**Optimising the management of bone disease for coeliac patients in a dietetic-led clinic**

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**Abstract**

Coeliac disease (CD) is a chronic autoimmune inflammatory condition of the small bowel; the only treatment is lifelong adherence to a gluten free diet (GFD). Adherence to a GFD also minimises the risk of associated conditions such as osteoporosis in CD patients. The present study aimed to evaluate and optimise management of bone disease in CD patients in a dietetic-led clinic.

This study was conducted in two parts: study 1 utilised retrospective data to evaluate management of bone disease with reference to British Society of Gastroenterology (BSG) guidelines in 229 CD patients. Based on the results from study 1, study 2 developed a tool to estimate dietary calcium intake in CD patients, which was then trialled on 50 patients.

There were no significant differences between the population demographics for study 1 and study 2. 65% of patients had a diagnosis of osteopenia or osteoporosis, in a female predominant population (74.6%). Reported mean dietary calcium intake was over estimated at 1239.6mg/day (SD ± 377.1mg) in study 1 and corrected to 852mg/day (SD ± 264.57mg) using improved methodology (study 2) (p≤0.05). Understanding and compliance with dietary advice correlated positively with GFD (p≤0.001) but not osteoporosis or fracture risk.

Overall patients attending the clinic did not meet the BSG recommended calcium intake. However, 30% of patients could meet the 2014 BSG target from oral diet alone. Utilising individual dietary prescriptions and targeted use of calcium supplementation maximised the opportunity to reduce risk of bone disease and improved compliance with BSG recommendations.

**Key words**

Calcium, coeliac disease, dietitian, gluten free diet, osteoporosis.

**Introduction**

Coeliac disease (CD) is a chronic autoimmune inflammatory condition of the small bowel generated by the ingestion of gluten in affected individuals [1] and characterised by atrophy of the villi in the small intestine due to enterocyte destruction. This villous atrophy results in the suboptimal absorption of micronutrients such as calcium, vitamin D, vitamin B12 and iron [2] and affects around 1 in 100 people in the UK [3].

Risk of osteoporosis and associated bone loss conditions are elevated in CD patients [4, 5], resulting in an elevated fracture risk when compared to matched controls (hazard ratio 1.30) [6, 7]. Those patients experiencing gastrointestinal symptoms at diagnosis are also predisposed to lower bone mineral density (BMD), compared to non-symptomatic patients [4, 8].

Adherence to a gluten free (GF) diet can lead to normalisation of BMD in children, but full normalisation of BMD is rarely observed in patients diagnosed as adults [7]. Increasing age and post-menopausal status also increases bone turnover and associated bone loss [9, 10]. The greatest improvements in adult BMD can be observed within the first year of adhering to a GF diet [9].

The diet of coeliac patients has a lower intake of vitamin D (p≤0.05) and calcium (p≤0.05), as well as energy and non-starch polysaccharide, when compared to dietary reference values and intake of the average UK population [11]. Dietary intakes significantly lower in vitamin D and calcium for CD patients potentially impact on bone remineralisation and therefore increases the risk of bone disease. This risk is recognised in the British Society of Gastroenterology (BSG) guidelines [1, 12] which recommend a dietary intake of 1000mg of calcium per day, with post-menopausal women and elderly men advised to consume a higher amount of 1200-1500mg per day. In 2010, this was revised to 1500mg per day [1], considerably higher than recommendations in other Western countries [13], and the UK recommended nutrient intake (RNI) for calcium in a general adult population (700 mg per day) [12]. Those patients identified as being deficient in dietary calcium should be offered calcium supplementation in line with BSG guidance [1, 14].

The risk of osteoporosis and low intake of relevant nutrients in the CD population suggests dietitians should consider optimising calcium intake, in addition to advising on a gluten free diet, for CD patients. To undertake this successfully the dietitian must accurately assess dietary calcium intake and monitor other bone disease risk factors such as menopausal status. Standard dietetic assessment does not always facilitate this, therefore there is a need to standardise and improve calcium estimation to minimise the risk of bone disease in this population.

The objective of this work was to evaluate the management of bone disease in a dietetic-led coeliac clinic to BSG guidelines [12, 14], with a secondary aim of designing an assessment tool to improve self-reported calcium intake estimation to assist clinical advice and intervention.

