



Original Article

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Information Needs of Punjabi Patients with Coeliac Disease

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Abstract

Ten NHS trusts, which served significant Punjabi populations, were sent Freedom of Information Requests and asked to provide details and/or samples of Punjabi literature on coeliac disease. They were also asked about group counselling sessions and lectures as well as individual counselling sessions and what provisions were made for them to be in Punjabi. Comparable data with regards to White British and Polish patients were requested. Responses were compared using a z statistic for proportions. Punjabi and Polish patients were significantly less likely to be offered literature in their own language or to attend group counselling sessions/lectures. Individual counselling was comparable, but in the case of Punjabi and Polish patients this would be through an interpreter.

Keywords

Information, Punjabi, Polish, White British, Literature, Sessions, Counselling

Introduction

In a study of South Asian and Caucasian patients from the Blackburn area of the North of England there was a significant difference in adherence to a gluten-free diet between the two groups [1]. Thirty nine percent of South Asian patients were non-adherent compared to 17% of Caucasian patients. Only 12% of South Asian patients were fully adherent to a gluten free diet compared to 67% of Caucasian patients. The authors considered such striking differences were likely to be complex, but drew attention to potential difficulties of engaging with a prescription of a gluten free diet and the possible role of language barriers.

These findings are disappointing in that 15 years earlier a study from Birmingham, UK had shown that amongst White British patients' compliance with gluten free diet was correlated with: Coeliac Society membership, understanding food labelling, obtaining sufficient gluten-free products, explanation by a physician, and regular dietetic follow-up. These factors were not seen amongst South Asians, who were less likely to attend dietetic clinics, join the Coeliac Society and be satisfied with information provided by doctors and dieticians [2]. The issue of difficulties in understanding food labelling was confirmed in a further study where over half of South Asians reported such a difficulty compared with just 4% of Caucasians. The importance of this issue is seen in that South Asians who did not understand food labelling had a significantly poorer dietary adherence than those who did [3]. Clearly, language barriers play a significant role in such difficulties, as demonstrated in a study of telephone

clinics [4]. Indeed, a recent systematic review of 40 published studies has shown that significant barriers to compliance include: lower knowledge of coeliac disease (35%); restaurant/supermarket shopping (30%); poor patient education from practitioner (17.5%); and low intention/motivation to adhere to a GFD (17.5%) [5].

An interesting study from Sweden has suggested that self-management education administered through a Coeliac School may be a promising tool to help patients cope with their disorder, especially when they had been diagnosed some years earlier [6]. However, whether such an approach would work in an entirely different community is open to serious question.

Since the early 1990s it has been recognised that coeliac disease was more common amongst people of Punjabi origin than amongst White British people or Gujarati migrants in the UK [7]. This finding has been confirmed in subsequent studies with evidence of a growing recognition of the disease

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Table 1: NHS trusts approached for details of their educational provision for patients with coeliac disease.

NHS Trust	Freedom of Information (FOI) Request
Barking, Havering & Red bridge University Hospitals NHS Trust	FOI 6867
Calder dale & Huddersfield NHS Foundation Trust	FOI 380-2020
Frimley Health NHS Foundation Trust	FOI 0358-20
The Leeds Teaching Hospitals NHS Trust	FOI 2020-0401
Northern Care Alliance NHS Group	FOI/10431
Sand well and West Birmingham NHS Trust	F20/0163
University Hospitals Birmingham NHS Foundation Trust	1038 4/21
University Hospitals of Derby and Burton NHS Foundation Trust	FOI 20.424
The Royal Wolver Hampton NHS Trust	FOI 7906
Walsall Healthcare NHS Trust	FOI 167.20

Table 2: Methods of information provision to patients with coeliac disease.

