

Experiences of coeliac disease and the gluten free diet: Feelings, motivations, and weight changes

Introduction

A previously common conception about coeliac disease was that patients were typically underweight at diagnosis, with weight loss resulting from gastrointestinal distress and malabsorption being a common presentation. Consequently, weight gain after diagnosis has been viewed as a positive outcome indicative of a restoration to health.

Although individuals with coeliac disease do have a lower BMI at diagnosis compared to the general population, it is now widely accepted that the vast majority of patients are of normal weight and a large minority are overweight at diagnosis.

Further, despite anecdotal evidence that weight changes (both loss and gain) are common after diagnosis with coeliac disease, and many individuals with the condition struggle to manage their weight while also maintaining a strict GFD, very little research has been conducted on this topic.

One aim of this study is to assess the prevalence of both weight loss and weight gain experiences following the initiation of a GFD and to determine the factors that patients themselves attribute weight changes to, as well as to assess the nature and extent of the relationship of such weight changes and attributions with a range of relevant variables including current weight loss intentions, body image, and the methods and barriers to successful weight loss in this population.

Who can take part?

Inclusion criteria for the study are:

- must be aged ≥ 18 years
- have received a biopsy confirmed diagnosis of coeliac disease

We kindly ask that people do not complete the survey on behalf of somebody else with coeliac disease (eg a child or other family member).

What is involved?

The study consists of an online survey that should take about 25 minutes to complete. We will ask you questions about your experiences of being diagnosed with coeliac disease and following a GFD, any symptoms you may be experiencing, your motivations for following a GFD, and what sometimes makes it hard.

We are also interested in any weight changes you may have experienced after starting a GFD, how you felt about those changes and your body, whether you are currently trying to lose weight, and if so, what you are doing, and what sometimes makes it hard.

We'll also ask for some information about you (eg your age, gender and where you live). All information collected is anonymous (we do not need your name) and we will not share the data with anybody outside of the core research team.

How to take part

If you are interested in taking part in the study, please follow this link:
http://nclpsych.eu.qualtrics.com/jfe/form/SV_1MLbQYMLHYU1JDD.

If you would like more information about the study either prior to or after completing the survey, please contact Dr Kirby Sainsbury
(Kirby.sainsbury@newcastle.ac.uk).

Please note that by making contact and showing an interest you are not obliged to take part in the study.

This is a study by Newcastle University and has been approved by the Newcastle University Medical Sciences Faculty ethics committee. The study has not received any funding.

Sandro Voi and Elizabeth Hogg are studying for a MSc degree in Foundations in Clinical and Health Psychology. Sally Tulip is studying for a MSc degree in Foundations in Clinical and Forensic Psychology. This research will form part of their dissertations, each of which has a different research question (1. the relationship between motivation, psychological resources, and adherence to a GFD and weight loss plans; 2. the relationship between weight changes at diagnosis and subsequent weight loss intentions, methods, and experienced barriers to weight loss in coeliac disease; 3. the relationship between weight changes at diagnosis, GI symptoms, anxiety, and body image in coeliac disease).