



Exploring psychosocial factors that contribute to adherence to a gluten-free diet (GFD) in individuals diagnosed with coeliac disease.

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Psychology Empirical Project

University of Wales Trinity Saint David

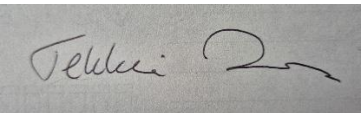
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Declarations

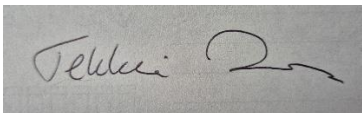
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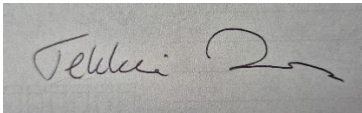
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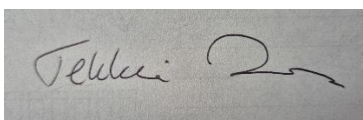
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AI acknowledgement

I acknowledge the use of Grammarly (<https://app.grammarly.com/>) while writing this empirical project for proofreading and spelling check.

I acknowledge the use of <https://www.wordclouds.com/> to make wordclouds for the appendices.

I confirm that I have not presented any AI generated text as my own work. I confirm I have copies of my drafts, notes, and other resources I used before, and after the use of AI tools which I may be asked to provide in evidence.

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Abstract

Coeliac disease is a common autoimmune disease and the only treatment for it is keeping a life-long gluten-free diet. Evidence suggests that adherence rates vary between 41% and 90% and there are several psycho-social factors that influence adherence. Current study aimed to explore the factors that affect adherence to a gluten-free diet and attempt to explain why people choose to adhere, or not to adhere to the diet. 15 participants filled out an online distributed questionnaire. The questionnaire included 10 open-ended questions regarding their experiences and opinions of coeliac disease and diet adherence. The 14 female and 1 male participants had a mean age of 44.33. Four themes emerged from the researcher's thematic analysis of the responses: negative emotions linked to being coeliac, the safety of home and the difficulties of out and about, motivations to follow a GF diet and others' perceptions of coeliac disease. The results of this study are evaluated in light of the body of knowledge already available in this field.

Introduction

Coeliac Disease (CD)

Coeliac disease (CD) is an autoimmune disease caused by a reaction to indigested gluten – a protein found in barley, rye, and wheat - primarily affecting the small intestine. The presentation of coeliac disease varies between individuals, which is why it can be misdiagnosed or diagnosed later (Catassi et al., 2022). The presentation of untreated coeliac disease can be the malabsorption of nutrition like iron or calcium that can show deficiencies in bloodwork, gastrointestinal symptoms like diarrhoea or constipation (Green & Cellier 2007), however not all patients diagnosed with coeliac disease experience the classical symptoms, some of them present as a silent coeliac; they have no symptoms (Reilly & Green, 2012). Coeliac disease affects about 1% of the UK and European population (Crocker et. al, 2020). The only treatment for coeliac disease currently is a life-long strict gluten-free diet (GFD) as the smallest amount of gluten can lead to an immune response (Sainsbury and Mullan, 2011). According to the NHS (2023), complications of coeliac disease if untreated or poorly managed could include osteoporosis, iron deficiency anaemia, vitamin B12 deficiency anaemia and bowel cancer for example.

Currently, there is no cure for CD, therefore maintaining a strict GFD is crucial for those who have been diagnosed with CD. However, reports suggest that the adherence to GFD varies between 41% - 90% (Hall et. al, 2009) some reporting intentional gluten consumption in as high as 40% of their participants (Hall et al., 2013). The wide range of adherence rates documented in the literature can be attributed to the various populations studied (adults, adolescents, children, and ethnic minorities), as well as the various approaches taken to assess adherence like a dietitian's assessment, faecal and urine tests, interviews etc. (Muhammad et al.,

2019), the quality of the studies, and the ways in which adherence is defined (strict, high, partial, fair, poor adherent, or non-adherent). There are no explicit instructions for how to investigate the significance of tracking adherence to a GFD (Wieser et al., 2021). For example, Gładys et al. (2020) used the Standardized Dietician Evaluation (SDE) and the Celiac Dietary Adherence Test (CDAT) to measure adherence, and they found that based on the SDE, 76% of participants showed good adherence while according to the CDAT only 48% of participants showed good adherence to a GFD.

Adherence can depend on many different factors. For example, studies found correlations between socioeconomic status or education (Casellas et al., 2006), age at diagnosis (Hankey & Holmes, 1994; Hogberg et al., 2003) and enjoying gluten-free food and feeling comfortable in not exclusively gluten-free restaurants (Enaud et al., 2022). However, findings regarding the correlation between presenting symptoms and dietary adherence are varied. This could be because of many reasons, many of the silent coeliacs will never be diagnosed, diagnosed late or misdiagnosed (Verkasalo et al., 2005). Studies also showed correlations between quality of life (QoL) and GFD adherence showing poorer QoL correlated with poorer GFD adherence (Sainsbury et al., 2013).

There are numerous obstacles to maintaining a GFD; hidden gluten in supposedly gluten-free foods, cross-contamination, societal pressure and poor or non-existent food labelling on packaged foods (Rajpoot et al., 2015). It is reported that adherence to a GFD varies between 41% - 90% (Hall et. al, 2019). To explain this variance, a number of theoretical frameworks for understanding health choices have been proposed.

The Theory of Planned Behaviour (TPB)

The Theory of Planned Behaviour (TPB), developed by Ajzen (1991), is a psychological framework used to predict and understand human behaviour by emphasizing the role of intention as the proximal determinant of action. The TPB posits that behavioural intention is shaped by three key constructs: attitudes toward the behaviour, subjective norms, and perceived behavioural control. Attitudes reflect an individual's evaluation of the behaviour as favourable or unfavourable, subjective norms represent the perceived social pressure to perform or refrain from the behaviour, and perceived behavioural control refers to an individual's perception of their ability to execute the behaviour, considering potential facilitators or barriers. The model suggests that stronger intentions, combined with adequate perceived control, increase the likelihood of behavioural performance, making it a robust tool for understanding and influencing behaviour in diverse contexts such as health, environmental sustainability, and consumer decision-making. It has been successfully applied in the field of health psychology to predict different health behaviours such as following a healthy diet in people with diabetes (Currie, 2010), medication adherence (Liddelow et al. 2020) and weight loss behaviour (Chung & Fong 2015). In line with the TPB, those who have strong beliefs in the seriousness and the serious consequences of CD are more likely to stick to a GFD (Ford et al., 2012). How strong these beliefs may be can also depend on the severity and type of symptoms, with some symptoms like anaemia correlating with poorer overall dietary adherence (Lee et al., 2022).

Following a GFD can be quite difficult however; it calls for motivation, understanding, and altered behaviour (Muhammad et al., 2019). Sainsbury and Mullan (2011) were the first to employ a health behaviour model to explore the attitudes and beliefs that CD patients have regarding their diet, as well as to use the

Planned Behaviour model to predict GFD adherence. Their study's objectives were to create a behavioural, normative, and control belief-based questionnaire, validate it, and ascertain whether the TBP is a reliable indicator of GFD adherence. They hypothesized that TBP would explain a sizable portion of the variation in GFD adherence, and that GFD adherence would be adversely affected by psychiatric diagnoses and a lack of awareness of GFD.

The study included 13 participants with a mean age of 47 who had received a biopsy diagnosis. The average duration of the individuals' GFD was 7.8 years. Nine standardized questions based on the TBP were asked of the participants during a one-on-one interview with the researcher. To determine the conditions in which the participants did not follow their diet, two further questions were added. While their study successfully designed the questionnaire and showed that the TBP indeed can predict if someone would follow the GFD and on what level, they did not explore the reasons for not following the GFD diet. Moreover, the TBP has been criticised as it ignores the unconscious and irrational impacts on behaviour since it only takes into account the conscious and rational aspects of decision making (Sniehotta et al., 2014). Therefore, it may be pertinent to consider an alternative model to explain adherence to a GFD and health choices may be the health belief model.

The health belief model

An alternative model to the TPB is the Health Belief Model (HBM), which is a psychological framework developed in the 1950's to explain and predict health-related behaviours, particularly in relation to the prevention and management of diseases. It suggests that an individual's decision to engage in health behaviours, such as adopting preventive measures or seeking medical care, is influenced by their

personal beliefs about health risks and the perceived benefits and barriers to taking action. The model highlights key factors, including perceived vulnerability, perceived severeness, perceived benefits, perceived obstacles and difficulties, cues to action, and self-efficacy, which altogether shape health behaviour decisions. Motivation is also a part of the model. In order to engage in a health behaviour, one has to be motivated, and the HBM can help enhance this motivation. According to Barberis et al. (2019), motivation can be autonomous or controlled depending on if the motivation comes from the person themselves, internally, or it is externally driven. Different types of motivations will have a different effect on adherence. Motivation varies from person to person and will have a different effect on adherence to GFD (Dowd et al., 2014)

The HBM is widely used in public health to design effective interventions and health promotion campaigns (Champion & Skinner, 2008). Studies showed that those who showed poor adherence to the GFD before, following an online course (Sainsbury et al., 2013) or nutrition counselling (Rajpoot et al., 2015), show improvements in their adherence. However, adolescents, for example, can still struggle with adherence because of their fear of isolation and stigmatisation that following a GFD could cause or that they think it would cause for them (Muhammad et al., 2019). They might know about the consequences of not following a diet, but they contradict their perceptions of social consequences, and this causes them discomfort. One way in which this discomfort may be explained is by considering the concept of cognitive dissonance.

Cognitive Dissonance

Cognitive dissonance is a psychological theory explaining the mental discomfort experienced when an individual simultaneously holds incongruous beliefs, values, or attitudes. First introduced by social psychologist Leon Festinger in 1957, cognitive dissonance theory suggests that people have an inherent desire for internal consistency (Ong et al. 2017). When confronted with inconsistencies between their beliefs and actions, individuals feel psychological tension, which they seek to resolve by altering their beliefs, attitudes, or behaviours. Cognitive dissonance occurs when a person experiences conflicting thoughts that challenge their sense of self or prior beliefs (Cooper, 2019). For example, a person who values health but smokes cigarettes may feel discomfort because their behaviour contradicts their belief in leading a healthy lifestyle. This inconsistency generates psychological distress, motivating the individual to reconcile the contradiction. They might achieve this by justifying their behaviour (e.g., 'Smoking helps me relieve stress'), changing their belief (e.g., 'A few cigarettes won't harm me'), or altering their behaviour (e.g., quitting smoking) (Keskindağ, 2023).

Several factors contribute to cognitive dissonance. One common cause is decision-making. When faced with two desirable choices, people may feel regret or doubt after making a decision, experiencing what is known as post-decision dissonance. For instance, after making a choice, one could worry that they did not make the right choice if a piece of information suggests that it was not the best choice, for example, purchasing an expensive phone, a person might worry about whether they made the right choice after reading bad reviews. To reduce this discomfort, they may seek out information that supports their decision, such as

reading positive reviews about the phone, while dismissing negative feedback (Suzuki, 2019).

Another source of cognitive dissonance is conflicting social norms and values. Individuals who are raised with a certain set of beliefs but later encounter opposing viewpoints may struggle with dissonance. For example, someone who grows up in a conservative household but later adopts progressive values may feel torn between familial expectations and personal convictions. For instance, Balestrino & Ciardi (2008) argued that the timing of marriage is affected by the cognitive dissonance between the perceived social norms and personal beliefs. Similarly, differences between cultural values can create dissonance like eating with hands is acceptable in some cultures while it is not part of the other cultures' ethics (Yahya & Sukmayadi, 2020). In relation to coeliac disease, social norms could mean that not eating gluten is often perceived as a 'fashion' or a 'fad' rather than a treatment for a condition. This may arise because of the number of people who chose to follow a GFD but do not have a formal diagnosis of coeliac disease (Villafuerte-Galvez et al., 2015). Therefore, misunderstandings may occur and a GFD will be perceived as something that people are only doing to stand out, be different, or follow a new trend that is not part of the social norm.

