# Challenges of managing diabetes in Asians

Kirpal Marwa, Shanaz Mughal, Harbinder Sunsoa, Roytun Bibi


## Introduction

**This article highlights the challenges faced by Asian people with diabetes and their families in understanding and managing their condition. It gives an insight into the formation of a focus group in the west Midlands called Focus on Asians with Diabetes (FAD), and the various initiatives that it has been involved with. The FAD group's aim is to improve the knowledge, understanding and management of diabetes in the Indo-Asian population using multimedia resources, and therefore promoting an improved quality of life. The challenges and dilemmas faced by the group when completing the projects undertaken and ensuring that they were culturally sensitive to meet the needs of Asians with diabetes are highlighted in this article.**


South Asians comprise around 3% of the UK's population, according to the National Statistic's 2001 census (*Figure 1*). Most Asians living in the UK come from India, Bangladesh, Pakistan and East Africa.

Diabetes is a growing problem. Estimates suggest that there are currently about 120 million people worldwide with diabetes and that this number is set to double by 2010 (Diabetes UK, 2000). Koppiker and Rao (2003) state that countries with the largest number of people with diabetes in 1995 were anticipated to remain the same by the year 2025, although numbers of people with diabetes would increase; India (19 million to 57 million), China (16 million to 38 million) and the US (14 million to 22 million).

Diabetes has particularly increased among south Asians in the UK, of whom 20% over the age of 40 years have type 2 diabetes (Barnett, 1999). The prevalence of diabetes is 15.2% in Asian communities in comparison with the white population in which the prevalence is only 3.8% (Burden, 2001). The prevalence of diabetes varies within the south Asian community. Shaikh et al (2001) suggest that diabetes affects over 20% of Muslims. Patel et al (2001) state that diabetes affects over 15.2% of Hindus.

A population survey carried out with 4395 Asian residents, by Simmons et al (1992) in Coventry, highlighed that 94% of the population were Punjabi Sikhs, Punjabi Hindus, Gujarati Muslims, Gujarati Hindus and Pakistani Muslims. Many of the participants will be from the Indian sub-continent around the world, which has a huge diversity of people with 14 major languages with approximately 100 different dialects.

## Background

Many barriers prevent healthcare professionals from delivering effective education and a good quality of care to the UK's ethnic minority population from south Asia. The term 'Asian' suggests a single cohesive group, but in reality the communities are from different countries and social classes, with different languages, religions and traditions (Marwa, 2000). Diversity in language, religion, cultural norms and expectations prevents effective communication, which creates misunderstanding between the majority and minorities (Ahmed and Atkins, 1996)

Burden (1998) suggests that the prevalence of diabetes is four times higher in Asians than in Caucasians and argues:

***'...that many health professionals tend to***

### ARTICLE POINTS

1. The prevalence of diabetes is 15.2% in the south Asian communities in comparison with the white population, in which the prevalence is only 3.8%.

2. Many barriers prevent healthcare professionals from delivering effective education and good quality of care to the UK's ethnic minority population from south Asia.

3. There is a significant lack of appropriate educational resources for British south Asian people.

4. Education is an essential component of management, as people with diabetes need to develop the skills to enable them to become experts in self-care.

### KEY WORDS

- **South Asians**
- **Focus group**
- **Cultural sensitivity**
- **Multimedia resources**

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**Figure 1. National Statistics 2001 Census**

| Ethnicity | | Religion | |
|---|---|---|---|
| Mixed race | 1.2% | Buddhist | 0.3% |
| White | 92.1% | Christian | 71.6% |
| Pakistani | 1.3% | Hindu | 1.0% |
| Indian | 1.8% | Muslim | 2.7% |
| Bangladeshi | 0.5% | Sikh | 0.6% |
| Other Asian | 0.4% | Jewish | 0.5% |
| Black Carribean | 1.0% | Other religions | 0.3% |
| Black African | 0.8% | No religion | 15.5% |
| Black other | 0.2% | Not stated | 7.3% |
| Chinese | 0.4% | | |
| Other | 0.4% | | |

***Source: National Statistics website: www.statistics.gov.uk***
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***group all Asian patients together and generalise their care.'***

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1 It has been estimated that in the UK there are over 2 million people who speak very little or no English, and the majority of these people are Asians (Mello, 1992).

