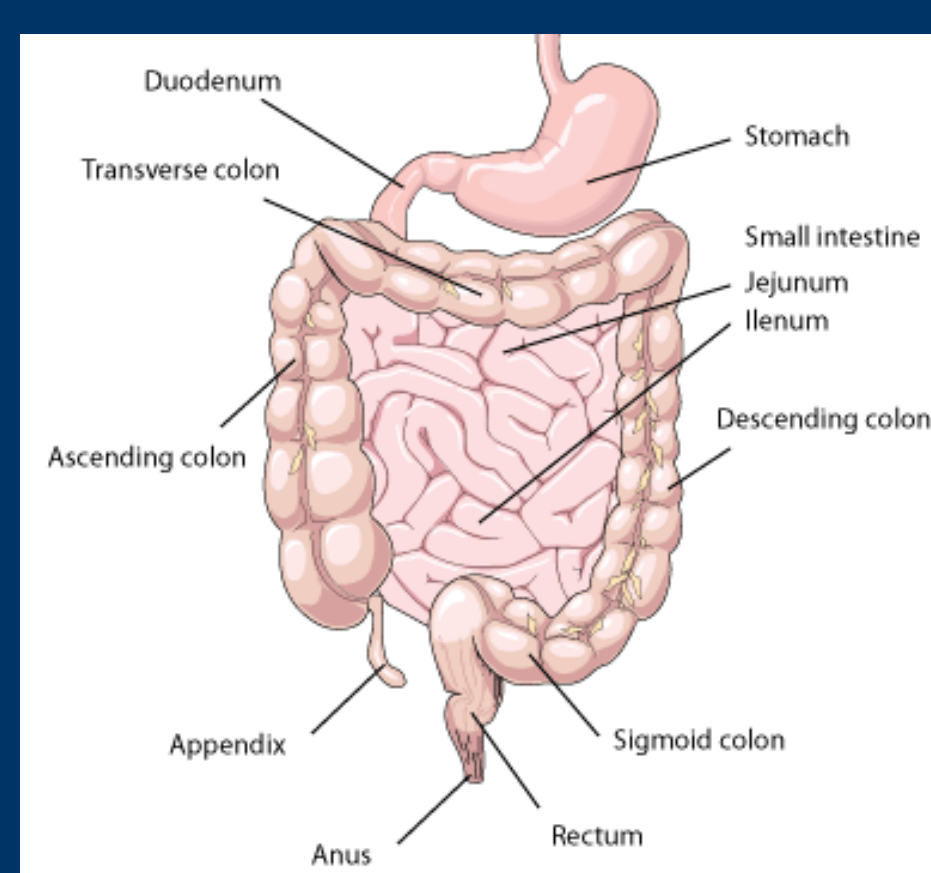


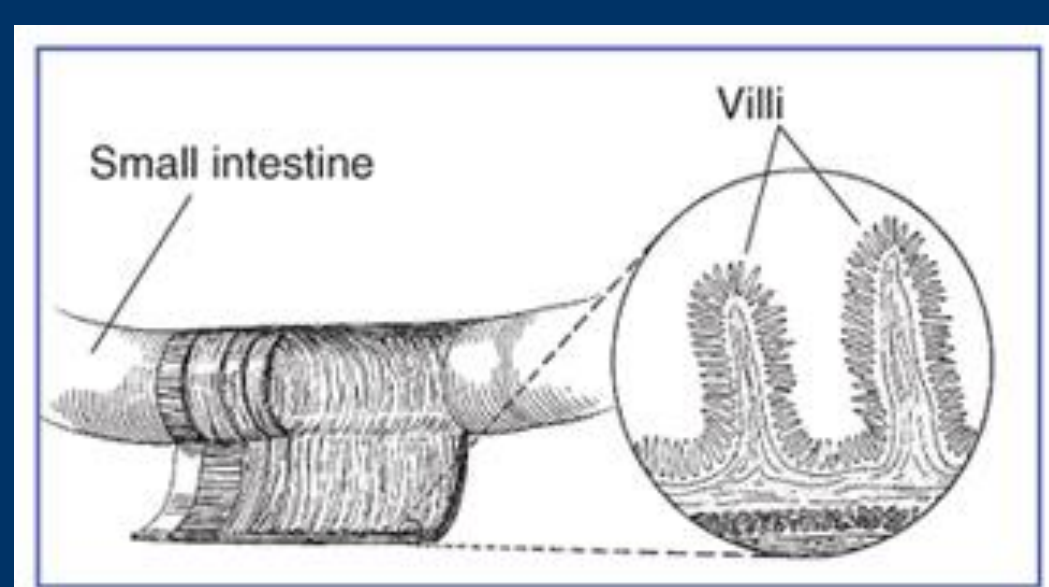


ABSTRACT

This study investigated the experiences of adults living with celiac disease (CD) – an autoimmune disorder of the digestive system. There is no cure and the only treatment is a lifelong gluten-free diet. Research shows that individuals with CD may face significant challenges in their daily lives. The framework of resilience has been used to understand coping mechanisms in chronic illnesses. Using this framework, semi-structured interviews were conducted with 14 adults with CD on Vancouver Island. The questions were designed to uncover positive or negative experiences, ways of coping, and resilience. The results showed that participants experienced challenges both physical and psychological. They were able to identify resources and behaviours that facilitated successful coping.