Cognitive dissonance can also apply when choosing between healthy and unhealthy food options. For example, for someone who has been diagnosed with coeliac disease, a normal slice of bread would not be a healthy choice. However, if they are experiencing no symptoms (silent coeliacs) their adherence might be lower because there is no physical presentation of the illness when eating gluten (Hall, 2009), therefore, they could convince themselves that for this one time it is okay.

The effects of cognitive dissonance can be both psychological and behavioral. People experiencing high levels of dissonance may suffer from anxiety, stress, or guilt. It can also influence decision-making and attitude changes, sometimes leading to rationalization or self-deception. In extreme cases, cognitive dissonance may even contribute to mental health challenges if individuals struggle to reconcile persistent contradictions in their beliefs or behaviors (Dilakshini & Kumar, 2020). When CD is left untreated, depressive symptoms, apathy, anxiety, and irritability are common mental health issues. CD patients on a GFD also had higher incidence of anxiety and depression symptoms (van Hees et al., 2013; Clappison et al. 2020)

Psychosocial factors

Research showed that quality of life (QoL) in coeliac patients is more strongly influenced by how difficult individuals perceive it is to maintain a GFD rather than their actual level of adherence to the diet. In other words, even if someone follows the GFD strictly, their QoL may be negatively affected if they find the process challenging or restrictive (Elwenspoek et al., 2024). Conversely, individuals who perceive the diet as easy to manage tend to report better QoL, regardless of their strictness in following the diet. This highlights the importance of addressing the psychological and social factors related to dietary management in coeliac disease. It suggests that healthcare providers should focus not only on encouraging dietary adherence but also on reducing the perceived burden of maintaining a gluten-free lifestyle to improve patient well-being (Barratt et al., 2011).

As GFD is the only treatment for CD it puts quite a psychological burden on the patient. They have to be constantly aware of food, what of and where is it made along with financial burden as GF food often more expensive (Villafuerte-Galvez et al., 2015), moreover, the availability of food in restaurants could be a social burden

that leads to negative peer pressure or social withdrawal (Karwautz et al., 2008; White et al., 2016). Enaud et al. (2022) found that those who trust non-gluten-free restaurants and have no fears of eating out, scored higher on the QoL scale. Additionally, how others perceive the seriousness of CD also affects the patients' mental health, as calling their only treatment for a chronic disease a 'fad' diet will upset them, and might cause anxiety (Trovato et al., 2020).

Aim and Rationale

Since strict commitment to a gluten-free diet for the rest of one's life is the sole treatment for coeliac disease, research is needed to explore how the adherence rates could be raised. As discussed, studies are attempting to shed light on what makes the difference between adherence rates, what obstacles people with CD face every day and what motivates them to follow a GFD. This current study aims to explore the factors that influence adherence to a gluten-free diet in order to provide a deeper understanding of why someone would choose not to follow a GFD and to address the research question; "What are the psychosocial factors that contribute to adherence to a gluten-free diet in people diagnosed with coeliac disease?". Given the paucity of research that links directly to adherence to a GFD in people with Coeliac Disease, the current study aims to acknowledge the findings from the limited existing research whilst applying psychological theory to participant responses in an attempt to explain how and why individuals choose to adhere (or not) to a GFD.

Methodology

Design

The study obtained ethical approval from the SREC within the department of Psychology and Counselling, University of Wales Trinity Saint David. Participant recruitment was achieved via a social media support group for people diagnosed with CD. Approval was sought from the group's administrative team, and as a result, an advertisement of the study was posted on the relevant social media channel. A non-experimental qualitative approach was developed to allow for a thematic analysis of participants' free-text responses on an open-ended questionnaire.

Participants

Participants were recruited using purposive sampling through a specific social support network on social media (Facebook). Participants were eligible to take part in the study if they were over the age of 18 with a formal diagnosis via endoscopy or blood test at least six months prior. There were 23 participants, however, eight had to be excluded as they only filled out the demographic questions and did not give answers to any of the open-ended questions. The remaining 15 participants were 14 female and 1 male, and the mean age of the participants was 44.33, and the mean of years since diagnosis was 11.06 years.

Procedure

An initial pilot study was carried out with two participants who were not included in the final data analysis. The result in the pilot study showed that the answers for the open-ended questions were long and detailed enough to carry out a thematic analysis. There were no changes made to the questions after the pilot study.

The study was in an online format with a questionnaire developed in the survey software `Qualtrics`. The questionnaire contained 10 open-ended questions. The anonymous link was posted on social media in the coeliac disease support group (Coeliacs UK) with a brief description of the study.

Before the participants could begin the questionnaire, they were directed to an information page that explained the purpose and aims of the study, their right to withdraw from the study at any time, and the anonymous and confidential nature of the study. They were also assured that there would be no personal data collected so the participants would not be able to be identified by any of their responses. Participants were informed that if they felt uncomfortable with any of the questions, they could simply withdraw by closing their browser and their data would not be saved. After they read the information page they were taken to a consent page, where they were required to read a series of statements and click on each one if they wished to accept them, thereby providing their informed consent to take part (e.g.: I understand that my participation in the study is voluntary, anonymous and confidential). Once participants had provided their consent, they were directed into the main body of the questionnaire.

Participants firstly completed the demographic questions (age; gender; years since diagnosis), then they were presented with the open-ended questionnaire. There was no time or character limit to answer the questions. After completing the questionnaire, participants were directed to a debrief page containing contact information of the researcher and supervisor should they have any questions or concerns after participating in the study. A link to the Coeliac UK website for more information about coeliac disease was provided should participants feel the need to seek further information.

Thematic analysis was carried out on all responses. During the familiarization phase, the researcher read the answers grouped by questions and, after each question, noted their initial thoughts. In the coding phase, the researcher wrote down the codes while reading through all the answers, but without grouping. As codes are the smallest analytical units, they were used to identify relevant aspects of the data that were related to the research question. Because of the similarities that occurred in the answers, codes sometimes appeared twice or were very similar; these were eliminated in the second coding phase. The remaining codes have been clustered into themes. The themes have been reviewed to make sure there is no overlap between them. The researcher defined and named the themes, making sure that they fitted with the research question. The analysis identified four main themes, these were: negative emotions linked to being coeliac, the safety of the home, the difficulties of out and about, motivations to follow a GF diet, and others' perceptions of coeliac disease.

Materials

The questions were a modified version of other closed and multiple-choice questions used in other studies (Pedoto et al., 2020; Miaja et al., 2020; Sainsbury and Mullan, 2011); therefore, a pilot study was carried out with two participants to ensure the viability of the questions prior to the final study. The responses of the two participants were not included in the final data analysis. Modifying the original questionnaires to an open-ended questionnaire allowed the researcher to collect responses that gave the opportunity to the participants to identify and explain their situation, motivation, etc. with their own words rather than choosing from a prewritten answer list. Data was collected via Qualtrics and stored on the researcher's personal computer. Thematic analysis was carried out on all the responses.

Results and discussion

Following a thematic analysis of the responses, four themes emerged. These are negative emotions linked to being coeliac, the safety of the home and the difficulties of out and about, motivations to follow a GF diet, and others' perceptions of coeliac disease. These themes are shown below in Table 1.

Table 1

Themes and quotes from the responses

Theme	Quote	Page and Line
Negative emotions linked to being coeliac	"Incredibly awkward - as if I'm just being fussy"	Page 2 Line 7
	"Uncomfortable"	Page 3 Line 21
	"... but I often find it is not what I want, is limited in choice and I feel I'm missing out. This sometimes gets me down."	Page 4 Line 26-27
	"Incredibly difficult because I know what normal pastry, pies, sausage rolls, cakes, pasta, Walkers crisps, Pringles, dry roasted peanuts taste like. There isn't a gf substitute that can mimic or taste like normal bread etc."	Page 5 Line 26-28
	"It is frustrating but it is what's best for my health"	Page 7 Line 4
	"Like a burden if I'm completely honest"	Page 7 Line 12
The safety of the home and the difficulties of out and about	"Fairly easy at home but socially it is extremely hard"	Page 1 Line 31

“ my family are aware and then I can live at ease in my house without fear of being accidentally glutened”

Page 2 Line 20-21

“Takeaways, meals out and on the go food is harder. I miss the spontaneity as I now have to research every option, double-check, explain my condition etc.”

Page 5 Line 6-8

“It can be really difficult when out and about or going to restaurants but I think you get used to it. It must be harder for children and teens I think.”

Page 6 Line 19-20

“It’s quite easy but it can be difficult if we are out and about”

Page 7 Line 14

“At home, Not difficult at all, when out its a minefield .”

Page 8 Line 25

Motivations to follow a GF diet

“I am physically ill if I eat gluten”

Page 1 Line 3

“To keep healthy and functioning in life”

Page 3 Line 13

“I get extremely unwell almost immediately but have also had to nurse my mother to her death from liver failure as a direct result of not following a gluten free diet after being diagnosed as coeliac.”

Page 4 Line 2-4

“The D&V can and will hospitalise me”

Page 6 Line 24

Others' perceptions of coeliac disease	“Nobody in my circle have coeliac disease and therefore are not overly understanding or sympathetic to my condition”	Page 2 Line 3-4
	“ I don’t have any family but my husband’s family can be problematic as they still don’t understand it or make much effort to keep me safe.”	Page 4 Line 6-8
	“I sometimes worry people think I’m going on about it or exaggerating its severity. I get sick of explaining it too.”	Page 5 Line 3-4
	“I find my wider family and friends understanding is limited they sometimes make me feel I’m over exaggerating or that it isn’t that serious...”	Page 7 Line 24-26

Negative emotions linked to being coeliac

As previously discussed, the only treatment for coeliac disease is following a strict GFD. Most coeliacs are aware of the consequences of eating gluten-containing food, so they will avoid it. However, the participants reported many negative feelings that come with being coeliac and the necessity of following the GFD in every life situation, especially in social situations. This can negatively affect their QoL and mental health. One participant wrote: “... but I often find it is not what I want, is limited in choice and I feel I’m missing out. This sometimes gets me down.” (Page 4 Line 26-27). Often choice is viewed as a crucial indicator of an individual’s independence and self-determination (Schwartz & Ward, 2004). If anyone walks into the closest

supermarket and finds the 'Free From' aisle, they will realise that it is usually not even a full aisle. Compare it to the rest of the supermarket, and it is clear that the safe choices are very limited. If someone with coeliac disease wants to choose from another aisle, they will have to read every single label. Moreover, if the label states that it may contain gluten, it is unsuitable for a person with coeliac disease. This will add to the cognitive load that people with CD already carry, reading every single label, constantly checking if ingredients have been changed, and constantly worrying if they will be able to actually buy anything in unfamiliar places, for example, when travelling or eating out. The cognitive load could be even more pressuring when the coeliac in the family is a child, and the responsibility lies on a parent to make sure they are following the GFD. Indeed, parents reported an increased mental load when caring for a child with CD (Gallegos et al., 2025).

Consider the social situation of going out for a meal. While there are gluten-free restaurants around the world, they can be hard to find. Individuals will have to research them, and if they are 'lucky' there may be one nearby. One participant wrote: "i think it's difficult in a social setting when everyone can order whatever they want without thinking but i'd have to plan ahead and ask loads of questions or miss out" (Page 2 Line 12-13). This shows how much planning and preparation are needed, in contrast to someone with no dietary needs who can simply walk into a restaurant. It also will depend on the staff and how uncomfortable a person will feel when explaining their conditions and needs.

Research showed that the perceived difficulty to maintain a GFD does have a negative influence on the QoL in coeliac patients; even if their adherence to a GFD is actually good, if they find it difficult, it will have an impact on them and on their mental health (Barratt et al., 2011). According to Hallert et al. (2002), women voiced greater worry about the effects on going out with friends and therefore having to miss out on

life's pleasures. A participant wrote: "Incredibly difficult because I know what normal pastry, pies, sausage rolls, cakes, pasta, Walkers crisps, Pringles, dry roasted peanuts taste like. There isn't a gf substitute that can mimic or taste like normal bread etc." (Page 5 Lines 26-28), if someone knows that there is a more preferable option for themselves, it is hard to feel good about a choice they made. According to the health belief model, if the person knows the benefits of their choice, they will choose it regardless of the fact that they are less favourable. But it will not necessarily make them feel good, again, it will affect their QoL and mental health. According to Clappison et al. (2020) and van Hees et al. (2013) depression rates are significantly higher among people with CD than control groups, and anxiety is also significantly higher in groups of patients with CD.

