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A dietitian-led coeliac service helps to identify and reduce involuntary gluten ingestion with subsequent reduction in the frequency of repeat endoscopies

Key Words: Gluten free diet, coeliac disease, celiac disease, dietitian, adherence, endoscopy.

Abbreviations

CD: Coeliac Disease

GFD: Gluten Free Diet

HCP: Health care professional

UK: United Kingdom

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Tables: 2 (see Figures and Tables attachment)

Figures: 5 (see Figures and Tables attachment)

ABSTRACT

Background: Dietitian-led coeliac clinics have the potential to be a cost-effective way of monitoring patients living with coeliac disease (CD). The aim of this service evaluation was to explore the impact of a dietitian-led coeliac clinic on gluten free diet (GFD) adherence and the frequency of endoscopies with repeat duodenal biopsies.

Methods: Adults with biopsy-proven CD were transferred to a new dietitian-led coeliac clinic where data was collected from medical records and analysed using SPSS. GFD adherence was assessed by a specialist dietitian, specialist nurse, consultant gastroenterologists, and a validated GFD adherence questionnaire. Repeat duodenal biopsy findings were compared with the most recent dietitian GFD adherence assessment. Project and ethics approval was granted by the hospital trust and affiliated university.

Results: Data from 170 patients (White; 51%, South Asian; 45%) are presented, with most being 35-64 years old (61%). Specialist dietitian assessments identified 67 (39%) of patients were adhering to the GFD, whereas prior gastroenterologist or a coeliac nurse assessment identified 122 (72%) ($p < 0.001$) and the validated GFD adherence questionnaire identified 97 (57%) ($p < 0.001$). Dietitian assessments identified involuntarily gluten consumption in 39/104 (38%) of those who self-reported GFD adherence, consequently avoiding the need for nine endoscopies with repeat duodenal biopsies once patients had received dietary education from the dietitian. On follow-up, within the dietitian-led coeliac clinic, significantly less patients consumed gluten involuntarily (14%, $p < 0.001$). In addition, a reduction in voluntary gluten consumption was observed from 3-5 to 1-2 times per month ($p < 0.001$) in 66 patients.

Conclusions: The dietitian-led coeliac clinic helped to identify involuntary gluten ingestion, avoid repeat endoscopies with duodenal biopsies and was associated with significantly improved GFD adherence.

INTRODUCTION

Coeliac disease (CD) is an autoimmune disease triggered by the ingestion of gluten. Gluten is a group of dietary proteins that cause damage to the small intestine, and extra intestinal symptoms, of these genetically predisposed individuals.¹ Currently, a gluten free diet (GFD) is the only available treatment and once implemented, symptoms and damage to the small intestine tend to resolve.^{2,3} Non-adherence of the GFD can result in ongoing intestinal inflammation leading to persistent symptoms, vitamin and mineral deficiencies, reduced bone density, intestinal lymphoma and small bowel adenocarcinoma amongst others.^{2,5-7} In the United Kingdom (UK) the estimated CD prevalence is 1%,¹ with a four-fold increase being observed between 1990 and 2011 (from 5.2 to 19.1 per 100 000 person years) which reflects an increasing prevalence worldwide.⁴

Dietitians have an important role in helping people achieve GFD adherence. This is because they are trained to assess patient knowledge, dietary adherence, nutritional status, psychosocial needs, monitor laboratory results, and provide individualised dietary advice.⁹ However, a recent survey completed by 158 dietetic departments in England that provided dietetic gastroenterology services identified that specialist dietetic CD clinics were not provided in 49% of these services,¹⁰ suggesting that adequate dietetic support for patients living with CD may be lacking.

National guidance is unclear about who should be responsible for monitoring patients living with CD. Whilst the National Institute of Health and Care for Clinical Excellence CD guidelines⁸ do not outline which healthcare professional (HCP) should be responsible for routine and annual follow-ups, the British Society of Gastroenterology suggest that “optimally, the [follow-up] clinic should have gastrointestinal and dietetic expertise”.¹ Due to this lack of clarity and due to variability in local resources, UK patients living with CD are usually monitored through either a hospital outpatient follow-up with a gastroenterologist, primary care follow-up with a General Practitioner or community pharmacy follow-up.¹¹ Historically, there has been an inclination for gastroenterologists to follow-up patients living with CD because they require annual blood tests and may also need further medical investigations if symptoms do not resolve.^{1,12} However, doctors receive little nutrition training in their career,¹³ meaning they may not be sufficiently trained to provide adequate and optimal GFD advice.