Method

*Study design*

## The study was divided into two components. Study 1 was a retrospective study analysing data collected to assess the current management of bone disease, with specific reference to calcium intakes, within the dietetic coeliac clinic with reference to BSG guidelines [12, 14]. All calcium intake estimations were recalculated using the calcium tool cited on the original dietetic record card (unknown reference source). The investigator calculated these intakes to provide a consistent criterion measure.

This evaluation highlighted key deficiencies in current practice, i.e. inaccurate calcium estimation, poor screening for fracture risk factors. Therefore, a prospective study was designed to assess the efficacy of a new proforma specifically adapted to provide a focused tool to support dietetic management of bone disease.

This proforma was an updated version of the original record card (see materials supplement) and provided an improved method for estimating dietary calcium intakes. The proforma also enabled the screening of symptoms, risk factors, dietary intake, compliance, degree of bone disease and medications prescribed, along with recording of patient demographics and documentation of advice. The proforma was then used to aid letter dictation and formed part of the patient’s medical record. This data was collected prospectively and the proforma was completed by the clinic dietitian.

Table 1: illustration of key information collated by the new proforma

|  |  |
| --- | --- |
| Additional information collated by the new proforma to meet BSG guidance (12, 14) | Information adapted for inclusion from the initial proforma that previously met BSG guidance (12, 14) |
| Compliance with calcium supplements. | Weight measured in kilograms (kg) by dietitian in clinic. |
| Accuracy of calcium intake estimations as measured using the calcium intake tool on proforma. | Height as reported by patient, recorded in metres (m). |
| Recording of menopausal state (females only).  | BMI calculated. |
| Recording of previous fractures reported by patient. | Weight change calculated by comparing the patient’s weight on previous clinic attendance to the current weight. |
| Recording of patients reported vitamin D exposure. | Recording of medication prescribed. |
| Quantification of number of cigarettes/tobacco smoked per day. | Bone mineral density (BMD) classification measured using a DEXA scan and as classified by radiology department at UHA. |
| Quantification of number of units of alcohol consumed per day. | Recording of reported weight bearing exercise by dietitian. |

All information as reported by the patient, unless stated otherwise.

Table 2: BSG guidelines [12, 14] for bone disease risk factors

|  |  |
| --- | --- |
| Weight bearing exercise | Smoking history |
| Menopausal status | Bone fracture history |
| Alcohol intake | Vitamin D exposure |

All data as reported by patient.

## Sampling and sample size

Retrospective study sample – all adult patients (18 years or over) who attended the dietetic-led coeliac annual review clinic between 1st January 2012 and 31st December 2012 (n = 229).

Prospective study sample – adult patients (18 years or over) who attended the dietetic-led coeliac annual review clinic over an eight week period, between 5th December 2013 and 6th February 2014 (n = 50).

As data was collected anonymously, therefore, it is not clear which, and how many participants, overlap between the two parts of the study. New patients are introduced to the clinic on a regular basis; some of the participants will be novel to the second part of the study only.

Inclusion and exclusion criteria

All patients who attended the adult annual review coeliac clinic on the dates stated above were included in the study.

No direct exclusion criteria were applied. However, due to the clinic requirements all patients newly diagnosed with CD or within the first three months post diagnosis were automatically excluded, as they attended the alternative clinic.

Ethical approval for the study was given by Life Sciences Faculty Research Ethics Committee University of Chester.

Statistical analysis

 A power calculation was performed in which a sample size of 50 was adequate in 95% of cases; therefore the retrospective sample size was also appropriate [15].

Data for study 1 were non-parametric and analysed using Chi-Squared tests, cross tabulation and/ or Fishers exact test (SPSS version 21). P<0.05 was accepted to denote statistical significance.

Data for study 2 were parametric analysed using two sample paired t-test, cross tabulation and Chi-Squared test (SPSS version 21). P<0.05 was accepted to denote statistical significance

**Materials**

Newly devised clinic proforma – see materials appendix.

