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Impact of Gluten-free Camp on Quality of Life of Children and Adolescents with Celiac Disease

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KEY WORDS

pediatric, sprue, quality of life

ABBREVIATIONS

CD—celiac disease

GFD—gluten-free diet

IBD—irritable bowel disease

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WHAT'S KNOWN ON THIS SUBJECT: No data have been published on the role of camp on the quality of life for children and adolescents with celiac disease. Limited data have been published on quality-of-life improvements for patients who are affected by inflammatory bowel disease.



WHAT THIS STUDY ADDS: We increased our knowledge about quality of life in the pediatric population affected with CD. Specifically, we studied the implications of a gluten-free camp on quality-of-life indicators in this population.

abstract

OBJECTIVE: A gluten-free camp allows children with celiac disease (CD) to enjoy a camp experience without concern and preoccupation with foods they eat or the stigma of their underlying disease. The objective of this study was to evaluate the impact of gluten-free camp on quality-of-life indicators for children and adolescents with CD.

METHODS: Children aged 7 to 17 years with CD were administered a 14-question survey at the beginning and the end of a 7-day gluten-free camp. Surveys used a Likert scale to examine general well-being, emotional outlook, and self-perception for the week before each survey. Differences between the time points were compared. Data were analyzed by paired *t* test.

RESULTS: Of the 104 campers who attended camp, 77 (21 male) completed the survey at both time points. Most (70%) had been on a gluten-free diet (GFD) for <4 years. All seemed to benefit from camp, no longer feeling different from other kids or feeling frustrated with a restricted diet. A more beneficial impact was found for campers who were on a GFD for <4 years. Overall, campers reported an improvement in 11 of 14 questions, statistically significant ($P < .05$) for 8 of those 11 questions. Improvement was observed in each of the 3 categories of questions: well-being, self-perception, and emotional outlook.

CONCLUSIONS: Children who had CD and attended a week-long gluten-free camp demonstrated improvement in well-being, self-perception, and emotional outlook. The positive effects of camp were more apparent among campers who had been on a GFD for <4 years compared with those who had been on a GFD for ≥ 4 years, suggesting an adaptation to CD with time. A gluten-free camp that provides an environment of unrestricted foods can at least temporarily alleviate stress and anxiety around food and social interactions. Durability of these observations on return to daily life requires additional study. *Pediatrics* 2010;125:e525–e529

Celiac disease (CD), or gluten-sensitive enteropathy, is a digestive disease characterized by intolerance to gluten, a protein composite found in wheat, rye, and barley. Even minimal exposure to gluten results in small intestinal injury that can lead to a variety of symptoms, including abdominal pain, weight loss, diarrhea, and irritability, and long-term complications such as osteoporosis, infertility, and malignancy.^{1–3} Patients with a diagnosis of CD must remain on a diet that completely excludes all forms of gluten, and adherence to a gluten-free diet (GFD) is often difficult for economic, social, and practical reasons.^{3–7} A survey by Rashid et al³ revealed that more than one quarter of children who were on a GFD had difficulty locating stores with gluten-free foods and determining whether a food was gluten-free. More than half of families with children who were on a GFD avoided restaurants all or most of the time, and 83% always carried gluten-free food.³

Studying health-related quality of life includes measures of changes to physical, emotional, social, and cognitive aspects of their disease over time and generally reflects the individuals' views of their health status. A chronic illness such as CD can reduce a child's quality of life, affecting life at home, at school, and during extracurricular activities.⁸ Camp can be another obstacle. Thousands of summer camps across the United States host >11 million children and adults each year⁹; however, for children with medical issues or severe dietary restrictions, camp can be challenging and even unmanageable. Recently, camps that cater to children who have CD and are on a GFD have become established across the United States in an effort to alleviate some of the isolation precipitated by the disease.¹⁰ Similar camps designed for children with other chronic diseases exist.^{11–14} Böhm et al¹¹ demon-

strated improved glycemic control among children with diabetes in a camp setting, and summer camps have been shown to improve quality of life in groups of children with pediatric end-stage renal disease, asthma, or inflammatory bowel disease.^{12–14}

