

Editorial

Punjabis and Coeliac Disease: A Wake-Up Call

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Abstract: Punjabis are one of the largest ethnic groups in the world, with at least 124 million members. Their diet is based around wheat cereals and they are now recognised to be at risk of coeliac disease. Indeed, the incidence of coeliac disease amongst Punjabi migrants is three times that of other Europeans, suggesting that in excess of 3 million Punjabi people may be affected by the condition. This review considers the history of coeliac disease and its lack of ready diagnosis in the Punjabi community, including the adverse outcomes as a result. It considers the poor-quality information available to Punjabi patients and tentatively suggests methods of dealing with these issues.

Keywords: coeliac; ethnicity; Punjabi; migrants; diet; epidemiology

Punjabis are the seventh largest ethnic group in the world, with more than 91 million Punjabis living in Pakistan and 33 million in India. The majority are Muslims, with Sikhs forming the second largest community. Their migration to other areas of the world started during the 1880s, when Sikhs serving in the British Army were posted throughout Asia and established communities in a number of countries. From 1900 onwards, migration became significant, with a diaspora of about 10 million people. In both the UK and Canada, there are at least 700,000 Punjabis, with 250,000 living in the USA and large populations in Australia, Libya, and the Philippines [1].

Wheat has long been a central part of the traditional diet of the Punjabi community, and the range of foods incorporating this cereal has extended with migration [2]. Wheat is the dominant cereal grown in both the Indian and Pakistani Punjab, and these areas have been the breadbasket for both countries long before their partition [3,4]. The association of coeliac disease with wheat consumption was first recognised by Willem Dicke in the 1940s [5]. Despite the identification of wheat cereals as the cause of coeliac disease, its recognition as a common cause of diarrhoea and anaemia amongst Punjabis was long delayed. Indeed, even in 2019, a systematic review of the world literature only identified 11 clinical papers which dealt with some aspect of the disease in the Pakistani Punjab [6]. Most were case reports or consisted of small series, with the majority dealing with paediatric cases.

However, the disease is certainly not new to the Punjab. In 1940, Taylor and Manchanda described macrocytic anaemia as being “fairly common in the Punjab” and reported 24 cases in men [7]. They noted that:

“The cases occurred in men of the poorest class between the ages of 25 and 60 years, whose diet was low in quality lacking proteins fat and vitamins and consisted mostly of whole wheat *chapati* and pulses (*dāl*)” [7].

Diarrhoea was a prominent additional feature in 12 of the cases. They also reported that such anaemia was common in Punjabi women of a similar social background. The condition was attributed to a combination of poor diet and possibly infection, and no consideration was given to the more likely explanation that this was coeliac disease. Such views continued to be held for a significant period. In 1968, a paper from the Christian Medical College in Ludhiana, Punjab, described villous atrophy in the jejunum of 26 of 45 Sikh patients with anaemia, in 24 of whom it was megaloblastic [8].

These patients were folic acid deficient, an association which had first been recognised twenty years earlier [9]. However, the authors only diagnosed two of the patients as having a gluten enteropathy, preferring to describe the remainder as having a “tropical malabsorption syndrome”. In the 1980s, low folic acid levels were reported in the Punjabi community in Canada, but again no consideration was given to the possibility of coeliac disease as its cause [10].

In 1973, a study from Birmingham identified 17 children of Pakistani and largely Punjabi origin who had coeliac disease [11]. This was one of the earliest reports of its occurrence in migrant communities. However, it was not until 1993 that the magnitude of the problem in Punjabi communities was first recognised. Sher et al. reported the first epidemiological study from Leicester, UK, based on histologically confirmed cases diagnosed between 1975 and 1989 [12]. The incidence in Punjabis was 6.9 cases/10⁵/year, with a relative risk compared to Europeans of 2.9 and 8.1 to the migrant Gujarati community. As expected, there was no difference between religious sectors within the Punjabi community. It was hoped that these findings would be a wake-up call to those caring for Punjabi patients with coeliac disease. Clearly, with a diet based around wheat cereals, appropriate cultural advice was critical to the provision of adequate care.

In 2004, a study from Birmingham, UK, found that Coeliac Society membership, understanding of food labelling, obtaining sufficient gluten-free products, explanation by a physician, and regular dietetic follow-up were associated with a high congruence to a gluten-free diet by Caucasian patients [13]. This was not so for South Asian patients, and the authors drew attention to the need to improve the treatment and support offered to this community. A recent survey of 375 patients has shown that there has been no improvement. A higher proportion of South Asian patients compared with Caucasians continue to report difficulties in understanding what they can eat and with the interpretation of food labels [14]. Similarly, in a study of 33 South Asian and 113 Caucasian adult patients in East Lancashire in the UK in 2019, 65% of Caucasian patients were fully adherent to a gluten-free diet compared to only 12% of Pakistani patients, who were mainly Punjabi [15]. Clearly, little effective action has been taken to address the issue of appropriate education and support. Although information leaflets in Punjabi are said to exist, they cannot be readily accessed on the internet, and the web page of the self-help organisation, Coeliac UK, is entirely in English.

The only epidemiological data from Punjab is a screening study of “healthy” schoolchildren in Ludhiana [16]. Children with symptoms consistent with a classical presentation for coeliac disease were identified through the use of a structured questionnaire, then tested for antitissue transglutaminase; of the 21 who were positive, 17 underwent duodenal biopsy, with a positive diagnosis in 14. Their prevalence of coeliac disease in 2006 was 326/10⁵ of the population. However, for symptomatic patients the study of 121 patients seen over a six-month period in Lahore with symptoms consistent with potential coeliac disease, in whom the diagnosis was confirmed in 12% of cases, raises the probability that the Ludhiana study under-estimated the true prevalence of the disease in the wider community [17]. The general lack of awareness of coeliac disease as a potential diagnosis in the community and amongst clinicians can be seen in the death of 3 of 126 children who presented with severe diarrhoea to a paediatric unit in Lahore over an 18-month period between 2014 and 2015 [18]. They were short, malnourished, dehydrated, and hypokalaemia. Comparable disease severity at presentation was reported from the city of Rahim Yar Khan in Punjab in 2011, where 25% of the children required admission to the intensive care unit on diagnosis [19]. It is to be hoped that the self-help group Punjab Celiac Society for Awareness will promote a wider appreciation of the disease and its consequences.

The education of both the community and clinicians is central to the more effective recognition and management of coeliac disease in both the Punjabi Diaspora and in India and Pakistan. In the Tees Valley in the north of England, Punjabi patients often come from groups with a poorer quality of life and, through lack of knowledge, accept only limited clinical services [20]. The issue is how best to overcome these barriers. To date, there have been no effective initiatives and there is an urgent need to embed information in the community and to support the community develop its own response to that

information. As long ago as 1994, gurdwaras and mosques in Southall, London, were ready to play a role in clinical work [21]. In the USA, imams have been shown to play a key role in framing concepts of health and disease [22]. However, faith leaders have different agendas to health workers, and often they lack a common language [23]. Indeed, health workers need to show cultural competence and sensitivity to overcome such barriers. The recruitment of faith-based and ethnic professional clinical associations to assist in the development of appropriate local programs is one approach which might prove effective.

Conflicts of Interest: The authors declare no conflict of interest.

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