

REVIEW

Gastroenterology and the provision of care to Panjabi patients in the UK

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Summary

Panjabi is spoken by 1.3 million people in the UK. It is the second most common language used in the country and is the first choice of 75% of Panjabis. It is becoming more common. For many patients it forms part of the barrier which limits access to gastrointestinal services. The provision of appropriate support services is woeful and yet seldom leads to formal complaints. This review considers the impact of gastrointestinal disorders on the Panjabi community and assesses some of the interventions that could be developed to ensure equity of care.

Introduction

At the beginning of the 21st century it was estimated that 1.3 million people in the UK spoke Punjabi, or more correctly Panjabi. This makes it the second most common language in the country.¹ Ethnologue estimates that for more than half a million people it is the first choice.² Panjabi continues to be important for the younger generation. In 2008, 1000 students took it as a GCSE subject and for 75% it was their mother tongue.^{3 4} Its significance for the healthcare system is the need to ensure that communication is both understood and effective. Ethnic inequalities in health and healthcare are marked with language being a key barrier to accessing services.⁵ Communication is, of course, a two-way process. Panjabi patients are likely to feel isolated and anxious. Can they make themselves understood? If a translator is used can they be assured that their answers will be treated in confidence? This is especially worrying if patient and translator know each other or live in similar areas of a town. This is even more so when a friend or relative is used in the consultation—a practice that is not uncommon in cash-strapped health units. In 1999 the Advisory Committee on Resource Allocation tried to overcome these restraints through:

‘the introduction of an English Language Difficulty Adjustment (ELDA) for the extra costs of interpretation, advocacy and translation services.’⁶

However, in 2009 ELDA was abolished. In 2011 the National Health Service established *Race for Health* to support and challenge its organisations in tackling health inequalities.⁷ It recognised that key indicators of which commissioners need to be aware include:

- ethnic and age/sex profile of local and national populations;
- health experience or services used, expressed using the same ethnic coding as that of the local/national population.⁸

This document acknowledges the need for community involvement, but no specific gastrointestinal diseases are considered within it and there are no examples of gastroenterologists dealing with issues of ethnicity and disease prevention or treatment. The situation was well summarised by Caroline Wright when she wrote for the BBC:

‘Although this is something often deemed controversial, poorer health outcomes, decreased comprehension of diagnoses and reduced satisfaction with care are all associated with limited English proficiency and cannot be ignored.’⁹

Indeed the General Medical Council puts the onus on all doctors to ensure that:

‘You must make sure, wherever practical, that arrangements are made to meet patients’ language and communication needs.’¹⁰

The Medical Protection Society underlines the importance of such an approach and acknowledges that:

‘Studies have shown that the use of professional interpreters improves care for patients with limited English proficiency. Patients who rate their translator highly

are more likely to rate their healthcare highly. Yet around the UK, the provision of and access to these services is inconsistent.¹¹

It draws attention to the National Register of Public Service Interpreters, which provides a quality-assured register of healthcare interpreters, although it does not regulate them.¹²

The Panjabi community in the UK

Panjabis first came to the UK in significant numbers as a result of World War 1. However, the main migrations followed World War 2 and the division of Punjab between Pakistan and India. These migrants came largely to work in the construction industry. In the 1950s and later there were significant migrations from East Africa. A later group came from Afghanistan and work and live around Southall.¹³ The Muslim Panjabi community largely lives around Birmingham, Bradford and Oldham.¹⁴ Sikhs are most commonly found in Birmingham, Ealing (Southall), Sandwell, Hounslow, Wolverhampton, Coventry, Redbridge, Leicester, Hillingdon and Slough.¹⁵

Panjabi is spoken by Sikhs, Muslims, Hindus and Christians. It has two main dialects—Western and Eastern—and these largely correspond with the division of Punjab between India and Pakistan. Within Panjabi there are various dialects, such as Mirapuri and also distinct languages such as Saraiki.¹⁴ There are no readily available data on the number of Saraiki speakers in the UK. It differs radically from the Panjabi of Lahore. In 1886 the British began a massive canal building programme in the Saraiki area of western Punjab and used Panjabis from the central part of the country as the workforce. Internal migration continued until the 1950s.¹⁶ For both clinicians and translators recognition of these linguistic differences is important for accurate and effective communication.