**Results**

## *Sample demographics*

## Table 3: Illustrates the sample demographics for studies 1 and 2

|  |  |  |
| --- | --- | --- |
| Sample demographics | Study 1 | Study 2 |
| Gender | **Male** | 26.2% (n=60) | 24.0% (n=12) |
| **Female** | 73.8% (n=169) | 76.0% (n=38) |
| Age at diagnosis | **Median** | 49.2 years (SD 17.4 years) | 52.0 years(SD 18.0 years) |
| **Range** | 2 years– 87 years | 7 – 88 years |
| BMI | **Median** | 26.7kg/m2(SD 5.7kg/m2) | 26.7kg/m2(SD 6.3kg/m2) |
| **Range** | 17-64kg/m2 | 19-50kg/m2 |

Sample demographics were comparable between studies (p=0.417; See Table 3). Median BMI of 26.7kg/m2 (overweight) [16] was observed in both studies. BMI ranged from 17kg/m2 (underweight) to 64kg/m2 (morbidly obese).

*Study 1*

Patients were reported to be compliant with the gluten free diet in 94% of cases in study 1(n=210). 92% had a ‘good’ understanding of the gluten free (GF) diet. Understanding of GF diet was positively correlated with compliance with the gluten free diet (p ≤ 0.001).

65% of this coeliac population have been diagnosed with bone disease, osteopenia or osteoporosis, with 59% receiving medication (calcium and/or bisphosphonates) for this condition. There was no correlation between osteoporosis and BMI (p=0.548).

Table 4: Data for Calcium Intake

|  |  |  |
| --- | --- | --- |
| Dietary calcium intake | Study 1 | Study 2 |
| Mean calcium intake | 1239.6 mg/d(SD 337.1mg/d) | 852.0 mg/d \*(SD 264.6mg/d) |
| Greater than 1000 mg/dLower recommendation [1, 12] | 68% | 30% |
| Greater than 1500 mg/dUpper recommendation [12] | 27% | 4% |
| Greater than 1500 mg/d with supplementation | 41% | 69% |
| Less than 1000mg/d no supplementation | 13% | 18% |
| Calcium intake recorded on record card | 70% | 98% |
| Overall compliance with prescribed supplementation | Unable to assess | 79% |

Data are presented as mean (SD) where appropriate or as percentage of patients. \* denotes a significant difference (p≤0.01).

Table 4 shows calcium intake for both study 1 and study 2. In study 1 68% of patients met the lower recommendation and 27% met the upper recommendation from dietary intake alone; this increased to 40% of patients with the use of supplements (see Table 4). In 16.6% of cases patients were prescribed calcium supplements when their dietary intake was greater than 1500mg/day and, notably, 30% of patients had an intake of less than 1500mg/day and were not prescribed calcium supplementation; of these 13% of patients had a dietary intake below 1000mg/day. The dietitian had recorded calcium intake as either adequate or inadequate in 70% of cases (Table 4).

No significant association was found between DEXA scan results (indicating level of bone disease after Z score interpretation by radiologist) and estimated calcium intake of less than 1000mg/day (p=0.532) or less than 1500mg/day (p=0.112). No significant association was found in the prevalence of bone disease in those patients without calcium supplementation despite dietary calcium intake of less than 1000mg/day when compared to those with adequate intakes.

On analysis, using ingredient breakdown provided by the product manufacturers and nutritional information tables [17], calcium intake in study 1 was found to be overestimated as values cited on record card were inaccurate. Screening for bone disease risk factors, see table 2, and compliance with calcium medication were also not screened for or prompted on record card. This led to the creation of the new record card utilised in study 2.

*Study 2*

59% of this coeliac population had been diagnosed with bone disease, osteopenia and osteoporosis, comparable to study 1 (65%, p = 0.518).

Figure 1: percentage of patients receiving medication to reduce the risk of bone disease

Figure 2: reported compliance with medication in study 2

Figure 3: Compliance with medication by diagnosis of bone disease

Overall, reported compliance with medication was high (see figure 2). However, 90% of patients with osteoporosis were compliant with calcium supplements compared to 71% with osteopenia and 33 % with normal bone densities (p≤0.05) (see figure 3).

