

The potential benefits of camps for children and adolescents with celiac disease on social support, illness acceptance, and health-related quality of life

Journal of Health Psychology

1–11

© The Author(s) 2020



Article reuse guidelines:
sagepub.com/journals-permissions
DOI: [10.1177/1359105320968142](https://doi.org/10.1177/1359105320968142)
journals.sagepub.com/home/hpq



Maor Shani^{1,2}, Lukas Kraft³, Marvin Müller⁴
and Klaus Boehnke^{1,5}

Abstract

Among $N = 165$ 14–22-year-old bearers of celiac disease (CD), the German-based study examined if participation in camps for children with CD is related to higher CD-related quality of life (CD-QoL); $N = 48$ of the study participants attended at least one camp. Camp participation was found to be related to higher CD-QoL, an effect mediated by having more friends with CD and by perceiving higher social support. Camp participation was also associated with higher illness acceptance and lower anxiety. Results show the potential benefits of recreational activities in CD treatment, to be further examined in experimental research.

Keywords

adolescents, celiac camps, celiac disease, health-related quality of life, psychosocial development

Celiac disease (CD) is an autoimmune disorder caused by gluten ingestion in genetically predisposed individuals, leading to a chronic inflammation in the small intestine (Catassi and Lionetti, 2020). The only available treatment is adhering to a strict lifelong gluten-free diet (GFD). Nonadherence is associated with increased morbidity and mortality (Coburn et al., 2020). In Germany, the prevalence of CD in children and adolescence is estimated at 0.9% of the respective population, which is comparable to other European countries (Laass et al., 2015).

Involving severe limitations on food intake, CD requires persistent vigilance and material adaptation. Unsuccessful adaptation can result in high psychosocial distress, especially among children (Coburn et al., 2020). Social domains

of life are negatively affected, including relationship with friends, participation in leisure activities, and daily food management (de Lorenzo et al., 2012). Woolley et al. (2019) recently demonstrated that people with food

¹Jacobs University Bremen, Germany

²Osnabrück University, Germany

³Independent researcher, Germany

⁴Accadis University of Applied Sciences, Germany

⁵National Research University Higher School of Economics, Russia

Corresponding author:

Maor Shani, Department of Developmental Psychology,
Osnabrück University, Seminarstr. 20, Osnabrück 49074,
Germany.

Email: maor.shani@uni-osnabrueck.de

restrictions experience greater feelings of loneliness, induced by limited ability to bond with others at the table. Similarly, studies show that in social situations, children and adolescents with CD often feel vulnerable, isolated, and stigmatized by others (Schroeder and Mowen, 2014). Meyer and Rosenblum (2017) found that children with CD require more preparation for food-related activities, tend to participate in fewer activities, and in some cases exhibit less enjoyment, compared with healthy matched controls. Moreover, since engagement in leisure activities allows young people to explore their identities, to develop a sense of confidence, and to prepare for life as adults (Mannell, 2007), diminished social participation can be detrimental to identity formation and social development (Allsop et al., 2013). The psychosocial repercussions of CD are often assessed using measures of *health-related quality of life* (HR-QoL), which refers to physical, mental, and social dimensions of functioning vis-à-vis one's disease (Karimi and Brazier, 2016), or using CD-specific measures (CD-QoL, Jordan et al., 2013), which emphasize perceived social isolation and exclusion.

Despite the growing awareness of the psychosocial challenges of CD and its implications for HR-QoL, psychological services are rarely integrated into CD treatment models (Coburn et al., 2019), and research on interventions is scarce (Howard and Urquhart-Law, 2014). In general, evidence suggests that interventions focusing on education and support can be effective in encouraging adherence to GFD (Sainsbury et al., 2015) and reduce the burden of CD (e.g. Coburn et al., 2019).

One particularly overlooked form of indirect intervention that emphasizes social participation is recreational camps for children and adolescents with CD. *Celiac camps* enable patients to experience developmentally adequate camp activities in a safe gluten-free environment, an experience that is often denied to them in regular camps (Faith et al., 2019). Studies revealed positive psychosocial outcomes of recreational or therapeutic camps for children with chronic illnesses, including those requiring adherence

to a special diet (Barone et al., 2016; Moola et al., 2014; Sendak et al., 2018)

Pertaining to CD, research has suggested that taking part in leisure activities has the potential to improve HR-QoL, by helping children to manage the discomfort they experience in the social sphere (de Lorenzo et al., 2012). Nevertheless, the benefits of celiac camps remain largely untested. Considering the unique characteristics of CD, which is less visible than many other chronic conditions, but highly restrictive of food intake, it seems important to empirically examine whether celiac camps improve HR-QoL. An exception is Bongiovanni et al. (2010), who evaluated the effectiveness of a 7-day summer camp for children and adolescents with CD (ages 7–17) in the US, and found that campers felt less different or embarrassed about their disease, and had fewer negative emotions such as anger and frustration after the camp. Still, Bongiovanni et al. (2010) studied a relatively small sample ($n = 77$), with no comparison group of non-campers, and measured a limited number of single items rather than validated scales to obtain CD-QoL. Moreover, the extent to which the experience of campers with CD in the US is akin to that of campers in a different social context, such as Europe, remains unknown.

