

Cycling is a lifestyle (if your food is with you): Celiac bicyclists experience's of cycling

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Abstract

Objective: The purpose of this study is to learn about the cycling experiences of celiac disease sufferers. **Method:** In this study, which employs a qualitative research design, in-depth interviews were conducted with five cyclists living in different cities throughout Turkey. The data obtained from the interviews were analyzed through the content analysis method. **Results:** The study's findings revealed that bicycling individuals have limited freedom due to difficulties in obtaining food and that routine medical examinations take time out of their lives. Meanwhile, it has been observed that they are ignored during bicycle tours due to the fact that they must bring their own food and that such tours do not provide food. They are socially isolated because they are unable to share food with others and have encountered difficulties while participating in cycling tours. Since the gluten-free diet is much more expensive than other foods and they receive no financial assistance, their spending must be restricted to basic necessities. **Conclusion:** In order for individuals with celiac disease to participate in cycling much more actively, arrangements should be made in social environments that meet the needs of this disease, and political regulations have a negative impact on active cycling.

Keywords: Celiac, bicyclist, gluten-free diet.

Introduction

Celiac is a systemic immune-mediated disease triggered by the consumption of gluten which is a protein complex found in wheat, rye, and barley for genetically prone individuals (Fasano & Catassi, 2012). 0.6 through 1.0 of the world population is affected by celiac (Biagi et al., 2010). The number of individuals affected by celiac disease in developing countries has been increasing due to wheat cultivation and changes in earthing process and awareness of the disease (Fasano & Catassi, 2012). Today the most plausible treatment for celiac is the adoption of a lifelong gluten-free diet (Cichewicz et al., 2019).

There exist a surplus of researches with a quantitative research approach bringing forward the difficulties experienced by adult celiac patients. However, it seems that there are few studies inviting celiac patients to express their experiences of gluten-free diet (Dowd et al., 2014; Foley, 2020; Houbre et al., 2018; Kaniyev, 2019; Rose & Howard, 2014; Sverker et al., 2005; Sverker et al., 2009). As for the celiac patients who exercise cycling, there is no qualitative study.

Nowadays, individuals prefer cycling in their daily lives for a variety of reasons. Among these include recreational purposes, transportation, sports, etc. Especially the working class leading urban life make separate planning for recreational activities and spare some time for such activities. Individuals widely prefer cycling for recreational purposes because it provides positive outcomes in terms of sustainability, energy efficiency, and public health (Pucher et al., 2010; Shaw et al., 2015; Titze et al., 2008; Tomlinson, 2003). Regarding cycling for transportation purposes in daily life, it makes the individuals affected from the health risk factors to a lesser degree (Huy et al., 2008). In this sense, it is possible to assert that individuals who rely on transportation by focusing on cycling, benefit from the elimination of the need for making separate plans for recreational purposes, cheap transportation, and protecting their health. Such benefits are critical for celiac cyclists who must adhere to a gluten-free diet for the rest of their lives, which is where this study began. We used the socio-ecological model (SEM) to investigate the experiences of celiac patients with regard to cycling, which they have incorporated for various purposes in their lives.

Socio - Ecological Model (SEM)

The use of SEM tackles multiple factors in the studies to determine the factors that have impacts on the physical activities of the individual and their involvement in sports, over the recent years (Dooris et al., 2007; Sallis et al., 2008). To make any behavior explicit, SEM (Golden et al., 2015), which depicts the dynamic relationship between the individual, social and environmental variables at different levels, will present a framework to find out the human experience of the bicyclists suffering celiac. Principally, SEM focuses on individual, interpersonal, organizational, community, and physical environment and policy factors (Berkes et al., 2008; McLeroy et al., 1988; Stokols, 1996). Such an approach is derived from the human development system, which is influenced by the individuals and organizations with whom the individuals interact, existing resources, and social