Ninety percent of patients reported compliance with a GF diet. As shown in Table 4 mean dietary calcium intake in these patients, using the new tool, was 852mg/day (SD 264.6mg/d), significantly lower than study 1 (p<0.01). When further analysing dietary calcium intake, fewer patients met the recommended intake of 1000mg/day or 1500mg of calcium per day from diet alone (27% and 4% respectively, Table 4). For patients prescribed supplements 69% had a total calcium intake of 1000mg/ day or more, (Table 4). In a small number of cases calcium supplements were prescribed when the dietary intake of calcium exceeded 1500mg/day (4%). Notably 30.6% of patients had a dietary intake of less than 1500mg/day calcium and were not prescribed calcium supplementation; of these 18.4% had a dietary intake below the minimum recommended intake (1000mg/day; see Table 4). The dietitian had correctly recorded this deficiency in 90% of cases and advised these patients to increase their dietary calcium intake in 78% of cases. Assessment of dietary intake was completed in 98% of cases in study 2.

No relationship was found between dietary intake of calcium and fracture rates. No association was found between reported compliance with the gluten free diet and prevalence of bone disease in either study 1 or study 2.

Dietetic screening of risk factors associated with bone disease increased from 71.4% to 98% following the implementation of the new dietary assessment tool. The number of risk factors screened for also increased, along with calcium medication compliance. Dietitians also reported positively on the new screening tool stating *“the new proforma provides a more accurate and thorough calcium assessment”* and *“the new proforma was more thorough in terms of portions of calcium and bone disease risk factors”.*

**Discussion**

Patients attending the dietetic-led coeliac service did not meet BSG guidance [1, 12, 14] for dietary calcium intake potentially impacting on effective long term management of bone disease in this population. Lack of compliance in the initial study is not clear due to inaccuracies in the calcium estimation values supplied by the record card. These inaccuracies meant dietary calcium intake was likely to be overestimated thus the true number of patients not meeting the recommended intakes was potentially underestimated. According to Bianchi and Bardella [18] this would potentially increase the risk of low BMD and osteoporotic fracture in the long term, however the current study did not find a correlation between calcium intake and bone fracture risk. In common with Fouda et al. [13] and Thompson et al. [19] suboptimal calcium intakes were observed, 886±332mg/d and 884.7±371.8mg/d respectively. As this is cross sectional data the long term impact of poor calcium intake needs further investigation.

These investigations demonstrated that, with dietetic support, 30% of patients can meet the current BSG recommended daily calcium intake of 1000 mg/d from diet alone, even when utilising a more accurate method of calculating dietary calcium intake (as in study 2). In fact 4% of patients meet the 2010 guidance recommendation of 1500 mg/d from dietary intake alone, using the estimation method trialled in study 2.

In this CD population the targeting of prescription of calcium and bisphosphonate supplements to those who need it could be improved as 18% of patients not achieving 1000mg/d calcium intake from their diet were not prescribed a supplement. Equally noteworthy when considering effective targeting of prescription is the fact that 17% of patients were prescribed supplements although their calcium intake exceeded 1500 mg/day. This suggests that the first level dietetic intervention could focus on increasing calcium intake from dietary sources, with a second level of intervention targeted on prescribing calcium supplements to those whose calcium intake remains poor after the first line intervention has been completed.

Reported compliance with supplementation was 77% for the study population, reflecting the prevalence of bone disease within this CD population (59% of patients). Those with a diagnosis of osteoporosis were more likely to be compliant; compliance in patients with no current diagnosis of bone disease was only 33% suggesting the presence of bone disease improves motivation more than prevention of bone disease in this population. Those with a diagnosis of bone disease were more likely to be prescribed supplements.

The compliance rates with prescribed supplements and GF diet reported in this study were high in comparison to other studies. This may be a product of the self-reported nature of the data; Leffler et al. [20] found adherence to a GF diet to be over reported in a CD population, with 70% of participants reporting strict adherence, compared with 50% when dietary adherence was assessed by a trained clinician. In a female population; Cramer et al. [21] reported compliance rates as low as 57.6% with bisphosphonate therapy, which further reduced to 31.7% twelve months post initial prescription in post-menopausal women, 87.5% compliance with calcium supplements was reported in the menopausal patients. Fouda et al. [13] also found both dietary histories and food diaries reported by the patients were inaccurate, subject to reporter bias; this emphasises the need for interpretation by a trained professional who is able to recognise and explore inaccuracies to improve the quality of information recorded and suggests compliance with a gluten free diet and prescribed supplements needs further study to ascertain actual intake.