Although a strict GFD is challenging, studies have shown that the adherence is high, as high as 98% among adults in the United States and 95% among children in Canada.^{3,15} Children are typically aware when they have ingested gluten: 54% of children in the study reported a symptomatic reaction within 0.5 to 60.0 hours after ingestion of a gluten-containing product.³ Almost all children recognized the importance to their health of eating a GFD.³

We surveyed a group of children who had CD and attended a gluten-free camp to assess whether the camp experience leads to improvement in measured quality of life. We specifically assessed general well-being, emotional outlook, and self-perception. We hope that our findings will help children with CD across the United States to find and use CD camps and that those camps will be encouraged to improve their programs and continue to improve on these relatively brief but invaluable experiences for patients with CD.

METHODS

We determined the effects of a gluten-free camp on children with CD at a 7-day gluten-free celiac camp in California. Children who were aged 7 to 17 years were administered a questionnaire by their camp counselor or a member of the study staff at both arrival to and departure from camp. All campers and their parents consented to the survey and were given the option to decline the survey at any time. Campers were offered assistance from a counselor and/or study staff

member to complete the survey. Each survey was labeled with a cabin name, number, and either the letter "A" if completed at the beginning of the week (precamp, or baseline) or the letter "B" at the end of the week (postcamp). For maintaining confidentiality, surveys did not include any identifying information to connect a particular camper to his or her answers. The "A" and "B" surveys were matched by coded numbers to compare the "before" and "after" for each camper. Only pairs of matched surveys were used in the analysis; surveys from individuals who completed only a single precamp or postcamp questionnaire were excluded from analysis.

The survey consisted of 14 questions that addressed symptoms, emotions, and perceptions of disease and self. The questions were divided into 3 categories: general well-being, emotional outlook, and self-perception. The survey used a 4-point Likert scale variation with responses scored as follows: 1, never; 2, some of the time; 3, most of the time; or 4, all of the time. A response of "don't know" was also possible. When a survey taker answered "don't know" for a particular question, that question was removed from analysis, because improvement from time "A" to time "B" could not be calculated. Space for comments was provided at the end of the survey.

Because few validated questionnaires for disease-specific health-related quality of life exist for pediatric patients with CD, we developed a questionnaire that was modified for CD from a conglomeration of 4 other validated surveys. Because the camp purports to offer a safe environment, specifically by providing a GFD, we combined the Short Inflammatory Bowel Disease Questionnaire^{16,17} with outcomes studied specifically in the impact of a GFD on patients with CD,⁴ effects of adhering to a GFD studied in children,³

and the IMPACT-35 questionnaire, a pediatric irritable bowel disease (IBD) quality of life questionnaire.¹⁸

Differences in Likert scores were compared between the 2 time points for each question. We categorized survey takers into 2 groups: Those who had been on a GFD for ≤ 4 years and those who had been on the diet for >4 years. Four years was used as an arbitrary metric to categorize the campers into those who had been on a GFD for a long time versus those who had a more recent diagnosis. Data were compared between the 2 groups as well as within each group for changes between the beginning (baseline) and the end of camp. Data were analyzed by using Student's *t* test for differences between means of answers for surveys that were done before and after camp and subdivided by age group and years on a GFD.

The institutional review board of the University of California, San Francisco, approved the study before camp began. Verbal consent or assent as appropriate was obtained at the time of distribution of the first survey. Children could also withdraw from the study by not completing the second survey.

RESULTS

Of the 104 campers who attended camp, 77 (21 [27%] male, 56 [73%] female) completed a survey both on arrival to and departure from camp, a 74% response rate. Of the 77, 54 (70%) campers had been on a GFD for <4 years (Table 1).