norms and rules (Golden et al., 2015). SEM, which was previously used to investigate human behaviors (Bronfenbrenner, 1979), has gradually been adopted to better understand the impact of the social and physical environment on the development and promotion of healthcare issues and physical activity policies in the following years (Giles-Corti & Donovan, 2002; Sallis et al., 1998; Stokols, 1996). The recommended dimensions for public health researches within the context of SEM perspective are the individual, community, environmental and political factors (Rayner & Lang, 2012; White et al., 2013). The individualistic factors are the factors that include demographic, psychological and behavioral characteristics. The process by which the attendants learned to live with celiac disease is included in this study to incorporate the individualistic characteristics. In the literature, environmental factors are also referred to as physical factors. It includes the availability of sports facilities, transportation difficulties, food served at the facilities, and environmental safety in terms of medical care. This study is particularly focused on the effects of the environmental conditions on the requirements for gluten-free nutrition due to celiac disease and accession to accurate food products. *Social factors* are the factors to include the effects of the social environment such as family and friends on the management of the individual suffering celiac disease. *Political factors* are the factors which include the policies and legislations at national level. The scope of this study includes bicycling festivals organized, planned, and conducted by institutions, political arrangements made in the celiac disease diagnosis process, and the sale of gluten-free foods.

The socio-ecological model (SEM) is used in the study scrutinizing the experiences of celiac children's parents (Neil, 2012) and in other studies analyzing the determinants of the nutritional behaviors of individuals suffering from distinct diseases that require specific diet (Caperon et al., 2019). Since celiac is a disease that requires a rarely known gluten-free diet, it is considered that the experiences of the bicyclists suffering celiac are of particular importance. In this context, this study aims to ascertain the cycling experiences of the cyclists suffering celiac and residing in different cities of Turkey for whom cycling serves different objectives, within the framework of SEM factors.

Methodology

The purpose of this study is to understand the experiences of bicyclists with celiac disease who incorporate cycling into their lives for various goals, as in the case of *Inci's lifestyle* using SEM. In this regard, we aimed to comprehend in-depth the interview with five adult individuals regarding the difference cycling made in their lives as a result of celiac disease, as well as how they placed cycling in their lives and interpreted the data analysis with the facts they had to face in their lives. Our research is based on an interpretative paradigm in which people with celiac disease assisted us in understanding the processes they have socially constructed in multiple settings in their lives through bicycling (Creswell, 2007). We used the qualitative research method to better understand

individuals' cycling experiences and collect detailed/rich data in line with the study's purpose and paradigms.

Participants

We defined the participants through the "criterion sampling method", one of the purposive sampling methods. Purposive sampling allows for studies with participants who meet a set of criteria that may fit the purposes and questions raised in the contents of the study (Patton, 2002). The criteria taken as the basis in defining the participants are: Active bicyclists all through their lives with a known diagnosis of celiac disease. We found participants by posting notices on community and association websites where cyclists are members. A total of five people volunteered to take part in this study. Synonyms for participantd were used to protect ethical procedure in the study. İnci, 33, is a sports specialist who was diagnosed with celiac disease five years ago. On the one hand, cycling is a way of life for İnci, but she also enjoys a variety of other physical activities. Kaan, 24, is a public employee who was diagnosed with celiac disease about ten years ago. Kaan is a motorcyclist as well as a bicyclist. Levent, a 34-year-old engineer, was diagnosed with celiac disease 2.5 years ago. Cycling is a passion for him that he cannot give up. Sedat, 46, is a computer programmer who was diagnosed with celiac disease 1.5 years ago. Cycling is a means of transport for him. Banu is a 36-year-old private company employee who was diagnosed with celiac disease three years ago. Cycling is a mode of transportation for her.

Data Sources

Since the participants are allowed to depict and express their previous and the most recent experiences, emotions, and opinions through their wordings (Patton, 2002), we have constructed the main data of the study through the semi-structured individual interview method. Individual interviews were conducted by the first author of this article, who is not only an academic in the field of sports management and recreation, but also an avid bicyclist.

From October to December 2020, we collected data for the study. One of the interviews was conducted at home, while the other four were digitally recorded in videos. We obtained the participants' permission to record the interviews. Individual interviews were completed in 30 to 45 minutes.