The present research

The current research examined the potential psychosocial benefits of celiac camps among youth in Germany. In the past two decades, the German Celiac Society (*Deutsche Zöliakie Gesellschaft*, DZG) conducted annual summer camps for children and adolescents with CD (aged 11–15). DZG camps implemented components of positive youth development programs, such as providing opportunities for sustained relationships, focusing on skill-building and self-care, and maintaining camp rules and facilities (Sendak et al., 2018). Activities in the camp offered supportive relationships, opportunities to belong, and positive social norms of behaviours, while addressing the special needs of participants and potentially facilitating their

development (Eccles and Gootman, 2002). Accordingly, a typical celiac camp lasted for 1 week and consisted mostly of common camping activities, including sightseeing, trips in nature, social games, and sports. The program also includes CD-focused activities, such as cooking together, visits to gluten-free bakeries and information sessions with professionals.

We hypothesized that there will be a positive relationship between participation in celiac camps and CD-QoL (Jordan et al., 2013). We also examined the extent to which camp participation is associated with higher general subjective well-being (SWB), which is not limited to aspects of managing CD. Furthermore, we tested three potential mechanisms through which camps may improve CD-QoL and SWB. Scholars have emphasized the need to better understand the mechanism that occurs in illness-related camps, in order to promote evidence-based practices (Moola et al., 2014), but so far little research has addressed this need. Since the study was cross-sectional, we could only offer insights into possible mechanisms using statistical mediation procedures.

Social support mechanism

Peer support is particularly important in adolescence, when orientation toward friends as a source of emotional support increases while parental control and support declines (Rageliènè, 2016). Social and emotional support from both family and peers have been found to foster better psychosocial functioning, emotional development, and well-being among people with chronic illnesses in general (La Greca et al., 2002), and with CD in particular (Howard and Urquhart-Law, 2014).

In celiac camps, campers often engage in active peer support through intensive socializing and sharing experiences (Faith et al., 2019). Studies found that developing friendships with peers throughout illness-related camps helped campers feel less socially isolated (Hill et al., 2015). Moreover, camps may lay the foundation for meaningful and long-lasting friendships with similar others (Darling, 2013). In turn, having

emotionally supportive friends with CD can help alleviate the stressors caused by the GFD, thereby improving CD-QoL. Bongiovanni et al. (2010) found that participants of a gluten-free camp positively evaluated their encounter with peers, and particularly liked sharing information and coping strategies with their camp friends. Similarly, Darling (2013) found that female adolescents with CD benefited from having CD friends, since they could understand and empathize with their challenges and experiences to a greater degree than unaffected friends.

Accordingly, we hypothesized that participation in celiac camps will predict having more friends with CD and higher perceived support. Moreover, we hypothesized that camp participation will predict higher CD-QoL and SWB first through having more CD friends, and then through experiencing more support (a serial mediation hypothesis, Hayes, 2017).

Social identity mechanism

A positive and adaptive *illness identity*, which refers to accepting one's disease as a part of their identity, was found to be associated with better self-management behaviour, higher satisfaction with life, and fewer depressive symptoms (Oris et al., 2016). Since leisure enables adolescents to obtain peer recognition and explore their personal and social identities (Thurber et al., 2007), celiac camps may increase illness acceptance. Studies on diabetes camps found that emphasizing autonomy and independence during the camp increase positive identification with the disease (Barone et al., 2016). Furthermore, Meltzer et al. (2018) showed that emotional support during the camp can improve positive identity development, since campers who share illness are likely to be accepting of others without judgment and stigmatizing behaviours.

Accordingly, we hypothesized that participation in celiac camps will be associated with better illness acceptance, and that illness acceptance will mediate the relationship between camp participation and higher CD-QoL and SWB, so that camp participation will

predict higher illness acceptance, which in turn will predict higher CD-QoL and SWB.

Anxiety reduction mechanism

Finally, by providing supportive social environment, celiac camps can alleviate the anxiety related to having CD, which refers to unpleasant feelings and worries regarding the burden of managing the GFD, social restrictions (e.g. in school), and possible adverse effects of digesting gluten (Howard and Urquhart-Law, 2014; Rose and Howard, 2014). Bongiovanni et al. (2010) found that children who attended a gluten-free camp felt more relaxed after the camp, and concluded that it can reduce anxiety in social interactions. Research on illness-related camps and anxiety has been scarce and led to inconsistent conclusions. Several studies found that camps helped to reduce the anxiety associated with the illness, but mostly for the short term (Moola et al., 2014; Simons et al., 2007). Considering the ambiguous nature of previous results, we explored the role of anxiety as a potential mediator in the expected positive relationship between camp participation, CD-QoL, and SWB, without prior hypotheses.

