ORIGINAL RESEARCH

Comparing alternative follow-up strategies for patients with stable coeliac disease

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ABSTRACT

Background Once clinically stable, patients with coeliac disease should have annual follow-up. Lack of capacity in gastroenterology outpatient clinics mean alternatives are required.

Objectives We studied the effectiveness of follow-up deferred to general practitioners (GP-FU) and compared this with a neighbouring Trust where follow-up was through a dedicated nurse-led telephone clinic (T-FU).

Design All patients with coeliac disease were posted a questionnaire examining patient satisfaction, adherence with gluten-free diet and calcium intake.

Results 517 of 825 patients (62.7%) completed a postal questionnaire (median age 61, 72% female). 28% of GP-FU and 84% of T-FU patients received an annual review. Of those seen, 33% (GP-FU) and 53% (T-FU) were weighed (χ^2 65.8, $p < 0.001$), 44% and 63% had symptom review (χ^2 81.1, $p < 0.001$) and 33% and 51% had dietary adherence checked (χ^2 60.6, $p < 0.001$). Almost all patients considered their adherence with gluten-free diet (GFD) good or excellent, although the majority of patients failed to achieve the recommended daily intake of calcium. GP-FU patients were more likely to receive calcium±vitamin D supplements (77% vs 42%, χ^2 88.2, $p < 0.001$) and they were also more likely to receive appropriate vaccinations (67% vs 38%, χ^2 17.6, $p < 0.001$).

Conclusions Discharge of patients with coeliac disease to primary-care in many cases results in their complete loss to follow-up. When patients were reviewed, either by GP-FU and T-FU, many aspects of their care are not addressed. Whether this will result in late complications remains to be seen.

INTRODUCTION

Coeliac disease affects about 1% of the Western European population.¹ Initially,

Significance of this study

What is already known on this topic

- Patients with stable coeliac disease transferred back to primary care are often lost to follow-up. When they are followed up, the standard of care is comparable with nurse-led hospital follow-up.
- Guidelines recommend that patients with coeliac disease receive annual review. Pressure on secondary care outpatient clinics often means this is deferred to primary care.

What this study adds

- Telephone clinic review resulted in more patients being reviewed and greater adherence to some though not all of the guidelines compared to Primary Care follow-up. Patients, however, expressed a preference for a face-to-face consultation.

How might it impact on clinical practice in the foreseeable future

- Novel methods to incentivise primary care colleagues to universally manage follow-up of patients with coeliac disease or alternative means of follow-up are needed if many patients are not to receive substandard care.

patients are usually managed by a combination of gastroenterologists and dietitians. UK^{2,3} and American⁴ guidelines recommend that all patients with coeliac disease, when clinically stable, are reviewed annually. This is to monitor the patient's clinical status, dietary adherence (including calcium intake) and to identify complications. Patients with coeliac disease have an increased risk of developing osteoporosis, vitamin deficiencies (sometimes causing anaemia), other autoimmune conditions such as hypo or hyperthyroidism as well as malignancy including small bowel

lymphoma and adenocarcinoma.^{5–8} Good adherence to a GFD can prevent the development of at least some of these complications.⁷

With increasing pressure on the availability of gastroenterology outpatient clinic capacity many hospitals have elected to discharge patients with well controlled coeliac disease back to their general practitioners (GPs).⁹

In both centres, being clinically stable meant that the patient was asymptomatic with normal laboratory parameters, and patient, dietician and clinician were satisfied that management had been optimised. Coeliac serology would also be expected to be negative prior to discharge from hospital outpatient clinics although there was no requirement for second duodenal biopsy. We appreciate that this pragmatic and common approach will fail to identify persistent villous atrophy, negative serology and apparently good adherence to GFD.⁸

A dedicated dietician-led coeliac clinic was established at Derriford Hospital, Plymouth in 2006. All newly diagnosed patients were referred to this clinic and discharged from the gastroenterology outpatient clinic when clinically stable back to their GP for long-term follow-up (GP-FU). Both patient and GPs were provided with a written proforma regarding the advisability of yearly follow-up, together with advice and recommended investigations as advocated by the current national guidelines.^{2,3}

At the neighbouring Trust, the Royal Cornwall Hospital, Truro, patients were seen within the gastroenterology and dietetic outpatient clinics as appropriate. Following a patient survey to determine follow-up preference,¹⁰ a dedicated annual telephone follow-up (T-FU) clinic run by a nurse specialist started in 2005 and clinically stable patients were reviewed annually by this service. Patients had blood checks completed either through their GP surgery or outpatient department as preferred and gave their weights and heights at the telephone consultation.