The digestive system



The lining of the small intestine

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INTRODUCTION

Research shows that a diagnosis of CD can be challenging for some individuals (Carrie & Chan, 2008), while in other cases facing a chronic illness could initiate a resilient response (Kralik et al., 2006). The psychological layers of this illness are complex because the only treatment for CD is a life-long gluten free diet (Braly & Hoggan, 2002), which requires the avoidance of one of the most popular grains used in North America today – wheat flour. While some may find relief in eating a gluten-free diet because of symptom reduction, others may resent the diet if they find it difficult.

The framework of resilience has been used to identify how individuals cope with long-term illnesses such as type-1 diabetes and chronic pain. Resilience can be defined as the ability to overcome significant adversity (Luthar et al., 2000). Persons with CD learn to adapt on a daily basis when adhering to a gluten-free diet. This may create stress in many situations where food is involved. Sharing food is a social act and deviating from the norm can cause stress and anxiety. The goal of this study is to learn how people with CD cope with any challenges they face. Understanding CD from the perspective of resilience has not been investigated until now. Through this research, insight was gained about how these individuals are coping, which provides direction for future research regarding how to promote successful coping in those who may be struggling.

METHODS AND MEASURES

Fourteen (n=14) adults with a diagnosis of celiac disease participated in this study. The participants were recruited by an ad in the Victoria Celiac newsletter and through posters placed in health food stores at locations on Vancouver Island.

A semi-structured qualitative interview was the method used to investigate the experiences of the participants. The interview questions were pilot tested and designed in collaboration with the Resilience Research Lab members at Vancouver Island University.

The interviews were transcribed verbatim and a content analysis was conducted by the primary investigator and two research assistants to examine themes in responses across questions.

RESULTS

How were your interactions with your physicians?

Half of the participants reported positive experiences and the other half reported negative experiences. On the positive side, the physicians were proactive, supportive, and took the symptoms seriously. On the negative side, some doctors disregarded the symptoms, ordered the wrong tests, or treated the symptoms and not the cause.

How has celiac disease impacted your life?

The positive impacts included feeling better physically, knowing how to stay healthy, and making new friends through the celiac association. The negative impacts were described as difficulty going to restaurants, which limited social interactions, increased anxiety when food preparation was not in their control, and the financial cost of the gluten-free diet.

"It's quite a radical change because it's not like something you can put on the back burner, you think about food, I mean 3 or 4 times a day, it affects every meal...it affects every time you go out to eat...and you eat at a friend's house or a restaurant so...you can never really forget that you've got celiac disease"

Have you had positive or negative experiences?

Positive experiences occurred when friends and restaurants were very accommodating. Negative experiences included being given gluten by mistake, travelling, business lunches, and difficulty finding gluten-free foods.

If you have been faced with a major challenge, how did you overcome it?

Participants managed challenges by carrying food when travelling or going out, educating themselves about CD, minimizing stress, phoning restaurants in advance, and food networking with others who have CD.

If you know of anyone who has faced a major health challenge would you call that person resilient?

Characteristics of resilience were described as having a positive attitude, accepting the situation, surrounding oneself with good people, persevering, and taking ownership of the illness.

"You take control of it...you control the disease, the disease doesn't control you"

DISCUSSION

The present study has a few limitations such as sample size and volunteer bias.

Firstly, the sample size in this study is small; therefore, the results cannot be accurately generalized to all persons living with CD. The data does reveal some consistent responses across participants, but overall the findings are still limited in terms of external validity.

Secondly, there is a possibility of volunteer bias. According to Palys (2003) individuals who "volunteer" to participate in research may be different from those who do not. Volunteers may have a stronger passion for raising awareness about CD, and or they currently are advocating for the disease in the community. Therefore, their responses may be different from those who are not active in the community.

CONCLUSIONS

This study explored the subjective experiences of adults living with CD. The challenges described are consistent with a previous study in Sweden in which 43 adults with CD were interviewed; their findings revealed challenges with food situations at work, travelling, meals at home, and meals with others outside the home (Sverker et al., 2005). Future research should address the under-diagnosis of this disease by educating physicians about CD to increase early intervention. In addition, research should address psychological supports and resources for persons with CD.

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