Another participant also stated they feel "Uncomfortable" (Page 3 Line 21) and "Incredibly awkward - as if I'm just being fussy" (Page 2, Line 7) when talking about and explaining their condition to others. Because so many people without coeliac disease follow a gluten-free diet, those with coeliac disease are increasingly confronted with misconceptions regarding the severity of their condition. This caused distress in some social circumstances (e.g., accidentally eating gluten-containing food) while making others easier to handle (e.g., more gluten-free options available at restaurants). Additionally, people with CD might think they may be viewed differently or even think they are high maintenance (King et al., 2019). One participant wrote they feel: " Like a burden if I'm completely honest" (Page 7 Line 12). An online questionnaire showed that those who just recently started their GFD found it even more difficult compared to those who have been doing it for a longer period of time. Also, they found that those who adhere to a very strict GFD have poorer QoL than those who follow a not strict GFD (Elwenspoek et al., 2024). This suggests the difficulties of following a strict GFD in their everyday life and the impact of doing it so

on their QoL and mental health. According to the planned behaviour model, the attitudes toward the behaviour (feelings about following GFD), the subjective norms (what others will think) and the perceived control (the level of control over what they eat) will predict if someone will and on what level engage in the behaviour.

According to the answers of the participants while they know following a GFD is a must for them in order to stay healthy, they often feel negatively about their diet because of the number of choices in safe food or safe places to eat, others' perception of their need to follow a GFD, the misunderstandings that is around coeliac disease, and the constant explaining that will make some uncomfortable and this will make it more difficult to adhere to a GFD. Research showed that educational intervention had a positive impact on the level of adherence among patients with coeliac disease. One implication is that an educational intervention for family and friends could make the person with CD feel better about themselves, reduce the explanation needed, change other perceptions and make those with CD feel more comfortable around social situations, improving their QoL and mental health.

The safety of the home and the difficulties of out and about

Most participants stated that they feel safe at home, where they are in control and know exactly what is in their cupboard and in the food they are eating. They felt safe making their own food and eating it at home. However, 'going out' and the 'outside world' was called "...minefield ." (Page 8 Line 25) According to the answers, accidental gluten consumption almost always happens away from home. For example, a participant said: " It has happened 3 times since diagnosis. The first was when a hotel swapped gf pasta for normal pasta and served it to me. The second was due to cross contamination at my in laws. The third was being given the wrong

food at a restaurant despite questioning it multiple times.” (Page 4 Lines 16-19).

Furthermore, according to a study by Barratt et al. (2011), 88% of participants said that eating out makes it difficult to follow a GFD, 72% said that travelling and 71% said that socialising are difficult situations, while only 11% said that they have trouble sticking to the diet at home.

Many studies will use blood tests to determine the anti-tissue transglutaminase (TTG) levels that would indicate if the individual were following a GFD (Leffler et al., 2007). It does not matter if an individual wants to follow a strict GFD when other people are making serious mistakes, causing their adherence level to be lower. This can have an impact on the results of the studies. While the anti-TTG levels are accurate to measure the adherence level to the GFD, it does not mean these people choose not to follow a diet. This indicates that when using this kind of measurement of adherence, further exploration should be conducted to determine whether gluten consumption was voluntary or not.

Eating gluten-containing food, however, is not always accidental. A participant wrote: “until i was around 17 i didn’t really care about what i ate and it was just easy to eat a full meal at school without having to check what was in it but when i cut it out and stopped eating it. after that i have only eaten it accidentally “ (Page 3 Lines 1-3). Being a teenager is hard enough without having a disease like CD that will put many restrictions on a person. An other participants also thought that it might be more challenging for a young person: “It can be really difficult when out and about or going to restaurants but I think you get used to it. It must be harder for children and teens I think.” (Page 6 Lines 19-20). While adherence among children is often higher, adolescents often report issues with following a GFD (Muhammad, 2019). According to White et al., (2016) adolescents experience social isolation and stigmatisation in social settings, and even in school. Restricted to follow a GFD made them feel visible

and different, making them a more likely target for social devaluation. Therefore, it is not surprising that adolescents will avoid social situations or will just eat any food when they are spending time with peers (Karwautz et al., 2008). The first time a person goes out on their own and starts making all of their own food choices is a particularly significant period of life for food choice. This marks the start of college life for a lot of young people. For young adults, who frequently have their first chance to prepare their own meals, the move to college or university is a crucial time (Wdowik et al., 2001). This could imply a need for the development of a scale to measure adherence and barriers to adherence among adolescents, just like the Diabetes College Scale for adolescents diagnosed with diabetes (Wdowik et al., 2001).

Furthermore, gluten is not only in food. It can be found in drinks, like beer. It is not as easy for someone with CD to go out for a drink. Adolescents with CD have the same desires as those without. They might want to spend time with their friends, going out for a meal, or have a few drinks, but while they have a disease that restricts what they can eat and drink. Similar findings were presented by Ouzouni et al. (2019) regarding the difficulties of adherence to a health regime among adolescents with type 1 diabetes. This could explain poor adherence rates among adolescents. However, it is important to note that social withdrawing is not only apparent among adolescents. One participant wrote: "If my work had arranged to go out for food I just wouldn't go if it was somewhere I couldn't eat." (Page 4 Lines 10-11).

On the contrary, most participants stated that they feel safe eating at home: "my family are aware and then i can live at ease in my house without fear of being accidentally glutened,..." (Page 2 Lines 20-21). The difficulty is not in preparing and cooking gluten free food at home: "My husband has adapted many recipes to make them gluten free and eats gluten free when he is with me and always brushes his teeth if he has had gluten so he can kiss me. My family use a separate worktop and

fridge. My dad sent me a free from recipe book for my birthday.” (Page 1 Lines 18-21). The difficult part is to buy the ingredients and food items: “Availability and cost of gluten free products such as pasta or bread” (Page1 Line 12). For example, Sainsbury’s Free From White Sliced Bread 535g costs £1.90 while Sainsbury’s Soft Medium Sliced White Bread 800g costs 74p (prices correct at the time of writing up this report on 01/03/2025). The financial impact of CD on families can cause even more difficulties in today’s cost of living crisis. At some parts of the UK, gluten-free food is available on prescription, while other parts of the country have prepaid-cards for those with CD (the amount they will get depends on age, currently a 12-year-old gets £54/ 3 months). However, financial costs are still a reported barrier to adherence to GFD (Muhammad, 2019). According to Villafuerte-Galvez et al., (2015) the costs of GF food do have an impact on adherence. 40% of their participants reported that the costs make adherence to GFD difficult, of whom 65.9% managed to keep adherence adequate. Additionally, Zysk et al. (2018) found that those with lower economic status had lower scores in emotional, social and worry-related aspects of QoL. This suggests that economic status is a critical factor in the well-being of CD patients. The financial burden of a GFD affects their emotional health and social interactions, making it a significant stressor. Although they prioritize spending on GF products for medical reasons, their financial situation can lower their overall quality of life. This aspect could be important when exploring adherence rates among those who mostly eat at home, making their own food. They might feel safe and know they will not consume any gluten, however, the price that they pay literally and metaphorically can be high.

Motivation to follow a GFD

Some form of motivation is always needed to follow any diet successfully. As mentioned before, the only treatment for CD currently is to follow a strict GFD.

According to the TPB and the HBM, it is more likely that an individual will engage in a behaviour if the attitudes towards the behaviour are supportive and there is motivation to engage in a behaviour. A study by Sainsbury and Mullan (2011) have demonstrated the significance of comprehending the elements that require diet adherence in individuals with coeliac disease, implying that behaviours related to adhering to a gluten-free diet are motivated by intentions, which are then impacted by beliefs. In particular, this study indicated that patients seemed to be more motivated by the benefits of sticking to a gluten-free diet than by the drawbacks, indicating the importance of various adherence-promoting factors when managing coeliac disease.

In the current study, participants were asked what motivates them to follow the GFD: “I am physically ill if I eat gluten” (Page 1 Line 3). The fact that consuming gluten makes them physically ill was an often-mentioned motivation. The fear of being physically ill from something that they eat is a big part of why those who have been diagnosed with CD follow a GFD (Sainsburys & Mullan, 2011). As CD is genetic and heritable, a person’s motivation sometimes comes from another family member’s suffering: “I get extremely unwell almost immediately but have also had to nurse my mother to her death from liver failure as a direct result of not following a gluten free diet after being diagnosed as coeliac.” (Page 4 Lines 2-4). According to Barberis et al. (2019), autonomous, or self-driven motivation will make people more likely to stick to their diet and those whose adherence is driven by this type of motivation will experience fewer anxiety and depression symptoms. However, those whose motivation is controlled, or externally driven, are more likely to have

inconsistencies in their adherence to a GFD and experience more anxiety and depression symptoms. According to Ford et al. (2012), the stronger a person's belief about the seriousness of their illness, the more likely they will follow the GFD. This is also in line with the TPB and suggests that it is indeed can be used to predict adherence (Sainsbury & Mullan 2011).

When the motivation is not to get ill, it is clear why someone with CD chose not to eat anything that contains gluten. However, some people with CD do not experience physical symptoms, or not severe ones: "...lack of understanding about how it affects your body, if people's reaction to gluten poisoning isn't as bad they may think "oh just this once" etc" (Page7 Lines 3-5). According to Hall et al. (2009) the results about the correlation between symptoms severity and adherence to a GFD are controversial. While some studies found no correlation between symptoms presentation and adherence level, there are studies that showed the less severe or missing symptoms are negatively correlated with adherence rate, while strong reactions to gluten reinforce strict adherence. Lee et al., (2022) findings supported the idea that different types of symptoms have different effects on adherence, for example, they found that weight loss and diarrhoea correlated with better adherence while anaemia and dermatitis herpetiformis correlated with poorer adherence. According to Dowd et al. (2014), the most frequently mentioned motivation to adherence was having the diagnosis of CD and experiencing general physical symptoms (e.g.: diarrhoea, vomiting) and those who consumed gluten on purpose reported less severe symptoms and pain than those who accidentally consumed gluten. Another motivating factor is long-term health: "To keep healthy and functioning in life" (Page 3 Line 13). Interestingly, according to Dowd et al. (2014), the group who reported that their motivation is long term health had the highest score in accidental gluten consumption.

Others' perception of coeliac disease

There are many misconceptions about coeliac disease. It is often called an allergy or a 'fad' diet. It is important to understand that in the case of CD, the body will attack itself when consuming gluten, it is an autoimmune disease, and the GFD is not a choice but the only treatment that exists at the moment. Participants mentioned that those around them who do not have the disease are not very understanding, maybe because they do not fully understand the severity of the disease: "Nobody in my circle have coeliac disease and therefore are not overly understanding or sympathetic to my condition" (P2 Lines 3-4). Patient education about CD is positively correlated with better adherence rates; therefore, this would imply that patients should be counselled together with their families, not only about the disease but about how to eat out (Rajpoot et al., 2015). This would not only help to make people more aware about the disease but the more educated are the people around the individual about their disease, the less they would worry about explaining their condition and that would lessen the stress that the constant explaining and worrying cause them: "I sometimes worry people think I'm going on about it or exaggerating its severity. I get sick of explaining it too." (Page 5 Line 3-4).

This shows how others' perception of coeliac disease can have a negative impact on those who have CD. For this participant, explaining their condition causes distress that adds to the cognitive load, and it will create a negative association with GFD that eventually can lead to poorer adherence levels in some cases. They were not the only ones feeling like the public's awareness of CD is limited. Some participants also thought that poor adherence can be associated with the lack of knowledge and awareness of others: "Silent symptoms and lack of social awareness" (Page 2 Line 11). Participants on many occasions stated that the times when they accidentally consumed gluten, it happened away from home, in a restaurant for

example, where the staff was not completely aware about what coeliac disease is: “It has happened 3 times since diagnosis. The first was when a hotel swapped gf pasta for normal pasta and served it to me. The second was due to cross contamination at my in laws. The third was being given the wrong food at a restaurant despite questioning it multiple times.” (Page 4 Lines 16-19) The TPB can explain these findings in light of ‘perceived control’, as when dining out, people with coeliac disease often experience a lower level of perceived control over their adherence to the GFD as they are relying on others. This perceived control is crucial in mediating the opportunity to follow a GFD (Hall et al., 2013).