Data Analysis

We analyzed the data through the deductive content analysis method (Patton, 2002). We decrypted the video recordings after their transfer into the digital environment. We, the two researchers, read the texts line by line and made use of the open coding method after which we drew up a list of codes. When theming the codes in a meaningful manner, we defined the organizational framework of the study (SEM) and the themes in line with the data collected (Patton, 2002).

Trustworthiness

The qualitative researchers aim at enhancing the quality of the research by designing and using the methodological strategies to maintain the "credibility" of the findings (Noble & Smith, 2015). In this study, we made every effort to increase the quality of the research by employing Tracy's (2010) credibility strategies. These include the intensive and detailed depiction in the presentation of the findings, long-lasting interaction with the participants, and presentation of detailed information about the participants. In the meantime, the review and coding process of the data were conducted independently within the scope of the diversification of the researchers (Patton, 2002).

Findings

Within the framework of SEM, the factors that are thought to have an impact on bicyclists' experiences with celiac disease are reviewed in four categories: Individual, social, environmental and political factors. Each factor is discussed in the context in which it is relevant.

Individual Factors

Cycling gives (un)freedom

As one of the physical activities, cycling which is considered to be an activity in leisure times, is defined to be a "lifestyle" for some participants (İnci, Kaan) who explicitly stated that cycling makes one feel happy and free. "Many things can be said", İnci says, "including freedom, affordability, economy, pleasure, happiness, and so on". "Wind blows on my face, which is something extraordinary", Banu says.

It was notable that participants who placed a strong emphasis on the relationship between nutrition and healthy cycling used the metaphor of "fuel" whenever they mentioned the need for food. Levent says "I can do whatever I want as long as I have food. I have issues when I run out of fuel". "Our fuel while riding bicycle is food, water... When you don't have access to high-quality fuel, your performance suffers. This case has a direct impact on it", İnci says. It can be concluded that cycling may be harmed by a lack of immediate access to healthy foods for celiac disease, which necessitates a gluten-free diet. Cycling, which makes one feel content and free, may turn into captivity for bicyclists with celiac disease who have a problem supplying food while cycling.

Routine medical examinations - Obtain information from social media

Patients with celiac disease must have regular check-ups as part of their routine. On the path to becoming acquainted with the gluten-free diet, the patient is given the steering wheel in order to gain control of celiac disease. İnci claims "You are referred to a dietician after being diagnosed. The dietician provides detailed information, beginning with what you should not consume and progressing to what you should consume, as well as alternatives to the prohibited aliments". Although care is taken to ensure that nutrients strictly adhere to the diet's requirements, the only

way to understand any gluten exposure in foods is through regular check-ups. According to Sedat *"I go to the doctor twice a year. They conduct celiac disease tests and determine whether the results are negative or positive"*. Aside from routine check-ups, social media and the information channels of the relevant associations are monitored to ensure that the most recent information is available. According to İnci *"I keep up with several associations via their social media accounts. As a result, I have instant access to the most recent data". "I search the net for the pages of doctors and hospitals, as well as articles"*, Sedat says. It could be argued that the desire to learn the most up-to-date information about the disease is one of the components of the process of learning to live with celiac disease, along with medical examinations. The assertion made by İnci that *"The Life With Celiac Association has a Facebook page. I saw the beer analysis there. I discovered that I could consume a number of beers. I was taken aback, but this made me extremely happy"*, highlights the fact that the respective associations are deemed to be information channels.

Environmental Factors

Outdoors, nutrition is a torment

It appears that the process of learning to live with celiac disease begins with changing nutritional habits after diagnosis. İnci stated that the experience of gluten-free cuisine at home is an essential part of the preparations for the new life: *"I re-established my kitchen, which turned out to be gluten-free. I provided gluten-free menu options to the guests"*. Sedat emphasizes the importance of diet, saying *"We altered the way we consume food. What matters is the diet"*.

