RESEARCH

Coeliac disease in Asians in a single centre in southern Derbyshire

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Abstract

Background Coeliac disease affects adult Asians from north India, Pakistan and Bangladesh in the UK but how commonly this occurs is unknown.

An audit of coeliac disease was therefore conducted in a well-defined area in southern Derbyshire.

Methods All white and Asian patients with biopsy-confirmed coeliac disease diagnosed between 1958 and 2008 were identified. Population data from the Office of National Statistics allowed the calculation of prevalence. Presenting symptoms, adherence to a gluten-free diet and follow-up record were determined for Asians and compared with matched white patients.

Results Among 1305 coeliac patients diagnosed between 1958 and 2008, 82 were Asian. Coeliac disease occurred significantly more frequently in Asian than white individuals and this could be attributed to the significantly higher prevalence in women 16 years and older and under 60 years of age. No Asian man over the age of 65 years was diagnosed with coeliac disease. Asians are more likely to present with anaemia and less likely to present with diarrhoea than white individuals. Asians are less likely to adhere to a strict gluten-free diet than white patients.

Conclusions This baseline audit indicates that increased efforts should be directed towards diagnosing coeliac disease in Asian men over the age of 65 years, in whom at present it is unrepresented. Strategies also need to be developed to help more Asian patients adhere strictly to the gluten-free diet.

Introduction

Coeliac disease was first described convincingly in children¹ and adults from north India² almost 50 years ago. Of 10 children, all had clinical features and small bowel radiological appearances indicative of coeliac disease. Small bowel biopsies taken in seven were all characteristic of coeliac disease. Eight children

showed a marked improvement on a gluten-free diet, with a reduction in faecal fat loss, and of six given a gluten challenge all relapsed.¹ In seven adults the diagnosis was based on steatorrhoea, abnormal small intestinal morphology, abnormal small bowel radiology and improvement on a gluten-free diet, present in all patients.² Interest waned until 1988 when again coeliac disease was described in Indian children.³ Since then coeliac disease has been increasingly identified mainly in north India in children and adults.^{4–8} With its vast population, the number of those with coeliac disease may be approaching 10 million.⁹ It is not surprising that coeliac disease occurs in north India, the so-called coeliac belt, because wheat is consumed in this area and the population carries haplotypes necessary for coeliac disease to develop.^{7, 10}

It would be expected that coeliac disease might develop in these populations and their descendants when they move to other parts of the world where wheat is eaten, and this was observed almost 40 years ago in children of Asian immigrants to Britain^{11, 12} and confirmed in adults in Britain^{13, 14} and Canada.¹⁵

The aim of this baseline audit was to determine the prevalence and characteristics of coeliac disease in adult Asians residing in a well-defined area in southern Derbyshire and known to a single dedicated coeliac clinic, and compare these with a matched group of white patients.

Methods

All adult patients (≥ 16 years of age) with coeliac disease diagnosed by small bowel biopsy residing in southern Derbyshire in the catchment area of the two district general hospitals (Derbyshire Royal Infirmary and Derby City General

Hospital) were identified. Extensive efforts were made to identify patients, and sources of information included the hospital diagnostic index, histopathology records, the dermatitis herpetiformis clinic, the immunology laboratories, the dietetic department and membership lists of Coeliac UK (formerly the Coeliac Society). Patients who were referred from other secondary care centres were excluded from consideration. The first diagnosis of coeliac disease in an adult in Derby made by jejunal biopsy was in 1958, and from 1972 onwards diagnoses were made every year. From 1978 until the end of 2008 patients were followed prospectively in a dedicated weekly clinic. During this latter period regular fortnightly meetings with consultant histopathologists to review small bowel biopsies ensured that all cases of coeliac disease being diagnosed were identified. Notes were available for all patients.

The diagnosis of coeliac disease was based on characteristic small bowel biopsy appearances of severe or total villous atrophy. Information collected for the audit included the ethnic origins of the patients, date of birth and date of biopsy diagnosis. The presenting symptoms were also recorded. The collection of these data was coordinated by a single investigator (GKTH) and stored on an Access database for ease of processing.

