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Conference on 'Malnutrition matters'

Symposium 1: Joint BAPEN and British Society of Gastroenterology Symposium on 'Coeliac disease: basics and controversies' Dietitians are better than clinicians in following up coeliac disease*

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It seems obvious to healthcare professionals that patients with coeliac disease should receive regular follow-up. Surprisingly, there is little evidence that patients benefit in terms of reduced morbidity or mortality. However, several authoritative bodies have published guidelines on the management of coeliac disease that recommend regular follow-up. There is good evidence that compliance with a gluten-free diet reduces the risk of complications such as osteoporosis or small bowel lymphoma. Compliance is enhanced particularly by education about the disease and the gluten-free diet and by support from peers or professionals. Such input can be provided by regular follow-up, which thereby should improve compliance and hence long-term health. The consensus of the recommendations for follow-up suggests an annual review by a physician and dietitian. At annual follow-up the disease status can be checked and nutritional advice can be given, including checking the adequacy of, and the compliance with, the gluten-free diet. Complications and associated medical conditions can be sought, genetic risks explained and support and reassurance given. Specialist dietitians have particular expertise in relation to diet and nutritional management; specialist clinicians have a broader range of expertise in many aspects of management of the disease. A team approach for providing follow-up is the ideal, with a clinician and dietitian, both with expertise in coeliac disease, being involved. No one particular group of healthcare professionals is necessarily better than the other at providing follow-up.

Coeliac disease: Gluten-free diet: Follow-up

The motion for the present debate assumes that patients with coeliac disease require and will benefit from formal follow-up. This conclusion seems obvious to healthcare professionals, although there is surprisingly little evidence to support it. It is a moot point whether the outcomes for patients in terms of morbidity or mortality would be different depending on their attendance at formal follow-up. If patients develop symptoms of relapse or complications they would normally seek medical help irrespective of regular follow-up. There is very little evidence that those patients being followed up in special clinics have better outcomes than those not being followed up at all.

Presumably because of the lack of such evidence, there is no uniform approach to follow-up despite various guidelines being published[1–6] that recommend follow-up. Many gastroenterologists frequently discharge patients from secondary care once they have been diagnosed and established on a gluten-free diet (GFD), and such a policy is actively pursued by several health authorities even when primary-care services, especially dietetics, are stretched. In such situations patients probably have little opportunity of follow-up. This situation of course cannot be strongly criticised, since the benefits of regular follow-up are insufficiently researched[7].

Abbreviations: GFD, gluten-free diet.

*A debate entitled 'Dietitians are better than clinicians in following up coeliac disease' was held at the Annual Meeting of the Nutrition Society and BAPEN on 4 November 2008. For the motion were Claire Stuckey and Jacqui Lowdon, adult and paediatric dietitians respectively, and against the motion was Peter Howdle, consultant gastroenterologist and Professor of Clinical Medicine. A unified account of the debate is summarised in the present paper.

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Nevertheless, expert opinion, as in published guidelines, does recommend regular follow-up for patients with coeliac disease by professionals with a specific expertise in the disease. It is thought that such follow-up should maintain good health, allow monitoring for long-term complications and associated conditions and provide advice and support.

Although there is a lack of good evidence concerning the benefits of follow-up, there is good evidence that adherence to a strict GFD reduces the risks of complications[8–10] and associated diseases[11] and improves quality of life[12]. Compliance with a GFD is improved by education and knowledge of the diet and the disease, by membership of a self-help society (e.g. Coeliac UK, High Wycombe, Bucks., UK), by availability of gluten-free products and by accessibility to a physician and dietitian[13–15]. Since most of this support can be provided by regular follow-up with healthcare professionals with specialised expertise, the enhancement of compliance with a GFD is the main reason for regular follow-up.

Several secondary queries arise such as: how often follow-up should occur; are there special groups of patients with coeliac disease, such as children or the elderly or those who present with overt symptoms, that particularly need follow-up; who should provide the follow-up. Such questions need researching.

Recommendations for follow-up of coeliac disease

There are several sets of published guidelines for coeliac disease that recommend regular follow-up[1–6].

