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Nutritional knowledge, eating habits and Quality of Life of coeliac disease patients

Purpose: Coeliac Disease (CD) is a lifelong autoimmune disorder and is managed with a strict gluten-free diet. At diagnosis, an individual's nutritional status is affected by how long CD has been active, their dietary intake, intestinal inflammation, and degree of malabsorption. This study explores if age and time since diagnosis affect nutritional knowledge, eating habits and emotional wellbeing of participants.

Methodology: An online survey using Qualtrics was conducted. The survey consists of 4 sections exploring (i) demographics, (ii) nutritional knowledge, (iii) eating habits and (iv) Quality of life (QoL). A total of 162 valid questionnaires were completed.

Findings: Those who'd been diagnosed for more than 5 years demonstrated better knowledge about gluten-free or gluten containing products. Social interactions are limited by concerns about becoming ill, unwanted attention, and increased financial costs. Eighty-eight % of participants would go hungry at social events. Those aged between 40 – 59 and above 60 years felt more financially restricted compared to younger adults ($\chi^2(4)=10.73$, $p=0.01$). Strong emotions were experienced by participants since diagnosed with CD. Anxiety, feelings of concern, sadness, depression, and fear have declined and happiness, confidence and being accepting of coeliac disease have increased since diagnosis across all years.

Originality: This study is one of the first few studies to investigate time since diagnosis and age-related differences in nutritional knowledge, eating habits and QoL of adults diagnosed with CD. Over time, negative emotions could potentially be alleviated with improved knowledge and experience.

Keywords: coeliac disease; eating habits; gluten-free; nutrition; Quality of life

Introduction

Coeliac Disease (CD) is a lifelong autoimmune disorder which can develop at any age. Currently one in 100 people in the UK are diagnosed with CD, with an estimated 500,000 undiagnosed cases (Coeliac UK, 2018a). CD damages the small intestine of genetically susceptible individuals when exposed to gluten (Lebwohl *et al.*, 2018). Common physical symptoms include, diarrhoea, constipation, anaemia, stomach cramps, chronic fatigue, and weight loss (NICE, 2015). Less typical manifestations include migraine, headaches, iron deficiency anaemia, skin rashes and bone disease (Rubio-Tapia *et al.*, 2013). New drug therapies based on increased understanding of the pathogenetic process of CD are underway, offering hope for future CD management (Kivela *et al.*, 2020). Currently, strict dietary exclusion of all foods containing gluten is the only treatment currently available (Ciacci *et al.*, 2015).

At diagnosis, an individual's nutritional status is affected by how long CD has been active, their dietary intake, intestinal inflammation, and degree of malabsorption (Theethira *et al.*, 2014). Post-diagnosis unintended weight gain and elevated cholesterol levels may occur because of intestinal healing and improved absorption (Welstead, 2015). Common nutritional inadequacies exist at diagnosis. Whilst some vitamin and mineral deficiencies are eliminated post-diagnosis, new deficiencies occur, excess fat intake continues, sugar intake increases, and dietary fibre and protein intake are low (Melini and Melini, 2019). In Miranda *et al.* (2014), non-gluten and gluten containing foods were compared: unfavourable differences in nutritional content were found in gluten-free (GF) foods, with higher levels of saturated fats, and lower levels of protein and fibre in non-gluten breads and pasta. When maintaining a GF diet, lack of vitamin and mineral fortification in non-gluten containing products poses a nutritional risk and increases the need for a diet rich in fruit, vegetables, nuts, seeds, meat, fish and poultry to ensure sufficient dietary requirements are achieved (Welstead, 2015). Vici *et al.* (2016) found that necessary avoidance of several grains, naturally rich in fibre, and consumption of alternative GF products made from refined flours, contributed to poor fibre intake. The inclusion of potentially unfamiliar alternative grains (AG) to diversify diet and meet nutritional needs, would require knowledge and education to raise awareness and consumption (Laheri and Soon, 2018).

