

Understanding Perceived Barriers to the Disclosure of Psychological Difficulties by Young People with Coeliac Disease

Introduction

Being diagnosed with coeliac disease means that you can no longer consume things containing gluten, such as bread or cake or you can become very ill. This can make situations involving food challenging, such as social situations or lunch at school. We know that being diagnosed with coeliac disease as a teenager can be particularly upsetting and can lead to problems such as anxiety or low mood. Research suggests that when young people are worried about the impact of their condition on their life, they can find it challenging to tell their doctor or ask for support. We would like to understand the experiences of young people with coeliac disease who attend the Paediatric Gastroenterology service at the Oxford Children's Hospital. We are particularly interested in the reasons why young people either feel able or unable to tell their doctor that they are experiencing difficulties relating to their wellbeing during their appointments, in order to improve support for young people. This study aims to recruit young people between the ages of 11 and 16, who are attending secondary school, to ask them about the things that make it easier or more difficult to share any concerns about their wellbeing with their doctor.

Who can take part?

If you would like to take part in the study you must:

- Have been under the care of the Paediatric Gastroenterology service at the Oxford Children's Hospital for at least 3 months and have had at least 1 follow-up appointment;
- Be between 11-16 years old;
- Have a medical diagnosis of coeliac disease, and no other diagnosed gastro-intestinal conditions;
- Be in years 7 – 12 at school;
- Be able to speak fluent English;
- Not be currently receiving psychological support from any psychological service.

What is involved?

Taking part would involve talking to me over a video-call about what it is like to have coeliac disease. This may take up to 90 minutes. I will also talk about your experience of speaking to doctors about how having coeliac disease makes you feel. Whatever you say will be kept private and your name won't be used. You would receive £5 for your time. Taking part is up to you and whatever you decide won't affect your care at the hospital.

How to take part

If you are interested in taking part in the study, or would like more information, please contact Miranda Wheeler on 07469432868, or via email at Miranda.Wheeler@hmc.ox.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 the University of Oxford and has been approved by the Health Research Authority and Health and Care Research Wales (HCRW) Approval Research Ethics Committee. The study is funded by the Oxford Institute of Clinical Psychology Training and Research.

Miranda is studying for a doctoral degree in clinical psychology. This research will form part of Miranda's dissertation.