2 The poorer health of south Asians compared to the white population may be due to factors related to occupation, social class, material living conditions and local area deprivation.

3 Education is an essential component of management, as people with diabetes need to develop the skills to enable them to become experts in self-care.

It has been estimated that in the UK there are over 2 million people who speak very little or no English, and the majority of these people are Asians (Mello, 1992). This can pose problems for healthcare professionals in the delivery of effective healthcare services in order to meet the needs of the patient. Asians who have migrated to the UK vary considerably in their literacy skills; a sizeable minority are unable to read either their own language or English (Karseas and Hopkins, 1987). Educational literature that is written in different Asian languages will not meet the educational needs of the South Asian community that are illiterate. Cultural and communication difficulties make this group more resistant to healthcare implementation strategies. Many healthcare professionals who care for Asian people with diabetes find it difficult to educate their patients with diabetes on how to accept and manage their condition. According to Vass (2003), patients will do well with compliance and will be more satisfied with their care if they fully understand their illness.

Chandola (2001) highlighted that Pakistani and Bangladeshi respondents had the poorest self-rated health. The poorer health of south Asians compared to the white population may be due to factors related to occupation, social class, material living conditions and local area deprivation.

The British Heart Foundation (2001) has highlighted the following points:

- South Asian men smoke more than the general population, particularly Bangladeshi men.
- As a community, south Asians eat the least fruit and vegetables of all ethnic groups.
- South Asian men and women are less likely to participate in physical activity than the general population.
- South Asian men and women are more likely than the general population to have central obesity (when fat is centred around the waist), placing an extra strain on the body and heart.
- South Asian men and women are much more likely to have low levels of protective high density lipoprotein cholesterol.

## Education

Educating and supporting patients in managing their daily life with diabetes are important goals of diabetes care. These goals demand not only good medical knowledge but also good communication skills in the members of the diabetes care team and in people with diabetes. This can be difficult when there are language, cultural and social barriers. Education is an essential component of management, as people with diabetes need to develop the skills to enable them to become experts in self-care (BDA, 1997).

The Audit Commission Report (2000) in the *Testing times* survey highlighted the gaps in diabetes care throughout the UK and identified two important points:

- Patient education was inadequate in half of the hospitals visited.
- Ethnic minority patients were twice as likely to report gaps in their understanding of care.

A Department of Heath survey (2001)

highlighted that diabetes services do not adequately meet the needs of ethnic minority populations. Early studies showed that Asians know less about their diabetes than Caucasians (Hawthorne, 1990). A recent study by Raleigh and Clifford (2002) highlighted that:

*'ethnic minority patients have a lower level of knowledge and access to information about diabetes and have a less satisfactory interface with services'.*

Reducing inequalities in healthcare and outcomes is a priority in the new NHS agenda but this goal is not being met. Patient education is paramount to enhance the quality of patients' health and the ultimate goal for providing education in any format is to get the message across (Web, 1997; Conlon, 2001; Campbell, 2001; Jones, 2001; DCCT, 1994; UKPDS, 1998; DoH, 2000).

## Focus group

Several studies have highlighted the need for culturally sensitive diabetes education which is adapted to the health beliefs and needs of ethnic communities to gain diabetes control and compliance (Needham, 2002; Marwa, 2000; Chowdhury et al, 2000; Greenhalgh et al, 1998). According to Dixit (2003) meeting the needs of the population requires sensitivity to the many traditions, cultures and religious practices that exist in the UK today, especially in diabetes related services and care. To ignore a person's culture is to ignore them and their identity, argues Papadopoulos et al (1998).