The incidence of Panjabi as the preferred language was reviewed in Middlesbrough in 1998. Only 5% of patients were told of the availability of professional interpreters, and none used the service.¹⁷ This observation has a direct link to contemporary work on the epidemiology of inflammatory bowel disease in the area.¹⁸ Three per cent of the population came from an ethnic minority and a poorer quality of life was clearly linked to social deprivation.¹⁹ Work by the Tees Valley Joint Strategy Unit identified the local Pakistani community as having multiple indicators of a lower standard of living.²⁰ This would suggest that Panjabi patients with inflammatory bowel disease often come from groups with a poorer quality of life and tend to accept limited clinical services. Similar aspects of social deprivation were reported in a study of coronary artery disease. They included length of working day, low income, crowded housing, liability to attack and perceived lack of social support (women).²¹ It is not surprising that it is often a simple lack of knowledge which limits a community from making best use of facilities.¹⁷ However, the onus lies with the provider to ensure that the

community is aware of these services. Use of written material is inadequate. In the West Midlands fewer Panjabis could write 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%).²¹ Any use of literature in Panjabi needs to recognise the different scripts used by Muslim and Sikh communities, as well as the existence of distinct languages such as Saraiki. It must be tested on a group of patients before release.²²

Gastrointestinal disease in the Panjabi community in the UK

Diseases tend to differ in their prevalence between communities in their home country and those living in a host country. With each generation there is a movement towards the prevalence seen among the indigenous population in the host country and at times to exceed it. This has been demonstrated among migrants from South Asia to Canada.²³ A recent study from Aberdeen, Dundee and Glasgow in 2009 showed that 20% of 111 people of South Asian origin, including Panjabis had gastrointestinal disease.²⁴ In this review we will consider the occurrence of gastrointestinal diseases in both the Punjab and the UK.

Gastrointestinal cancer

A study from Luton explored the meanings of cancer and perceptions of cancer services among South Asians living in Luton. Focus groups included Panjabi-speaking Muslims originating from Pakistan and a separate group of Sikhs originating from the Indian Punjab. Overall, participants in the study expressed a keen desire for the information relating to cancer to be made available through their community social networks. The lack of information resulted in low levels of awareness and cancer was often perceived as an incurable disease. This reflected the fact that access to appropriate services had been at a relatively late stage of the illness.²⁵ This study from 2004 emphasised the need for education which can influence how people manage cancer and access cancer services. In addition, a study of breast cancer among Panjabi women suggested that it was seen as a family event and models of care need to be family centred as well as culturally appropriate.²⁶

Oesophageal and gastric cancer

Traditionally, gastric and oesophageal cancer were considered relatively uncommon in Punjab and this was attributed to the infrequent use of betel nut or paan by this community.²⁷ However, a recent study from Rawalpindi of ex-servicemen and their dependants from a rural area in Northern Punjab showed that oesophageal cancer tended to be commoner in women and gastric cancer in men.²⁸ Fourteen per cent of the patients with gastric cancer in the study were under the age of 40 years at the time of diagnosis. Most patients worked in the farming industry and it was suggested that exposure to an unknown source of fertilisers or

radioactivity might be aetiological factors. Work on nitrate contamination of well water in farms across Muktsar, Bathinda and Ludhiana districts of Punjab suggested that this could play a part.²⁹ In 2011 there was evidence that the wells of Bathinda were also contaminated by uranium³⁰ as was the food.³¹ Other work has shown arsenic to be a significant contaminant.³² These changes mean that gastro-oesophageal cancer should be seriously considered when there is an appropriate history among young patients who are recent migrants from both West and East Punjab. This experience is in contrast to the general experience of falling gastric cancer rates.