All patients diagnosed with coeliac disease were offered a gluten-free diet with a review at 6 weeks and then as deemed necessary. For the purposes of this audit patients were classified by an experienced dietitian as adhering strictly to a gluten-free diet (not ingesting any gluten) or taking gluten. Their dietary status was assessed when last seen in the coeliac clinic. All patients were offered an annual review in the coeliac clinic but would be seen at any time if there were concerns.

The Asians in the series originated from north India, Pakistan and Bangladesh. The number of whites and Asians within the catchment area of the hospitals was derived from the Office for National Statistics and the statistics department of the newly established Royal Derby Hospital, which recently replaced the two district general hospitals. Figures were available each year from 2001 for men in the Asian population for ages 16 years and older and under 65 years and 65 years and older and for women aged 16 years and older and under 60 years and 60 years and older. Corresponding figures were also available for the white population.

In order to compare the Asian with the white population a group of white individuals was chosen to match the Asians for gender and date of birth. When possible the exact date of birth was matched, otherwise the white person with the nearest date of birth was used. The difference in the dates was never more than 4 months. The two groups were analysed to determine when coeliac disease was diagnosed,

presenting symptoms, adherence to gluten-free diet and follow-up record.

Data were analysed by *t* tests (haemoglobin and weight loss) and χ^2 tests (all other results) using Vassar statistics (VassarStats, a free on-line package).

This project was registered with and approved by the audit office of the Royal Derby Hospital.

Results

Between 1958 and the end of 1971 only eight patients with coeliac disease were diagnosed. Since 1972 diagnoses have been made each year; 1305 patients were diagnosed between 1958 and the end of 2008 and of these, 1270 were followed prospectively. Of the 1305 patients, 1222 (419 men; 803 women) were from the white population, 82 (19 men; 63 women) were Asian and one (man) was of mixed Afro-Caribbean and white race.

Prevalence

The first adult Asian patient with coeliac disease was diagnosed in 1989, and since then cases have been diagnosed each year. At the end of 2008, 82 cases had been encountered. By mid-2002, approximately half the Asian patients had been diagnosed so that the mid-year population numbers for 2002 were used to calculate the prevalence and compare with the prevalence in the white population (table 1). The numbers of white and Asian individuals in the catchment area of the Derby hospitals for mid-2002 by gender and

Table 1 Number of Asian patients with coeliac disease diagnosed in the catchment area of the Derby hospitals from the first diagnosis in 1989 to the end of 2008

Year	Men	Women	Total
1989	1	0	1
1990	0	1	1
1991	0	1	1
1992	0	1	1
1993	0	1	1
1994	0	1	1
1995	0	1	1
1996	0	1	1
1997	1	4	5
1998	2	3	5
1999	0	4	4
2000	1	7	8
2001	0	6	6
2002	0	4	4
2003	5	5	10
2004	1	5	6
2005	2	7	9
2006	3	3	6
2007	1	4	5
2008	2	4	6
Total	19	63	82

Table 2 Number of white and Asian individuals in the catchment area of the Derby hospitals mid-2002

Age (years)	White men	Asian men
≥16 <65	173 000	7500
≥65	38 600	500
Age (years)	White women	Asian women
≥16 <60	158 400	7000
≥60	66 000	900

Source: Office for National Statistics, 2010.

age ranges under consideration are shown in table 2. Table 3 shows the changes in population numbers for white and Asian individuals for 2001, when figures in this format first became available, compared with 2008. Also shown are the numbers of patients with coeliac disease diagnosed in these years. It can be seen that although there has been an increase in the population served by the Derby hospitals a fall in the number of diagnoses of coeliac disease being made in white individuals has been observed but it has remained the same in the Asian population.

The overall prevalence in the white population was 1 : 356 and in the Asian population 1 : 193, a highly significant difference ($p < 0.001$). Of those aged 16 years and over and under 65 years, the prevalence in white men was 1 : 549 and for Asians it was 1 : 395 (not significant). For white men 65 years and older the prevalence was 1 : 371, but no diagnoses were made in Asian men in this age group. For white women 16 years and over and under 60 years the prevalence was 1 : 273 and for those 60 years and older it was 1 : 296. For Asian women 16 years and over and under 60 years the prevalence was 1 : 116 and for those 60 years and older it was 1 : 300. The results for the white and Asian women 16 years and older and under 60 years were highly significantly different ($p < 0.001$).