Considering that social media is a central part of our everyday life, it is not surprising that coeliac disease as a topic can be found on these platforms. In a recent study, Trovato et al. (2020) analysed X (formally known as Twitter) posts that had mentioned coeliac disease. During the analysis, they found that there are many people who often self-diagnose with assumed gluten-related symptoms, and because of the increasing numbers of people who chose to follow a GFD without any clinical diagnosis, it could seem that it is just another fashion diet. This also could have an impact on those who are officially diagnosed, causing them anxiety. It is evident that media portrayal of CD has an impact on how the public perceives this illness: “. It just frustrated me if someone then Thinks I’m making a choice to not eat it and therefore wouldn’t matter if I had a little of something that has been contaminated.” (Page 10 Lines 15-17).

According to Verma and Brains (2022), analysing newspapers during coeliac awareness week showed an increase in the number of articles about CD, including articles that were to raise awareness and the increased popularity of GFD and the problems associated with it. They also noted that many of the celebrities who follow a GFD are not doing it because of medical issues. This can also contribute to the

perception of a GFD and therefore coeliac disease (Verma & Brains 2022). It is understandably difficult for the public to fully understand the severity of CD and the serious consequences of not following GFD for a person with CD after the current media portrayal of the disease. As indicated from this research, other people's perceptions (family members, friends or strangers) of the disease is an important factor when investigating what can affect adherence to a GFD in people with CD. It is also evident that implementing education interventions would be a good tool to raise adherence levels. However, more research is needed on what would make dining out less of a barrier to adhere to a GFD. In line with both the HBM and the TPB, the role of others' perceptions, beliefs and social norms are clearly central to understanding why adherence to a GFD can be an issue.

Limitations of the current study

Although the findings of the current study are important in understanding which psycho-social factors and how and why they affect adherence to a GFD, there are limitations that should be noted. One limitation is that all participants but one were female, and as Hallert et al. (2002) argued, females score significantly lower on the QoL scale than males. Therefore, these results are mostly relevant to the female population with CD. Because of the recruiting method, participants were all from the UK and those who use social media. Further research is needed to explore if there are differences in adherence between those who use these platforms for support and those who do not. There were many participants who had to be excluded from the study because they only answered the demographic questions, and for unknown reasons, they did not proceed to the open-ended questionnaire. This may be because they decided to withdraw from the study, or because of technical issues

such as the lack of familiarity with online questionnaires. Further research should explore different ways of distributing the questionnaire (e.g., through GP surgeries or via the post).

Findings of the current study showed that teenagers may have a lower adherence level than adults, but because our criteria stated participants have to be over 18 years old, the relevant responses came from people who remembered their teenage years and their adherence back then. Future research could focus on adolescents and their issues with adherence to a GFD, and could be important in aiding the development of interventions that are aimed at adolescents and their peers. It is also important to note that the current study did not measure actual adherence to a GFD, therefore there is no data showing the participants' actual adherence level. It would have been interesting to compare actual adherence levels with the experienced and perceived barriers by the participants.

Conclusion

In conclusion, the current study aimed to examine the psycho-social factors that affect the adherence to a GFD in people with CD, additionally to see how these factors could affect adherence. It is clear that most of the people who have been diagnosed with CD are somewhat motivated to follow a strict GFD, but these motivations vary from person to person, and for some it is stronger than for others, and motivation is not the only factor contributing to adherence. Results also demonstrated that there are many psycho-social factors that affect adherence, and worryingly, many of these can have a negative effect. In addition to motivation, emotional well-being, fear of symptoms and health consequences, cognitive load, social support, fear of stigma, dining out and practical barriers like the availability of

food and the cost of GF products are all factors contributing to adherence. As shown, counselling and education about CD can help to raise adherence levels, however these interventions should include and explore each of these aspects above and help people not just to learn how to maintain a strict GFD but also, how can they manage the social pressure and make sure that they take care of themselves emotionally and physically. Interventions and research should focus on how to make following a GFD both practical and enjoyable in line with the health behavioural models that explain our dietary choices.

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Appendices

Appendix A – Ethical Approval Form

APPLICATION FOR ETHICAL APPROVAL

RESEARCH STUDENTS

This form is to be completed by the student within **SIX** months for full-time students and **TWELVE** months for part time students, after the commencement of the research degree or following progression to Part Two of your course.

Once complete, submit this form via the ***MyTSD Doctoral College Portal*** at (<https://mytsd.uwtsd.ac.uk>).

This document is also available in Welsh.

RESEARCH STAFF ONLY

All communications relating to this application during its processing must be in writing and emailed to pgresearch@uwtsd.ac.uk , with the title ‘Ethical Approval’ followed by your name.

STUDENTS ON UNDERGRADUATE OR TAUGHT MASTERS PROGRAMMES should submit this form (and receive the outcome) via systems explained to you by the supervisor/module leader.

In order for research to result in benefit and minimise risk of harm, it must be conducted ethically. A researcher may not be covered by the University’s insurance if ethical approval has not been obtained prior to commencement.

The University follows the OECD Frascati manual definition of **research activity**:
“creative work undertaken on a systematic basis in order to increase the stock of knowledge, including knowledge of man, culture and society, and the use of this stock of

knowledge to devise new applications”. As such this covers activities undertaken by members of staff, postgraduate research students, and both taught postgraduate and undergraduate students working on dissertations/projects.

The individual undertaking the research activity is known as the “principal researcher”.

Ethical approval is not required for routine audits, performance reviews, quality assurance studies, testing within normal educational requirements, and literary or artistic criticism.

Please read the notes for guidance before completing ALL sections of the form.

This form must be completed and approved prior to undertaking any research activity. Please see Checklist for details of process for different categories of application.

SECTION A: About You (Principal Researcher)

1	Full Name:	Zsuzsanna Telekesi			
2	Tick all boxes that apply:	Member of staff:	☐	Honorary research fellow:	☐
	Undergraduate Student	☒	Taught Postgraduate Student	☐	Postgraduate Research Student

3	Institute/Academic Discipline/Centre:	Psychology and Counselling
4	Campus:	Carmarthen
5	E-mail address:	2203653@student.uwtsd.ac.uk

6	Contact Telephone Number:	
For students:		
7	Student Number:	2203653
8	Programme of Study:	BSc Applied Psychology
9	Director of Studies/Supervisor:	Karen Eaton Thomas

SECTION B: Approval for Research Activity

1	Has the research activity received approval in principle? (please check the Guidance Notes as to the appropriate approval process for different levels of research by different categories of individual)	YES	☒	NO	☐
					Date
2	If Yes, please indicate source of approval (and date where known): Approval in principle must be obtained from the relevant source prior to seeking ethical approval	Research Degrees Committee	☐		
		Institute Research Committee	☐		
		Other (write in) Karen Eaton Thomas (dissertation supervisor)	☒	July 2024	

SECTION C: Internal and External Ethical Guidance Materials

	Please list the core ethical guidance documents that have been referred to during the completion of this form (including any discipline-specific codes of research ethics, location-specific codes of research ethics, and also any specific ethical guidance relating to the proposed methodology). Please tick to confirm that your research proposal adheres to these codes and guidelines. You may add rows to this table if needed.	
1	UWTSD Research Ethics & Integrity Code of Practice	☒

2	UWTSD Research Data Management Policy	☒
3	UWTSD Student Code of Conduct	☒
4	UWTSD Data Protection and Storage Protocol	☒
5	BPS Code of Human Research Ethics	☒
6	BPS Code of Ethics and Conduct	☒
7	BPS Data Protection Regulation	☒
8	BPS Ethics Guidelines for Internet-mediated Research	☒

SECTION D: External Collaborative Research Activity

If there are external collaborators then you should gain consent from the contact persons to share their personal data with the university. If there are no external collaborators then leave this section blank and continue to section E.

1	Institution				
2	Contact person name				
3	Contact person e-mail address				
4	Is your research externally funded?	YES	☐	NO	☐
5	Are you in receipt of a KESS scholarship?	YES	☐	NO	☐

6	Are you specifically employed to undertake this research in either a paid or voluntary capacity?	Voluntary	YES	☐	NO	☐
7		Employed	YES	☐	NO	☐
8	Is the research being undertaken within an existing UWTSD Athrofa Professional Learning Partnership (APLP)?	If YES then the permission question below does not need to be answered.	YES	☐	NO	☐
9	Has permission to undertake the research has been provided by the partner organisation?	(If YES attach copy) If NO the application cannot continue	YES	☐	NO	☐

Where research activity is carried out in collaboration with an external organisation

10	Does this organisation have its own ethics approval system?	YES	☐	NO	☐
	If Yes, please attach a copy of any final approval (or interim approval) from the organisation (this may be a copy of an email if appropriate).				

SECTION E: Details of Research Activity

1	Indicative title:	An exploration of psychosocial factors that may contribute to adherence to a gluten-free diet (GFD) in individuals diagnosed with coeliac disease.		
2	Proposed start date:	19/11/2024	Proposed end date:	21/05/2025
Introduction to the Research (maximum 300 words per section) Ensure that you write for a <u>Non-Specialist Audience</u> when outlining your response to the points below: • <i>Purpose of Research Activity</i> • <i>Proposed Research Question</i>				

	• <i>Aims of Research Activity</i> • <i>Objectives of Research Activity</i> Demonstrate, briefly, how Existing Research has informed the proposed activity and explain • <i>What the research activity will add to the body of knowledge</i> • <i>How it addresses an area of importance.</i>
3	Purpose of Research Activity The purpose of this study is to write a dissertation. It will explore the psychosocial factors contributing to adherence to a gluten-free diet (GFD). Gluten consumption in genetically predisposed people results in coeliac disease, an autoimmune condition that mostly affects the small intestine. (Catassi et al., 2022) The only treatment for coeliac disease is a lifelong gluten-free diet. Reports suggest that the adherence ranges between 42% - 91% (Hall et al., 2009). According to the theory of planned behaviour the intention to perform a behaviour is influenced by attitudes, subjective norms and perceived level of control (Ajzen, 1991). The theory of planned behaviour was also used to predict adherence to a gluten-free diet in one published theory-based study on coeliac disease. It explained 22% of the actual adherence and 37% of the variance in the intention to follow a strict gluten-free diet (Sainsbury and Mullan, 2011). Of 203 adults who have been diagnosed with coeliac disease 21 reported they did not follow a strict gluten-free diet because they felt like they were less sensitive to it therefore they were willing to take chances, because they were less careful when eating out and because they love the taste of gluten-containing food. (Dowd et al. 2013) Festinger's theory of cognitive dissonance states that when a person's beliefs, attitudes, and behaviours are inconsistent, they will experience discomfort. In this scenario, the person is aware that there is a healthier alternative to the food they choose. They will attempt to minimize this emotion by trying to rationalize their actions, concentrating solely on some of the information, or placing the blame elsewhere (Ong et al., 2017). The purpose of this study is to explore why people with coeliac disease do not always follow a strict GFD knowing that it is the only treatment for their condition. Given the fact that adherence to a gluten free diet is an important aspect of a Coeliac sufferer`s health and well-being, there is surprisingly little empirical

evidence that may shed light on our understanding of what motivates an individual`s dietary choices when faced with a lifelong debilitating illness. The purpose of this current study is to explore psychosocial influences that Coeliac sufferers feel contribute to why they do, or do not, adhere to a gluten free diet.

Ajzen, I. (1991). The theory of planned behavior. *Organizational behavior and human decision processes*, 50(2), 179-211.

Catassi, C., Verdu, E. F., Bai, J. C., & Lionetti, E. (2022). Coeliac disease. *The Lancet*, 399(10344), 2413-2426.