With increasing patient demand and the role of allied health professionals advancing to manage more complexities presented by the service user,¹⁴ the multidisciplinary team need to find ways to work more efficiently. Traditional clinics are delivered with the medical or nursing team leading reviews that also include a GFD adherence assessment, which can lead to repetition and inaccuracies. A plausible solution entails upskilling dietitians to be the main HCPs in charge of monitoring patients living with CD. This can be achieved through dietitian-led coeliac clinics, where specialist dietitians with expertise in CD can offer optimal GFD advice, and either be upskilled to request and monitor basic medical tests and/or seek gastroenterologist involvement where necessary. Dietitians are in a good position to do this because they are trained within healthcare settings and are also trained in counselling and behaviour change techniques, which are vital when implementing the GFD. Moreover, a skilled dietitian assessment is considered the non-invasive gold standard for GFD adherence, as it can identify if there are inadvertent sources of dietary gluten.^{15,16} This model of work could save considerable gastroenterologist time and healthcare money, whilst also improving patient experience.

A previous UK service evaluation¹⁷ analysed data for 99 patients living with CD who were monitored for annual review appointments during two consecutive years by a specialist dietitian with expertise in CD. Despite 72% of patients self-reporting GFD adherence, only 54% were identified as adherent by the dietitian at baseline assessment. There was also a significant increase in the number of patients adhering to the GFD as reported by the dietitian on follow-up (54% vs 66%, $p=0.037$). However, most patients (79%) had not been receiving any follow-up prior to the clinic, making it hard to compare what the benefits were compared to follow-up appointments delivered by other HCPs.

In summary, there is minimal published evidence evaluating dietitian-led coeliac clinics. Therefore, the aim of this study was to investigate the effectiveness of a dietitian-led coeliac clinic on GFD adherence and on the frequency of repeat endoscopies with duodenal biopsies. The secondary aim was to compare the difference in GFD adherence assessments between the specialist dietitian and other health professionals, as well as patient self-reported adherence.

METHODS

Study Design

This is a prospective longitudinal service evaluation of a newly established adult dietitian-led coeliac service within a UK National Health Service trust '[removed for blind peer review]'.

Adults included were over the age of 18 years with a biopsy-proven CD diagnosis who had been living with the condition for at least two years, to ensure they were established on the GFD. Previous care holders were required to be either a consultant gastroenterologist or coeliac nurse in secondary care. Finally, patients were included if they had attended an initial and follow-up appointment in the dietitian-led coeliac clinic. The initial appointment occurred between the 1st of January and the 31st of December 2019, with the follow-up occurring within 2 years of the initial assessment. This is to account for limited services being available during the COVID-19 pandemic. In normal circumstances patients would be followed-up at 3, 6 or 12 months depending on their needs and clinical judgment, but this was not possible due to temporary staff redeployment and clinic cancellations in response to pandemic pressures. Patient demographic data collected included age, gender, ethnicity, and number of years living with a CD diagnosis. Data was recorded from medical records after patients had received routine clinical assessments as part of standard care in the respective clinics.

Figure 1 summarises key data collected from different appointments. Historically, secondary care CD patients were monitored by either a coeliac nurse or any of ten hospital gastroenterologists in a mix of face-to-face or telephone clinics. They were allocated 5-10 minutes per follow-up appointment and their adherence assessment predominantly entailed asking patients if they were following a GFD as well as using Immunoglobulin A Tissue Transglutaminase values from blood tests if these were available before the appointment. Their adherence assessment from the last appointment prior to the dietitian-led coeliac clinic was utilised for comparison with other adherence outcomes collected.

The dietitian-led coeliac clinic was set-up and run by a gastroenterology dietitian whose post was mainly dedicated to CD. They received additional CD specific

training and support to order and analyse relevant CD bloods, with agreed medical support from a consultant gastroenterologist as required. Consequently, the full caseload of patients under the coeliac nurse were transferred to the dietitian-led coeliac clinic and consultant gastroenterologists had the option to also transfer coeliac patients' care for ongoing follow-up at any stage. The dietitian used specialist CD knowledge to identify voluntary and involuntary gluten ingestion through detailed questions which also enquired about how gluten cross-contact was avoided through food label reading, with food preparation in the house and when consuming food from outside of the house. If patients reported they were not eating gluten on purpose, but the dietitian identified sources of gluten in their diet or habits that did not minimise the risk of cross-contact, they would be deemed to be eating gluten involuntarily. Appointments lasted 20-30 minutes and the dietitian provided individualised advice, education, and resources to improve dietary adherence, as well as facilitating behaviour change and encouraging patients to join Coeliac UK, the independent UK charity for people living gluten free.