Campers reported an overall improvement between the beginning and the end of camp (measured by a negative change in mean) in 11 of the 14 questions, reaching statistical significance ($P < .05$) in 8 of these 11 questions. Improvement was seen in each of the 3 categories of questions: well-being, self-perception, and emotional out-

TABLE 1 Description of Survey Takers by Gender and Time on GFD

Age, y	n (%)	Gender		Time on GFD, y	
		Male	Female	<4	≥ 4
7–10	26 (34)	11	15	23	3
11–13	30 (39)	5	25	17	13
14–17	21 (27)	5	16	14	7
Totals, N (%)	77 (100)	21 (27)	56 (73)	54 (70)	23 (30)

look. Worsening (equivalent to a positive change in mean) was reported in 3 of the 14 questions; however, the worsening was not statistically significant for any of those 3 questions (Table 2). Analysis for effects of gender or length of time on GFD did not show any significant differences ($P = .90$). Children who had been on a GFD for <4 years had more items (7 of 14 questions) with statistically significant changes compared with those who had been on a GFD for ≥ 4 years (2 of 14; Table 3).

One of the 14 survey questions was confusing: "Overall, in the past week, how much did you believe you could be healthy without having to follow a special diet?" Campers, as directly observed by the study staff, expressed confusion about this item while completing the survey, explaining why so few answered the question.

Three of 14 survey questions garnered a negative change in mean, indicating a worsening during the course of camp (Table 3). These 3 questions, all pertaining to well-being, involved trouble with stomach pain, feeling fatigued or worn out, and a problem with diarrhea. All changes were <0.1 , and none was statistically significant ($P > .05$).

DISCUSSION

Celiac camp enables children with CD to enjoy the camp experience freely without concern for and preoccupation with the foods that they are eating or the stigma of their underlying disease. This is the first study to evaluate the short-term effect of a specialized summer camp on children with CD in the United States. Our report substantiates that our camp has modest but significant effects on improving chil-

TABLE 2 Results of Survey Questions

Question	N	Baseline	Camp End	Δ in Mean	P
Emotional outlook					
Felt frustrated that you could not eat something you wanted to	73	2.01	1.08	−0.93	$<.001$
Felt angry about having to follow a special diet	76	1.62	1.08	−0.54	$<.001$
Felt angry as a result of your CD	75	1.55	1.08	−0.47	$<.001$
Felt relaxed and free of tension	70	2.19	1.89	−0.30	.017
Felt discouraged or unhappy	74	1.42	1.28	−0.14	.077
Self-perception					
Felt different from other kids because of CD	76	1.95	1.17	−0.78	$<.001$
Felt embarrassed because you had to bring your food to a meal	77	1.47	1.09	−0.38	$<.001$
Had to delay or cancel social engagement because of your CD	76	1.16	1.01	−0.15	.021
Thought about gaining or losing weight	76	1.66	1.50	−0.16	.900
Believe you could be healthy without having to follow a special diet	61	3.33	3.31	−0.02	.921
Well-being					
Difficulty doing sports or leisure activities because of your CS	69	1.29	1.10	−0.19	.027
Troubled by stomach pain	75	1.48	1.55	0.07	.439
Felt fatigued or worn out	70	1.59	1.63	0.04	.643
Had a problem with diarrhea	75	1.15	1.16	0.01	.784

TABLE 3 Results of Survey Questions for Campers on a GFD for ≥ 4 and < 4 Years

Question	GFD < 4 y			GFD ≥ 4 y		
	N	Δ in Mean	P	N	Δ in Mean	P
Emotional outlook						
Felt frustrated that you could not eat something you wanted to	51	-1.16	$<.001$	22	-0.41	.016
Felt angry about having to follow a special diet	53	-0.87	$<.001$	23	-0.26	NS
Felt angry as a result of your CD	53	-0.66	$<.001$	22	-0.18	NS
Self-perception						
Felt different from other kids because of CD	53	-0.87	$<.001$	23	-0.57	.012
Felt embarrassed because you had to bring your food to a meal	54	-0.56	$<.001$	23	-0.13	NS
Well-being						
Difficulty doing sports or leisure activities because of your CD	48	-0.19	.038	21	-0.19	NS

dren's quality of life, on the basis of the indicators measured, during their time at camp.