A focus group in the west Midlands was formed in 1998 called Focus group for Asians with diabetes (FAD). Their mission statement is to:

*'improve the knowledge, understanding and management of diabetes in the Indo-Asian population, using multimedia resources, therefore promoting an improved quality of life.'*

The group informally evaluated current educational material for the Asian community and their families:

- There was a significant lack of appropriate educational resources for British Asian people with diabetes and their families.
- Educational material produced was not culturally appropriate or sensitive.
- The language level used was inappropriate, too clinical and did not reflect the everyday language spoken by the majority of the Asian community in the UK.
- The literature was not always available in all of the major Asian languages (Punjabi, Hindi, Gujarati, Urdu, Bengali).
- Not enough information was available in different formats (visual or audio) for people unable to read or write their own mother tongue.
- Leaflets were often either photocopied, hand written and lacked entertainment value.

## Aims of FAD

The aims of the group are:

- To provide an advisory and consultative role to improve the knowledge, understanding and

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1. Reducing inequalities in healthcare and outcomes is a priority in the new NHS agenda but this goal is not being met.
2. The mission of FAD is to improve the knowledge, understanding and management of diabetes in the Indo-Asian population, using multi-media resources, therefore promoting an improved quality of life.
3. Informal evaluation showed that there was a significant lack of appropriate educational resources for British Asian people with diabetes and their families.

*Figure 2. FAD were present during the editing and filming of educational material for south Asians with diabetes.*

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1 Informal evaluation of the educational material produced in association with FAD has been positive.

2 The educational material is used during one to one consultations, group sessions and in waiting rooms.

3 FAD will continue to work together in an advisory and consultative role improving the outlook for the Asian community through the use of multieducational and culturally appropriate interventions.

**FIGURE 3: INITIATIVES TO DATE**

- Dispelling the myths and misconceptions. A video that was released in 1997 in Punjabi and was sponsored by LifeScan.
- Understanding and managing diabetes within the Asian community. A video that is in five Asian languages, English and possibly Mirpuri and was sponsored by LifeScan.
- Getting started with insulin injections. A video which is available in five Asian languages and English and was sponsored by Becton Dickinson.
- Instructional video on Humapen which is available in five Asian languages and English and sponsored by Eli Lilly (FAD were consulted and present for editing and voice over).
- FAD worked on a consultative basis with Eli Lilly on an interactive CD-ROM titled 'Diabetes type 2' which is available in Punjabi, Urdu and Bengali.

management of diabetes in the South Asian population.

- To provide the most appropriate, effective and culturally sensitive educational material to reinforce and support healthcare professionals when delivering diabetes education.

The FAD group members have similarities. They are all Asian and work in the field of diabetes. But what makes them unique and successful in their initiatives is the fact that they all bring different cultural, religious and language skills as well as a wealth of knowledge and experience of working with Asian people with diabetes and their families.

FAD has worked with LifeScan and Diabetes UK in an advisory capacity to produce some excellent materials, including multilingual videos and supportive literature.

The group have been responsible for writing the script of two videos: *Dispelling the myths of diabetes within the Asian community* (Punjabi version) and *Understanding and managing diabetes with the Asian community* (in English and five Asian languages as well as awaiting translation into Mirpuri). FAD were also present during filming and editing of the videos (see *Figure 2*). These have been well received by patients, their carers and healthcare professionals in the west Midlands. All members are in positions where they can empower other healthcare professionals working in the field of diabetes.

## Time constraints

Projects can take years to complete and many hurdles need to be overcome. The FAD group members are all DSNs who have heavy workloads and family commitments. There is a need for dedication and committment; much of the work is done outside of work time. In order to receive funding, credibility and worth needed to be approved before companies will sponsor the projects. Initiatives to date can be seen in *Figure 3*.