Whilst excellent nutritional knowledge and eating habits are essential, and support groups helpful (Coeliac UK, 2019a), there are other reasons why people with CD struggle, notably the mental burden of day-to-day coping with dietary restriction and fear of gluten contamination (Zingone *et al.*, 2015). There are increased levels of lifetime depression amongst some people with CD, including those who practice intentional strict GF dietary adherence (van Hees *et al.*, 2013). Whilst strict adherence to a GF diet increases the chance of physical recovery, it may contribute to higher levels of anxiety and depression (Ludvigsson *et al.*, 2018). Causal links may include social anxiety (Addolorato *et al.*, 2008), fear of food contamination (Zarkadas *et al.*, 2013), and poor nutritional content (Staudacher, 2015). After diagnosis, patients may feel overwhelmed as they come to terms with the disease. This was evidenced by Zarkadas *et al.* (2006) who found lower QoL for patients in the first year after diagnosis due to greater burden to the newly diagnosed CD patient. Whilst following GF diet, patients may be overloaded with dietary information and preventative strategies to avoid gluten (Ciacci *et al.*, 2015). White *et al.* (2016) report higher costs, poorer palatability and reduced enjoyment of GF foods negatively impact psychological wellbeing. Zysk *et al.* (2018) found that the economic status of a CD patient was one of the main socio-demographic influencing. Low economic status led to lower QoL in social and emotional fears and worries. As GF products are more expensive (Singh and Whelan, 2011), this may be burdensome for low income CD patients.

In self-reported GF dietary adherence, perceived health, vitality, and Quality of Life (QoL) was reduced, despite purported compliance (Hallert *et al.*, 2003). Eating a separate diet to others, dealing

with un-informed catering staff, and constantly questioning the GF status of foods, imposes social restrictions, limits foreign travel, contributing to increased anxiety (White *et al.*, 2016). The symptoms of CD may therefore have a physical aetiology, e.g., malabsorption caused by a failure to achieve full physical intestinal recovery (Paarlahti *et al.*, 2013), nutritional deficiencies caused by dietary inadequacy (Shepherd and Gibson, 2013), and manifestations of a psychosocial disturbance caused by constant dietary vigilance (Ludvigsson *et al.*, 2018). Negative attitudes towards following the GF diet may harm an individual's relationship with food, leading to disordered eating habits (Satherley *et al.*, 2015), adversely impacting their QoL. When enjoyment of food is impaired, psychological distress and reduced QoL can be observed (Satherley *et al.*, 2018). Following new dietary practices, not being able to eat out, having to read food labels, and a lack of dietary alternatives contribute to the difficulties diagnosed people face (Araujo and Araujo, 2012).

In "extreme dietary vigilance" amongst both teenagers and adults, there were lower reported energy levels, greater fatigue, and lower QoL scores than for those less vigilant (Wolf *et al.*, 2018b). By contrast, according to Marsilio *et al.* (2020), adherence to the GF diet resulted in higher QoL scores, but a significantly higher percentage of non-adherent participants reporting low scores for dysphoria. Notably, and of great concern, the greater the perceived burden of living with CD, the poorer adherence to the GF diet (Shah *et al.*, 2014). Adherence to the GF diet is influenced by several factors, including age at diagnosis and knowledge of GF foods (Muhammad *et al.*, 2019). Adults diagnosed in childhood report higher rates of non-adherence to the GF diet than those diagnosed as adults (Hall *et al.*, 2009). Wagner *et al.* (2008) notes that children moving from paediatric CD care are at greater risk of non-dietary compliance, increased physical symptoms and poorer QoL. Silvester *et al.* (2016a) report on coeliac participants' current age groups, nutritional knowledge, and gluten exposure, but did not consider how this impacts QoL. Gray and Papanicolas (2010) report on age group related levels of health and QoL, based on CD symptoms, but not on how nutritional knowledge or eating habits affect them. Paarlahti *et al.* (2013) researched factors predicting ongoing GI symptoms and reduced QoL, by current age, and time since diagnosis while Zarkadas *et al.* (2013) investigated the emotional impact and difficulties experienced by CD patients who follow a GF diet and found that women were more accepting of CD than men and negative emotions were experienced less frequently among those who'd been following GF diet for more than 5 years. There are limited studies that sought to discover in which ways current age, and time since diagnosis affect nutritional knowledge, eating habits and QoL collectively. This study aims to investigate time since diagnosis and age-related differences in nutritional knowledge, eating habits and QoL of adults diagnosed with CD. Expanding understanding of age-related differences may identify issues which, for example, only young adults or elderly adults experience, and could contribute to the development of tailored age-appropriate adult healthcare regimes and educational support.

