume the cake at the party or eat out at restaurants with their friends, other children and adolescent activities may also pose a risk for an individual with celiac disease. In fact, the National Foundation for Celiac Awareness (2014) noted that hidden gluten is contained in numerous products used in children's classrooms. Glue, envelopes, and papier-mâché, for example, all contain hidden gluten, which could pose a risk and keep students with celiac disease from participating in these activities. Although a 504 plan provides for provisions of equal access and education, the lack of available substitutes for these items may present as a problem. As a result, parents, teachers, school counselors, and administrative staff must be creative with class activities to ensure that all students have an opportunity to participate.

School Accommodations

Provisions for nondiscrimination protections of individuals with disabilities within public education and through federally funded programs were first addressed by Section 504 of the Rehabilitation Act of 1973 and eventually strengthened by the guidelines set forth in Section 504 of the American with Disabilities Act of 1990. Under these guidelines, individuals with a documented or perceived physical or mental impairment that results in significant limitations in one or more major life activities is identified as an individual with a disability and therefore is protected under these provisions (U.S. Department of Education, 2013). Individuals requiring accommodations to ensure that their children, who meet the criteria for being an individual with a disability, are being provided equal access to services have the option of seeking a 504 plan. While 504 plans are traditionally identified as plans dealing with classroom or educational accommodations (e.g., extra test time, a seat in the front of the room, etc.), the American Celiac Disease Alliance (2014) points out that the National School Lunch Program is a federally funded program in which 504 plans can be applied.

While packing a child’s lunch may be the safest process in ensuring that lunches are gluten-free and were prepared in a gluten-free environment, the increased cost of gluten-free products or various other factors may make this option unfeasible. Therefore, a parent can seek out accommodations to ensure that their children are being provided a gluten-free meal. Although documentation of disability from a qualified professional is often the only requirement to seek these accommodations, the completion of a 504 specific enough to meet the child’s needs but broad enough to cover various potential situations is necessary to ensure compliance with the child’s dietary needs (Celiac Disease Foundation, 2014). Gluten-free alternatives within the lunch room as well as alternatives within the classroom are some areas which may need to be considered in the development of these plans.

The provisions associated with 504 plans within the school system are beneficial to individuals who qualify; however, these accommodations may only be available to individuals with documented cases of celiac disease in which the parent or physician can provide a compelling argument that the conditions of the disability rise to the level of significant limitations (U.S. Department of Education, 2013). Furthermore, not all situations may provide equal accommodations (e.g., a school field trip to a local skating rink may not provide gluten-free alternatives in the event that the destination provides pizza for all of the students). Although the U.S. Department of Health and Human Services (2012) recommends that parents not publicize the presence of celiac disease in their children to avoid setting them apart, failure to disclose the presence of celiac disease may result in the impossibility of identifying those with celiac disease and may complicate the social stigma associated with those who are identified.

The lack of knowledge about celiac disease, coupled with stigmatization for those who are different, provides a prime opportunity for advocacy among school counselors. For example, school counselors can encourage an environment of diversity by developing age appropriate disability trainings to be integrated into classes or assemblies, offering groups to individuals who feel marginalized, encouraging the purchase of gluten free products within the classroom, and educating teachers to identify and target bullying. While targeting celiac disease specifically in some advocacy efforts may be difficult, encouraging individuals to gain knowledge and acceptance is instrumental in discouraging stigmatization and increasing an individual’s willingness to seek support (Center for Parent Information and Resources, 2015).

School Counselor Considerations

According to the Children's National Medical Center (2014), approaches to addressing the symptoms and effects of celiac disease for adolescents must focus on improved accuracy and ease of diagnosis, treatment, and awareness, using a five-pronged approach: (a) addressing physical needs, (b) addressing psychological needs, (c) increasing awareness of best practices in treating celiac disorders and accompanying symptoms, (d) community outreach and advocacy, and (e) scholarly research. While a collaborative approach between the parents, family, treatment professionals, and community members of a child with celiac disorder is ideal, the role of the school counselor cannot be underscored. Given the numerous roles in which school counselors serve for children within the school environment (e.g., academic support, career support, and social support), they are in an instrumental position to help students dealing with implications associated with celiac disease (Haskins, 2012).