Topic	English (n = 10)	Punjabi (n = 10)	Polish (n =10)
Written Information	10	1**	0
Group Sessions	4	0	0
Individual counselling	10	8*	8*

in the South Asian community [8]. Against this background of an increasing case load in the Punjabi/South Asia community and issues of compliance related to communication barriers a Freedom of Information study was undertaken to identify what practical approaches were being taken in NHS Trusts where there is a substantial Punjabi community.

Methods

Methodology

Freedom of Information requests were sent to ten NHS trusts which served communities with a significant Punjabi population (Table 1). The Trusts were asked to provide information on whether their dietetic departments provided:

1. Group educational sessions/lectures to patients with coeliac disease.
2. Individual counselling sessions to patients with coeliac disease and whether these were in:
 1. English
 2. Punjabi
 3. Polish

They were also asked to provide copies of any written material on coeliac disease in these languages, which they made available to patients. Questions on Polish provision were included as a migrant control.

Analysis

Responses from the trusts were collated and a comparison

of proportions using a z statistic was undertaken. (<https://www.socscistatistics.com/tests/ztest/default2.aspx>).

Results

Patients from the White British community were significantly more likely to receive written information in an appropriate language than either Punjabi ($z = 4.1, p < 0.00001$) or Polish patients ($z = 4.5, p < 0.00001$). Group sessions in English were significantly commoner ($z = 2.2, p < 0.03$) (Table 2).

Discussion

There is a clear distinction in the availability of written information about coeliac disease for White British patients and those of Punjabi or Polish origins. Although all three groups may be equally proficient in their use and understanding of English, this is not always the case. In the West Midlands fewer Punjabis could read English (41%) than speak it. Of those who could write English, only 63% considered that their standard was good, with fewer women than men able to do so (37% vs. 53%) [9]. In addition, the content of written material is directed towards a typical British diet and fails to adequately take account of other food patterns. In the case of the one trust which did provide written material in Punjabi, it was using Gurmukhi script so restricting its availability to Sikh and Hindu patients. Muslim Punjabis would require the material to be written with a script in an Urdu-like style for it to be capable of being read and should be tested on a group of patients prior to release [10].

The Punjabi and Polish communities in the UK are sizeable and amongst the largest ethnic minorities. With a comparable or greater prevalence of coeliac disease, there may well be 7000 Punjabis with coeliac disease and 5000 Poles with the condition, based on various estimates and census data. Against this background there is an urgent need to produce educational material which is fit for purpose. In the case of the Punjabi community, their diet is very much centred around wheat as a staple food. A gluten free diet is a substantial challenge and potentially impacts adversely on family dynamics.

Consequently, there is a need to look at a broader

educational program in the Punjabi community bringing in gurdwaras, temples and mosques, as well as community associations. With an increased awareness of the disease, it may become possible for patients to more readily accept and acknowledge their condition. At present, the concept of providing large educational classes to Punjabi patients seems impractical and, indeed, none of the trusts in this study offered this option. However, individual counselling with the use of translators creates its own difficulties. In India repeated personal counselling of patients with coeliac disease led to a much greater compliance with a gluten free diet [11]. In the UK when older patients were offered an opportunity to consult with a member of their own ethnic group, who spoke their language, take up of medical and other services was significantly increased [12]. Such findings would support the training of lay advisers from the Punjabi community who could offer a service directly to newly diagnosed patients and support them in an on-going way.

Although this study was directed at understanding the provision of information to Punjabi patients with coeliac disease, the experience of the Polish community was no different. Polish literacy rates exceed 98% and so the provision of written material in Polish should be good practice in all trusts with a significant Polish community. Indeed, the national Polish Coeliac Society provides a comprehensive body of literature, which could be easily accessed.

Overall, there is a need to develop an effective approach to the management of patients from minority communities, who have coeliac disease. In the case of the Punjabi and Polish communities there are a substantial number of patients and Coeliac UK could facilitate the development of links to other national organisations and the development of appropriate information and support packages where such organisations do not exist or have limited resources, such as the Punjab Celiac Society for Awareness.

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