Methodology

Questionnaire Development

The questionnaire had 4 sections exploring (i) demographics (gender, age and time since diagnosis), (ii) nutritional knowledge, (iii) eating habits and (iv) Quality of life (QoL). Participants were asked 5 closed questions to assess GF knowledge. Questions were designed based on Silvester et al. (2016a, 2016b), assessing how participants gained their understanding of CD and how they applied their nutritional knowledge to everyday living. Participants were asked about 12 everyday food items, whether they consider them 'safe', 'unsafe' or a 'food to question'. The Coeliac UK Food and Information Checker was the main reference point for correct answer verification (Coeliac UK, 2019b). Foods categorised as 'safe' are buckwheat flour, lentils, cocoa, rice, maltodextrin, and barley malt vinegar. 'Foods to question' are oats, tamari and flavoured yoghurts. 'Unsafe' foods are barleycup, spelt and bulgar wheat. There were closed questions exploring eating habits, based on early research by Lamontagne et al. (2001) and built on by Araujo and Araujo (2011). These questions aimed to identify how eating habits are affected by the requirement to consume only GF foods. There were closed questions assessing emotions and impact on daily life (Dorn *et al.*, 2010; Zarkadas *et al.*, 2013). The survey was designed using Qualtrics XM software. Hertzog (2008) suggested a sample size of 10 - 40 for pilot studies and due to the inclusion criteria required for this population, a pilot sample of 10 subjects were deemed sufficient. The survey was pilot tested and subjected to face validity with 10 CD patients to assess the feasibility, clarity and time required to complete the questionnaire.

Data collection

To be eligible to take part in the survey, participants had to be ≥ 18 years of age. Participants had to have been clinically diagnosed with Coeliac Disease (Ludvigsson *et al.*, 2014). Clinical diagnosis of CD is achieved by serological testing to measure antibody levels in blood and small intestinal biopsy to check for damage to the gut lining (Coeliac UK, 2022; Lindfors et al., 2019). The survey was advertised on Coeliac UK's social media network, local clinics, and coeliac support groups in UK. Online survey has a response rate of 20 – 30%, hence the study was advertised as widely as possible. Based on the sample size calculation (confidence level: 95%; population size: ~670,000 [using the value of 'one in 100 UK population is affected by CD' as the basis for the calculation of the affected population] and margin of error: 5%), the study requires more than 380 patients. The survey was conducted from February to March 2019.

Statistical analyses

Descriptive statistics, Chi square (χ^2), Mann-Whitney U and Kruskal Wallis tests were conducted. Significant value is set a $p < 0.05$.

Results and Discussion

A total of 217 participants returned the survey, of which there were 162 valid responses. Similar studies had recruited between 50 – 100 participants with CD (Laheri and Soon, 2018; Lee et al., 2009). The demographics of participants' characteristics are shown in Table 1. All participants made use of all the suggested five methods of nutritional knowledge sources. Social media and websites and Coeliac support groups were the two main sources of information. Strict GF dietary adherence is reported most frequently followed by rare, unintentional consumption. Participants were asked if they still experience GI symptoms when following a GF diet of which 48.1% still experienced the symptoms. Rice, potato and gluten free bread were the most common food sources preferred by the participants whilst amaranth and buckwheat were least common.