Common School Products Containing Gluten	
Play-Doh Paints (Finger and Face) Markers Glue, Glue Sticks, and Paste Hand Stamps	Hand Lotions Stickers Band-aids Sunscreen

Figure 1. Common School Products Containing Gluten

Addressing Physical Needs

As displayed in Figure 1, many products commonly found in classrooms often contain varying amounts of gluten. Even in small amounts, contact with gluten can have harmful effects on an individual with celiac disease (Clark, 2015). Specifically, exposure to these substances might impact children and adolescents' thought processes, emotions, behaviors, and social interactions (Beaudoin, 2010). Unfortunately, these symptoms are often misattributed to behavioral and/or psychological causes, resulting in student referrals. Focusing on ways to reduce the presence of gluten within the classroom is one way to reduce these symptoms and associated referrals. As Harsay (2012) revealed, school counselors are often faced with high caseloads, reducing their ability to be effective with individuals who could benefit most from their services. The reduction of inappropriate referrals by targeting teacher and administrator education on the potential effects of the physical environment on student experience offers an opportunity to reduce this barrier.

School counselors have the opportunity to provide psychoeducation regarding the relationships between physical and psychological health. While this applies in the case of celiac disease, the interdependency of the two concepts has far broader implications (Clark, 2015). Substituting gluten-free products for those containing gluten is one area of exploration. Websites such as that provided by the Celiac Disease Foundation (2014) may be one place to look for information on finding gluten free products. Education for parents regarding the potential presence of celiac disease among their children's classmates may also support more effective planning for activities. For example, if parents know that a child in their son's class has celiac disease, they can communicate their desire to bring in cupcakes in advance to provide the parents of the child with celiac disease to prepare gluten-free cupcakes to supplement the traditional ones.

While changes in the classroom may rely on the implementation of others, school counselors have the opportunity to attempt to eliminate gluten-containing products in their own office. For example, if a school counselor engages with children through the use of Play-Doh, which contains gluten, they may wish to utilize Crayola Model Magic, which is gluten-free. Although slight, these changes have the potential to make a significant impact on those individuals with celiac disease (Beaudoin, 2010).

Addressing Psychological Needs

The ability to make changes in the physical environment in order to foster inclusion is important (University of Chicago Celiac Disease Center, 2013); however, gluten-free options are not always available. Resulting lifestyle restrictions, on the other hand, may be more difficult on an individual. The presence of psychological implications of living a gluten-free lifestyle should be an area explored. According to Brislin (2008), this is one area where school counselors' experience and training can be utilized. In the study, Brislin found that school counselors' use of skills training was found to be effective in increasing individuals with disabilities' feelings of empowerment while also providing increased education and tolerance for those without. Because of this reported success, skills training should be considered by school counselors to address the needs of those with celiac disease. Given the lack of research on skills training for those with celiac disease, individual and group methods should be explored.

Whereas skills training has the potential to increase education and empowerment for individuals with celiac disease, other therapeutic methods may be beneficial for targeting other aspects of the financial and social toll that the restrictions of a gluten-free lifestyle may have on a student. After reviewing information on celiac disease, Flamez et al. (2014) concluded that celiac disease may be best approached through a more systemic focus of care. Unfortunately, this has been an area of counseling literature which has been relatively neglected. Still, arguments by Flamez et al. and Sperry (2013) point to the effectiveness of team approaches in addressing issues of chronic illness. One of which, systems approaches infused with psychoeducation, should be further explored in its effectiveness with children and adolescents with celiac disease.

As Clark (2015) pointed out, treatment of celiac disease might benefit from borrowing upon the efficacy of treatment for other similar disorders, most namely diabetes. Given the social aspect of eating, especially among children and adolescents, this is an important element to consider when developing a treatment plan. Psychological effects of the limitations caused by celiac disorder should, therefore, be monitored by counseling staff.

