

Celiac Disease Knowledge and Practice of Dietitians in Rural New South Wales, Australia

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Abstract

This study aimed to evaluate dietetic practices for patients with celiac disease and knowledge of celiac disease amongst rural dietitians. This study comprised of two parts: 1) a retrospective file audit of patients with celiac disease attending a rural dietetic outpatient clinic in NSW, Australia from 2007 to 2014 and 2) a cross-sectional survey of 25 dietitians within a rural Local Health District in NSW. Celiac disease related knowledge and diet therapy practices were assessed. Data were reported using descriptive statistics. The patient file audit (n = 17) indicated that the majority of patients (59%) had no follow-up with a dietitian. Education topics provided by dietitians included gluten-free food options (53%) and label reading (41%). Dietitians (n = 18, 72% response rate) achieved a mean score of 73% (range 48% - 90%) for celiac disease related food knowledge and 69% (range 50% - 90%) for screening and diagnosis knowledge. Perceived barriers for compliance with a gluten-free diet included limited access to dietitians, as well as limited availability and cost of gluten-free products. Current practices of rural-based dietitians in NSW are variable for patients with celiac disease, suggesting that evidence-based guidelines and continuing education are needed for rural-based dietitians in the specialized area of celiac disease.

Keywords

Celiac Disease, Dietitians, Diet Therapy, Evaluation, Rural Health

1. Introduction

Celiac disease is a genetically linked, systemic immune disease that requires lifelong adherence to a gluten-free

diet as the cornerstone to treatment [1]. For those with celiac disease, the dietary consumption of gluten, a protein found in wheat, rye, barley and triticale, results in chronic inflammation of the intestinal mucosa [1]. Clinical manifestations of the disease can include nutrient malabsorption, abdominal discomfort, steatorrhea, anaemia, gastrointestinal upset and weight loss [1] [2]. Worldwide, the prevalence of celiac disease has been reported to be one in 266 [3]. In Australia, the prevalence of celiac disease is increasing and is estimated to affect approximately one in 70 people, or 1.4% of the population [4].

There has been limited research to date into the diet therapy and follow-up provided by dietitians for patients with celiac disease [5]. Currently, there are no evidence-based guidelines within Australia for the management and follow-up of patients with celiac disease [5]. Several international guidelines exist, however, recommendations vary greatly [6]–[10]. Despite the variation in guidelines originating from the USA and UK [6]–[10], current practices are falling well below the most lenient interpretation of existing guidelines [11]. Furthermore, many recommendations are vague, lack an evidence-base or are formed through general consensus [6]–[8] [11] [12]. Gaining a better understanding of current diet therapy practices and patient outcomes can assist in the development of evidence-based recommendations for the long term follow-up and management of patients with celiac disease, which may ultimately improve the quality of care and patient outcomes [11].

The necessity for long term follow-up of patients with celiac disease has been well established in the literature [9] [11] [13]–[16]. Recent international research has shown that patients with celiac disease are not adequately or consistently followed-up after diagnosis [17]. A recent study in the USA found that despite referral to see a dietitian ($n = 413$), only 79% of those diagnosed with celiac disease had seen a dietitian, and of those who had seen a dietitian, 39% had only one consultation [17]. The American Gastroenterology Association recommends that patients are evaluated at “regular intervals” or by periodic visits by a “physician and a dietitian” [7]. Whilst the number of patients with celiac disease who receive follow-up is unknown within Australia, studies in the USA suggest that follow-up is suboptimal [11] [18]. Additionally, there is a lack of evidence regarding who should be responsible for patient follow-up and how often this is required [9]. A survey of patients with celiac disease in England indicated a preference for dietitian led follow-up, with the availability of a doctor [16].

Research suggests that regular consultation with a dietitian is required for patients with celiac disease, however, it also identifies that not all dietitians are familiar with the complexities of the gluten-free diet [19]. A recent study in Canada found that regular contact with a dietitian was highly valued [20], however, a study in the USA found no association between dietitian intervention and improved quality of life, reduced symptom severity or adherence to the gluten-free diet [17]. Adherence to the gluten-free diet is associated with weight gain [21] and reversal of nutritional deficiencies including folate, thiamine and anaemia [22] [23]. However, the gluten-free diet can still be nutritionally inadequate, particularly without appropriate diet therapy and education to achieve satisfactory micronutrient intakes [23].