Insert Table 1 here

Participants were asked about 12 everyday food items, whether they consider them 'safe', 'unsafe' or a 'food to question'. The Coeliac UK Food and Information Checker was the main reference point for correct answer verification (Coeliac UK, 2019b). Foods categorised as 'safe' are buckwheat flour, lentils, cocoa, rice, maltodextrin, and barley malt vinegar. 'Foods to question' are oats, tamari and flavoured yoghurts. 'Unsafe' foods are barleycup, spelt and bulgar wheat. Table 2 highlights the % of food items identified correctly as safe, questionable or unsafe by different age and years since diagnosis groups. There was significant association between age groups and whether or not the groups reported tamari as a food to question ($\chi^2(4)=8.48$, $p=0.04$). More than 40% of the older participants identified tamari as food to question while 23% of younger participants reported correctly. Time since diagnosis revealed significant association in identifying correct safe foods and food to question. These were buckwheat flour ($\chi^2(4)=9.69$, $p=0.04$), lentils ($\chi^2(4)=10.01$, $p=0.04$), rice ($\chi^2(4)=15.66$, $p=0.01$) and tamari ($\chi^2(4)=10.70$, $p=0.03$) (Table 2). Those who'd been diagnosed for more than 5 years demonstrated better knowledge about GF or gluten containing products.

Insert Table 2 here

There were no significant differences in checking the label between gender, age groups and year of diagnosis. However, females, participants above the age of 60 and those newly diagnosed with CD were found to check for gluten free wording and Crossed Grain symbol more often. There was also strong agreement that participants' nutritional knowledge had improved since their diagnosis. Males tend to agree that they eat more healthily since diagnosed with CD. Participants also agreed that their cooking and food preparation skills had improved over time (Table 3).

Insert Table 3 here

Table 4 shows being a coeliac could restrict participants from socialising. Most participants were found to go hungry at social events, females were more likely to feel being restricted due to risk of falling ill or due to the attention brought forth by being a coeliac. There were significant association between age groups and feeling of being restricted by the financial cost of GF food. Those aged between 40 – 59 and above 60 years felt more restrictive compared to the younger adults ($\chi^2(4)=10.73$, $p=0.01$).

Insert Table 4 here

Figure 1 contrasts the percentage point differences based on how the participants felt when first diagnosed with CD to how they feel today. Happiness, confidence and being accepting of CD have increased since diagnosis across all years. Those recently diagnosed with coeliac disease (< 1 year) showed the greatest level of acceptance (61.54%), but the same group was least confident in managing CD (15.38%). Participants were more relieved when newly diagnosed and reductions in feelings of relief were most noticeable among those who'd been diagnosed for 1 – 2 years. Feeling anxious, concerned, sad and depressed about the diagnosis have fallen across all groups.

Insert Figure 1 here

Discussion

The female to male participant response ($n=138$) females, to ($n=24$) males is a ratio of 5.8:1 women to men. Similar to previous studies, there is a female predominance of diagnosed coeliac disease (Dimidi *et al.*, 2021; Jansson-Knodell *et al.*, 2018; Tan *et al.*, 2021). Women are also more likely to experience abdominal pain, iron deficiency anaemia, decreased bone mineral density and were more likely to seek medical care (Ballester-Fernandez *et al.*, 2021; Castro *et al.*, 2015; O'Shaughnessy *et al.*, 2021; Tan *et al.*, 2021). Online data collection methods via Coeliac support groups may account for some difference, as women use social media to seek advice and offer support more frequently than men (Kimbrough *et al.*, 2012). Research suggests that the more nutritional knowledge gained about the GF diet and CD, the greater the dietary adherence achieved (Lamontagne *et al.*, 2001). It is important that the sources of knowledge acquisition are both accurate and available, at the time they are needed. Findings showed that more than 80% of the participants use social media and websites to gain CD knowledge. Social media, and online health forums have an overall positive effect; with their use individuals are better able to deal with their condition both socially and practically (Tanis, 2008). Coeliac support groups were the second most preferred choice of information followed by healthcare providers. Health related online social networking and coeliac support groups offer the opportunity to share personal stories, make friends, and reduces isolation by providing emotional support from others who experience similar issues (Chung, 2013), this is important if healthcare services are limited.