Dowd A.J., Tamminen K.A., Jung M.E., Case S., McEwan D. & Beauchamp M.R. (2013) Motives for adherence to a gluten-free diet: a qualitative investigation involving adults with coeliac disease. *J Hum Nutr Diet*. doi:10.1111/jhn.12203

Hall, N. J., Rubin, G., & Charnock, A. (2009). Systematic review: adherence to a gluten-free diet in adult patients with coeliac disease. *Alimentary pharmacology & therapeutics*, 30(4), 315-330.

Ong, A. S. J., Frewer, L., & Chan, M. Y. (2017). Cognitive dissonance in food and nutrition—A review. *Critical reviews in food science and nutrition*, 57(11), 2330-2342.

Sainsbury, K., & Mullan, B. (2011). Measuring beliefs about gluten free diet adherence in adult coeliac disease using the theory of planned behaviour. *Appetite*, 56(2), 476-483.

Sainsbury, K., Mullan, B., & Sharpe, L. (2013). Reduced quality of life in coeliac disease is more strongly associated with depression than gastrointestinal symptoms. *Journal of psychosomatic research*, 75(2), 135-141.

	(this box should expand as you type)
4	Research Question What are the psychosocial factors that contribute to adherence to gluten-free diet in people diagnosed with coeliac disease? (this box should expand as you type)
5	Aims of Research Activity This study aims to explore the psychosocial factors that influence adherence to a gluten-free diet. (this box should expand as you type)
6	Objectives of Research Activity The objectives of this study are to investigate on a deeper level how people diagnosed with coeliac disease perceive the importance of following a strict gluten-free diet (GFD) and what are their reasons behind doing (or not doing) it. This study will utilise an open-ended questionnaire so participants can express their feelings and reasoning behind their level of following a gluten-free diet with their own word rather than choose from a list of answers.

	Hopefully, this will lead to a deeper understanding to why adherence to a GFD diet varies considerably between individuals diagnosed with Coeliac Disease. (this box should expand as you type)
	Proposed methods (maximum 600 words) Provide a brief summary of all the methods that may be used in the research activity, making it clear what specific techniques may be used. If methods other than those listed in this section are deemed appropriate later, additional ethical approval for those methods will be needed. You do not need to justify the methods here, but should instead describe how you intend to collect the data necessary for you to complete your project.
7	1. A non-experimental qualitative approach will be undertaken completing a thematic analysis of participants' free-text responses to an open-ended questionnaire (see appendix 1). Participants will be recruited using purposive sampling through specialist GFD) social support networks on social media (e.g. Facebook). 2. Approval for the advertisement (see appendix 2) of the study that will be posted on social media will be sought from the academic director of Psychology and Counselling department, Associate Professor Dr Paul Hutchings. Approval for the study has been granted from the Specialist Support group: Coeliacs in the UK 3. Participants will be eligible to take part in the study if they are over the age of 18 diagnosed with coeliac disease provided they have been diagnosed via an endoscopy or blood test at least 6 months previously. 4. The study will be an online questionnaire through the survey software Qualtrics. It will consist of 10 open-ended questions. The link will be posted on social media in the coeliac disease support group named above alongside a brief description of the study. Before the participants can answer the questions, they will be provided with an information sheet (see appendix 3) that explains the nature of the study, the aim of the study, the type of questions that they will be presented with,

their right to withdraw, and that the study is completely anonymous and confidential. They will also be informed that there will be no personal data collected so the participants will not be able to be identified by their answers.

5. Participants will be asked to provide as much detail as possible, but can choose to leave out any questions that they do not wish to answer. They will be reminded not to include any personal data that might make them identifiable such as name, age, gender, place where they live, etc.

6. Participants will be informed that if they feel uncomfortable with any of the questions, they can simply at any point withdraw by closing their browser and their data will not be saved. After they read the information sheet, a consent page containing a series of statements will be presented to participants. If participants agree to the statements, they will tick each one before continuing onto the `next` page. At this point, participants will have acknowledged that they have provided their consent by continuing into the main body of the questionnaire. (see appendix 4).

7. After this, participants will be presented with an open-ended questionnaire (see appendix 1) which can be completed at the participants own pace. There is no time or character limit to answer the questions. The open ended questions will be a modified version of other closed and multiple-choice questions previously used in other studies which will be trialled via a pilot study before data collection will begin to ensure their suitability for use.

8. On completion of the questionnaire, participants will be directed to a debrief page (see appendix 5) which fully explains the purpose of the study and includes the contact details of the researcher and supervisor, should the participants wish to ask any questions or get in touch. It will also include a link to the Coeliac UK website for more information about coeliac disease.

9. Additionally participants will be reminded of their right to withdraw for a final time before clicking the `submit responses` button.

	10. Data will be collected via Qualtrics and stored on the researcher's university account before being exported into excel and a word document for analysis. The data will be stored electronically in the researchers university password protected OneDrive account until the relevant exam board has taken place. Following this, the data will be deleted. (this box should expand as you type)
	Location of research activity Identify all locations where research activity will take place.
8	The study will be online based. (this box should expand as you type)
	Research activity outside of the UK If research activity will take place overseas, you are responsible for ensuring that local ethical considerations are complied with and that the relevant permissions are sought. Specify any local guidelines (e.g. from local professional associations/learned societies/universities) that exist and whether these involve any ethical stipulations beyond those usual in the UK (provide details of any licenses or permissions required). Also specify whether there are any specific ethical issues raised by the local context in which the research activity is taking place, for example, particular cultural and/or legal sensitivities or vulnerabilities of participants. If you live in the country where you will do the research then please state this.
9	N/A (this box should expand as you type)

10	Use of documentation not in the public domain: Are any documents NOT publicly available?	NO	☒
		YES	☐

11	If Yes, please provide details here of how you will gain access to specific documentation that is not in the public domain and that this is in accordance with the current data protection law of the country in question and that of England and Wales. <i>(this box should expand as you type)</i>		

	Does your research relate to one or more of the seven aims of the Well-being of Future Generations (Wales) Act 2015?	YES	NO
12	A prosperous Wales	☐	☐
13	A resilient Wales	☐	☐
14	A healthier Wales	☒	☐
15	A more equal Wales	☐	☐
16	A Wales of cohesive communities	☐	☐
17	A Wales of vibrant culture and thriving Welsh language	☐	☐
18	A globally responsible Wales	☐	☐
19	If YES to any of the above, please give details:		
	As the study explores the adherence to a gluten free diet with people who have been diagnosed with coeliac disease and the only course of treatment for their condition is a GFD, the study relates to the aim of informing and contributing to a Healthier Wales. <i>(this box should expand as you type)</i>		

SECTION F: Scope of Research Activity

	Will the research activity include:	YES	NO
1	Use of a questionnaire or similar research instrument?	☒	☐
2	Use of interviews?	☐	☒

3	Use of focus groups?	☐	☒
4	Use of participant diaries?	☐	☒
5	Use of video or audio recording?	☐	☒
6	Use of computer-generated log files?	☐	☒
7	Participant observation with their knowledge?	☐	☒
8	Participant observation without their knowledge?	☐	☒
9	Access to personal or confidential information without the participants' specific consent?	☐	☒
10	Administration of any questions, test stimuli, presentation that may be experienced as physically, mentally or emotionally harmful / offensive?	☐	☒
11	Performance of any acts which may cause embarrassment or affect self-esteem?	☐	☒
12	Investigation of participants involved in illegal activities?	☐	☒
13	Use of procedures that involve deception?	☐	☒
14	Administration of any substance, agent or placebo?	☐	☒
15	Working with live vertebrate animals?	☐	☒
16	Procedures that may have a negative impact on the environment?	☐	☒
17	Other primary data collection methods. Please indicate the type of data collection method(s) below.	☐	☒
	Details of any other primary data collection method: The questionnaire will be made via Qualtrics that will be the primary data collection method. (this box should expand as you type)		

If NO to every question, then the research activity is (ethically) low risk and **may** be exempt from **some** of the following sections (please refer to Guidance Notes).

If YES to any question, then no research activity should be undertaken until full ethical approval has been obtained.

SECTION G: Intended Participants

If there are no participants then do not complete this section, but go directly to section H.

	Who are the intended participants:	YES	NO
1	Students or staff at the University?	☐	☒
2	Adults (over the age of 18 and competent to give consent)?	☒	☐
3	Vulnerable adults?	☐	☒
4	Children and Young People under the age of 18? (Consent from Parent, Carer or Guardian will be required)	☐	☒
5	Prisoners?	☐	☒
6	Young offenders?	☐	☒
7	Those who could be considered to have a particularly dependent relationship with the investigator or a gatekeeper?	☐	☒
8	People engaged in illegal activities?	☐	☒
9	Others. Please indicate the participants below, and specifically any group who may be unable to give consent.	☐	☒
	Details of any other participant groups: (this box should expand as you type)		

	Participant numbers and source Provide an estimate of the expected number of participants. How will you identify participants and how will they be recruited?	
10	How many participants are expected?	For the purpose of this study, approximately 15 participants will be recruited. The questionnaire access will be closed after the desired number of participants have been reached. <i>(this box should expand as you type)</i>
11	Who will the participants be?	Participants will be adults aged over 18, who have been diagnosed with coeliac disease at least 6 months ago via endoscopy or blood tests. <i>(this box should expand as you type)</i>
12	How will you identify the participants?	Participants will be recruited through a special support group for people with coeliac disease on social media. Approval for the advertisement (see appendix 2) of the study that will be posted on social media will be sought from the academic director of Psychology and Counselling department, Associate Professor Dr Paul Hutchings. Approval from the administrator of the Facebook group has also been obtained. <i>(this box should expand as you type)</i>

	Information for participants:	YES	NO	N/A
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13	Will you describe the main research procedures to participants in advance, so that they are informed about what to expect?	☒	☐	☐
14	Will you tell participants that their participation is voluntary?	☒	☐	☐
15	Will you obtain written consent for participation?	☐	☒	☐
16	Will you explain to participants that refusal to participate in the research will not affect their treatment or education (if relevant)?	☐	☐	☒
17	If the research is observational, will you ask participants for their consent to being observed?	☐	☐	☒
18	Will you tell participants that they may withdraw from the research at any time and for any reason?	☒	☐	☐
19	With questionnaires, will you give participants the option of omitting questions they do not want to answer?	☒	☐	☐
20	Will you tell participants that their data will be treated with full confidentiality and that, if published, it will not be identifiable as theirs?	☒	☐	☐
21	Will you debrief participants at the end of their participation, in a way appropriate to the type of research undertaken?	☒	☐	☐
22	If NO to any of above questions, please give an explanation			
	As the study will be online based there will not be a provision for written consent to be obtained, however participants will be required to click on a number of statements including 'I consent to take part' that indicates their consent for participation. <i>(this box should expand as you type)</i>			

	Information for participants:	YES	NO	N/A
24	Will participants be paid?	☐	☒	☐
25	Is specialist electrical or other equipment to be used with participants?	☐	☒	☐

26	Are there any financial or other interests to the investigator or University arising from this study?	☐	☒	☐
27	Will the research activity involve deliberately misleading participants in any way, or the partial or full concealment of the specific study aims?	☐	☒	☐
28	If YES to any question, please provide full details			
	(this box should expand as you type)			

SECTION H: Anticipated Risks

	Outline any anticipated risks that may adversely affect any of the participants, the researchers and/or the University, and the steps that will be taken to address them.		
	If you have completed a full risk assessment (for example as required by a laboratory, or external research collaborator) you may append that to this form.		
1	Full risk assessment completed and appended?	Yes	☐
		No	☒
2	Risks to participants For example: sector-specific health & safety, emotional distress, financial disclosure, physical harm, transfer of personal data, sensitive organisational information		
	Risk to participants: 1. The topic area discussed in the questionnaire is of a sensitive nature as it will discuss a life-long health condition. While answering questions participants might feel upset or distressed.	How you will mitigate the risk to participants: 1. In line with UWTSD and BPS guidelines participants will be informed of the nature of the study. Participants will have the option not to continue after reading the information sheet and the consent form. The participants will be also informed that if at any point through study they feel upset and do	

		not want to continue with the study, they have the right to withdraw without penalty by simply closing their browser. They will be reminded that they do not have to answer any questions that they do not wish to and participants are also advised not to take part if they feel that answering the questions might cause them distress. The questions selected are chosen from previous studies in the topic area and have been selected to minimise the potential for distress.
	2. As the questions are all related to a life-long condition, participants may worry about their health while answering the questions.	2. In the debrief page it is acknowledged that answering the questions may make participants worry about their health and condition therefore it will be suggested that in this case, they should contact a health professional such as their doctor or dietitian. 3. Participants will be informed that there will be no personal data collected such as age, gender, name, etc. Participants will be asked not to include any of these data in their answers as if they do the researcher will not be able to include their answers in the study.