Increasing Awareness in Best Practice

Given the relative infancy of the integration of celiac disease into psychological research, there does not exist any empirical evidence targeting one counseling approach as superior to another in the treatment of individuals with celiac disease (Clark, 2015). In fact, the only treatment which has been found to address the direct symptoms of celiac disease is the adoption of a gluten-free lifestyle (Flamez et al., 2014). Still that does nothing to establish the services which can or should be offered to those effected directly by the elimination of gluten from their diet.

Targeting the immediate physical environment and offering psychological supports are two approaches (University of Chicago Celiac Disease Center, 2013). According to the Celiac Disease Foundation (2014), it is often the presence of low knowledge and belief in unproven myths that are regarded as the most dangerous to those with celiac disease. This combination is potentially dangerous for individuals with celiac disease. The myths, including a belief that celiac disease is a food allergy or intolerance when it is in fact an autoimmune disease; a belief that a label of gluten-free on foods means that they are safe for individuals with celiac disease to consume when in fact gluten-free indicates that the gluten content is 20 parts per million or less (ppm) and may not necessarily have been prepared in a gluten-free environment; a belief that gluten disorder is equitable to a wheat allergy when gluten is found in other products such as barley and rye; and a belief that a small amount of gluten is not harmful to an individual with celiac disease when amounts greater than 20 ppm can cause significant effects, may result in gluten being inadvertently introduced into an individual’s diet. Because of this, school counselors should engage in education and advocacy for individuals with celiac disease as a means of increasing awareness and decreasing the social effects of ignorance of the disease.

Community Outreach and Advocacy

The discrepancies in the gluten-free definition in terms of a medical definition as opposed to a regulated definition is extremely important. Based on the ways regulations are currently stated, a restaurant can offer gluten-free choices prepared in the same conditions as those with gluten (University of Chicago Celiac Disease Center, 2013). It is this area that may need the most education and outreach. Because the introduction of even a little gluten can have significant effects, the importance of openness and communication within the community should be addressed.

Given that food has the potential to have a significant effect on children, community outreach and advocacy might also follow in the footsteps of programs that have addressed children’s nutrition through advocacy for the reduction of diabetes. While diabetes has gained significant support through programs like Let’s Move (The White House, 2015), celiac disease remains relatively untargeted. This must change in order to effectively foster a positive environment for those with celiac disease.

Research and Publications

The lack of an established effective treatment approach to working with children and adolescents with celiac disease provides the opportunity for further research into evidence-based practices. Therefore, school counselors have the ability to contribute their knowledge, awareness, and experience through scholarly research and publications. According to Lapan, Wells, Petersen, and McCann (2014), school counselors have a unique opportunity to share practical experience through research. As facilitators between the counseling and education professions, participating in research is one way that school counselors can support in the increased understanding of celiac disease and the development of effective therapeutic approaches to addressing the associated symptoms.

Case Illustration

Kaylen is getting ready to begin her first year at Heritage Elementary School in Lexington, North Carolina. Prior to the start of school this year, Kaylen was living with her parents in Fort Bragg, North Carolina. Due to her parent's separation, however, she was forced to relocate with her mother, who decided to move closer to her family for increased support. Kaylen has serious reservations about this relocation and having to make new friends. She had grown used to her old friends who had attended preschool, kindergarten, and the beginning of elementary school with her.

Kaylen was diagnosed with celiac disease at the age of two. As a result of her intense reactions to gluten, she was placed on a stringent gluten-free diet. Instituting the diet was hard on Kaylen at first; however, Kaylen's parents had substantial support from the other parents in the small military community with instituting gluten-free choices and activities in her school and various social events. For birthdays and other celebrations at the school, the other parents always ensured that everything was gluten-free. Unlike the previous environment, many of the individuals who attend Kaylen's new, small private school are on a financial scholarship, and Kaylen's mother believes that the other parents in this community will be less willing or able to accommodate in the ways that the previous community did.