The aim of our audit was to examine the effectiveness of both approaches (GP-FU *vs* T-FU) in terms of patient satisfaction, adherence against national guidelines and efficacy.

METHODS

University of Plymouth Hospitals NHS Trust, Plymouth and the Royal Cornwall Hospital, Truro are neighbouring teaching hospitals in the South West of England with 900 and 750 beds, respectively.

Dedicated dietetic-led, hospital-based clinics were set up at Derriford Hospital, Plymouth in 2006. A specialist nurse-led telephone clinic at the Royal Cornwall Hospital, Truro in 2005. We identified all patients referred to both services up until the end of 2014 from clinic databases. All patients had a positive diagnosis of coeliac disease with confirmatory serology and typical duodenal histology. All patients were clinically stable at the point of discharge from hospital outpatient clinics.

Table 1 Baseline characteristics

	GP follow-up	Telephone follow-up
Questionnaires: sent	285	540
Questionnaires: returned	173 (61%)	344 (64%)
Age (years)	60 (48–78)	62 (49–73)
Sex ratio M:F	1:3.2	1:2.3
Length of diagnosis (years)	4 (3–6)	9 (5–11)*
Age and length of diagnosis are shown as median (IQR)		
Annual review		
Annual review achieved†	48 (28%)	290 (84%*)
Weight measured‡	16 (33%/9%)	154 (53%/45%*)
Symptoms reviewed‡	21 (44%/12%)	183 (63%/53%*)
Diet reviewed‡	16 (33%/9%)	148 (51%/43%*)

*P<0.001.

†Number (% of those patients who returned their questionnaire).

‡Number (% of those patients who were reviewed/% of all those returned their questionnaire).

GP, general practitioner.

In 2016, postal questionnaires were sent to all identifiable patients from both services. The questionnaires explored patient engagement and satisfaction with medical supervision and monitoring of their coeliac disease (eg, yearly blood tests and vaccinations). Questions also asked about their adherence with a GFD (using a 5-point Likert scale¹¹) and patients were asked to complete a 1 week food diary to assess dietary calcium intake.

The audit was approved by the hospitals audit department (Plymouth: CA_2015-16-383 & Truro: 552).

Data were assessed for Normal distribution using the Shapiro-Wilk test. Data were generally non-parametrically distributed, so is presented as median (IQR). χ^2 , Fisher's exact (χ^2 statistic and p value) and Wilcoxon signed rank tests (p value and 95% CI) were used to assess differences where appropriate, with statistical difference being p<0.05.

RESULTS

A total of 517 (63%) questionnaires were returned (61% and 64% in GP-FU and T-FU, respectively). The median age of patients was 60 (GP-FU) years and 62 years (T-FU) with more than two-thirds of the patients being female (see [table 1](#) for complete demographics). Patients undergoing telephone follow-up (T-FU) had been diagnosed longer. Of those patients returning their questionnaires, those undergoing telephone follow-up (T-FU) were more likely to receive an annual review (χ^2 162.7, p<0.001), have their weight measured (χ^2 65.8, p<0.001) their symptoms assessed (χ^2 81.1, p<0.001) and their diet reviewed (χ^2 60.6, p<0.001) ([table 1](#)). Of those who had annual review in Primary Care 33%–44% recalled having their diet,

Table 2 Annual review

Annual review	GP follow-up		Telephone follow-up	
	Occurred (n=48)	Did not occur (n=125)	Occurred (n=290)	Did not occur (n=54)
GF prescription*	39 (81%)	76 (61%)	186 (64%)	26 (48%)†
GFD compliance (Very poor, poor, Fair, Good, Very good)	1, 0, 3, 21, 23	3, 4, 15, 46, 57	0, 0, 19, 74, 191	1, 0, 1, 15, 35
Blood tests‡	34 (71%)	14 (11%)	225 (78%)	14 (26%)
Vaccinations*§	32 (67%†)	11 (9%)	110 (38%)	10 (19%)
Calcium±Vitamin D supplements taken*	37 (77%)	80 (64%)	121 (42%)	15 (28%)
Dietary calcium (mg/day)¶	1044 (821–1298)	814 (525–1174)	907 (653–1276)	940 (655–1226)
Total calcium intake ≥1000 mg/day*	23 (48%)	37 (30%)	143 (49%)	20 (37%)

*Number (% of patients)

†P<0.001.