Compliance with a GFD is essential for prevention not only of symptoms but also of long-term complications that can occur later in life. Few studies have examined the impact of following a GFD on the quality of life of children with CD. A GFD is restrictive and can especially have an impact on social aspects of a child's life. We report the impact of 1 week of camp where all food was gluten-free, and all children had unrestricted access in an environment where everyone was eating the same food as their peers. In addition, children were able to learn from their peers during informal and impromptu discussions relating to coping daily with CD and its associated restrictions.

Because CD typically does not bear outward physical stigmata and children who have CD are mostly asymptomatic while on a GFD, dietary restriction is a major quality-of-life issue for children and adolescents with CD. Camp that provides only gluten-free products allows children to set aside the worry of foods contaminated with gluten. It is clear that children benefited in many ways. Our study focused on quality of life at camp as it relates to CD or a GFD directly, not on quality of life of the child in general. As some studies show, children with CD may report negative

or neutral quality of life, which does not translate into their generic opinion of their quality of life.¹⁹ We surmised that removing the hindrance of daily food choices allowed children to evaluate themselves without the burden of their chronic disease.

Our study also demonstrates differences between children who more recently initiated a GFD compared with children who had been following a GFD for a longer period (>4 years). We used time on a GFD rather than age at CD diagnosis to categorize the population because for some children, the restrictive diet and diagnosis did not occur at the same time; however, a GFD does likely correspond closely to the length of time a child has had a diagnosis of CD, so it can be used as a proxy for time of diagnosis. Our surveys demonstrated that camp had a positive effect on all children in almost all quality-of-life categories. The effect was more prominent for children who more recently had started a GFD (≤ 4 years). Children who had been on a GFD for a longer period had more overall positive ratings at the beginning of camp, so these children had less change in their scores from the beginning to the end of camp. This suggests that perhaps it is not just CD but also the restrictions of a GFD that shape children's perceptions of their disease and their quality of life and that, over

time, children adapt to their diet by learning to accept the social consequences of maintaining a GFD. Although we did not study the cause of the observed differences between the 2 groups, it is possible that the children who were on a GFD for <4 years benefited more from the camp because they had a chance, possibly for the first time, to interact with other children who already had been on the diet for a longer time and developed coping mechanisms.

Survey comments provide some insight into the increase in stomach pain, fatigue, and/or diarrhea during the course of 1 week at camp. For example, a response similar to, "I only felt pain because I ate too much food!" was mentioned frequently in the extra comment space provided. Children also wrote that they were tired from all of the camp activities, and staying so busy made it hard to feel "relaxed." One week of unlimited gluten-free food and many activities may have led to stomach pain from overeating and fatigue from overexertion and excitement.

Our study has several limitations. Although our questionnaire was based on other validated measurement tools, it was not specifically validated. In addition, 2 of the underlying questionnaires were developed for children with IBD, not CD. Although this poses a problem because of the differences in symptoms, both diseases affect the gastrointestinal tract and have some overlapping symptoms and social implications to children and adolescents. Furthermore, our study population is composed of children who had CD who attended celiac camp, leading to possible selection bias because we used no control group of children without CD or children who had CD and did not attend camp with which to compare our data. Not all campers completed the survey at both the beginning and the end of camp, particularly older

boys, and because more female campers attended camp overall, boys were underrepresented relative to girls.

This report provides the first information to explore quality-of-life changes of children who were on GFD before and after a camp experience in which all meals were prepared and safe. Some children at camp not only were following a GFD but also were lactose intolerant or casein-free, making their restrictions more complex. These children were provided healthy and comparable alternatives and were included in the study, although the influence of the more complex diets that they were provided was not dis-

cerned. Campers for the most part were young and from California, so conclusions are most accurately extrapolated to California residents only. Perhaps most important, we cannot extrapolate the long-term effects of camp.

Overall, children who had CD and attended a week-long gluten-free camp demonstrated improved well-being, self-perception, and emotional health. The positive effects of camp were more evident among campers who had been on a GFD for <4 years compared with ≥4 years, suggesting adaptation to life on a GFD with time. A gluten-free camp that provides an environment of unre-

stricted foods at least temporarily alleviates stress and anxiety around food, especially in regard to social interactions and self-perception. Durability of these observations on return to daily life requires additional study.

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