

Title: Psychological resources to meet the needs of children and young people with coeliac disease

Summary:

Today, the term “gluten free” is common in our lives, with most large supermarkets and restaurants stocking gluten free foods. Because of this, many people believe the gluten free diet must be simple to follow. It is not. People with coeliac disease must think about crumbs, the way food is cooked, and the damage that can be triggered by tiny exposures to gluten. Imagine being a child at a friends’ party wondering what the birthday cake tastes like, as you eat your gluten free biscuit. Imagine having to tell your friends why you are eating that biscuit. Now imagine that child’s parent, who is worried their child might be pressured into eating the cake anyway, or concerned their child might get contaminated by gluten. The psychological and social effects of these situations are significant and can have long-lasting effects.

Many children and young people struggle with the psychological and social impact of coeliac disease. Although official guidelines ensure that advice and information around the gluten free diet is provided to families living with coeliac disease, currently there are no tools or resources to support their psychological wellbeing and adjustment to the gluten free diet.

This project will adapt existing psychological resources that are used in other health conditions, for families living with coeliac disease. We will work with families and NHS clinicians to adapt these resources for families with coeliac disease, and then invite 50 families to test these resources. This will give us enough information to see whether these psychological resources are useful to families with coeliac disease. Before providing these resources to all families with coeliac disease, we need to know that they are effective at improving psychological wellbeing and supporting effective management of the gluten free diet. The information from this project, will help us to fund a further study that can help us answer these questions.

Title: Characterising the Risk Factors, Presenting Symptoms and Incidence of Coeliac Disease in Children

Summary:

Autoimmune conditions are a type of long-term illness that involve the body's defence or immune system mistakenly attacking the body's healthy tissues, which can cause a variety of short- and long-term health problems. These conditions are relatively rare, but the earlier we detect them and start treatment, the better the outcomes for patients. Coeliac disease is one type of autoimmune condition which causes a variety of problems in the body, mainly in the gut, in response to gluten—a protein commonly found in wheat and other grains.

The symptoms of coeliac disease can be very general and can include stomach pain, bloating, tiredness, and poor growth. In some cases, symptoms can be very mild or present for a long time before they are noticed or before coeliac disease is identified. When these conditions begin, often during childhood, it can often be hard for General Practitioners (GPs) to know if the symptoms children have are because of a more common illness with similar symptoms or from coeliac disease. This can lead to a delay in ordering the tests needed to detect the condition and delay the start of treatment—the mainstay of which is a diet avoiding gluten. Late diagnoses mean people live with symptoms for longer and may spend more time in the hospital or have worse health outcomes in the long-term because of the prolonged inflammation and damage to the body.

One way to help GPs diagnose conditions as early as possible is with risk prediction tools. These tools put multiple pieces of information together to say which patients are at low risk and which are at high risk of a specific illness. Using a tool like this, when a GP sees a child with a general complaint like feeling tired, but with a high risk of coeliac disease, the GP would decide to check for coeliac disease early, but a similar child at low risk who also feels tired would not need the same blood work or tests. In this study, we are going to compare the data from millions of patients to identify the symptoms and risk factors that are candidates for use in creating a risk prediction tool for coeliac disease.

Title: Establishing the prevalence of coeliac disease in a paediatric neurology cohort who present to a tertiary centre with unexplained ataxia or peripheral neuropathy.

Summary:

Coeliac disease is a condition where the body recognises the protein gluten found in wheat, barley, rye and oats, which then causes an auto-immune response. This response can cause damage to the lining of the intestine or other tissues such as the skin or nerves.

There are classical signs of coeliac disease in children that often present as diarrhoea, weight loss and tiredness which can relate to low levels of nutrients such as iron and calcium. Scientific studies have proven that coeliac disease can present in adults who might not have these classical symptoms but may present with neurological damage. These neurological symptoms might include headache, anxiety, depression and movement or coordination difficulties.

There are very few scientific studies looking at whether children also may present with these symptoms. Often these neurological symptoms can worsen over time, so early diagnosis of coeliac disease or gluten neuropathy in children may be important to prevent the damage to the nerves that might be difficult to repair after many years.

Our study will be aiming to do an extra blood test to screen for coeliac disease for the children who are referred to the neurology doctors at our tertiary centre. This blood test will include checking for the antibodies to gluten called tTG.

The patients that we will include will have unexplained symptoms of balance, speech or coordination difficulties (ataxia) or numbness, pain or weakness in the hands or feet (peripheral neuropathy). By screening these children, we will see a snapshot of how many children who present to the neurology doctors with these symptoms may actually have coeliac disease or gluten neuropathy. If we find any children who do test positive, then we can send them for further investigation, follow-up and treatment with the gluten free diet if needed.

The authors of the study hope this will help raise awareness of the need to screen children with neurological symptoms for coeliac disease.