Kaylen's mother knows that Kaylen often feels left out when they are at an event with limited gluten-free options and foods with gluten that look very appetizing. Kaylen is too young to understand why the other children do not have the same dietary restrictions. Kaylen's mother requests a meeting with school personnel to discuss Kaylen's strict dietary needs and concerns regarding the potential interactions with others in the class. While her mother understands that others in the class cannot be required to adhere to a gluten-free diet, she wants the school to make accommodations. Specifically, she wants the school to provide her daughter with a gluten-free lunch so Kaylen does not feel left out by having to pack. She also wants the school to discontinue activities that allow the kids to bring their own foods, including celebration of birthdays, and wants the school to provide gluten-free alternatives at school sponsored activities.

Although the counselor understands Kaylen's mother's concerns, she is also familiar with the regulations regarding disability accommodations and realizes that these accommodations are outside the reasonable scope. While she wants Kaylen to have a smooth transition to the new school, she knows that there is only so much that she and the school can do. Consequently, the counselor develops a plan to help Kaylen's integration into the school while respecting the needs of the other students and parents of the Heritage community.

The counselor approaches the teachers about conducting a psychoeducational series regarding the effects of food on the body and decides to introduce the children to healthy food choices including gluten-free foods. Because the counselor knows that there is a push within the state to increase healthy food choices for children, she drafts a grant proposal to gain additional funding. From the larger presentations school wide, the counselor also plans to develop a smaller voluntary cooking group and hosts lunchtime cooking parties. In addition to these groups, the counselor increases her visibility in the cafeteria, providing positive feedback to children in the cafeteria who make healthy food choices. The counselor then extends the outreach to parents and the local community.

Implications for School Counselors

Kaylen's case illustrates the potential social impact of childhood disorders affecting an individual's dietary behaviors. Unlike diabetes, which can be controlled through medications and often includes the reduction and not elimination of specific foods, celiac disease requires the total elimination of gluten not only in an individual's diet but also in their use of common household products. Because food is an instrumental part of socialization in the United States (U.S. Department of Health and Human Services, 2014), children with celiac disease face not only the normal concerns of adolescence but also the increased restrictions of their diet.

Although the social effect of celiac disease in an adolescent setting is important to consider, the potential for celiac disease symptoms to mock psychiatric diagnosis is also necessary to consider when working with this population. The underdiagnosis of celiac disease in children may potentially lead to overdiagnosis of other disorders. Consequently, school counselors are in a position to increase education of the factors and symptoms associated with celiac disease and the importance of diet and lifestyle in reducing these symptoms.

Implications for Future Research

A study conducted by Falco, Bauman, Sumnicht, and Engelstad (2011), regarding topics published in the *Professional School Counseling* journal between 1997 and 2006, revealed that less than 15% of the articles focused on issues associated with students with developmental, cognitive, psychological or physical disabilities. The percentage of students receiving disability-related services in the school is 13% with countless others with disabilities not obtaining such services (U.S. Department of Education, National Center for Education Statistics, 2013). The presence of both visible and hidden disabilities in the educational environment calls for considerable more research to target these issues in the classroom and school environment. While Section 504 of the American with Disabilities Act provides provisions for immediate accommodations, addressing the social stigma of being labeled as a child with a disability or as being different is less often researched. Furthermore, this lack of research leads to an unclear establishment of whether students with disabilities are having their psychological needs met. Given this gap, future research should target programs implemented to reduce the social stigma associated with students with disabilities and increase the inclusion of students.

Conclusion

Celiac disease is a lifelong autoimmune disease that is triggered by products containing gluten. Despite its prevalence in about 1% of the population, it is often misdiagnosed due to its symptoms being similar to other mental health disorders. Without a clear understanding of how celiac disease manifests itself in children and the social impact of being prescribed a gluten-free lifestyle, there is an increased potential that children with celiac disease may feel marginalized in society and may develop underlying health concerns. While changes in the household may be more easily implemented, the potential to make changes within the school to reduce stigma for these children will likely be more difficult.

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