Because working people spend the majority of their time outside, it can be argued that daily nutrition is to a large extent obtained outside. This may be difficult for a celiac patient who must follow a gluten-free diet. Levent's assertion that *"You go out, and when you go to a cafe, you are unable to eat anything. Everyone is staring at you, and they don't want to eat before you"*, demonstrates that a scarcity of outdoor options may become a long-term problem. İnci expresses her fear of any gluten symbol on a packaged market product, which is one of the alternatives for celiac sufferers outdoors, with the phrase that *"«It may contain gluten» it is written on the food packages. It does not say «It contains» but «It may contain» which causes confusion"*. Inadequacies and lack of confidence in alternative gluten-free food options at cafes and restaurants make celiac patients reliant on the foods they prepare. Diets become significantly more difficult when there is limited freedom to eat outside. Tuba says *"You must choose each and every food that you will eat. This is a problem. I'm wondering if I have it if it will cause stomach aches or other problems. I'm not sure, but I'm worried. I prefer to eat and drink in tranquility"*.

The traditionalization of bringing food close at hand has proven to be the only way to deal with the problems that arise from eating outdoors as a cyclist with celiac disease. Kaan and Levent put emphasis on long lasting cycling tours. *"When I go on long term tours, there are always gluten-free foods on a corner of my bag, such as bread, pasta, and so on"*, Kaan says. Levent asks *"What do we*

normally do when we go on a long bike tour? You go somewhere and eat something after cycling 30-40 meters. This is where the problem begins. You should bring loaves of bread, figs, dates, or something similar. This is something I try to do".

Being ignored during cycling festivals

When participating in cycling festivals, which are characterized as a recreational activity with daily cycling activity and accommodation organizations overseen by cycling communities and associations, the issue of aliment comes to the fore. İnci and Levent, who were involved in such organizations, stated that they were unable to place themselves in the catering services provided as part of the organized activities. *"I have attended several organizations, and I have also participated in day trips, whether long or short distance", İnci says "I don't have any problems on day trips because I can bring my daily aliment with me. However, for multi-day tours, I should make an extra effort in terms of planning and budgeting."* Levent claims *"In the festivals, there are pre-determined routes. People go out to eat for lunch. What are you having for lunch? In most cases, it is the sandwich. Under such circumstances, there we face problems".*

When leaving the house, the difficulties in obtaining food are evident, particularly in terms of emotions, economics, and time management (time to elapse for making nutritional plans). Similar problems emerge during cycling festivals, such as patients with celiac disease being ignored, particularly when it comes to catering services. This prevents cyclists with celiac disease from getting the same level of satisfaction from their leisure activities.

Social Factors

Feeling isolated within an environment

It has been observed that the difficulties encountered while adhering to a gluten-free diet bring together psychological challenges that have implications for social relationships. When it comes to eating and drinking with others, it is unavoidable to feel alienated from the environment. *"We went to a place with the cycling group", Banu says "Everyone was eating Turkish bagels somewhere. I brought some items with me. They were trying to persuade me to eat. You are unable to eat and thus feel isolated".* The fact that others are unaware of celiac disease causes distress in addition to the feeling of isolation in a social setting. According to İnci *"When I go to see someone, I am frequently asked, «What are we going to offer you?» I sometimes bring own food. If the hosts are unmoved or encounter such a situation for the first time, they may be offended".* The most important factor in overcoming such problems is for individuals to gain sufficient knowledge about the disease and act accordingly.

Feeling of "someone making life difficult for others"

The inclusion of any celiac disease patient in any social setting may limit the options for catering activities for the others. This puts a strain on the celiac patient's emotions. İnci claims that *"I am*

thinking that I'm bothering the others. This could refer to my dietary preferences, as well as the places I intend to visit. This isn't just a personal issue for me. People around me should be mindful of this. This exhausts me psychologically, and I believe it exhausts those around me as well".