This study was conducted in a dietetic outpatient clinic of a rural hospital and Local Health District (LHD) in NSW, Australia. This regional centre comprises an approximate population of 71,375 for the Local Government Area (LGA) [24]. Current incident rates of celiac disease within the rural LGA are unknown, however, based on estimated Australian prevalence rates, there are likely to be approximately 400 individuals with the condition. Within the rural setting, dietitians and other allied health professionals usually have a generalist role, providing diet therapy for a wide range of caseloads and patient groups [25] [26]. Given the specialised nature of managing celiac disease and the need for generalist dietitians to be adequately trained [5], this study will investigate the current practices of rural-based, generalist dietitians. The aims of this study are: 1) to review the diet therapy and follow-up of patients with celiac disease attending a rural outpatient clinic in the rural LHD of NSW and 2) to assess the current knowledge, dietary management and follow-up strategies of dietitians in a rural-based setting within the rural LHD.

2. Methods

The study comprised of two parts: 1) a retrospective file audit and 2) a cross-sectional survey of rural-based dietitians. The retrospective file audit was undertaken within the rural hospital outpatient dietetic clinic. Patient files with a celiac disease diagnosis were accessed for the time period 2007 to 2014. A cross-sectional survey for dietitians was developed to obtain subjective data regarding diet therapy practices and knowledge of celiac disease. The survey was distributed to dietitians within the rural LHD, NSW. Study approval was obtained from both the Hunter New England and University of Newcastle Human Research Ethics Committees.

Eligible patient files were identified for inclusion and exclusion by an administrative assistant. Files were deemed suitable for inclusion to the study if the subject had attended an outpatient clinic within the rural health service and had a diagnosis of celiac disease. Files were excluded from the study if they did not have a positive celiac disease diagnosis, or if the file corresponded to an inpatient setting. Patient files that met the inclusion criteria for the study were located, copied and manually de-identified by administrative staff. De-identified files reviewed by the researchers included patient file entries by dietitians, relevant patient notes, letters and pathology reports.

Data collected included date of consultations, number of appointments, relevant diagnoses, family history, anthropometry values, biochemistry results, symptoms, education and dietary intake. Each data set was assigned a study identification number. All data were entered into an excel spreadsheet for subsequent analysis.

Rural-based dietitians working within the LHD were invited to participate in a cross-sectional survey via email. The survey comprised of three sections; demographic characteristics (six questions), patient profile (six questions) and celiac disease related knowledge and practices (18 questions). Questions relating to key areas of knowledge relating to celiac disease were developed, to support safe and effective practice. Eligible participants were emailed a survey link, hosted by *Survey Monkey*[®]. A reminder email was circulated to all participants after two weeks, allowing up to four weeks to complete the survey.

Descriptive statistics were used for analysis of all data obtained. Quantitative data were represented using mean and range for continuous data, and counts and proportions for categorical data. Additionally, survey questions were grouped to generate overall scores for “food knowledge” (maximum score of 31) and for “screening and diagnosis knowledge” (maximum score of five). Correct answers were awarded one (1) mark, incorrect answers zero (0) and half a mark (0.5) for answers of “unsure”. Qualitative data were categorised for basic content analysis. Post-codes were utilised to determine rural classifications using the Australian Statistical Geography Standard (ASGS) Remoteness Index [27].

3. Results

3.1. File Audit

A total of 17 patient files were analysed for part (1) of the study. Files from 2010 to 2014 were accessible and nine files were excluded from the analysis. **Table 1** describes the demographic characteristics of the audited files. All patients had a confirmed diagnosis of celiac disease with 53% being newly diagnosed. Majority of patients (64.5%) were seen within five weeks of the initial referral date and most (65%) were referred by a gastroenterologist. Patient file notes were documented in by a total of seven dietitians.