Colorectal cancer

Traditionally colonic cancer was thought uncommon in the Punjab.³³ Mahotra suggested that this was the result of a diet rich in roughage, including cellulose, vegetable fibre and short chain fermented milk products. This was reflected in the low mortality figures reported for Panjabi migrants to the UK in 1984.³⁴ However, in 2005 the Punjab Cancer Registry was established and its initial reports dealt with Lahore where colorectal cancer is now the fourth commonest cancer, representing 3.25% of the total cancer load.³⁵ Interestingly, in the UK there is a suggestion that the relative incidence of colorectal cancer in the younger age groups is increasing and there is likely to be a significant jump in the number of cases of colorectal cancer identified in the Panjabi community.³⁶ A subsequent study has shown that these younger Asian patients tend to present later with more advanced disease.³⁷

Pancreatic cancer and chronic pancreatitis

Studies from the cancer registries in the Indian subcontinent suggest that pancreatic cancer is uncommon.³⁸ However, in 1999 an increased risk of pancreatic cancer in migrant Panjabis in the UK was recognised.³⁹ This trend is consistent with other migrant studies of pancreatic cancer among South Asians.⁴⁰ Among Panjabis chronic pancreatitis is not uncommon, with 38% of cases related to alcohol.⁴¹ The majority (95%) of patients present with abdominal pain and calcification of the pancreas is frequent.

Clearly, alcohol has an established role in the development of chronic pancreatitis. In a survey of four villages in Punjab 78% of the population used alcohol.⁴² A later study reported that 11% of users were alcohol dependent.⁴³ During the 1990s and 2000s alcohol consumption increased enormously in the state of Punjab. In a survey by the Institute for Development and Communication over 60% of households were affected by alcohol abuse.

Over two-thirds of the victims were regular alcohol users and 26% recreational drug users.⁴⁴ Although these studies were conducted in India, alcoholism is also a problem among Panjabi Muslims and has been reported from Lahore.⁴⁵ Patterns of regular drinking by Sikh men are seen in the UK.⁴⁶ In a study of the

Panjabi community of Metropolitan Toronto increased levels of acculturation were associated with increased lifetime use of alcohol and more liberal attitudes toward the use of alcohol. Those who had lower levels of acculturation experienced more alcohol-related problems. This was particularly true for men.⁴⁷ In the UK consumption is higher in Sikhs than in Hindus or Muslims, and heavy spirit drinking appears to be especially common among Sikh men.⁴⁸ In a qualitative study from the West Midlands wives and daughters of men with recognised alcohol problems initially resigned themselves to the problem and later defended their husbands or fathers.⁴⁹

Inflammatory bowel disease

The Panjabi community is at an equivalent risk of developing inflammatory bowel disease (table 1). Indeed there is good evidence that the risk is probably greater than for the indigenous population of the UK. Reports from the British Cohort⁵⁴ and Leicester⁵⁵ show that Asian young people born in the UK are at even greater risk of developing ulcerative colitis and this is likely to be more severe than among other young people in the country. It is possible that changing social practices may play some role. For example, betel nut chewing seems to offer some protection against ulcerative colitis,⁵⁶ whereas the use of recycled cooking oils seems to be linked to a greater risk of developing Crohn's disease.⁵⁷ A recent study from Uttar Pradesh in India would suggest that any patient from India or Pakistan who works with animals and is suspected of ulcerative colitis or Crohn's disease should be tested for *Mycobacterium avis* subspecies *paratuberculosis* (MAP). Fifty per cent of goat herds who were suspected of Crohn's disease were positive for MAP on stool culture and this was particularly so in those with abdominal pain and diarrhoea. The longer the exposure to goats the higher the risk.⁵⁸

In a study from the Punjab all patients with ulcerative colitis felt that allopathic medication was the best treatment, but a significant number (81%) reported use of some form of non-allopathic treatment in the previous 3 years. Thirty per cent were using these in addition to allopathic drugs. Forty patients (28%) had resorted to homoeopathy, 20 (14%) to ayurvedic, and 58 (41%) to indigenous medication during their disease.⁵⁹ There is evidence that this is also true in the UK.⁶⁰ In addition to the use of complementary therapy there is a tendency towards significantly low levels of adherence to 5-aminosalicylic acid treatment among patients of South Asian origin. This has been reported in studies both from India⁶¹ and the UK.⁶²