Method

Procedure and participants

We utilized a retrospective cross-sectional design among adolescents and emerging adults (aged 14–22), who were invited to take part in an online survey. This age group was selected to include individuals who attended camps in recent years and can be still regarded as youth (e.g. Gerking and Khaddaria, 2012). Given the rarity of CD in the general population (<1%), the only viable sampling method was convenience sampling. Participants were recruited through the DZG, and eligibility was determined according to self-reported CD diagnosis.

The sample was sufficient according to a-priori power analysis (see Supplemental Material). Participants ($N = 165$) completed the questionnaires between February and April 2019. The Ethics Committee of the first author's institute approved the study. Participants younger than 18

were asked to obtain parental informed consent before completing the questionnaire, and all participants consented to the survey before its onset.

Sample characteristics are presented in Supplemental Table 1 for the entire sample and for campers (29%) and noncampers (71%). Most participants were female, which mirrors their higher prevalence among CD patients (Singh et al., 2018). Campers and noncampers did not differ significantly in their average age, but the former were diagnosed at a younger age compared to the latter, $t(143) = 3.28, p < 0.001$. Therefore, the robustness of findings was examined by controlling for age of diagnosis in the analysis. No other significant differences were found between the groups in the characteristics summarized in the table. Interestingly, self-reported GFD adherence levels were high in both groups, resulting in a ceiling effect.

Measures

All instruments were either originally developed in German, obtained as validated German translations, or translated to German using translation and back-translation procedure by multilingual individuals. Scores for multiitem scales on all variables were obtained by calculating an arithmetic mean for all items, after reversing scores on reverse-worded items. Higher scores represent higher qualities of the measured constructs.

CD Quality of life was measured using the CDPQoL (Jordan et al., 2013), a paediatric CD-specific instrument capturing domains of CD-QoL among adolescents (13–18). CD-specific measures of HR-QoL were found to reveal lower quality of life compared to generic instruments, and therefore they may be more appropriate for revealing the relationship between camping and HR-QoL (Häuser et al., 2006; Jordan et al., 2013). The CDPQoL includes 17 items measuring four dimensions, and was previously validated in the US (Jordan et al., 2013; Wolf et al., 2018). For each item, participants were asked to indicate how often it has been a problem for them in the past month (e.g. 'I get embarrassed when I am at restaurants'), on a scale ranging from 0 (*never*) to 4 (*almost*

always). The dimensions of the CDPQoL are: *Social*, which focuses on self-esteem and perceptions of being a burden on others ($\alpha = 0.84$); *Uncertainty*, which refers to worries about the future ($\alpha = 0.61$); *Isolation*, which measures perceived alienation from family and friends ($\alpha = 0.72$); and *Limitations*, which measures negative feelings related to avoidance techniques ($\alpha = 0.63$). The dimensional structure of the CDPQoL was examined in a confirmatory factor analysis, which confirmed the structure (see Supplementary Materials). To enable comparison with previous research, mean scores on all CDPQoL subscales were converted to a scale ranging from 1 to 100. An Overall CDPQoL score was also calculated ($\alpha = 0.90$).

Perceived support refers to subjective perceptions of understanding and sympathy individuals feel from their friends with regard to their CD. It was measured with five items adapted from existing measures of social support (Procidano and Heller, 1983; Zimet et al., 2010). Each participant rated their level of agreement with the items on a 5-point scale (1 = *completely disagree*, 5 = *completely agree*). Example item: 'I feel comfortable eating together with my friends', $\alpha = 0.67$.

Subjective well-being (SWB) was measured using a German version (Hoffmann, 2002) of the single-item happiness measure (Fordyce, 1988). Participants rated their overall general happiness on a scale ranging from 1 (*extremely unhappy*) to 10 (*extremely happy*). Scale anchors were labelled with a series of mood adjectives (e.g. 7 = *mildly happy*, 'feeling fairly good and somewhat cheerful').

Illness acceptance, a measure of adaptive integration, was adapted from the Illness Identity Questionnaire (Oris et al., 2016). It refers to the degree to which patients accept the disease in their identity and focus on self-management without feeling overwhelmed (five items, e.g. 'My celiac is a part of who I am'). Participants rated their agreement with each item on a scale from 1 (*completely disagree*) to 5 (*completely agree*). The scale demonstrated high internal consistency ($\alpha = 0.84$).

CD-related anxiety was measured using a short and validated situation-adapted version of

the State-Trait-Anxiety Inventory (Marteau and Bekker, 1992), which was translated to German and validated by Grimm (2009). Participants rated the extent to which they experience six emotions (e.g. 'I am intense') when they think about having CD, on a scale ranging from 1 (*not at all*) to 4 (*very*), $\alpha = 0.67$.