Adherence to a GF diet is fundamental to the health and wellbeing of people diagnosed with CD. More than half of the participants reported strict GF diet. Similarly, Dimidi et al. (2021) found that half to three quarters of their participants adhered to GF diet. Whilst rare intentional failures to adhere to a GF diet do occur, rare unintentional gluten consumption is far greater (30.2%), consistent with findings by Hall et al. (2013) where 54% reported unintentional consumption. Despite following GF diet, almost half of the participants experienced some form of gastrointestinal symptoms. Rice was the most common food source, but participants were less likely to consume amaranth and buckwheat. This is consistent with previous studies where rice was reported as the most popular grain, but most participants reported never having consumed amaranth and buckwheat (Laheri and Soon, 2018; Nicklas *et al.*, 2013). It is possible that misconceptions about pseudo-cereals such as amaranth and buckwheat contain gluten when it is actually GF leading to lower rate of consumption (Kmietowicz, 2017). Lack of awareness as identified in this study and accessibility to alternative grains too may play a role.

Establishing the difference between safe, unsafe or foods to question is a critical skill to learn, and some foods pose more problems than others. To date, the inclusion of oat in GF diet remains a debatable topic in the scientific community. Oats remain questionable due to possible cross contamination (Colombo *et al.*, 2021; Fritz & Chen, 2018). Although pure oats were found to be well-tolerated by most CD patients in moderate amount (50 – 70 g / day for adults) (Cohen *et al.*, 2019), nevertheless the potential for sensitivity exists as oat avenins may influence the immunoreactivity of peptides at intestinal level (Kosova *et al.*, 2020). Varieties and cultivars differ in oat avenins, possibly contributing to different research findings for oats safety, and may also contribute to the confusion surrounding their consumption (Comino *et al.*, 2015). Inherently GF grains and seeds pose a dilemma for people with CD as these products may contain traces of gluten due to the growing and manufacturing processes increasing their risk of contamination and highlighting the need to consume only those which are labelled "Gluten Free" (Thompson *et al.*, 2010). This study revealed significant association between years since diagnosis and identification of safe foods especially cocoa, lentils and rice. Previous research revealed for those most recently diagnosed, it takes around 6 months to identify gluten containing and GF foods (Clerx *et al.*, 2019). Confusing unsafe foods with safe foods is also of considerable concern. Incorrect identification of bulgar wheat (25.93%) and spelt (20.37%) as safe in this study potentially puts participants at risk from gluten exposure. It is possible that because bulgar wheat (which is unsafe), sounds similar to buckwheat (which is safe), may have led to participants' confusion.

Those who were diagnosed for less than a year were found to consistently reported higher levels of checking 'Gluten-Free' wording, 'Crossed Grain' symbol and nutritional content. Checking food labels is a fundamental tool in the management of CD and label reading skills are necessary to avoid gluten

(Gutowski *et al.*, 2020). This study showed that newly diagnosed patients tend to be more anxious and were concerned about adhering to GF diet. This may be the key factors to why newly diagnosed patients were more likely to scrutinise the front of pack labelling for GF label. All groups were found to consistently checked for GF wording more frequently compared to Crossed Grain symbol. Sielicka-Rozynska *et al.* (2020) found their respondents paid more attention to verbal GF claims than pictures on packaging. In fact, Sielicka-Rozynska *et al.* (2020) suggested that the combination of the Crossed Grain symbol and a GF verbal statement helped to strengthen respondents' decision making. Whilst those who'd been diagnosed for longer believed their nutritional knowledge has improved, however there were no significant differences in their self-reported eating practices. Most participants also somewhat disagreed that their cooking and food preparation skills did not improve since their diagnosis.

Over 88% of all participants in this study reported often going hungry at social events, with those in the age range 30-39 reporting the highest rate (92.5%). Participants going hungry at social events may be attributed to fear of gluten contamination (Zingone *et al.*, 2015; Zarkadas *et al.*, 2005). Hiding CD from others and not wanting to place dietary burdens on friends and family may be an additional reason that going hungry is so frequently reported (Sverker *et al.*, 2005). Shah *et al.* (2014) identified that the higher the perceived importance of maintaining a GF diet, the more difficult eating away from home became.