Coeliac disease

In 1993 Panjabi migrants living in Leicester were recognised as being at high risk of coeliac disease. The incidence of the disease was four times greater than among English inhabitants and eight times greater than among Gujaratis.⁶³ In the 1970s there had been

an indication that coeliac disease might be commoner among Panjabis than originally thought. In Birmingham Nelson *et al* had reported coeliac disease in 17 children of migrants from the Punjab.⁶⁴ Clinical presentation for Panjabi patients is often associated with vitamin D deficiency, a high alkaline phosphatase and iron deficiency.⁶⁵ For Panjabis a gluten-free diet can present problems. It can affect family life and can set the patient aside from other members of the community, presenting particular difficulties at communal events. Educational material in Panjabi is limited and a study of 40 patients from the West Midlands has shown that they were less likely to attend dietetic clinics, join the Coeliac Society and be satisfied with information provided by doctors and dieticians than the indigenous population.⁶⁶

Disease prevention

There is recent evidence that patients from ethnic minorities show significant differences in access to, and uptake of, cancer screening. Breast and cervical cancer screening are well established in the UK, but figures consistently show a lower uptake by ethnic minorities and is particularly low in the Muslim population. Four out of ten women opt out of both breast and bowel cancer screening and there also appears to be difficulty in ensuring continuity of uptake.⁶⁷ Despite these limitations in the provision of care few patients from a Punjabi background complain.⁶⁸

Colorectal cancer screening

The UK colorectal cancer screening pilot programme among the general population reported an overall uptake of 62% for faecal occult blood testing (FOBT) for English people. This was considered acceptable, but uptake was low in the South Asian community, with figures for Muslims as low as 32%.⁶⁸ In the general population the uptake of FOBT screening was two and a half times lower among Muslims and Sikhs. Colonoscopy uptake rates were also significantly lower among Asians (55%) compared with 74% for non-Asians.⁶⁹ A study from the USA suggested that low uptake of screening for colorectal cancer in the general population may be due to a lack of awareness and inadequate provider counselling rather than a poor acceptance of the scheme.⁷⁰⁻⁷² To encourage participation and improve compliance, recommendation by a doctor was suggested to have a major impact.⁷³⁻⁷⁷ These findings have been confirmed in the colorectal cancer screening program in the UK where Sikhs and Muslims have the lowest uptake rates. This may also, in part, reflect a lower level of confidence in the procedure than among White Europeans.⁶⁹ At present the main response to this issue has come from the voluntary sector. The charity, Bowel Cancer UK, has produced a short DVD in which South Asian actors discuss the risk of bowel cancer, how to reduce the risk, and screening (the faecal occult blood test). However, the DVD, which is entitled *Sehat Apni Apni (Our Own Health)*,

is in English with the option to watch it dubbed into Hindi or Punjabi.⁷⁸

Development of a better model of care

Following the passing of the Race Relation Amendment Act 2000, it is a statutory duty on all NHS agencies to 'have due regards to the need to eliminate unlawful discrimination' and maintain racial equality. Availability of care is a function of the interaction between provider services, users and planners. Quality of care is defined as client-centred services, meeting their needs and expectations. It is a continuing process that incorporates patients' rights and their satisfaction with the system. It entails access to accurate, appropriate, understandable and unambiguous information at convenient times with no physical barriers. It helps patients make a well-judged decision based upon information, understanding and options that is informed choice rather than coercion. It embodies the concepts outlined in *Equity and Excellence. Liberating the NHS*. This document centres on the concept of 'no decisions about me without me.'⁷⁹ The unmet needs of migrants has been well demonstrated in a study of Panjabis aged between 19 and 90 in British Columbia.⁸⁰ Participants discussed unmet healthcare needs as related to a variety of aspects of accessibility including: lack of choice in the gender of a provider, particularly for women preferring to have a female doctor or a lack of a primary healthcare provider who was accepting new patients and spoke Panjabi. Without these basic provisions we will be unable to provide a gastroenterological service which involves patients in effective decision-making.