CD friendship was measured using two questions, to account for potential variation in the understanding of the concept of friendship (e.g. Berndt, 1982): 'How many people with celiac do you know outside your family?' and 'How many friends do you have who also have celiac?'. In both questions, response options were 1 (*none*), 2 (*1–2 people*), 3 (*3–5 people*), or 4 (*6 people or more*). Scores for these questions were positively correlated, $r = 0.50$, $p < 0.001$.

To obtain scores for *celiac camp participation*, respondents were asked to indicate how often they participated in camps for adolescents with CD (e.g. summer camp). The response options were 0 (*never*), 1 (*once*), 2 (*2–3 times*), or 3 (*4 times or more*). Two variables were computed: one in which responses were dichotomized between those who never attended any camp (*noncampers*) and those who attended at least one camp (*campers*); and one referring to the *frequency* of participation, by using the measure as continuous.

Adherence to GFD was determined using two questions. Participants were asked to rate the extent to which they maintain their gluten-free diet on a scale ranging from 1 (*not at all*) to 10 (*very strongly*), and to indicate how often they eat something that contains gluten on a scale from 1 (*never*) to 10 (*every day*). After reverse-scoring the second question, the two items were strongly correlated ($r = 0.67$, $p < 0.001$).

General health satisfaction was measured using a single item asking participants to rank the extent to which they are satisfied with their health on a scale ranging from 1 (*very unsatisfied*) to 5 (*very satisfied*).

Finally, participants were asked to mention their *gender* (male, female, or other), *age* (years), *age of diagnosis* (years), and perceived family income on a scale from 1 (*very low*) to 5 (*very high*).

Statistical analysis

Data were analysed using SPSS and JASP software. Prior to main analyses, multivariate normal distribution and linearity were examined in the dependent variables, and statistical assumption violations were not detected. Missing values accounted for < 10% of the data. Little's test of missing data was nonsignificant, $\chi^2(343) = 328.14, p = 0.71$, which indicated that data were missing at random. Therefore, missing data were imputed using the recommended procedure of expectation maximization (Molenberghs and Verbeke, 2005). Hypotheses were examined using the imputed dataset with no missing values.

All tests were two-tailed, with $p < 0.05$ considered statistically significant. Between-sample *t*-tests were used to compare campers and noncampers across psychosocial variables, while bivariate correlations were calculated to examine direct relationships between the variables. Indirect effects were examined using path analysis with PROCESS V. 3.3 Macro in SPSS (Hayes, 2017), using bootstrapping biased-corrected confidence intervals with 5000 random re-samples. Only variables with significant bivariate correlations with both the predictor (frequency of participation) and the outcome (CDPQoL) were included.

Data sharing statement

The complete dataset used for all analyses, together with the syntax and output for the analyses, are included in the supplementary material.

Results

Celiac disease quality of life

The overall CDPQoL average was 61.09 ($SD = 19.46$), which was lower than the mean score found by Jordan et al. (2013) and by Wolf et al. (2018) among teenagers in the US ($M = 71.7$ and $M = 70.1$, respectively). Moreover, patients below the age of 18 ($M = 58.89, SD = 19.74$) had on average lower CDPQoL scores than patients who were 18–22 years old ($M = 65.66,$

$SD = 18.87$), $t(150) = 2.14, p = 0.034$, Cohen's $d = 0.35$. Gender differences were insignificant ($p = 0.13$).

The relationship between camp participation and psychosocial variables

Supplemental Table 2 presents Ms and SDs across psychosocial variables for campers and noncampers, results of independent samples *t*-tests, and bivariate correlations between all variables. Participants who attended at least one camp reported having more friends with CD ($d = 1.11$) and less anxiety ($d = 0.43$) compared with those who did not attend any camp. Campers also had higher average scores of illness acceptance ($d = 0.36$), compared with noncampers. Moreover, campers had on average higher CDPQoL in two domains and in the overall score ($d = 0.36$), so that they perceived themselves to be less restricted socially ($d = 0.42$) and less isolated ($d = 0.34$) by their disease, compared with those who attended no camp. All differences remained significant after controlling for age of diagnosis in one-way ANCOVA, except for the difference in illness acceptance, which became nonsignificant ($p = 0.20$).

These relationships held also when camp participation was examined as a continuous variable, considering the frequency of participation: The latter was linked to having more friends, lower anxiety, higher acceptance, and higher CDPQoL in the social and isolation dimensions and in overall CDPQoL. Although campers did not have significantly higher perceived support than noncampers, there was a positive relationship between the frequency of participation and perceived support. All correlations remained significant after controlling for age of diagnosis. Interestingly, although participation and friendship were unrelated to SWB, higher SWB was related to higher support, more positive illness acceptance, and lower anxiety. Higher SWB was also related to higher CDPQoL in all four domains.