Family as supporting network

While the requirement for gluten-free nutrition has negative reflections on the social relations, family as a supporting network is an important gain for a celiac patient. Banu says *"My husband and children conceded superbly. And whenever I want to eat something, the way they warn me saying that «do not eat this, it is not good for you mom, do not eat it. Well, we will not have it»"*, put emphasis on the support to be provided by the family. İnci claims that social environment may sometimes be challenging adding that *"They argue that whether or not I enjoy their meals and they ask me «Why don't you eat? Nothing happens if you eat this. You will not die»."* Kaan, on the other hand, claims *"My family was the most supportive. I am thankful"*. This draws attention to the fact that the family is crucial in improving the adverse conditions due to disease in daily life.

Political Factors

Insufficient State Funds

It is a complicated process because such products are not only scarce but also expensive. *"Things we buy are too expensive. That is to say, they are three times more expensive than ordinary people's products. Some are even four times the price of comparable products"*, says Sedat. According to Levent, *"The products are not cheap. A kilogram of flour costs TRY 24 or TRY 25"*. The level of income is expected to be a determinant of nutritional trends. State assistance is critical for celiac disease patients. Kaan expresses his dissatisfaction with the state, claiming that the government's support for nutrition is insufficient *"I think our country, our state does not have enough respect for us. TRY 108 is given once a month. Today's price of pasta is TRY 25"*. It appears unlikely that a celiac patient on a low income cannot live a fulfilling life.

Long diagnosis process / mistreatment methods

When discussing medical experiences, the participants all emphasize the lengthy diagnosis process and methods of mistreatment. Because of the longer diagnosis periods, the time elapsed between diagnosis and accurate treatment is working against the patient: *"I visited the hospital for three years. They were unable to identify the disease. They told me I had an ulcer, gastritis, and reflux"*, Sedat says. *"I had iron deficiency after I was 17 years old, and I took pills from time to time. I was 28 years old when I was diagnosed"*, İnci says. It is possible to argue that the time elapsed between accurate diagnoses is extremely difficult for celiac patients. The long diagnosis period, combined with the mistreatments, causes patients to live a life that is far from healthy, both mentally and physically.

Following a diagnosis, the accompanying diseases appear as complicated medical experiences. *"I have two diseases"*, İnci says, referring to the difficult problems that arise as a result of the other diseases that accompany celiac disease. *"Thyroid and celiac disease. Thyroid glands, in particular, should be checked on a regular basis. It has an immediate and direct effect. I become exhausted if I am unable to take the pills for a few days"*. Kaan emphasizes the fact that he suffers from the negative effects of diabetes more than celiac disease while riding by stating that *"Celiac does not affect much; diabetes affects more. My blood sugar levels occasionally fall"*.

Discussion and conclusion

The purpose of this study is to evaluate the cycling experiences of bicyclists with celiac disease within the context of SEM factors. The study's findings show that bicyclists with celiac disease experienced their survival with celiac disease accompanied by challenges/struggles that have repercussions on their lives and cannot be ignored in addition to their cycling experience within the SEM (individual, social, environmental, and political) categories in their entirety. Under this caption, the sub-themes representing each of the SEM factors are discussed separately from cycling experience.

Regular medical examinations and information acquisition from relevant associations via social media are among the individual factors that have an impact on the life experiences of celiac disease patients. Patients with celiac disease can be informed of their level of exposure to gluten traces in foods thanks to medical examinations. In terms of social media and related associations, they have access to the most up-to-date information on celiac disease and safe food products. The information obtained may be explained using stimulation to compensate for the failures of medical personnel (dietician, physician, etc.) to provide adequate information (Houbre et al., 2018; Rose & Howard, 2014).

The difficulties in a gluten-free diet appear to be the root of the fundamental problems that have an impact on the daily lives of celiac disease patients. Concerning their experiences under the heading of environmental factors, it is possible to assert that the challenges observed in nutrition outside the home stand out. The kitchen is set up in such a way that gluten-free products are preferred. However, daily lives are significantly led outside the home, and the difficulties encountered in supplying gluten-free food outside are critical for the individual with celiac disease, who challenges and makes such individual unhappy on occasion. It combines constant alertness for being conscious of the food consumed on a daily basis (Sverker et al., 2005) and the need to create a nutritional plan (Houbre et al., 2018). Long-term travel away from home exhibits a similar pattern (Foley, 2020).