	3. Participants might worry about their personal data and that they would be identifiable by their answers. 4. As participants will be required to complete the questionnaire on Qualtrics, the researcher will not be present if there are any issues with the wording of the questions. 5. As coeliac-disease been correlated with anxiety and depression, the study might can be a trigger to some of the participants. <i>(this box should expand as you type)</i>	4. At the end of the study participants will be provided a debrief form. It will give contact details to the researcher and supervisor if they wish to discuss any of their concerns or questions regarding the study. They are also reminded that they can withdraw from the study at any point if they wish to do so. 5. Participants will be informed that if at any point during the study they feel uncomfortable or any of the questions raise any concerns they can withdraw from the study by closing their browser. It will be suggested that if they feel worried about their condition or mental health they should contact a healthcare professional such as their doctor or GP. <i>(this box should expand as you type)</i>
3	If research activity may include sensitive, embarrassing or upsetting topics (e.g. sexual activity, drug use) or issues likely to disclose information requiring further action (e.g. criminal activity), give details of the procedures to deal with these issues, including any support/advice (e.g. helpline numbers) to be offered to participants. Note that where applicable, consent procedures should make it clear that if something potentially or actually illegal is discovered in the course of a project, it may need to be disclosed to the proper authorities	

	N/A <i>(this box should expand as you type)</i>	
4	Risks to the investigator For example: personal health & safety, physical harm, emotional distress, risk of accusation of harm/impropriety, conflict of interest	
	Risk to the investigator: 1. The researcher may feel emotional distress while reading the answers of the participants, due to personal experience of Coeliac disease themselves. 2. As the email of the researcher will be provided there is a risk that the researcher will receive emails which are negative in nature. 3. There is also a risk of the researcher being accused of harm or impropriety by participants.	<i>How you will mitigate the risk to the investigator:</i> 1. The researcher chose their dissertation topic with a clear understanding of the nature of the study. The researcher will turn to their supervisor immediately with any concerns. 2. The researcher's university email address will be provided only, no personal details will be shared. If the researcher receives any emails that feel negative or unwelcomed the researcher will report this to their supervisor. 3. The researcher will follow the UWTSD and BPS research guidelines and codes of conduct. The study will not take place until the researcher receives full approval. If there is any accusations the researcher will immediately report this to their supervisor. 4. Any emails that will be sent to the researcher that they unable to answer

	4. As the researcher's email address will be provided there is a risk that they will be asked questions that is above their level of knowledge. 5. As the research will be aimed at a particular group and the link to the questionnaire will be distributed on Facebook there is a risk that the researcher will be contacted via Facebook messenger. <i>(this box should expand as you type)</i>	or deal with will be forwarded to their supervisor. 5. Participants will be asked to only contact the researcher regarding the study via the provided university email address. The social media settings will be set so that participants can not reply personally to the advertisement, they are only able to access the link within the ad, which takes them directly to the study. <i>(this box should expand as you type)</i>
5	University/institutional risks For example: adverse publicity, financial loss, data protection	
	Risk to the University: 1. The reputation and integrity of UWTSD could be endangered if the researcher do not follow the codes of ethics and research protocols. 2. Data could be exposed or leaked. <i>(this box should expand as you type)</i>	<i>How you will mitigate the risk to the University:</i> 1. The UWTSD Research and Ethics & Integrity Code of Practice and the BPS Code of Ethics and Conduct will be followed at every stage of the research and all participant responses will be treated professionally and respectfully at all times. 2. The researcher will use Qualtrics for the questionnaire and the data collected will be stored in line with UWTSD Research Data Management rules and only used for the purpose of

		this study. The data will be stored on the Qualtrics platform securely. <i>(this box should expand as you type)</i>
6	Environmental risks For example: accidental spillage of pollutants, damage to local ecosystems	
	Risk to the environment: N/A <i>(this box should expand as you type)</i>	<i>How you will mitigate the risk to environment:</i> N/A <i>(this box should expand as you type)</i>

	Disclosure and Barring Service			
	If the research activity involves children or vulnerable adults, a Disclosure and Barring Service (DBS) certificate must be obtained before any contact with such participants.	YES	NO	N/A
7	Does your research require you to hold a current DBS Certificate?	☐	☒	☐
8	If YES, please give the certificate number. If the certificate number is not available please write "Pending"; in this case any ethical approval will be subject to providing the appropriate certificate number.			

SECTION I: Feedback, Consent and Confidentiality

1	Feedback What de-briefing and feedback will be provided to participants, how will this be done and when?
	Participants will be directed to a debrief page following completion of the survey questions. The debrief page will include the purpose and the aim of the study and ensure that the

	participants are happy to submit their responses and remind them of the final opportunity to withdraw from the study. It will include the email address of the researcher and the supervisor if the participants have any questions or concerns regarding the study. It will also advise participants to contact their medical professional if they have any concerns regarding their condition. The debrief sheet will also include a link to the Coeliacs UK website for more information about Coeliac disease. <i>(this box should expand as you type)</i>
2	Informed consent Describe the arrangements to inform potential participants, before providing consent, of what is involved in participating. Describe the arrangements for participants to provide full consent before data collection begins. If gaining consent in this way is inappropriate, explain how consent will be obtained and recorded in accordance with prevailing data protection legislation.
	Upon clicking the link to the study, participants will be first taken to an information page that explains the nature of the study and what will the study involve. Examples of the questions will also be included on the page. Following the information page, participants will next be presented with a list of statements to indicate their understanding of the study and their consent to take part. If they agree to each of the statements, they will then be required to click on a `next` button, which will take them into the main part of the survey. They will be informed that this is their consent to take part. <i>(this box should expand as you type)</i>
3	Confidentiality / Anonymity Set out how anonymity of participants and confidentiality will be ensured in any outputs. If anonymity is not being offered, explain why this is the case.
	The link to the questionnaire will be distributed on the Coeliac social support social media page. In the post the researcher will ask everyone who is willing to participate in the study not to comment under the post that they have participated to ensure the anonymity of the participants. Participants will be informed that there will be no personal data collected through the study and only the researcher and the supervisor will have access to their data. Participants will be also asked not to include any personal details in their answers that can

	lead potentially lead back to them. All data will remain confidential and will be only used for the purpose of this study. <i>(this box should expand as you type)</i>
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SECTION J: Data Protection and Storage

	Does the research activity involve personal data (as defined by the General Data Protection Regulation 2016 “GDPR” and the Data Protection Act 2018 “DPA”)?	YES	NO
1	“Personal data” means any information relating to an identified or identifiable natural person (‘data subject’). An identifiable natural person is one who can be identified, directly or indirectly, in particular by reference to an identifier such as a name, an identification number, location data, an online identifier or to one or more factors specific to the physical, physiological, genetic, mental, economic, cultural or social identity of that natural person. Any video or audio recordings of participants is considered to be personal data.	☒	☐
	If YES, provide a description of the data and explain why this data needs to be collected:		
2	Qualtrics provides an unique identifier for each participant, which will be deleted and replaced by a pseudonym once the information is extracted from Qualtrics into Microsoft office 365. <i>(this box should expand as you type)</i>		
	Does it involve special category data (as defined by the GDPR)?	YES	NO
3	“Special category data” means sensitive personal data consisting of information as to the data subjects’ – (a) racial or ethnic origin, (b) political opinions, (c) religious beliefs or other beliefs of a similar nature,	☐	☒

	(d) membership of a trade union (within the meaning of the Trade Union and Labour Relations (Consolidation) Act 1992), (e) physical or mental health or condition, (f) sexual life, (g) genetics, (h) biometric data (as used for ID purposes),		
	If YES, provide a description of the special category data and explain why this data needs to be collected:		
4	 (this box should expand as you type)		

	Will data from the research activity (collected data, drafts of the thesis, or materials for publication) be stored in any of the following ways?	YES	NO
5	Manual files (i.e. in paper form)?	☐	☒
6	University computers?	☐	☒
7	Private company computers?	☐	☒
8	Home or other personal computers?	☐	☒
9	Laptop computers/ CDs/ Portable disk-drives/ memory sticks?	☒	☐
10	“Cloud” storage or websites?	☒	☐
11	Other – specify:	☐	☒
12	For all stored data, explain the measures in place to ensure the security of the data collected, data confidentiality, including details of backup procedures, password protection, encryption, anonymisation and pseudonymisation:		

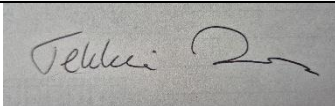
	All data will be anonymous. The data will be stored in the researcher's Qualtrics account that is under password protection. Qualtrics data will be downloaded onto the researcher's laptop what is under password protection. The data and dissertation materials will be stored on the researcher's university OneDrive account which is password protected. . <i>(this box should expand as you type)</i>
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Data Protection			
	Will the research activity involve any of the following activities:	YES	NO
13	Electronic transfer of data in any form?	☒	☐
14	Sharing of data with others at the University outside of the immediate research team?	☐	☒
15	Sharing of data with other organisations?	☐	☒
16	Export of data outside the UK or importing of data from outside the UK?	☐	☒
17	Use of personal addresses, postcodes, faxes, emails or telephone numbers?	☐	☒
18	Publication of data that might allow identification of individuals?	☐	☒
19	Use of data management system?	☐	☒
20	Data archiving?	☐	☒
21	If YES to any question, please provide full details, explaining how this will be conducted in accordance with the GDPR and Data Protection Act (2018) (and any international equivalents, where appropriate): Qualtrics data will be downloaded to the researcher's password-protected personal laptop and stored in the researchers university password protected OneDrive account. The final dissertation will be shared with UWTSD academic staff in a form of written thesis and a presentation. <i>(this box should expand as you type)</i>		
22	List all who will have access to the data generated by the research activity:		
	Zsuzsanna Telekesi (researcher)		

	Karen Eaton-Thomas (supervisor) <i>(this box should expand as you type)</i>
23	List who will have control of, and act as custodian(s) for, data generated by the research activity:
	Zsuzsanna Telekesi (researcher) <i>(this box should expand as you type)</i>
24	Give details of data storage arrangements, including security measures in place to protect the data, where data will be stored, how long for, and in what form. Will data be archived – if so how and if not why not.
	The data will be stored in the researcher's Qualtrics account that is under password protection. Qualtrics data will be downloaded onto the researcher's laptop what is under password protection. All data and dissertation materials will be stored on the researcher's university OneDrive account. Once the final report for the Psychological Empirical project has been confirmed by external examiners all of the data will be deleted from the researcher's personal laptop and OneDrive account. Data storage will follow the UWTSD Research Data Management Policy. <i>(this box should expand as you type)</i>
25	Please indicate if your data will be stored in the UWTSD Research Data Repository (see https://researchdata.uwtسد.ac.uk/). If so please explain. <i>(Most relevant to academic staff)</i>
	It will not be stored in the UWTSD Research Data Repository. <i>(this box should expand as you type)</i>

26	Confirm that you have read the UWTSD guidance on data management (see https://www.uwtSD.ac.uk/library/research-data-management/)	YES	☒
27	Confirm that you are aware that you need to keep all data until after your research has completed or the end of your funding	YES	☒

SECTION K: Declaration

	The information which I have provided is correct and complete to the best of my knowledge. I have attempted to identify any risks and issues related to the research activity and acknowledge my obligations and the rights of the participants. In submitting this application I hereby confirm that I undertake to ensure that the above named research activity will meet the University's Research Ethics and Integrity Code of Practice which is published on the website: https://www.uwtsd.ac.uk/research/research-ethics/		
1	Signature of applicant:		Date: 20.10.2024

For STUDENT Submissions:

2	Director of Studies/Supervisor:	Karen Eaton-Thomas	Date: 23.10.2024
3	Signature:	K. M. Eaton-Thomas	

For STAFF Submissions:

4	Academic Director/ Assistant Dean:		Date:
5	Signature:		

Checklist: Please complete the checklist below to ensure that you have completed the form according to the guidelines and attached any required documentation:

☒	I have read the guidance notes supplied before completing the form.
☒	I have completed ALL RELEVANT sections of the form in full.
☒	I confirm that the research activity has received approval in principle
☐	I have attached a copy of final/interim approval from external organisation (where appropriate)

☐	I have attached a full risk assessment (where appropriate) <i>ONLY TICK IF YOU HAVE ATTACHED A FULL RISK ASSESSMENT</i>
☒	I understand that it is my responsibility to ensure that the above named research activity will meet the University's Research Ethics and Integrity Code of Practice.
☒	I understand that before commencing data collection all documents aimed at respondents (including information sheets, consent forms, questionnaires, interview schedules etc.) must be confirmed by the DoS/Supervisor, module tutor or Academic Director.