The mediating role of perceived support, illness acceptance and anxiety

Path analysis was performed using overall CDPQoL scores as the outcome. A parallel mediation model (Supplemental Figure 1) examined the role of perceived support, illness acceptance, and anxiety in mediating the effects of camp participation on overall CDPQoL. The total effect of participation on overall CDPQoL ($\beta = 0.21, SE = 0.08, p = 0.007$) became insignificant when the three mediators were entered into the regression ($\beta = 0.04, SE = 0.06, p = 0.051$), suggesting full mediation. The total indirect effect was significant: $\beta = 0.17, SE = 0.05, 95\% \text{ CI } [0.08, 0.27]$. Examination of specific indirect effect showed that the effect of camping on CDPQoL was mediated by perceived support ($\beta = 0.07, SE = 0.03, 95\% \text{ CI } [0.02, 0.13]$) and by anxiety ($\beta = 0.09, SE = 0.04, 95\% \text{ CI } [0.02, 0.18]$), but not by illness acceptance ($\beta = 0.01, SE = 0.01, 95\% \text{ CI } [-0.02, 0.04]$). These indirect effects remained significant after controlling for a set of sociodemographic and personal variables found to be related to camp participation and CDPQoL (see Supplemental Material): perceived support: $\beta = 0.05, SE = 0.03, 95\% \text{ CI } [0.01, 0.10]$; anxiety: $\beta = 0.07, SE = 0.04, 95\% \text{ CI } [0.002, 0.144]$ (significant covariates on CDPQoL: perceived family income: $\beta = 0.13, SE = 0.09, 95\% \text{ CI } [0.008, 0.357]$, gender: $\beta = 0.13, SE = 0.15, 95\% \text{ CI } [0.031, 0.641]$).

To further elucidate the mechanism of camps' effects, a serial mediation model was examined, in which two mediators, friendship and perceived support, were hypothesized to form a chain of effects linking celiac camps to overall CDPQoL (Supplemental Figure 2). In this model, higher frequency of camp participation predicted higher overall CDPQoL, first through having more friends with CD, and then through perceiving more support, as indicated by a significant serial indirect effect: $\beta = 0.06, SE = 0.03, 95\% \text{ CI } [0.009, 0.123]$. The indirect effect remained significant even when controlling for covariates as in the previous model: $\beta = 0.06, SE = 0.03, 95\% \text{ CI } [0.01, 0.11]$

(significant covariates on CDPQoL: perceived family income: $\beta = 0.17, SE = 0.10, 95\% \text{ CI } [0.051, 0.440]$).

Finally, we examined alternative mediation models in which frequency of participation was the outcome variable, in order to account for the possibility that having friends with CD predicts camp participation through CDPQoL and/or support, acceptance, and anxiety. These alternative models yielded no significant indirect effects (see Supplemental Material).

Discussion

This retrospective study examined the relationship between participation in celiac camps and psychosocial outcomes among German youth with CD. We demonstrated the potential benefits of such camps in several psychosocial factors, using both disease-specific and general indicators. The findings overall support our hypotheses regarding the positive relationship between camping and psychosocial factors, although effect sizes were mostly small to medium. Specifically, we show that camp participation is positively associated with social and supportive domains of CD-QoL (Jordan et al., 2013). Campers showed better psychosocial adjustment than noncampers in perceptions and emotions associated with their condition that arise in social situations, so that they feel less embarrassed in restaurants or being a burden on others. Campers were also found to have lower feelings of alienation and perceived stigmatization, which may manifest in social avoidance or nervousness in social events. This finding is consistent with studies on recreational or therapeutic camps for children with chronic conditions, and add to the accumulated evidence that such activities are prone to have benefits for HR-QoL (e.g. Bongiovanni et al., 2010; Moola et al., 2014; Sendak et al., 2018). Moreover, our findings show the potential benefits of *recurring participation* in camps, in concordance with recent findings that returning participation in diabetes camp or participation in follow-up activities brought about yet more significant benefits (Barone et al., 2016).

Participation in celiac camps was related to having more friends with CD and to higher levels of perceived social support. These results are also consistent with research demonstrating that peer relationships and support are among the positive outcomes of illness-related camps (Bongiovanni et al., 2010; Meltzer et al., 2018). In fact, improving social support constitutes a core objective of interveners in the field, who design camps accordingly (Faith et al., 2019). Using path analysis on cross-sectional data, we found support for a serial mediation model, according to which camp attendance predicted having more friends with CD, which, in turn, predicted higher perceived social support, and which afterwards predicted higher CD-QoL. This may indicate that campers rely on socioemotional support through interactions with positive peers, which presumably extend beyond the camp setting, when friendships are formed and maintained. These results add to the growing evidence that peer support for youth with chronic conditions contributes to their psychosocial development (La Greca et al., 2002). The role of friendships in the social support mechanism is also in line with previous research indicating that young people with CD obtain meaningful support from peers with CD, who can relate to their experience better than non-CD friends (Bongiovanni et al., 2010; Darling, 2013).