Anthropometry data were documented in 53% of patient files, allowing Body Mass Index to be determined, with 78% a healthy weight. Seventy six percent of files reported biochemical markers of nutritional risk. Of those tested for iron ($n = 11$) and vitamin B₁₂ ($n = 9$), 18% and 22% respectively, had results consistent with deficiency. Of the 11 patients who had folate levels tested, no deficiencies were evident. **Figure 1** displays the reported clinical symptoms in patient files, as documented by dietitians.

All of the 17 patient files reviewed included a diet history whereby inadvertent gluten consumption was identified by the researcher in 94% ($n = 16$). Few dietitians (24%) documented an assessment of the nutritional adequacy of dietary intakes, based on patient reported diet histories. A variety of nutrition education topics covered by dietitians, see **Figure 2**.

3.2. Dietitian Survey

For part (2) of the study a total of 18 surveys were returned, a 72% response rate. Descriptive data, patient profiles and dietetic practices of survey respondents are reported in **Table 2**. Majority of respondents were female (94%) and aged between 26 - 35 years (50%), with 67% of dietitians having greater than 5 years of experience. Of the respondents, 39% suggested that three follow-up appointments are necessary for patients with celiac disease, and 55.5% indicated that this should occur within four weeks of an initial consult.

Twelve dietitians completed the knowledge component of the survey. Of survey responders, a mean score of 69% (range 50% - 90%) was calculated for knowledge of celiac disease screening and diagnosis techniques. No clear trend was identified between years of experience and knowledge in this area. The mean score for celiac disease related food knowledge was 73% (range 48% - 90%). No clear trend was identified between food knowledge scores and years of experience, or number of patients with celiac disease seen in the previous 12

Table 1. Demographic and clinical characteristics of audited patient files with celiac disease attending rural outpatient dietetic clinic from 2010-2014 (n = 17).

Area of Enquiry	Percentage of patient files n (%)
Gender	
Male	5 (29)
Female	12 (71)
Age (years)	
1 - 15	5 (29)
>15 - 30	4 (23)
>30 - 45	2 (12)
>45 - 60	3 (18)
>60 - 75	3 (18)
Geographic location	
Inner regional	9 (53)
Outer regional	8 (47)
Reason for referral	
CD	16 (94)
CD and "other" ^(a)	1 (6)
Referral source	
Gastroenterologist	11 (65)
General Practitioner	5 (29)
Allied Health Professional	1 (6)
Appointment Status	
Newly diagnosed CD	9 (53)
Previously diagnosed CD	8 (47)
Documented evidence of CD diagnosis	
Positive bowel biopsy only	3 (18)
Positive CD serology only	4 (23)
Positive bowel biopsy and CD serology	4 (23)
Other ^(b)	6 (36)
Time between referral date and dietetic consult (weeks)	
0 - 5	11 (64.5)
>5 weeks up to 10	3 (17.5)
>10 weeks up to 20	2 (12)
>20	1 (6)
Follow-up appointments attended	
0	13 (76)
1 - 2	2 (12)
3 or more	1 (12)
Failure to attend appointments	
0	13 (76)
1 - 2	2 (12)
3 or more	1 (12)
Family history of CD	
Yes	5 (29)
No	12 (71)

^(a)"Other" condition: Irritable Bowel Syndrome, ^(b)Other includes doctor letter only, doctor letter plus sighted or unsighted serology. BMI = Body Mass Index, CD = Celiac Disease.

months. One third of dietitians were able to correctly categorise eight listed grains correctly. Similarly, correct responses for the classification of single ingredients ranged from 17% to 92% and 33% to 100% for whole food items or meals. All responding dietitians recognised the importance of label reading, with 58% able to correctly identify whether a product was gluten-free or gluten containing from a provided food label.

Table 2. Descriptive data, patient profiles and dietetic practices of surveyed rural-based dietitians within Local Health District (n = 18, unless otherwise stated^(c)).