‡Blood count, haematinics, thyroid function.

§Capsulated bacteria (Pneumococcal, haemophilus or meningococcal).

¶Dietary calcium (median, IQR).

GF, gluten-free; GFD, gluten-free diet; GP, general practitioner.

symptoms or weight reviewed (9%–12% of the total of those referred back for Primary Care management). For those patients who actually received an annual review, there was no difference between GP-FU or T-FU regarding assessment of weight, symptoms or diet (table 1).

Patients undergoing GP-FU were more likely to receive a prescription for gluten-free products (χ^2 100.6, $p<0.001$) (table 2). Between the two follow-up modalities, self-reported adherence with a GFD was higher for T-FU (χ^2 26.5, $p<0.001$) whether they were reviewed (χ^2 12.8, $p=0.005$) or not (χ^2 9.8, $p=0.043$). Overall adherence was reported as good or excellent: 97% for T-FU and 85% for GP-FU. Reported adherence with a GFD was no different at each centre between those who were reviewed and those who did not receive an annual review.

Calcium and/or vitamin D supplements were more likely to be prescribed for GP-FU patients (χ^2 88.2, $p<0.001$) and they were more likely to receive pneumococcal vaccine (χ^2 17.6, $p<0.001$). Blood tests were done more frequently in the T-FU patients (χ^2 24.7, $p<0.001$).

Overall dietary calcium intake did not differ between follow-up modalities and the median dietary intake was below the daily recommended intake of 1000 mg/day (table 2). In those patients undergoing GP-FU, calcium intake was higher in those who attended appointments than those who did not ($p=0.009$, 95% CI 56 to 349), and this difference was not seen in the T-FU group.

There was no difference between follow-up methods regarding ‘other forms of support’ (mainly Coeliac UK and social media) (table 3). Patients in the T-FU group who received annual review were more likely to use these forms of support than those not having

Table 3 Patient preference for annual review

Annual review	GP follow-up		Telephone follow-up	
	Occurred (n=48)	Not achieved (n=125)	Occurred (n=290)	Not achieved (n=54)
Other forms of support Coeliac UK members:Other social media:no support use	30:1:17	66:8:51	174:29:97	20:3:31
GP review suggested	31 (65%)	27 (22%)	38 (13%)	3 (6%)
Patient recalls being told that they should have an annual review with their GP				
Review worthwhile	23 (48%)	73 (58%)	183 (63%)	34 (63%)
Required help with diet	0 (0%)	19 (15%)	47 (16%)	13 (24%)
Referred to a dietician	2 (4%)	9 (7%)	59 (20%)	14 (26%)
Preferred follow-up	37:11:0:0:2	69:53:0:0:14	52:15:185:57:3	24:9:13:16:2
Preferred follow-up professional: GP:dietician:nurse:hospital specialist:other				
How would prefer FU	44:4:3:1	95:20:13:5	109:120:63:1	37:10:5:0
Preferred follow-up method: Face-to-face:telephone:email:other				

*P<0.001.

FU, follow-up; GP, general practitioner.

appointments (χ^2 12.5, $p=0.002$). This difference was not seen in those in the GP-FU group.

Sixty-one per cent of patients regarded the need for annual review as being worthwhile, significantly more in those undergoing T-FU (χ^2 107.8, $p<0.001$). Patients undergoing T-FU were more likely to feel they required help with their diet (χ^2 36.7, $p<0.001$) and were more likely to be referred to a dietician as a result of annual review (χ^2 18.9, $p<0.001$) than those under GP-FU. When asked for a preference regarding modality of annual review, patients undergoing GP-FU preferred this while those undergoing T-FU preferred nurse-led telephone follow-up. Of those patients in both groups who did not receive any follow-up appointments, 52% preferred GP *vs* 35% dietician and 7% nurse-led follow-up. Most patients (55%) expressed a preference for any follow-up appointment to be face-to-face, including those who had not received any follow-up appointments. For those patients undergoing T-FU for which the appointments occurred 38% expressed a preference for GP *vs* 41% dietician and 21% nurse-led.