Age at diagnosis of coeliac disease

The 82 Asians were diagnosed with coeliac disease at a mean age of 36 years 1 month, while the figure for

white individuals was 34 years 3 months, a non-significant difference.

Features at presentation

The commonest feature at presentation in the Asians was anaemia present in 35 patients with an average haemoglobin of 9.1 g/dl, while 21 white patients were anaemic with an average haemoglobin of 9.5 g/dl, not a significant difference. Anaemia was significantly more common in Asian than white patients ($p < 0.03$). More white individuals had diarrhoea (33) than Asians (18) ($p < 0.01$). Weight loss affected 16 Asian and 18 white individuals averaging 6.9 kg and 5.1 kg, respectively, for the groups but the difference was not significant. Other symptoms considered, such as abdominal distension, abdominal pain and lethargy, were common in both groups but no significant differences were found.

Among Asians, 11 had a combination of weight loss and diarrhoea compared with 15 among white patients. Only four and five patients in these respective groups had a combination of weight loss, diarrhoea and anaemia.

Gluten-free diet

Of the Asians, 77 accepted advice to start a gluten-free diet compared with 76 white patients, and of these 71 (92%) and 67 (88%), respectively, remained on the diet. Fifty-four white patients were strict on the diet (did not consume any gluten) compared with only 37 Asians ($p < 0.01$). Only 13 (37%) of 35 Asians who presented with anaemia adhered to the gluten-free diet strictly compared to 15 (71%) of 21 white individuals ($p < 0.01$), while for those presenting with diarrhoea, a similar proportion in each group remained on the diet.

Follow-up

Four patients in the Asian group and two white patients left the area. At the end of 2008, 45 Asian and 42 white individuals were under regular follow-up in the coeliac clinic.

Table 3 Changes in population in the catchment area of the Derby hospitals comparing 2001 (when figures in this format first became available) and 2008 for whites and Asians

Population	Age (years)	2001	2008	Increase	% Increase
White men	≥16 <65	172 300 (21)	177 550 (12)	5250	3
	≥65	38 300 (10)	42 250 (7)	3950	10
Asian men	≥16 <65	7200 (0)	8600 (2)	1400	19
	≥65	500 (0)	800 (0)	300	60
White women	≥16 <60	157 600 (39)	159 000 (19)	1400	0.9
	≥60	65 800 (13)	77 200 (15)	11 400	17
Asian women	≥16 <60	6600 (6)	9100 (2)	2500	38
	≥60	900 (0)	1200 (2)	300	33
Total whites		434 000 (83)	456 000 (53)	22 000	5
Total Asians		15 200 (6)	19 700 (6)	4500	30

In brackets are the numbers diagnosed with coeliac disease in these years.

Discussion

Coeliac disease, once considered a disorder of Europeans, is now known to arise in other people who possess the genetic markers necessary for the disorder to develop and who consume gluten. When members of these populations migrate to other wheat-eating areas of the world, the propensity to develop coeliac disease moves with them. While it has been known for many years that coeliac disease does occur among Asians in Britain progress in identifying the disorder in this group has been slow.

It is remarkable that in an area with a major interest in coeliac disease and a dedicated coeliac clinic established in 1978, an Asian with coeliac disease was not diagnosed until 1989, by which time some 200 cases from the white population had been diagnosed. Since then Asians with coeliac disease have been diagnosed each year. The overall prevalence was significantly higher in Asian than white individuals and this could be attributed to the significantly higher prevalence in Asian women in the age band 16 years and older and under 60 years. A study from Leicester also showed that coeliac disease is commoner in some south Asian populations than in Europeans, and it was speculated that dietary factors might be of importance in this regard.¹³ Of concern is the fact that no Asian man 65 years of age or older was diagnosed with coeliac disease in this audit. It may be that coeliac disease really is rare among this group, although this explanation is unlikely. It is possible that elderly Asian men do have symptoms but for cultural or other reasons are reluctant to discuss their health problems. In any event, coeliac disease must occur in this group but is undiagnosed. It may well be that healthcare professionals do not regard coeliac disease as a likely diagnosis that affects elderly Asian men and should test for this much more commonly.