The National Institutes of Health statement[6] has published six key elements of follow-up, which reiterates some of the factors affecting compliance with a GFD and also includes some of the potential benefits to the patient that should improve long-term health:

C: consultation with a skilled dietitian;
E: education about the disease;
L: lifelong adherence to a GFD;
I: identification and treatment of nutritional deficiencies;
A: access to an advocacy group;
C: continuous long-term follow-up by a multidisciplinary team.

A summary of the recommendations for follow-up is as follows:

British Society of Gastroenterology: in 1996, six- to twelve-monthly medical follow-up in secondary care[1]; in 2002, jointly with primary care[2];
Primary Care Society for Gastroenterology: in 2001, annually, team approach (i.e. primary- or secondary-care physician with a special interest and dietitian)[3];
American Gastroenterological Association: in 2001, annually[4]; in 2006, regular intervals with physician and dietitian[5];
National Institutes of Health: in 2005, annually, physician and dietitian[6].

The consensus of these recommendations is therefore annual follow-up by a physician and dietitian.

Follow-up interventions

If regular follow-up takes place there are several areas for intervention. The disease status can be checked (e.g. BMI, symptoms, nutritional indices, serology for coeliac antibodies). The adequacy of the GFD and compliance can be checked as well as providing advice about gluten-free products and prescriptions. Nutritional advice and management recommendations can be given (e.g. anaemia, osteopenia and osteoporosis, vaccination). Persisting symptoms, complications and associated medical conditions can be considered and relevant investigations and treatment instituted. Genetic risks and recently-publicised research can be discussed, family education and support can be given and reassurance about the long-term outcomes.

What can healthcare professionals do at follow-up?

These interventions can be undertaken by more than one healthcare professional, although there are strong recommendations that an expert dietitian should be involved[16–19]. There are some established dietitian-led clinics[20] with access to a gastroenterologist as necessary. Some patients prefer this management pathway[17]. A dietitian, expert in coeliac disease, can:

check the nutritional status of the patient;
check the nutritional adequacy of a GFD;
assess the strictness of the GFD and compliance;
provide prescription advice for gluten-free foods;
provide labelling information;
educate about gluten and the diet;
help the family in the understanding of the diet and disease;
provide reassurance and support.

Dietitians, of course, are well aware of the social and psychological aspects of food and how these factors may affect an individual's nutritional state. They also possess the skills of motivational interviewing to encourage behavioural change and can thus help patients to adhere to a strict GFD. Such skills are particularly important in helping older patients, since many patients with coeliac disease are now being diagnosed at a later age.

Currently, however, most follow-up is carried out by clinicians with an interest in coeliac disease (i.e. a gastroenterologist or primary-care physician). Such medical professionals are expert in:

assessing the clinical state of the patient;
assessing and investigating the cause of persisting symptoms (e.g. wrong diagnosis, colitis, pancreatic insufficiency, lactose intolerance, complications);
interpreting results (e.g. serology, dual-energy X-ray absorptiometry scans);
advising about treatment (e.g. osteoporosis);
advising about the need for vaccination;
assessing for long-term complications or associated diseases and their possible treatment (e.g. diabetes, thyroid disease, ulcerative jejunitis, refractory disease, malignancy);

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advising about genetic risks and recent publicised research findings;
providing support, reassurance and education to the patient and family.

Conclusions

Although the evidence supporting regular follow-up is lacking, there are recommendations for such follow-up from authoritative bodies. Follow-up should reduce ill-health and it should certainly improve compliance with a GFD and provide reassurance and education. To achieve these ends a broad range of expertise is necessary, hence a team approach is recommended. Clinicians have a wide range of expertise and can successfully fulfil many of the recommended interventions. However, dietitians have highly-specialised knowledge in their field and can better fulfil some of the specific interventions.

The debate concluded that there should not be an assumption that one particular group of healthcare professionals was better than another at providing follow-up for patients with coeliac disease. Individual situations would dictate whether follow-up led by one or other of the professionals, but with reciprocal help available as necessary, was preferable in certain circumstances. However, it was concluded that a team approach was the ideal, with a clinician and dietitian, both with expertise in coeliac disease, being necessary to provide the best follow-up for patients with coeliac disease.

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