Area of Enquiry	Percentage of patient files n (%)
Gender	
Male	1 (6)
Female	17 (94)
Age (years)	
18 - 25	2 (11)
26 - 35	9 (50)
36 - 45	6 (33)
>55	1 (6)
Geographic location	
Inner regional	13 (72.5)
Outer regional	5 (27.5)
Primary outpatient focus	
Generalist	14 (78)
Specialist ^(d)	4 (22)
Years of dietetic experience	
>1 up to 5	6 (33)
>5 up to 10	7 (39)
>10 up to 15	1 (6)
>15	4 (22)
Hours worked per week as outpatient dietitian	
1 up to 5	2 (11)
>5 up to 10	6 (33)
>10 up to 20	5 (28)
>20 up to 30	2 (11)
>30	3 (17)
Number of newly diagnosed CD outpatients in last 12 months	
1 - 2	9 (50)
3 - 4	7 (39)
>5	2 (11)
Number of follow-up appointments with outpatients with CD in last 12 months	
1 - 2	10 (5)
3 - 4	5 (28)
>5	3 (17)
Dietitian identification of nutrients at risk for patients with CD ^(c)	
Iron	11 (92)
Calcium	7 (58)
Vitamin B ₁₂	9 (75)
Fibre	6 (50)
Vitamin D	3 (25)
Folate	3 (25)
Dietitian focus during nutritional assessment for patients with CD ^(c)	
Sources of gluten in the diet	12 (100)
Nutritional adequacy/five food groups	6 (50)
Nutrients at risk (iron, folate B ₁₂ intakes)	9 (75)
Fibre intake	12 (67)

^(c)Results reported for n = 12 survey respondents for this particular question, ^(d)Specialist areas include renal and diabetes. ^(e)Results do not tally to 100% as respondents could choose multiple responses to the survey question, CD = Celiac disease.

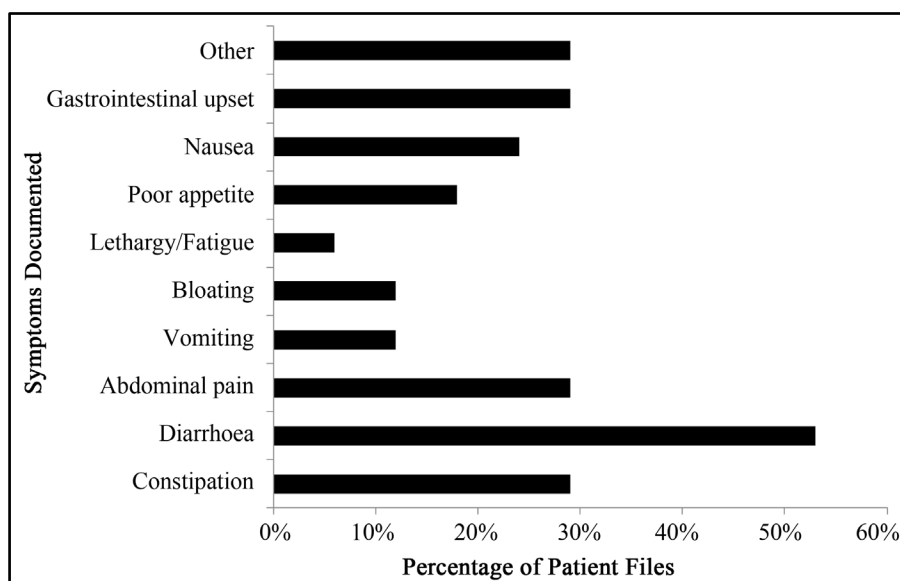


Figure 1. Proportion of clinical symptoms documented by dietitian in audited patient files with a celiac disease diagnosis attending rural outpatient dietetic clinic from 2010-2014.