RESEARCH STUDENTS ONLY

Once complete, submit this form via the **MyTSD Doctoral College Portal** at (<https://mytsd.uwtsd.ac.uk>).

RESEARCH STAFF ONLY

All communications relating to this application during its processing must be in writing and emailed to pgresearch@uwtsd.ac.uk , with the title 'Ethical Approval' followed by your name.

STUDENTS ON UNDERGRADUATE OR TAUGHT MASTERS PROGRAMMES should submit this form (and receive the outcome) via systems explained to you by the supervisor/module leader.

APPENDICIES

Appendix 1 – Questionnaire (online – free text)

Please take your time to read the following questions that relate to your diagnosis of Coeliac disease. You are free to write as much or as little as you wish and you can leave out any questions that you do not wish to answer. The box will expand as you type your answers and there are no time or word restrictions. Thank you in advance for your time.

1. Following a gluten free diet can be difficult at times, what are your **thoughts** about this?
2. In your own words, could you tell me why adhering to a gluten free diet is so **important** to someone who is diagnosed with Coeliac Disease?
3. What are the main reasons that **motivate** you to adhere to a gluten free diet?
4. Friends and family can be a source of social support and help you to manage your Coeliac condition. Could you describe the **support** that you receive from family and friends in helping you manage your condition?
5. Thinking about when you meet **new people**, for example going out for a meal with new work colleagues, how would you make them aware of your diagnosis in conversation?
6. How do you **feel** when talking about your condition with other people?
7. Gluten is contained in many food products, how would you describe your **knowledge** of gluten containing foods?
8. How difficult is it for you to **avoid** eating food which contains gluten?
9. Can you recall any particular **circumstances** where you have eaten food containing gluten, and if so, what was the reason for doing so?
10. What do you think contributes the most to **poor adherence** to a gluten-free diet?

Questions adapted from Sailsbury and Mullan (2011) and Dowd et al. (2013).

Appendix 2 – The advertisement that will be posted on the social media support group

Dear Group Members,

I am a final year Applied Psychology student at UWTSD Carmarthen and am currently working on my dissertation which is exploring the psycho-social factors that contribute to the adherence of a gluten-free diet for people diagnosed with Coeliac disease.

Participation in this study is completely voluntary, anonymous and confidential. The study has obtained ethical approval from the UWTSD Ethics Committee. To participate you must be over 18 years old with a formal diagnosis of Coeliac disease.

If you feel that you would like to participate, please click on the link below where you will find more information about this study. If you have any questions, please contact me at 2203653@student.uwtsd.ac.uk.

Appendix 3 – Information page that will be presented before the consent page and the questionnaire

Information sheet

This document provides important information about the study so please read it carefully before you consent to participate in the study.

This study is conducted by a level 6 Applied Psychology student for their dissertation.

The title of the study is: An exploration of psychosocial factors that may contribute to adherence to a gluten-free diet (GFD) in individuals diagnosed with Coeliac disease.

The purpose of the study is to explore the factors that affect the adherence to a gluten-free diet in individuals who have been diagnosed with Coeliac disease.

In order to take part in this study you have to be over 18 years old on the day when you fill out the questionnaire and have had a formal diagnosis of Coeliac disease.

The questionnaire involves reading and answering 10 questions that ask you about your experience of following a gluten free diet. You can write as much or as little as you wish, and you can skip any questions that you do not want to answer. An example of one of the questions is as follows:

“What are the main reasons that **motivate** you to adhere to a gluten free diet?”

The study should take no longer than 15 minutes and any responses that you provide will be completely anonymous and be stored confidentially under GDPR guidelines and UWTSD Research Data Management Protocols. You will not be asked to provide any personal details or information that could be used to identify you.

You also have the right to withdraw from the study at any point by closing your browser, and your data will not be stored. At the end of the questions, you will be directed to a debrief page and offered a final opportunity to withdraw, or alternatively to submit your responses.

If you decide to submit your answers, after this point there will be no way to identify your answers, therefore you will not be able to withdraw your data after this point. Following the completion of the Dissertation and the relevant examination board, all stored data will be deleted.

Because of the nature of the study, questions might be upsetting or raise concerns for some individuals. Therefore if you think that answering these questions will cause you distress, please do not continue with the study and close your browser now.

Additionally, if at any point during the study, you begin to feel uncomfortable or have concerns about the questions please close your browser and do not continue.

If you have any questions about the study, please use the email addresses provided below.

Finally, on completion of the questions you will be taken to a debrief page, where a full explanation of the study will be provided, along with a copy of the email addresses provided below.

If you would like to participate in the study, please proceed to the consent form.

Appendix 4 – Consent form for the study that will be presented after the Information page and before the questionnaire.

Consent to participate in the study

Please read the following statements and IF you agree to them tick the circle alongside each one.

I understand that the study is being carried out by a level 6 Applied Psychology student for their dissertation to explore the factors that affect the adherence to a gluten-free diet ☐

I understand that my participation in the study is voluntary, anonymous and confidential ☐

I understand that I have the right to withdraw at any point during the questionnaire by closing my browser and I do not have to give any reason or explanation ☐

I also understand that after submitting my answers there is no way to identify my data therefore there is no way for me to withdraw it after that point ☐

I am aware that the questions will ask me about my condition therefore they can be upsetting. If any of the questions make me feel uncomfortable or upset, I am aware that by closing my browser, I can leave the study and withdraw my data ☐

I understand that after answering the questions I will be provided with a debrief sheet that will include further information and contact details to the ☐

researcher if I have any questions or concerns about the study that I would like to discuss

I understand that the researcher NOT a medical professional therefore they are not in a position to advise me about coeliac-disease or gluten-free diet adherence ☐

I agree to take part in this study conducted by Zsuzsanna Telekesi, Psychology and Counselling, University of Wales Trinity Saint David, Carmarthen, under the supervision of Karen Eaton-Thomas ☐

I understand that by clicking the `arrow` to enter the survey, I am providing my consent to take part in this study ☐

Appendix 5 – Debrief sheet that will be presented after filling out the questionnaire.

Debrief sheet

Thank you for taking part in this study!

The aim of the study was to explore what are the factors that can affect the adherence to a gluten free diet in individuals who have been diagnosed with coeliac disease. Currently there is limited research exploring the psychosocial reasons that influence why (or why not) individuals adhere to a gluten free diet. This study aimed to apply psychological theory to help understand why some individuals manage their condition well and others may struggle. Apart from following a gluten free diet, there is little in the way of treatment for Coeliac sufferers, therefore gaining a deeper insight into how this could be managed is important.

If you feel the study raised any concerns about your condition please contact your GP, consultant or dietitian for medical advice.

If you have any queries about the study, please contact the researcher:

Zsuzsanna Telekesi via email 2203653@student.uwtsd.ac.uk

Or the supervisor: Karen Eaton-Thomas via email k.eatonthomas@uwtsd.ac.uk

For more information about Coeliac-Disease please visit the Coeliac UK website [Home - Coeliac UK](#).

If you are happy to your answers to be saved, please click on 'Submit', or if you decide to withdraw from the study, please close your browser now!

Thank You again for taking time to participate in the study!

Zsuzsanna Telekesi

BSc Applied Psychology, UWTSD

Appendix B – Responses

Difficult but essential

Gluten causes damage to the gut

I am physically ill if I eat gluten

They understand it's necessary and will always make sure there is gluten free food available

I just tell them I need to eat gluten free

Comfortable

Getting better, important to read labels as it's in lots of things, you can't just assume it's gluten free

Not very, there's not two of us in the house so our main meals are always gluten free

Friends house and it was cross contamination due to shared cooking utensils

Availability and cost of gluten free products such as pasta or bread

It be adapted how I cook at home but it's challenging to eat out

Because the immune system will damage the lining of the small intestine if you eat gluten

Because the low ferritin caused by being an undiagnosed coeliac negatively impacted my life and I have been advised to do so by my doctor

My husband has adapted many recipes to make them gluten free and eats gluten free when he is with me and always brushes his teeth if he has had gluten so he can kiss me. My family use a separate worktop and fridge. My dad sent me a free from recipe book for my birthday. My friends do gluten free food at parties and make sure food isn't cross contaminated in their homes when I eat there.

I'm coeliac I can't eat gluten

Fine

Expansive as I have done a lot of research

Not at all I just don't

Only once, some pickled onions right at the start and because I forgot about malt vinegar. I haven't eaten anything with gluten in since

I have kept to a strict gluten free diet since diagnosis so I wouldn't know. I just stopped eating gluten overnight and haven't since

Fairly easy at home but socially it is extremely hard

The damage done by gluten to someone with coeliac disease is very unpleasant

To protect my health and to be able to function with normally daily living

Nobody in my circle have coeliac disease and therefore are not overly understanding or sympathetic to my condition

Id explain to them about my coeliac disease but would still feel awkward knowing that they dont understand really.

Incredibly awkward - as if im just being fussy

Very good now but very poor when initially diagnosed

I chose not to eat unless 100% confident

Never intentionally after diagnosis

Silent symptoms and lack of social awareness

i think it's difficult in a social setting when everyone can order whatever they want without thinking bud i'd have to plan ahead and ask loads of questions or miss out however it's usually fine when at home alone

because if you don't, each time you digest the gluten it damages your body a tiny bit and means that your body doesn't require the nutrients it needs to grow and develop your body

i feel so much better when i've not eaten it, i'm not bloated and my hair and skin are so much healthier

my family are aware and then i can live at ease in my house without fear of being accidentally glutened, my friends are aware of the condition and are patient when deciding where to eat

when deciding a place to eat i would give options of places i knew were safe and then say why i would prefer to eat then hope they understand

generally fine however it frustrates me when people don't try to understand what the condition is and how it will affect me

my knowledge is generally good, gluten in foods is often the actual ingredients like flour in a cake but also flour to thicken a liquid or stretch out ingredients. the things i tend to forget to check are things like vitamins or cheese etc

usually relatively easy but with the cost of living etc a lot of companies use flour to stretch out the batch to make the cost cheaper and will make all of their products in the same factory which is a cross contamination risk

until i was around 17 i didn't really care about what i ate and it was just easy to eat a full meal at school without having to check what was in it but when i cut it out and stopped eating it. after that i have only eaten it accidentally

school / ease of eating a meal deal or food on the go that is actually nutritious

It is difficult at celebration times of the year, holidays and when you are travelling, as there are few options available. However, it isn't impossible. It feels very unfair when shopping you can see so much food which is unavailable to you, and such a tiny section of things that are. Often GF foods are nasty and unpalatable, so causing waste. It also difficult because often it is thought of as a fad diet, or that you are just difficult.

The outcome of not staying gluten free is pain, discomfort, a lack of cognitive ability, anxiety, muscle pain, even if you have only digested a crumb. Also, the damage this will cause internally can shorten your life.

To keep healthy and functioning in life.

My husband is happy to eat gluten free, but does have his own bread, toaster, and snacks. However, sometimes he can be careless and not fully understand when I am firm about these situations. My married children don't really think about it, and rarely cater for me at any occasions, feeling I should be responsible for my own nutrition and needs.

I don't eat out with new people generally. However, in the past, I found I was left out (uninvited) of these sort of gatherings once I had explained my situation.

Uncomfortable

Good, it's been a very long time to learn. I have further intolerances which further restrict my diet.