The feeling of being isolated from other people, giving the image of a person making life difficult for others, and the support of the family are the social factors affecting the daily routines of celiac disease patients. The difficulties of a gluten-free diet are exacerbated by feelings of isolation in

social settings due to not consuming any foodstuff (Houbre et al., 2018; Sverker et al., 2005), a lack of understanding or an exaggerated understanding of the other individuals to arrange in the way they consume foods. Concerns about being perceived as a person who is constantly bothering family members or friends (Sverker et al., 2005; 2009) never get the tails off celiac patients. As time passes, all of these processes pave the way for celiac disease to become a social disease (Bacigalupe & Plocha, 2015; Schroeder & Mowen, 2014). Although some family members have been observed to act in such a way that they refuse to acknowledge the disease at times (Houbre et al., 2018), it can be concluded from this study that the participants regard their families as a supportive network, similar to the research conducted by Foley (2020).

The celiac patients' experience within the context of political factors includes a lack of government funds and a lengthy diagnosis period with incorrect treatment methods. Celiac patients expect the government to consider taking a much more realistic approach to improving the negative conditions they face on a daily basis (Foley, 2020; Houbre et al., 2018). Long period of diagnosis and mistreatment until the diagnosis is cliché. The diagnostic ambiguities for celiac disease cause the celiac patient to live with an unnamed disease for a few months or even years (Houbre et al., 2018). Patients with celiac disease must spend most of their time and energy moving to and from the hospital.

The individual factor affecting the cycling experience of celiac cyclists is the "freedom coming by bicycle", which changes depending on whether there is food in the saddle of the bicycle. Even though each individual's interpretation of the bicycle differs, it represents "*Freedom*" (İnci) and "*Happiness*" (Banu). Others (Kaan) see it as "*A way of life*". If food is a problem, any celiac patient who feels happy and free on the bike will be interrupted by such feelings. Bringing food has become a traditional measure to overcome the problem of nutrition during long-distance travel. However, the difficulties associated with the limited variety of gluten-free foods that can be brought with the patient (Zarkadas et al., 2013) limit the freedom. When a celiac bicyclist says, "*When cycling, I'd like to wear only my sports gear and not bring anything with me*", problems arise (Levent).

The most important environmental factor affecting celiac patients' cycling experiences make it clear that they are ignored during cycling festivals. The festivals, which are mostly organized by cycling communities and associations, are recreational organizations that include camping and cycling tours over a couple of days.

The relevant community/association meets the participants' standard needs (accommodation, food, shower, etc.) in such activities organized for bicyclists with priorities of meeting with nature and socialization. Applications for participation in such festivals, in which the first author of this study frequently participated, are usually found to be admissible months before the activity, and plans for such activities are thus produced (Preparations for the bicyclist gears to fit the sizes of the participant, defining the routes and camping areas, sponsorship agreements, etc.). However, it is notable that most tours exclude celiac patients when making food arrangements. Celiac

patients who feel isolated and socially invisible in their lives outside of the home due to limited food options (Rose & Howard, 2014) cannot evade similar feelings in such tours in which they participate. This means that celiac patients are unable to participate in long-distance tours as well as other activities (Schroeder & Mowen, 2014). Despite these obstacles, celiac patients who choose to participate in these activities will not be satisfied because such organizations are physically demanding and they will be deprived of their daily meals.

It can be concluded that a variety of factors influence the experiences of cyclists with celiac disease, both during cycling and in their daily lives. We can assert that such factors moulded within the framework of a socio-ecological model develop perspectives that reflect individuals' experiences.

Recommendations

The transformation of celiac disease, which includes a lifelong gluten-free diet, into a social disease in a short period of time, represents an indicator to raise awareness, particularly among food producers. The Ministry of Health should undertake studies to raise awareness among restaurant and cafe owners about the importance of accurate information. Furthermore, the Ministry of Health should organize in-service training for health workers to reduce the time it takes to diagnose celiac disease. The government funds set aside for celiac disease patients should be adjusted to reflect current food prices.

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