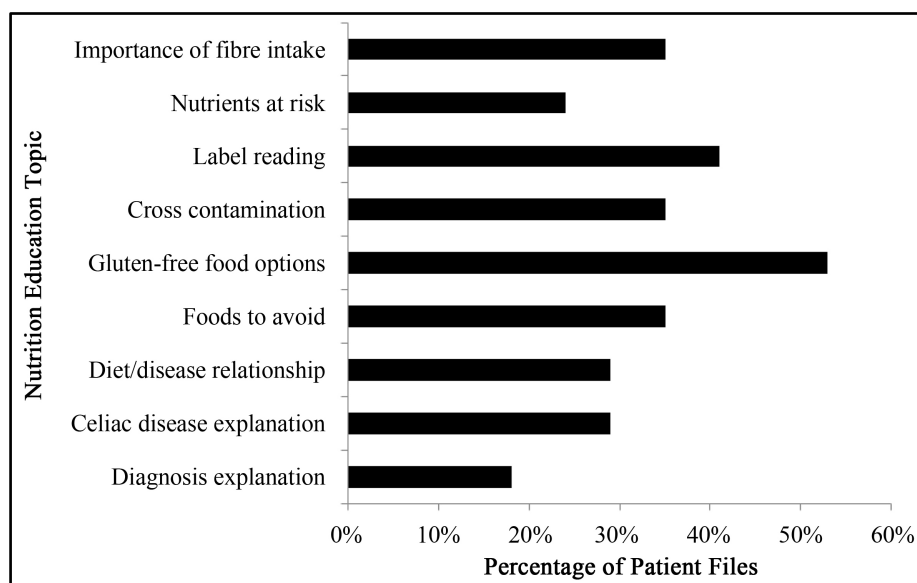


Figure 2. Proportion of nutrition education topics documented by dietitian in audited patient files with a celiac disease diagnosis attending rural outpatient dietetic clinic from 2010-2014.

Refer to [Table 3](#) for nutrition education priorities and perceived barriers, as ranked by survey respondents. Dietitians stated that increased awareness and greater importance placed on the gluten-free diet would alleviate these barriers, as well as group education sessions for patients with celiac disease.

4. Discussion

This is the first known study to evaluate dietitian practices and knowledge in relation to celiac disease management in Australia. It provides a detailed description of the current provision of dietetic services in a rural-based setting and an assessment of celiac disease associated knowledge amongst rural-based dietitians. Given the specialist nature of celiac disease and dietary intervention being the only effective treatment option, there is an important role for dietitians to play [28] [29]. Consistent with current research [11] [17], this study found that

Table 3. Nutrition education priorities and barriers to following a gluten-free diet, as ranked by surveyed rural-based, outpatient dietitians within local health district (n = 18, unless otherwise stated^f).

Area of Enquiry	Mean Priority Score
Nutrition education priorities	Score out of 9^f
Gluten-free diet	1.00
Foods to avoid	2.82
Label reading	4.08
Gluten-free food options and brands	4.67
Cross contamination	5.42
Nutrients at risk	5.58
Nutritional adequacy	6.00
Adequate fibre intake	7.00
Adequate protein intake	8.75
Barriers to following gluten-free diet	Score out of 5^f
Access to gluten-free products	2.25
Cost of gluten-free products	2.75
Access to dietitian for appropriate advice	2.75
Availability of gluten-free products	3.50
Access to appropriate education materials	3.75

f. Lowest scores indicate highest priority, as ranked by survey respondents.

follow-up with a dietitian is inadequate for patients with celiac disease. Fifty nine percent of patients did not return for follow-up, a higher proportion than reported previously in the literature, with 39% not returning for follow-up [17]. A review of patient files could not clarify reasons for the limited follow-up by dietitians in this study. It was unclear whether patients were discharged from the service by the dietitian, no appointment was scheduled or the patient failed to attend. Survey results were consistent with regard to limited follow-up strategies, with 50% of dietitians recommending only one or two appointments for newly diagnosed patients. There is evidence indicating the need for long term follow-up, with at least an annual review following diagnosis [9] [11] [13]–[15] [18] [30] [31]. Whilst the majority of patients were seen for an initial assessment within one to five weeks, exact waiting times were unable to be calculated, as it was unclear whether appointments were sought at the date of referral.