**Conclusion**

The data from this study supports the role for dietetic led clinics to monitor and evaluate the status of CD patients. This monitoring includes consideration of risk for bone disease and the use of individualised dietary prescriptions that not only promote compliance with GF dietary advice but also advice on dietary measures to address other nutritional concerns, such as low dietary calcium intake. With appropriate support many patients can meet guideline recommendations for calcium via oral intake alone and adhere to a gluten free diet. Where the patient is unable to meet recommended intakes, or other risk factors are present, accurate information gathering and record keeping can support appropriate targeting for further treatments such as calcium supplementation prescription. In cases where calcium and vitamin D deficiencies are identified a combined supplement may be required.

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**Stating of competing interests**

The authors have no competing interests.

**List of abbreviations**

BMI – Body Mass Index

BMD – Bone Mineral Density

BSG – British Society of Gastroenterology

CD – Coeliac Disease

DEXA – Dual Energy X-ray Absorptiometry

GFD – Gluten Free Diet

SPSS – Statistical Package for Social Sciences

UHA – University Hospital Aintree NHS Foundation Trust

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**Materials**

**COELIAC DISEASE CLINIC PROFORMA**

**MEDICAL**

Weight: …………….kg Height: …………….m BMI: …………….kg/m2 Weight loss: ……………..%

Date of diagnosis: …………………………………………………………………

Symptoms prior to diagnosis: ………………………………………………. Symptoms resolved: Yes No

Family history: CD T1DM IBD Flu jab

Bowel habit: Normal Diarrhoea Blood Constipation

New symptoms: Appetite Lethargy Rash Other N/A

Medication: Ca2+ supplements Date started: …………………… Compliant: Yes No

Bisphosphonates Iron B12

Other medication (please list): …………………………………………………………………………………………………………

Bloods requested: Yes No Refused

First DEXA scan date: ………… Result: Normal Osteopenia Osteoporosis

Last DEXA scan date: ………… Result: Normal Osteopenia Osteoporosis

DEXA scan requested: Yes Not required Info for first DEXA not available

**DIETARY**

Gluten consumed: Never Occasionally Accidentally Frequently

Checking labels: Yes No

Prescribed products: Yes No Quantity: ………………………..

Prepayment certificated: Yes No Coeliac UK member: Yes No

Cross contamination: Separate toaster Separated butter

**BONE DISEASE RISK FACTORS**

Weight bearing exercise: Yes No Previous fractures: Yes No

Post menopause: Yes No N/A Vitamin D exposure: Yes No

Alcohol (drinks/day): 0 1-2 3-4 5-6 7-9 9+

Smoking (cigarettes/day): 0 1-5 6-10 11-15 16-20 21-30 31+

Comments/outcome:…………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………….

**Materials Continued**

**DIET HISTORY ASSESSMENT**

Compliant: Yes No

|  |  |  |
| --- | --- | --- |
| Morning |  | **250mg Ca2+ per portion:**200ml semi/skimmed milk200ml ca2+ fortified soya milk150g yoghurt30g/matchbox cheese4 small sardines with bones200g/1/2 tin custard/rice pud50g/2xmatchboxes plain tofu150g dried figs**50mg Ca2+ per portion:**2tbs fromage frais1 orange100g green vegetables100g baked beans25g milk chocolate2tbs cottage cheese2xslices GF white breadTotal/day:Advised to increase: |
| Mid morning |  |
| Lunch |  | **Iron containing foods:**90g red meat – 3mg100g liver – 11mg80mg dried figs/apricots – 3mg2tbs cashew nuts – 1.5mg90g spring greens/lentils – 1mgTotal/day:Advised to increase:Advised on Vitamin C: |
| Mid afternoon |  | **CHO**Portions/day:High fibre: |
| Evening |  | **Protein**Portions/day: |
| **Fruit**Portion /day:**Vegetables**Portions/day: |
| Supper/late evening |  | **High fat/sugar**BiscuitsCakesCrispChocolateTakeaways |