DISCUSSION

An annual follow-up was considerably more likely to occur in those receiving a nurse-led telephone follow-up (T-FU) appointment than those being followed up by their general practitioners (GP-FU) (84% *vs* 28%) despite consultation with primary care colleagues beforehand including an agreed written proforma for management. In those patients undergoing T-FU, self-reported adherence with a GFD was higher and they were more likely to be weighed, have blood tests taken and have dietary adherence and symptoms reviewed. There was no difference in dietary calcium intake between methods of follow-up. Those patients undergoing GP-FU were more likely to receive calcium and vitamin D supplements and vaccinations than those undergoing T-FU. As the majority of patients with coeliac disease failed to achieve recommended daily intake of calcium from diet alone, this would appear an important difference. A high percentage of patients with coeliac disease returned their questionnaires making it likely that their responses were reliable.

Adherence with a GFD was good or excellent in 89% of patients, which compares favourably with other studies (42%–91%).¹² The clinical symptoms of coeliac disease range from asymptomatic to severe. At discharge from face to face outpatient clinics in both hospitals, all patients were in clinical remission. Evidence suggests that a planned long-term strategy for patient follow-up is essential.¹³

From our data, a concerning large percentage of patients fail to have annual follow-up when care is transferred back to primary care and possibly as a result reported adherence with a GFD is less. Attendance at a GP surgery required patients to proactively book an appointment whereas for T-FU appointments were initiated by the healthcare provider perhaps explaining

the greater take up. It is not clear why patients who did not attend either types of annual review given the majority felt annual review was worthwhile. Given a preference, most would prefer a face to face meeting with either a GP or dietitian except those under T-FU who would prefer a nurse. A previous survey showed a patient preference for long-term follow-up with a dietician with a doctor being available if needed.¹⁴ The majority of patients appeared most satisfied with the follow-up modality with which they had been engaged. Both GP and nurse-led telephone follow-up satisfied many of the requirements of guidelines for annual review of symptoms and monitoring but neither appeared to fulfil all needs. Novel means of ensuring that patients discharged from gastroenterology outpatient follow-up continue to have annual review are required. This could involve virtual clinics with reminders been sent to patients. Alternatively in Scotland, ongoing management reverts to community pharmacists under the gluten-free products scheme.¹⁵

Probably the key element is that the patients are contacted proactively. Compared with traditional consultant-led hospital outpatient clinic review, it is likely to be more cost effective if patients are being seen by a suitably trained dietitian, nurse or GP who are able to follow guidelines. Pressures on gastroenterology outpatients clinics mean new methods of ensuring annual follow-up are required¹⁶ but our study suggests that even with clear management plans and proformas, care may still be suboptimal.

While a high percentage of patients returned their questionnaire, it is possible that differences in adherence exist with those who did not. We relied on the accuracy of patient reporting (which may be unreliable).² It was beyond the scope of this study to examine whether clinical outcomes (eg, osteoporotic fracture) or surrogate endpoints (eg, bone mineral density) were reduced because of the failure to achieve annual review or whether it affected health-related quality of life. Community pharmacy-led follow-up as relatively recently introduced in Scotland was not available in South West England so we are unable to compare this modality.

We acknowledge that relying on self-reported adherence to diet and of patient recall regarding aspects of their care could potentially give misleading results.

CONCLUSION

This study has highlighted problems both with deferral to general practitioners with standardised protocol (few patients receive annual follow-up) and with a dedicated nurse-led telephone clinic (fewer receiving appropriate vaccinations and calcium). With increasing pressure on the availability of gastroenterology outpatient clinic capacity, many hospitals have elected to discharge patients with well controlled coeliac disease back to community care. Discharge of patients with stable coeliac disease from formal gastroenterology or dietetic review led to many patients not receiving

annual review. Even when they do receive annual review, both GP proforma driven and nurse-led telephone follow-up have not met all standards of care. Dietary calcium intake was shown to be below recommended daily intake and supplementation should be considered more frequently. Without incentives, it would seem unlikely that annual GP review is likely to occur. Novel means of ensuring annual follow-up and standardised care such as a proforma-led telephone clinic with tests co-ordinated from a virtual clinic would optimise patient care with lowest costs.^{17 18} Such a clinic could be co-ordinated by either a nurse or dietitian with a specialist interest in coeliac disease and ensure dietary compliance (including calcium and vitamin D intake), appropriate investigations and vaccinations are achieved. Where required these virtual clinics could refer/advise patients to attend their GP's surgeries or a dietetic clinic.

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