A principle finding of this study, as reflected in both the file audit and survey, is that celiac specific nutrition education, follow-up protocols and self-reported practices of dietitians are variable. This may be attributable to a lack of guidelines for celiac disease in Australia and provides a strong argument for the development of evidence-based guidelines for the nutritional management of celiac disease. However, similar results have been observed in the USA [11], where guidelines exist. Receiving consistent, appropriate and prompt dietary advice after a celiac disease diagnosis is considered important in initiating and maintaining dietary adherence [32]. Various studies have shown improved gluten-free dietary adherence with regular dietetic review [30]–[33]. A study in the UK concluded that there is a wide variation in the method of diet therapy being provided to patients diagnosed with celiac disease [29], consistent with the findings in this study.

Many of the audited patient files had limited biochemistry data available. The need for dietitians to ensure that relevant pathology requests are completed by medical practitioners is imperative, given that the gluten-free diet is associated with nutritional inadequacies [26] [34] as shown in the current study with 18% and 22% of patients tested exhibiting iron and vitamin B₁₂ deficiencies respectively. Documentation by dietitians provided limited detail regarding the nutritional adequacy of the diet, despite all files having a documented diet history. Ensuring nutritional adequacy is an important task for dietitians and serves as a critical component of any nutritional assessment and should not be overlooked in a dietary assessment of a newly diagnosed patient with celiac disease.

It is not surprising that there is variability in the current level of care, given the lack of management guidelines coupled with the specialized nature diet therapy for celiac disease. Given that 78% of dietitians included in the current study were fulfilling generalist dietetic roles and, therefore, practice across a wide range of clinical areas, the challenge for rural based dietitians is to provide a range of generalist services whilst being able to provide expert advice across a range of more specialist areas. Further research is needed to determine whether dietitian knowledge varies across a range of practice settings and specialist areas of practice.

Documentation of the specific nutrition education provided by dietitians was limited in the present study,

however data collection was reliant on the content that was documented in the audited patient files. This may not be representative of all education topics actually being provided by dietitians. Given that patient file documentation facilitates the coordination of diet therapy and continuity of care [35], priority should be placed on detailed documentation as part of standard dietetic practice. In the present study, a large proportion of dietitians did not complete the knowledge section of the survey, possibly due to lack of confidence and/or knowledge of the topic. Of the responding dietitians, scores for celiac disease related “food knowledge” and “screening and diagnosis knowledge” were highly variable. Dietitians were not specifically instructed to access resources during the survey and therefore it is unclear to what extent this occurred. On the whole, the findings suggest that further continuing professional development and education is required, as previously suggested by Zarkadas *et al.* [36] and Case [37].

The present study has demonstrated that dietitians perceive the most significant barriers to following a gluten-free diet within rural locations to be limited availability, increased cost of gluten-free products and access to dietitians for appropriate education. These findings are confirmed by studies in the USA [38] and UK [39] which reviewed the availability and cost of common food items, concluding that gluten-free options were both less available and more expensive than their gluten containing counterparts. With regard to limited access to dietitians for appropriate advice, similar results have been observed in the USA, whereby 40% of surveyed patients with celiac disease agree that “it is difficult to find a dietitian knowledgeable about the gluten-free diet” [17].

A key limitation of this study is the relatively small sample size (part 1) and possible responder bias for the dietitian survey (part 2). Limitations of the current study were primarily within the sourcing of patient files for part (1) of the study. The number of patient files reviewed was small due to difficulties locating files prior to 2010 which were removed from the dietetics department for storage purposes. Additionally, the limited detail of diet therapy provided in patient files by dietitians limited the amount of reportable data for this study.

5. Conclusion

The main findings from this study are echoed in the literature and demonstrate inconsistencies regarding the optimal method of dietetic practice for the management and follow-up of patients with celiac disease. This may be a factor contributing to the variation in practices for celiac disease management, observed in the current study. The present study was solely within a rural setting, however, the findings may have implications for dietitians’ practicing across various practice settings. A broader sample of dietitians across various practice settings would provide further evidence for typical baseline practice. These findings do not aim to provide conclusive recommendations for practice, but rather to establish a baseline of current practice and knowledge in a rural setting, to further inform improvements to practice.

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