Not difficult as I rarely eat out, and cook from scratch at home. Holidays pose a difficulties, but I never gain weight on a holiday

This has only happened to me when a reliable source has changed their ingredients without notification (health bars) or cross contamination.

Feelings of being singled out or made to feel that you are being difficult.

I think it can be difficult to find suitable options or to always feel different to others but I don't find it difficult to adhere to the diet as I understand the consequences.

To prevent damage to the small intestine which can lead to life limiting illnesses such as cancer and organ failure as well as other impacts such as osteoporosis, infertility and a whole host of short term symptoms that differ for individuals.

Personally it is to maintain my quality and longevity of life as well as the immediate impacts it has if I eat gluten. I get extremely unwell almost immediately but have also had to nurse my mother to her death from liver failure as a direct result of not following a gluten free diet after being diagnosed as coeliac.

My friends will always make sure I am catered for or let me choose where we eat. I also now have some gluten free friends which is incredibly helpful. I don't have any family but my husbands family can be problematic as they still don't understand it or make much effort to keep me safe.

I would raise it when appropriate and explain what it means. Usually in a general conversation about food or visiting somewhere. If my work had arranged to go out for food I just wouldn't go if it was somewhere I couldn't eat.

Mostly fine but I also get fed up of being different.

Excellent

Not at all - I find it easy to avoid foods containing gluten. I don't allow it in my house and am always prepared if out.

It has happened 3 times since diagnosis. The first was when a hotel swapped gf pasta for normal pasta and served it to me. The second was due to cross contamination at my in laws. The third was being given the wrong food at a restaurant despite questioning it multiple times.

Understanding of the consequences, feeling embarrassed or different and the costs of gf replacement food. I also think there is a lot of ignorance in our community about how much food is naturally gluten free and I don't think people cook as much at home as they used to, preferring to rely on convenience food. Personally I love cooking and turning recipes into a gf option.

It is often difficult but necessary. I feel the psychological element is often harder than the reality. There is usually gluten free food available to me but I often find it is not what I want, is limited in choice and I feel I'm missing out. This sometimes gets me down.

Coeliac Disease can cause short term symptoms but also long term damage.

Long term damage worries me.

My friends and family are understanding and know the risks. My children who are 20 and 19 are great in accepting we are now a GF household even though they don't have CD. My non-resident partner is also thoughtful as are most friends. Some people are less so, such as colleagues and acquaintances

I say I have Coeliac Disease and that I can't eat gluten because it will make me extremely ill and cause long term damage

Mostly ok but I sometimes worry people think I'm going on about it or exaggerating its severity. I get sick of explaining it too.

Very good, I did a lot of research when first diagnosed.

Not that difficult at home. I miss certain snacks and it annoys me that I can't always find GF versions, and that GF versions when available are so expensive, full of additives, poor quality and not always great tasting. Takeaways, meals out and on the go food is harder. I miss the spontaneity as I now have to research every option, double-check, explain my condition etc.

I was served the wrong dessert in a restaurant once. I've not eaten gluten knowingly.

Lack of knowledge and crosscontamination perhaps, but probably mostly not wanting to follow it because it is a bit depressing sometimes.

Yeah it can be quite difficult when I want to eat something but it isn't gluten free.

It's really important since if you were to have something which is not gluten free then you could get very ill and won't be a nice feeling.

The main thing is I don't want to be ill and it's not too bad food either.

Well, my family help me give me recipes to cook and make gluten free food which is really nice and tasty!

I firstly tell them that I have coeliac disease so they are aware of my allergy.

I don't really mind it I just want to make them aware.

Well, my knowledge on what I can and can't have is quite good and I can always check the ingredients on the food to check if it's fine to eat or not.

It's not quite difficult at all since I have had this allergy/disease for a while now.

I can't recall any moment that I ate food containing gluten.

Something that contributes is enjoying making new food to try or just having fun cooking gluten free food so you enjoy and keep to the diet.

Incredibly difficult because I know what normal pastry, pies, sausage rolls, cakes, pasta, Walkers crisps, Pringles, dry roasted peanuts taste like. There isn't a gf substitute that can mimic or taste like normal bread etc. Also, gf ingredients are extremely expensive to buy. You have to bulk buy on the internet to avoid the packaging and postage and still it's expensive. Manufacturers of naturally gf products like dried lentils, chickpeas, buckwheat, tapioca, Cadburys chocolate, to name but a few warn us that it 'may

contain gluten' due to the factory processes!!! I would like gf foods to be more affordable. Manufacturers to rethink their production lines so that naturally gf foods remain gf. Also, that food manufacturers substitute wheat flour to a gf equivalent.

Maintaining a gluten free diet is essential as it is the only treatment for me, there is no medication for being Coeliac. My digestive system cannot process gluten if I did it would degrade the lining of my small bowel and lead to bloating, constipation, unbearable colic pains. Poor absorption of vitamins etc. It could lead to a perforated small bowel or cancer.

To be pain free, have normal bowel motions, feel well and confident in myself.

They are supportive when eating out that they make sure there is gf options for me. My husband tries to tidy up in the kitchen to avoid cross contamination.

I think most are aware that there are people that have different dietary needs. I would be open about being Coeliac.

I feel fine.

I'm aware of gluten warnings on food products, barley vinegars, wheat, rye, spelt etc.

It can be difficult at times, but I do carry a gf snack with me just in case.

No I cannot recall I avoid gluten at all costs.

I imagine it's down to the texture and taste of gf breads, scones, pies, pasta etc. The substitute flours can be gritty due to the rice flour, and when eaten can leave your mouth feeling dry and the food tends to stick in between your teeth. This doesn't happen with normal baked goods.

It can be really difficult when out and about or going to restaurants but I think you get used to it. It must be harder for children and teens I think.

If I have even a breadcrumb of gluten I immediately get D&V, fever, sweating, pain. Also even if you don't have a reaction like that it's an auto immune disease so you'll do damage to your body by eating gluten

The D&V can and will hospitalise me

My Mum's also a coeliac so my Dad and my partner have become experts at cooking gluten free. My friends are really good at checking for GF options when we eat out

I'd tell them when a meal is suggested

Very comfortable, doesn't bother me at all

Very good - gluten is hidden everywhere though

Quite difficult but becomes easier when you've been doing it for a long time

Not intentionally, last time I did by accident was about 5 years ago and was wiped out for 4 days unable to leave the bathroom

Lack of knowledge about foods containing gluten, lack of understanding about how it affects your body, if people's reaction to gluten poisoning isn't as bad they may think "oh just this once" etc

It is frustrating but it is what's best for my health

People don't realise how serious the effects of coeliac disease can be. I've been extremely sick before just from cross contamination, so avoiding all BROWS is essential.

I don't feel ill all the time if I keep my diet gluten free

My close family and friends are extremely thorough and triple check all labels and actively work to avoid any cross contamination.

Always one of the first things I tell people!

Like a burden if I'm completely honest

I am pretty clued up on everything I know mostly what is safe and what is that

It's quite easy but it can be difficult if we are out and about

I had to eat gluten before having my bloods tested for coeliac disease. It was horrific!
people not being educated enough about it

Since diagnosis I follow as strict diet the difficulty I find it trusting the understanding of the seriousness when it comes to friends and family and when eating out

Apart from the adverse reaction of the were to consume the tiniest amount of gluten is the health issues that can be detrimental if it is not followed

Adverse reactions and detrimental health issues if I didn't

My immediate family understand and try their best to support but I find my wider family and friends understanding is limited they sometimes make me feel I'm over exaggerating or that it isn't that serious and on a lot of occasions specially when going out I feel that I'm a hinderance because I'm limiting the place we can go to eat or celebrate

I tell them I'm coeliac and need to follow a strict gf diet

Tiresome

I have no option to be extremely knowledgeable since diagnosis before hand I would have not had a clue

After so many years easy at home hard out due to possible cross contamination

Never unless accidentally been gluten by someone else's mistake

If someone was not clue up on long term effects or if they had no symptoms when eating gluten

Not difficult at all. Much easier than 10 years ago. Slightly difficult if you want a day out tho, as not much available.... but I KNOW that b4 i go

If i don't, I'm ill. Today stomach upset within 10 mins, itchy for 2 days, banging headache for 2-3 days

I have coeliac disease

Zero help

Tell them beforehand, and if nobody listens, or I think the place is unsuitable, then I won't go

Fine

Fab

Not difficult...i can read

Only at restaurant when they didn't understand contamination

Lack of brains

Its much easier now than it used to be

The side effects of gluten poisoning can be devastating. I was erroneously diagnosed with bipolar disorder

To avoid a manic episode

Zero. They were totally unsympathetic. I was a nuisance

I speak directly to the waiter stating I have Coeliac disease

There is greater understanding now and usually they know or have a relative with the condition.

Comprehensive

At home, Not difficult at all, when out its a minefield .

Many times. It was always a mistake by the kitchen and often backtracked to foreign food handlers

Ignorance of the importance by food handlers

It can be very difficult at times because of availability of food, being different especially when out. Not being able to eat the foods I used to enjoy and watching others eat things

If you have coeliac it is important to stick to the diet in order for your stomach to heal and then remain healthy. It's important so that you are able to absorb the nutrients that you need to be and feel healthy. To stop you developing other diseases and disorders associated with poor diet such as weak bone and having higher risks of cancer

Feeling unwell when eating gluten. Wanting to increase my other vitamin levels. Not wanting to develop other diseases

My partner is greta. They eat gluten free at home with me most of the time. My mum also has coeliac so is a help with getting ideas and encouragement to keep to the diet.

If talking about food I would be open and say o can't eat certain foods early on however would only say that if talking about food. I am also allergic to peanuts so am more open about that big tell people on the back of telling them about nut allergy.

I'm ok with talking about it. I feel better now I don't eat gluten so is a motivated. It doesn't really worry me to tell people about it. If just frustrated me if someone the. Thinks I'm making a choice to not eat it and therefore wouldn't matter if I had a little of something that has been contaminated.

Yea lmy knowledge is quite good. I understand it well.

It's difficult on a daily basis so shoo mainly is M&S ad they label the food well. However I stick to the same foods that I know are ok. If I'm going out again stick to similar foods.

I haven't out if choice but had some recently in hospital because they gave me the wrong porridge. I also eat something whilst out but the rest isn't didn't prepare the foods well.

Feeling unwell if I eat gluten.

Appendix C – Examples of codes sorted in themes

Negative emotions linked to being coeliac

A word cloud featuring various negative emotions and experiences. The words are arranged in a roughly circular shape, with some words being larger and more prominent than others. The colors of the words include shades of red, orange, yellow, green, and blue. The words include: frustrating, being different, awkward, hinderance, ashamed, fed up, they don't care, depressing, tiresome, left out, difficult, being singled out, sick of explaining, exaggerating, gets me down, and embarrassed.

frustrating
being different
awkward
hinderance
ashamed
fed up
they don't care
depressing
tiresome
left out
difficult
being singled out
sick of explaining
exaggerating
gets me down
embarrassed

The safety of the home and the difficulties of out and about

not what I want
 crosscontamination
 difficult when out
 have to cater for myself
 holidays are difficult
 difficult out and about
 ignorance by food handlers
 easier at home
 difficult on the go
 GF household
 minefield
 they don't understand
 difficult out and about
 travelling
 limited choice
 cost of living

Motivations to follow a GF diet

protect health
 I feel better
 hospitalised
 being ill
 immediate effects
 very ill
 to avoid manic episode
 pain free
 physically ill
 health issues
 don't want to be ill
 keep healthy
 seeing someone die
 consequences of not staying gf
 damages your body
 long term damage
 long term effects
 prevent damage
 silent symptoms

Others' perceptions of coeliac disease

A word cloud representing various perceptions of coeliac disease. The words are arranged in a cluster, with some being larger and more prominent than others. The colors of the words include shades of pink, blue, green, and purple. The text includes:

- my kids don't care
- ignorance
- lack of education
- my husband is great
- understanding
- my family is great
- people don't realise
- they don't understand
- they are unsympathetic
- they don't realise how serious
- not enough education
- zero help
- they don't think it's serious
- no coeliac friends
- no understanding
- lack of brains
- I was left out