In line with previous findings that leisure activities increase sense of belonging among children with illnesses (Meltzer et al., 2018; Schroeder and Mowen, 2014), and self-worth and social acceptance (Allsop et al., 2013; Meltzer et al., 2018), we found that camping was related to positive acceptance of CD as part of one's identity. The findings also revealed a negative relationship between celiac camps and CD-related anxiety, a construct rarely examined in the context of research on CD management. Our findings are consistent with several studies that observed anxiety reduction in illness-related camps (Moola et al., 2014; Simons et al., 2007), and demonstrate the potential long-term benefits of celiac camps in reducing anxieties that result from CD and its everyday management.

We did not find a significant correlation between camping and SWB. This finding is not

surprising, considering that SWB is affected by a multitude of psychological, sociocultural, and socioeconomic factors (e.g. D'Agostino et al., 2019), and that experiences related to CD may not be salient enough to improve overall SWB. Still, SWB was significantly and positively related to CD-QoL, social support, and illness acceptance, and negatively related to anxiety. Therefore, SWB may be still influenced by CD-related psychosocial experience. This is also in concordance with recent findings showing that recreational camps improve hopefulness, optimism, and purpose in life (Meltzer et al., 2018).

Finally, to our knowledge, this is the first study that examined the prospect for positive outcomes of celiac camps in a European context, where celiac camps have been carried out for decades. Using a valid measure of CD-QoL, we find evidence for the perceived burden of the disease among German youth, with overall lower average CD-QoL scores compared to previous results from the US (Jordan et al., 2013; Wolf et al., 2018), which may suggest a relatively low adaptation of youth with CD in Germany. Further research on cross-cultural differences in CD-QoL is required to better understand the common and unique challenges facing young people with CD across the world.

Limitations and directions for future research

Two main limitations of this study should be explicated and thoroughly considered when interpreting its results. First, we utilized a retrospective cross-sectional design that prohibits causal inference. It is possible that adolescents who are better adapted and are more interested in socializing with similar others, are also those who seek out camps. It is also possible, for example, that having friends with CD and positive experiences in leisure activities with similar others encourage adolescents to attend more camps. In this sense, we merely provided an increment to rigorous research on the psychosocial contributions of celiac camps. This limitation is particularly relevant for findings of mediation effects, in which we utilized statistical techniques to examine

processes among variables measured at one point of time. Although we could not find evidence for mediation effects in alternative models, mediation analysis can be informative in revealing causal mechanisms, to the extent that it is based on well-founded theory (MacKinnon et al., 2007). We view our findings as initial evidence for the potential of causal relationships that should be examined in intervention studies. It is particularly important to include equivalent comparison groups (e.g. registration waiting list), as randomized controlled trials are rarely feasible in the field (Moola et al., 2014). Moreover, research should examine the durability of possible positive outcomes using follow-up measurements. Finally, it is important to identify individual-level variables that may moderate the effect of camping on CD-QoL.

Second, the extent to which the sample was representative remains unknown. Due to our sampling method, it is likely that most participants were already engaged in CD-related networks and may have been more motivated to effectively cope with CD. High levels of self-reported GFD adherence in our sample may provide some evidence for that. Accordingly, the findings might be less applicable for youth with low adherence. In future studies, broader sampling strategies should be employed (e.g. recruiting participants through medical clinics).

Finally, the readers should interpret the results of our analysis with covariates with caution, since they were characterized by low variability and were often skewed.

Implications for practice

Despite those limitations and the limited scope of our research, we believe that the findings have important implications for improving HR-QoL among children and adolescents with CD. In line with increasing awareness of the benefits of psychosocial support in care for people with CD via self-help groups and peer models (Coburn et al., 2019), our findings should encourage healthcare professionals and caregivers to refer young people with CD to take part in recreational activities designed for their needs. This, of course, is

accompanied by an encouragement for CD societies to offer such activities for their members.

Intervenors may also benefit from integrating methods found to be effective in medical specialty camps, such as facilitated discussions aiming to increase self-efficacy and autonomy (Hill et al., 2015), or educating on the risks of nonadherence (Ludvigsson et al., 2016). Evidence-based techniques may increase the potential of celiac camps to produce valued and durable outcomes.

Finally, we recommend that intervenors create further opportunities for online and offline sustained relationships between campers, considering that lasting friendships are important for socioemotional support.

Acknowledgements

We thank the German Celiac Association (Deutsche Zöliakie Gesellschaft) for their assistant in recruiting participants for this study.

Author's contributions

MS: Conceptualization, formal analysis, investigation, methodology, resources, validation, writing – original draft.