Eating habits are also affected by the availability of GF foods and by their cost (Hopkins and Soon, 2019). There were significant association between age groups with feelings of being restricted by the financial cost of gluten free foods. GF products cost on average 2 - 4 times more than gluten containing foods (Hopkins and Soon, 2019; Jegede *et al.*, 2021; Vriesekoop *et al.*, 2020). Although GF foods are increasingly available, those in budget and convenience stores, reported to be frequented by lower income people, remain limited and can affect GF dietary adherence (Hopkins and Soon, 2019). Necessary changes to eating habits and a perpetual need to be vigilant during food choice is also seen to impose social restrictions and social discomfort (Satherley *et al.*, 2018, Addolorato *et al.*, 2008, and Zarkadas *et al.*, 2013). Acquiring the skills to assess gluten risk, and to enquire about a food's GF status in restaurants and eating away from home is reported to take 1-2 years (Clerx *et al.*, 2019).

There are often strong emotions experienced by those who must follow a GF diet. Not being able to socialise, travel and eat with others, feelings of isolation and exclusion, difficulty in finding GF foods, fear of 'being a bother', restricted food choice and hypervigilance could impact on Quality of Life (Crocker *et al.*, 2018; Silvester *et al.*, 2016b; White *et al.*, 2016; Zarkadas *et al.*, 2013). A substantial number of people with CD report reduced health related QoL whilst attempting to maintain a GF diet (Paarlahti *et al.*, 2013). Figure 1 shows the emotions experienced by participants over time. Anxiety,

feelings of concern, sadness, depression, and fear declined across all time periods. Wolf et al. (2018) reported that individuals with coeliac disease are extremely vigilant in adhering to a strict gluten-free diet and this may increase symptoms such as anxiety and concern. Over time, such negative emotions could potentially be alleviated with improved knowledge and experience. Our findings corroborate with Fernandes and Lopes (2022) who reported that patients' experience improves over time with regular follow up and was associated with better GF diet compliance and improved prognosis. CD is a highly complex condition, and could be considered as a hidden disability, one which impacts a broad range of areas in the lives of those diagnosed (Carrie and Chan, 2008).

Limitations

The survey was adapted from other questionnaires and was only pilot-tested and subjected to face validity. Participants included those who self-reported that they were diagnosed clinically. There is a lower share of male respondents compared to female patients, thus the responses are heavily skewed towards female respondents' perceptions. Participants were recruited from local support groups, clinics and Coeliac UK and would have received some form of help and support from such organisations and may be more knowledgeable and adherent to the diet. The survey was self-reported hence may be subjected to optimistic bias where participants overate their adherence to a GF diet. Although participants were recruited on the basis of self-reporting their diagnosis and while they considered themselves to have been given a diagnosis of coeliac disease, it is possible that they may not have coeliac disease. Coeliac disease affects 1% of the population, there's been a rise in number of individuals self-reporting gluten-sensitivity and consume a gluten-free diet despite not being clinically diagnosed (Imran, 2018). In the absence of evaluation by a physician or a skilled dietitian with expertise on CD and GF diet, the data cannot be translated into clinical practice.

Conclusion

There is considerable complexity surrounding the acquisition of nutritional knowledge for people with CD. Acquisition of nutritional knowledge takes time; those diagnosed for longer i.e. more than 5 years demonstrated greater knowledge about gluten-free and gluten containing foods. Majority of participants report going hungry at social events. Social interactions are limited because of concerns about becoming ill, from unwanted attention, and due to increased financial costs. Although nutritional knowledge, eating habits and Quality of Life (QoL) are repeatedly researched as separate entities, it is important to remember that each one is inextricably linked to the others. People's lives are complex, and diagnosed individuals navigate CD with different knowledge, life experience, economic status, and social skills, all of which influence post-diagnosis management. It is recommended that further studies to explore the influence of social-demographics and if participants have access to clinical and dietary support to assess CD patients' adherence to GF diet and overall wellbeing.

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