During the assessment the dietitian also used the validated Biagi GFD adherence questionnaire (Figure 2).¹⁸ Scores from 0 to 2 were deemed as non-adherence. The dietitian also asked patients if they thought they were following a strict GFD. If they reported they were not, they were then asked to quantify how much gluten they had eaten on purpose over the last month and the frequencies were divided into five different categories which were ranked: 1-does not eat any gluten voluntarily, 2-eats gluten voluntarily 1-2 times per month, 3-eats gluten voluntarily 3-5 times per month, 4-eats gluten voluntarily 6-10 times per month, 5-eats gluten voluntarily more than 10 times per month. The clinic offered both face-to-face appointments and telephone appointments before the COVID-19 pandemic. At the start of national lockdown in the UK in March 2020, all appointments were offered as telephone appointments due to hospital regulations. Face-to-face clinics were then re-started again in September 2021. Thus, most follow-up appointments were delivered as telephone appointments.

To identify the frequency of repeat endoscopies with duodenal biopsies within the first year the dietitian-led coeliac clinic was implemented (1st January 2019 to 31st December 2019), medical records were checked for all patients who had received one and then they were compared with the most recent specialist dietitian

adherence assessment. Due to the COVID-19 pandemic, many endoscopies were cancelled or significantly delayed during 2020 and 2021, so data for these years was not included. From the histology report and gastroenterologist interpretation it was identified if active or inactive CD was reported. Additionally, patients with persisting issues who were referred to the specialist dietitian by a consultant gastroenterologist for a thorough GFD adherence assessment prior to considering performing repeat duodenal biopsies were also quantified. Medical records were checked to find if the dietitian had identified gluten ingestion in their assessment and if repeat duodenal biopsies were consequently either avoided or performed.

Ethical approval via the UK Health Research Authority was not required for this study because it was deemed an evaluation of the dietetic service. Local approval was given by both Research and Development and Information Governance departments at the local trust '[removed for blind peer review]', as well as receiving ethical approval from a university '[removed for blind peer review]'.

Statistical Analysis

Data were analysed using SPSS statistical package V.27 (IBM Corp.). Descriptive statistics data was expressed as frequencies and percentages for categorical variables and as medians for ordinal data. To compare different adherence assessments Cochran's Q Test was used followed by McNemar tests for pairwise comparisons with a Bonferroni correction for multiple tests. To identify changes to voluntary gluten consumption over time Wilcoxon Signed Rank Test was used. To identify changes to involuntary gluten consumption over time a Related Samples McNemar Change Test was used. A p-value < 0.05 was considered to be statistically significant.

RESULTS

A final sample of 170 patients were included in the study, those excluded are detailed in Figure 3.

Patient demographics

Most patients were female (77%) and there was a similar proportion of White (51%) and South Asian patients (45%). Patient demographics are displayed in

Table 1. Most patients had been living with CD for more than 5 years (82%) and most were under the care of a coeliac nurse prior to accessing the dietitian-led coeliac clinic (65%). Follow-up appointments in the dietitian-led coeliac clinic took place at an average of 297 (\pm 159) days between initial and follow-up appointment. Furthermore, 34% received a follow-up dietitian appointment within six months of the initial appointment in comparison to 66% who were reviewed between six and twenty-four months post initial appointment.

Differences in GFD adherence using different assessment methods

All patients (n=170) had GFD adherence assessed by four different methods. The specialist dietitian identified significantly less patients to be following a GFD compared to all other methods of assessing adherence (Figure 4 and Table 2), thus able to identify sources of gluten ingestion that other methods were unable to. Conversely, when adherence was assessed by a gastroenterologist or a coeliac nurse, GFD adherence was reported to be significantly higher than all other assessment methods, indicating sources of gluten ingestion may have been missed in those assessments.

Impact of the dietitian-led coeliac clinic on voluntary and involuntary gluten ingestion

Out of all patients, 38% (n=66) reported to the dietitian they were eating gluten-containing foods on purpose at their initial assessment. After further dietetic advice was provided, there was a significant reduction in self-reported gluten ingestion at the follow-up appointment from a rank score of 3 (gluten-containing foods consumed 3 to 5 times per month) to a rank score of 2 (gluten-containing foods consumed 1 to 2 times per month) ($z=-5.70$, $p<0.001$ with a large effect size ($r=0.50$); Wilcoxon signed rank test).

Sixty one percent (n=104) of all patients self-reported they were following a strict GFD during their initial appointment with the specialist dietitian. However, 38% (n=39) were identified to be eating gluten involuntarily by the specialist dietitian assessment. There was a significant reduction in the proportion of patients identified to be eating gluten involuntarily on follow-up ($p<0.001$) (Figure 5).