Asians with coeliac disease are statistically more likely to present with anaemia and less likely to present with diarrhoea than their white counterparts. These observations are difficult to explain but should alert clinicians to the fact that coeliac disease ought to be considered a possible diagnosis in unexplained anaemia in Asians. Other symptoms associated with coeliac disease were similar in the two groups. It has again been shown that only a minority of patients present with a combination of weight loss and diarrhoea, or weight loss, diarrhoea and anaemia, classic features, which can delay the diagnosis of coeliac disease.

While similar numbers of Asian and white individuals commenced and remained on a gluten-free diet, significantly fewer Asians adhered to this strictly. Only about one-third of Asians who presented with anaemia stayed on the diet strictly compared with two-thirds of white patients ($p < 0.02$). Others have also found that significantly more white patients never ingested gluten or did so less than once per month compared with Asians.¹⁶ Asian patients may find it

more difficult to adhere strictly to a gluten-free diet for a number of reasons. If their command of English is poor, understanding food labelling will be compromised. They often live within an extended family setting, which puts increased pressure on them to comply with their cultural norms and so neglect the gluten-free diet. In addition, making Asian foods with gluten-free products can be very difficult, and patients may not understand the process of obtaining prescriptions for gluten-free products, which compounds the problems. In the study already referred to¹⁶ factors that correlate with strict adherence to a gluten-free diet included membership of Coeliac UK, an understanding of what coeliac disease is, food labelling and the prescription process and regular dietetic follow-up.

Only approximately half of patients in each group were under regular follow-up in the coeliac clinic. This does not mean that they were not having any follow-up because follow-up of these patients is increasingly taking place in the general practice setting by doctors, dieticians or nurses.

Reasons why the diagnosis of coeliac disease is established are quite complex, including awareness of the condition by healthcare workers, recognition of so-called atypical presentations and the importance of only mild symptoms. An earlier study showed that in Derby for the quinquennium 2003–7, 15 times more patients with adult coeliac disease were being diagnosed than during the years 1973–7.¹⁷ This increase cannot be accounted for simply by the increase that has occurred in the catchment area of the Derby hospitals through the years, which has been relatively modest as shown in table 3. Consideration must also be given to increasing awareness of the many ways coeliac presents and the availability of reliable serological screening tests. Although the trend in the number of diagnoses being made has been upward, for the white population fewer diagnoses were made in 2008 than in 2001, perhaps reflecting a plateau effect, whereas for Asians the numbers remained the same.

The strength of this audit is that it was carried out in the well-defined catchment area of the Derby hospitals in which all patients with adult coeliac disease had been identified since diagnoses were first made in 1958. The majority were followed prospectively. In addition, figures were available for white and Asian individuals in this area. A potential weakness of the audit is that some patients diagnosed in the area were not known to the coeliac clinic. This possibility can never be ruled out completely, but because such stringent methods were used to capture patients this would be a minor deficiency at most.

In conclusion, it has been shown that overall coeliac disease is more common in Asians than in the white population in Derby. Asians are more likely to present with anaemia and less likely to have diarrhoea. The diagnosis is more common in Asian women aged 16 years and older and under 60 years than in their

white counterparts. Of concern is the fact that no Asian men over 65 years of age were diagnosed, although the condition must affect this group. Efforts need to be made to improve the diagnostic yield in this cohort. Asians are less likely to be strict on their gluten-free diet than whites and strategies need to be devised to correct this so that Asians receive optimal care. The speculations made as to why elderly Asian men do not present and why Asians have poorer compliance with the gluten-free diet could be explored by discussions with Asians themselves.

Key messages

Coeliac disease occurs more commonly in Asian than white individuals which can be attributed to a higher prevalence in women 16 years and older and under 60 years of age. The diagnosis is not being made in Asian men over the age of 65 years and efforts should be directed to increasing the diagnostic yield in this cohort. Asians are less likely to adhere strictly to a gluten free diet than whites and this aspect of their care requires attention.

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