LK: Conceptualization, investigation, project administration, resources.

MM: Conceptualization, project administration, resources

KB: Resources, supervision, writing – review and editing.

All authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article

Funding

The author(s) received no financial support for the research, authorship, and/or publication of this article.

ORCID iD

Maor Shani  <https://orcid.org/0000-0002-5301-5332>

Supplemental material

Supplemental material for this article is available online.

References

- Allsop J, Negley S and Sibthorp J (2013) Assessing the social effect of therapeutic recreation summer camp for adolescents with chronic illness. *Therapeutic Recreation Journal* 47(1): 35–46.
- Barone MTU, Vivolo MA and Madden PB (2016) Are diabetes camps effective? *Diabetes Research and Clinical Practice* 114: 15–22.
- Berndt TJ (1982) The features and effects of friendship in early adolescence. *Child Development* 53: 1447–1460.
- Bongiovanni TRS, Clark AL, Garnett EA, et al. (2010) Impact of gluten-free camp on quality of life of children and adolescents with celiac disease. *Pediatrics* 125(3): e525–e529.
- Catassi C and Lionetti E (2020) Celiac disease: A journey through time and space. In: Longhi S, Monteriù A, Freddi A, et al. (eds) *The First Outstanding 50 Years of "Università Politecnica Delle Marche"*. Berlin: Springer, 203–219.
- Coburn S, Rose M, Streisand R, et al. (2019) Psychological needs and services in a pediatric multidisciplinary celiac disease clinic. *Journal of Clinical Psychology in Medical Setting*. Epub ahead of print 31 October. DOI: 10.1007/s10880-019-09673-9.
- Coburn S, Rose M, Sady M, et al. (2020) Mental health disorders and psychosocial distress in pediatric celiac disease. *Journal of Pediatric Gastroenterology and Nutrition* 70(5): 608–614.
- D'Agostino A, Grilli G and Regoli A (2019) The determinants of subjective well-being of young adults in Europe. *Applied Research in Quality of Life* 14(1): 85–112.
- Darling AA (2013) *Exploring Factors of Non-Compliance for Adolescents with Celiac Disease*. St Paul: St. Catherine University. Available at: <https://sophia.stkate.edu/cgi/view-content.cgi?article=1168>.
- de Lorenzo CM, Xikota JC, Wayhs MC, et al. (2012) Evaluation of the quality of life of children with celiac disease and their parents: A case-control study. *Quality of Life Research* 21(1): 77–85.
- Eccles JS and Gootman JA (2002) *Community Programs to Promote Youth Development*. Washington, D.C.: National Academy Press.
- Faith MA, Mayes S, Pratt CD, et al. (2019) Improvements in hope and beliefs about illness following a summer camp for youth with chronic illnesses. *Journal of Pediatric Nursing* 44: 56–62.
- Fordyce MW (1988) A review of research on the happiness measures: A sixty second index of happiness and mental health. *Social Indicators Research* 20(4): 355–381.
- Gerking S and Khaddaria R (2012) Perceptions of health risk and smoking decisions of young people. *Health Economics* 21(7): 865–877.
- Grimm J (2009) State-trait-anxiety inventory nach spielberger. Deutsche lang-und kurzversion. *Methodenforum der Universität Wien: MF-Working Paper 2009/02*.
- Häuser W, Gold J, Stein J, et al. (2006) Health-related quality of life in adult coeliac disease in Germany: Results of a national survey. *European Journal of Gastroenterology & Hepatology* 18(7): 747–754.
- Hayes AF (2017) *Introduction to Mediation, Moderation, and Conditional Process Analysis: A Regression-Based Approach*. New York: Guilford Publications.
- Hill E, Gagnon R, Ramsing R, et al. (2015) Measuring the impact of a medical specialty camp: Using self-determination theory. *Therapeutic Recreation Journal* 49(4): 310.
- Hoffmann D (2002) *Attraktion Und Faszination Medien: Jugendliche Sozialisation Im Kontext von Modernisierung Und Individualisierung*. Münster: LIT Verlag Münster.
- Howard RA and Urquhart-Law G (2014) Psychological well-being of children and young people with coeliac disease. In: Martin C and Dovey T (eds) *Paediatric Gastrointestinal Disorders: A Psychosocial Perspective*. London, UK: Radcliffe Publishing, pp. 186–207.
- Hu L and Bentler PM (1999) Cutoff criteria for fit indexes in covariance structure analysis: Conventional criteria versus new alternatives. *Structural Equation Modeling: A Multidisciplinary Journal* 6(1): 1–55.
- Jordan NE, Li Y, Magrini D, et al. (2013) Development and validation of a celiac disease quality of life instrument for North American children. *Journal of Pediatric Gastroenterology and Nutrition* 57(4): 477–486.
- Karimi M and Brazier J (2016) Health, health-related quality of life, and quality of life: What is the difference? *Pharmacoconomics* 34(7): 645–649.
- La Greca AM, Bearman KJ and Moore H (2002) Peer relations of youth with pediatric conditions and health risks: Promoting social support and