Repeat duodenal biopsies

During the first year in which the dietitian-led coeliac clinic was implemented, 10% (n=17) required repeat duodenal biopsies due to persisting issues or symptoms. All patients who displayed biopsy features of active CD (n=9) were also identified to be eating gluten through the specialist dietitian assessment (n=9). Six of these procedures were requested by a gastroenterologist prior to the specialist dietitian assessment. All patients who did not have active CD on histology findings (n=8) were also identified as being adherent to the GFD by the specialist dietitian. Five of these procedures were requested after the specialist dietitian assessment to further explore persistent issues or symptoms.

For 9 other patients with persisting issues, gastroenterologists requested a specialist dietitian assessment prior to considering repeat duodenal biopsies. Persistent gluten ingestion was identified by the specialist dietitian for all 9 patients, and they were educated on how to improve adherence, inclusive of the practicalities of living gluten free. All improved adherence and their issues or symptoms improved on follow-up, thus a repeat endoscopy with duodenal biopsies was avoided for all.

DISCUSSION

This study highlights the clear value of a specialist dietitian assessment of GFD adherence in comparison to other methods, as dietetic assessments were associated with accuracy of assessing involuntary gluten ingestion, contributing to improved GFD adherence and the avoidance of repeat duodenal biopsies. Therefore, a dietitian-led coeliac clinic may be an effective way of helping patients improve GFD adherence whilst also reducing unnecessary investigations. This can help patients reduce symptoms and improve quality of life whilst also resulting in significant cost-savings for health services and reducing outpatient waiting lists for consultant gastroenterologists.

When comparing assessments of adherence to the GFD there was a disparity between HCPs, where gastroenterologists and nurses identified a higher proportion of patients as following a GFD, compared to the specialist dietitian assessment. One of the reasons for this may be that the skilled dietitian assessment was able to identify if there were inadvertent sources of dietary gluten, and this is why it is considered the non-invasive gold standard for GFD adherence.^{15,16} However, it

needs to be acknowledged the assessments were not undertaken at the same timepoint, thus adherence may have also changed between different HCP assessments and our data did not account for this. To our knowledge there is no other research that compares all the GFD adherence assessments that we used in our study. Future studies should ensure different adherence assessments for the same patients are compared in close time proximity. Our data also showed that despite the validated adherence questionnaire we used in our study¹⁸ being a tool any HCP can use, accuracy in comparison to the dietetic assessment at the same time point was limited. This may be due to phrasing of the tool's questions. For example, by asking 'do you check the labels of packaged foods?', one cannot assume that just because patients check food labels it means that they know how to identify all gluten-containing ingredients correctly. This lack of knowledge with identifying gluten is a common occurrence that has been identified in previous studies.^{16,19} Thus, recurringly, it is likely the main reason why adherence levels were reported as lower when patients were assessed by a specialist dietitian compared to all other three methods, was because the dietitian assessment consisted of more detailed questioning around involuntary gluten ingestion.

Patients who were eating gluten voluntarily displayed improved GFD adherence after two appointments in the dietitian-led coeliac clinic. These findings are similar to those from a recent study which found that the use of a telephone appointment, by a HCP with expertise in nutrition and CD, through individualised nutrition counselling improved GFD adherence in 30 UK patients living with CD who were not adhering to a GFD.²⁰ The intervention group significantly improved adherence to the GFD after 3 and 6 months ($p < 0.01$) but not after 9 and 12 months. In the current study, voluntary gluten ingestion reduced despite an average of 297 (± 159) days between dietitian appointments, with a maximum cut-off point of two years between appointments due to service delays caused by the COVID-19 pandemic. Whilst one of the strengths of our study was the larger number of patients, we did not monitor any other factors that may have affected GFD adherence like age at diagnosis, symptoms experienced, mental health status, membership of a local support group or society and quality of life, amongst others.²¹ Measuring these factors and measuring changes in GFD education would have helped improve comparison with other studies and shed more light on the causality of our findings.

Our findings of patients ingesting gluten involuntarily are comparable to a UK study (n=99) whereby at initial dietitian appointment 72% of patients self-reported they were following a GFD, yet only 54% were considered to be adhering to the GFD by the specialist dietitian after involuntary gluten ingestion was identified.¹⁷ Our study found 61% perceived they were following a GFD, yet only 39% were deemed to be following a GFD by the specialist dietitian at the initial appointment. Despite patients being diagnosed with CD for a considerable amount of time (12 years on average) and receiving routine CD care from a gastroenterologist or coeliac nurse, we found that involuntary dietary transgressions were still identified by the specialist dietitian. Without these opportunities to identify inadvertent gluten ingestion and further improve adherence, patients could suffer for longer with persisting symptoms and CD complications could increase over time. According to a recent systematic review which explored the challenges of monitoring GFD adherence on follow-up, cross-contact of gluten free foods is one of the main causes of inadvertent gluten ingestion.²³ Therefore, adequate nutritional counselling and adequate GFD assessment techniques are necessary to better identify adherence and prevent the risk of ongoing complications, which can in turn reduce healthcare usage long-term.