A study among Panjabi women living in British Columbia has shown that translations alone will not meet their needs. The community needed to be made aware of the role of prenatal preparation so that it could endorse women's participation. The solution was to bring representatives from a variety of service agencies together with members of the community. It also needed 'buy-in' from the doctors serving the women of the community.⁸¹ The need for community and family involvement has also been seen in studies among Panjabi women with breast cancer.²⁶ The role of simple education is probably limited. For example, in a study of glycaemic control among Pakistani women from South Wales following an educational intervention, illiterate patients did not do as well as their literate peers, continuing to score less on knowledge parameters. They also did not show an improvement in glycaemic control.⁸²

In studies from Middlesbrough written information in minority languages, professional interpreters, examination of female patients by women doctors and culturally suitable food were confirmed as priority needs. Staff training and community education was seen as essential to the successful implementation of better care for patients of Panjabi and other groups.¹⁷ ⁶⁸ People with limited command of English find it

Table 1 Inflammatory bowel disease and intestinal tuberculosis amongst Panjabis in India and the UK

Disease	Location	Period	Incidence (cases/10 ⁵ /year)	Reference
Ulcerative colitis	Punjab	1990s	6	50
	Leicester	1980s	16.5	51
Crohn's disease	Leicester	1980s	3.4	52
Abdominal tuberculosis	Leicester	1980s	8.7	53

difficult to obtain adequate healthcare and health information. Language barriers mean that they have insufficient knowledge about the range of health services available, and very little health-related information meets their individual language needs.⁸³ The use of telephone translation services is a poor substitute for the provision of a truly patient-centred service. They will be used by patients when no alternative exists but the practical difficulties associated with them, the impersonal nature of the service and the selecting out of people who need them as 'different' compromises every aspect of high-quality care. In addition, the belief that these problems will disappear with time owing to the absorption of a migrant community into the host community is not substantiated by research. In a study from Glasgow long-established residents had consistently worse results. More were overweight, reported heart trouble and respiratory conditions, had had accidents, needed glasses and took time ill in bed. It was unlikely that these results are explained by positive selection of recent migrants. These results did not endorse the assumption that the UK environment had promoted higher levels of health in migrants longer exposed to it, nor that the stress of a move promotes higher levels of illness in recent migrants.⁸⁴

Any new model for the care of Panjabi patients' needs to bridge the gap between provider opinion and users' perceptions of the service. The best prospect for achieving this outcome is likely to be through use of participatory meetings and research. This is not simply an exotic variant of consultation. Instead, it is active co-research, by and for those to be helped. Nor is it used by one group of people to get another group of people to do what is thought best for them. Rather, it is a genuinely democratic non-coercive process whereby those to be helped, determine the future of their own decisions.⁸⁵ Participatory research can help to:

- identify barriers which deter communities from using services;
- provide a better understanding of hypothesised barriers;
- facilitate greater understanding and awareness of a community's needs;
- develop relevant social skills among healthcare consumers and among health mediators and so

- reduce disparities in health outcomes;
- hold communities responsible for their own decisions by engaging them in defining and supporting the quality of services they want;
- enable providers to identify and recognise root causes of problems with their services.

Participatory meetings will help clinicians and other healthcare providers become more aware of supportive networks in the Panjabi community. These can be based around a neighbourhood, place of origin or, perhaps most importantly, marriage. Although such networks can be supportive, they may also be watchful and controlling.⁸⁶ An understanding of their local significance is critical to the development of a Panjabi patient-centred service. A potential example of such an approach is Apnee Sehat. This model of care aims to redesign patient care pathways, involving new partners for access such as pharmacists in the community. It will look to signpost high-risk individuals identified by healthcare providers in the community. Apnee Sehat aims to develop integrated healthcare models overcoming traditional barriers to specialist support for community services, while working closely with GPs and consultants. An example will be the development of one-stop shops for communities.⁸⁷

Such one-stop shops will need to consider the approaches taken by the Panjabi community to the discussion of personal problems. It would appear that most Panjabis prefer to discuss such problems with someone of a similar age.²¹ People were twice as likely to choose a neighbour of a similar age as their confidante than a son or daughter. That person was almost three times as likely to be a woman. When offered the opportunity to consult with a member of their own ethnic group who spoke their language, take up of services was much increased.⁸⁸ However, the patient is likely to take a family member to the consultation rather than a neighbour or friend.²¹

The Panjabi community in Britain is substantial. As yet clinicians, nurses, managers and self-help organisations in the field of gastroenterology have failed to provide adequately for their needs. This failure includes the recognition of increased frequency of certain diseases, diagnostic and therapeutic needs. The underlying problem is the inadequacy of communication and

it needs to be improved. The use of local participatory meetings will allow the emergence of community-owned solutions.

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