- healthy lifestyles. *Journal of Developmental & Behavioral Pediatrics* 23(4): 271–280.
- Laass MW, Schmitz R, Uhlig HH, et al. (2015) The prevalence of celiac disease in children and adolescents in Germany: results from the KiGGS study. *Deutsches Ärzteblatt International* 112(33–34): 553.
- Liu X and Wang L (2019) Sample size planning for detecting mediation effects: A power analysis procedure considering uncertainty in effect size estimates. *Multivariate Behavioral Research* 54(6): 822–839.
- Ludvigsson JF, Agreus L, Ciacci C, et al. (2016) Transition from childhood to adulthood in coeliac disease : The Prague consensus report. *Gut* 65(8): 1242–1251.
- MacKinnon DP, Fairchild AJ and Fritz MS (2007) Mediation analysis. *Annual Review of Psychology* 58: 593–614.
- Mannell RC (2007) Leisure, health and well-being. *World Leisure Journal* 49(3): 114–128.
- Martéau TM and Bekker H (1992) The development of a six-item short-form of the state scale of the Spielberger State—Trait Anxiety Inventory (STA). *British Journal of Clinical Psychology* 31(3): 301–306.
- Meltzer LJ, Graham DM, Leija S, et al. (2018) Benefits of disease-specific summer camps: Results from quantitative and qualitative studies at Roundup River Ranch. *Children and Youth Services Review* 89(January): 272–280.
- Meyer S and Rosenblum S (2017) Activities, participation and quality of life concepts in children and adolescents with celiac disease: A scoping review. *Nutrients* 9(9): 1–15.
- Molenberghs G and Verbeke G (2005) *Models for Discrete Longitudinal Data*. Springer Series in Statistics. New York, NY: Springer Verlag.
- Moola FJ, Faulkner GEJ, White L, et al. (2014) The psychological and social impact of camp for children with chronic illnesses: A systematic review update. *Child: Care, Health and Development* 40(5): 615–631.
- Oris L, Rassart J, Prikken S, et al. (2016) Illness identity in adolescents and emerging adults with type 1 diabetes: Introducing the illness identity questionnaire. *Diabetes Care* 39(5): 757–763.
- Procidano ME and Heller K (1983) Measures of perceived social support from friends and from family: Three validation studies. *American Journal of Community Psychology* 11(1): 1–24.
- Rageliene T (2016) Links of adolescents identity development and relationship with peers: A systematic literature review. *Journal of the Canadian Academy of Child and Adolescent Psychiatry* 25(2): 97–105.
- Rose C and Howard R (2014) Living with celiac disease: a grounded theory study. *Journal of Human Nutrition and Dietetics* 27(1): 30–40.
- Sainsbury K, Mullan B and Sharpe L (2015) Predicting intention and behaviour following participation in a theory-based intervention to improve gluten free diet adherence in coeliac disease. *Psychology & Health* 30(9): 1063–1074.
- Schroeder RD and Mowen TJ (2014) ‘You can’t eat what?’ Managing the stigma of celiac disease. *Deviant Behavior* 35(6): 456–474.
- Sendak MD, Schilstra C, Tye E, et al. (2018) Positive youth development at camps for youth with chronic illness: A systematic review of the literature. *Journal of Youth Development* 13(1–2): 201–215.
- Simons LE, Blount RL, Campbell R, et al. (2007) Decreases in anxiety associated with participation in a camp for children with cardiac defects. *Cardiology in the Young* 17(6): 631–637.
- Singh P, Arora A, Strand TA, et al. (2018) Global prevalence of celiac disease: systematic review and meta-analysis. *Clinical Gastroenterology and Hepatology* 16(6): 823–836.
- Thurber CA, Scanlin MM, Scheuler L, et al. (2007) Youth development outcomes of the camp experience: Evidence for multidimensional growth. *Journal of Youth and Adolescence* 36(3): 241–254.
- Wolf RL, Lebwohl B, Lee AR, et al. (2018) Hypervigilance to a gluten—Free diet and decreased quality of life in teenagers and adults with celiac disease. *Digestive Diseases and Sciences*. Epub ahead of print 31 January. DOI: 10.1007/s10620-018-4936-4.
- Woolley K, Fishbach A and Wang R (2019) Food restriction and the experience of social isolation. *Journal of Personality and Social Psychology* 119(3): 1–37. DOI: 10.1037/pspi0000223.
- Zimet GD, Dahlem NW, Zimet SG, et al. (2010) The multidimensional scale of perceived social support the multidimensional scale of perceived social support. *Journal of Personality Assessment* 52(1): 37–41.