In the first year the dietitian-led coeliac clinic was implemented, nine endoscopies with repeat duodenal biopsies were avoided, due to the specialist dietetic assessment identifying gluten ingestion before the procedure. This is of useful clinical relevance, due to increasing pressures and waiting times for outpatient gastroenterology services and endoscopy waiting lists. According to 2019/2020 National Tariff, an endoscopy with duodenal biopsies was costed at £398,²⁴ meaning that an estimated £3,582 was likely saved by avoiding these nine procedures in 2019 alone. For the small cohort of patients who did have repeat duodenal biopsies (n=17), the dietitian assessment was validated when compared to biopsy findings. This finding is comparable to a study whereby patients with and without histological remission had similar dietitian dietary adherence scores (n=44).¹⁶ This is also clinically useful to know, as it has previously been demonstrated that the most common cause of persistent symptoms in CD is ongoing gluten exposure.²⁵⁻²⁸ Thus, using a specialist dietitian assessment to help identify inadvertent gluten ingestion before considering a more invasive and costly

endoscopy with repeat duodenal biopsies is likely to be safe and useful for many patients. Despite this, current recommendations for exploring persistent CD symptoms recommend a dietitian assessment is offered after repeat duodenal biopsies have been performed.²⁹ Conversely, if the dietitian assessment identifies that patients are adhering to a GFD and having persistent symptoms, other reasons for the symptoms can still be explored. No medically adverse incidents occurred within the dietitian-led coeliac service when data was analysed, and no medical staff reported incidents either. Therefore, it is likely that most patients living with CD can be managed safely in a dietitian-led coeliac clinic with selected gastroenterologist input, which in turn can provide other direct cost-savings, as a previous service evaluation suggested that a dietitian appointment can cost about half of what a gastroenterologist or nurse follow-up appointment costs (£54 vs £110).³⁰ Furthermore, it is also likely that patients will be satisfied with dietitian-led coeliac services as a previous study indicates that patients preferred method of coeliac disease follow-up was to see a dietitian with a doctor being available as necessary.³¹

It would be helpful for future research to collect more patient views on dietitian-led coeliac services, so that services can better understand how satisfied patients are with this change to their care provision and what patients expect from this type of service. It would also be useful for services to know how many gastroenterologist appointments can be saved using a dietitian-led coeliac clinic. Furthermore, it would also be helpful for studies to include more repeat duodenal biopsy findings for better specialist dietitian assessment comparison, as well as blinding biopsy results from the dietitian, since the dietitian could see biopsy result findings before assessing some patients and this could have biased the dietitian assessment for these select patients. We acknowledge that none of the assessments from different HCPs were standardised, however appointments delivered by the CD nurse, or the specialist dietitian were delivered primarily by the same person. Finally, we also acknowledge the observational nature of our study. A randomised controlled trial design is needed to clearly determine the efficacy of a dietitian-led coeliac clinic.

In conclusion, our study shows that the implementation of a dietitian-led coeliac clinic can improve the identification of inadvertent gluten ingestion and reduce

unnecessary repeat duodenal biopsies. In addition, patients who attended the dietitian-led coeliac clinic displayed better GFD adherence. Our data can inform clinical practice by highlighting the variety of benefits this clinic model can offer, with many hospitals looking for ways to improve cost-efficacy and reduce unnecessary endoscopy and outpatient gastroenterology waiting times. Dietitian-led coeliac clinics do exist, but there are few in the UK and even less around the world. Our study is a step towards evidencing ways of offering more cost-effective and patient-benefiting CD services, whilst also improving access to specialist dietitians.

Ethics statement

Ethical approval via the UK Health Research Authority was not required for this study because it was deemed an evaluation of the dietetic service. Local approval was given by both Research and Development and Information Governance ‘[removed for blind peer review]’, as well as receiving ethical approval a university ‘[removed for blind peer review]’.

Transparency Declaration

The lead author affirms that this manuscript is an honest, accurate and transparent account of the study being reported. The reporting of this work is compliant with STROBE. The lead author affirms that no important aspects of the study have been omitted and that any discrepancies from the study as planned have been explained.

Conflict of interests

The authors declare no conflicts of interest.

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