## Conclusion

Informal evaluation of the educational material produced in association with FAD has been positive. Appropriate language was used and the videos were culturally sensitive and realistic; patients were able to identify with the characters. The educational material is used during one to one consultations, group sessions and in waiting rooms. It is also used in health promotion events to raise awareness of diabetes within the south Asian community. These educational resources allow healthcare professionals an alternative approach when helping south Asian patients with diabetes to accept and manage their diabetes. Communication between healthcare professionals and Asian people with diabetes and their families is facilitated.

The group will continue to work together in an advisory and consultative role improving the outlook for the

Asian community through the use of multieducational and culturally appropriate interventions. It is hoped that the NHS will recognise the effort that is needed to develop services which meet the needs of the South Asian community. These have to be properly established and funded in order to improve care. ■

'It is hoped that the NHS will recognise the effort that is needed to develop services which meet the needs of the south Asian community.'


Ahmad WIU, Atkins K (1996) Race and Community. In Ahmad WIU, Husband C (Eds) *Race and community care: an introduction.* Open University Press, Bucks

Audit Commission (2000) *Testing times: a review of diabetes services in England and Wales.* Audit Commission, London

Barnett AH (1999) *Diabetes and the vascular system. Diabetes and vascular disease – an overview* Zeneca

BDA (1997) *What care to expect.* British Diabetes Association, London

British Heart Foundation (2001) *Coronary heart disease statistics diabetes supplement: statistics survey.* British Heart Foundation

Burden M (1998) Approaches to managing diabetes in Asian people *Community Nurse* May, 31–34

Burden AC (2001) Diabetes in Indo-Asian people *The Practitioner* **245**: 445–51

Campbell I (2001) Mild diabetes – or is it? *The British Journal of Diabetes and Vascular Disease* **1**(1): 75

Chandola T (2001) Ethnic and class differences in health in relation to British south Asians: using the new national statistics socio-economic classification. *Social Science and Medicine* **52**:1285–96

Chowdhury AM, Helman C, Greenhalgh T (2000) Food beliefs and practices among British Bangladeshis with diabetes: implications for health education. *Anthropology and Medicine* **7**: 209–26

Conlon D (2001) Diabetes top 10 websites *British Journal of Diabetes and Vascular Disease* **1**(1): 73–74

Diabetes UK (2000) *The missing million report: perceptions and reality of diabetes today* Diabetes UK, London

DCCT (1994) *Balance Supplement* British Diabetes Association, London

DoH (2000) *The vital connection: an equalities framework for the NHS.* Department of Health, London

DoH (2001) *Health survey for England 1999.* Department of Health, London

Greenhalgh T, Helman C, Chowdhury AM (1998) Health beliefs and folk models of diabetes in British Bangladeshis: a qualitative study. *British Medical Journal* **316**: 978–83

Hawthorne K (1990) Asian diabetics attending a British hospital clinic: a pilot study to evaluate their care. *British Journal of General Practice* **40**: 243–47

Jones R (2001) Focus on obesity, *The British Journal of Diabetes and Vascular Disease* **1**(1): 76–77

Karseas P, Hopkins E (1987) *British Asian health in the community.* John Wiley and Sons Ltd, Portsmouth

Koppiker N, Rao M (2002) The impact of heart disease and diabetes on our community http://www.saraswatsamajuk.org/general/healthMattrs.html (Accessed: 05/11/03)

Marwa K (2000) Influence of culture on Asians with diabetes living in the UK. *Diabetes and Primary Care* **1**(4)

Mello M (1992) Plugging the gap *Nursing Times* **88** (44) 34–36

National statistics online census (2001) http://www.statistics.gov.uk HMSO, London

Needham I (2002) *Diabetes health promotion in minority ethnic communities: report of a research and development programme in Wales. A Diabetes UK report.* Diabetes UK, Wales

Patel V, Morrisey J, Goenka N, James D, Shaikh S (2001) Diabetes care in the Hindu patient: cultural and clinical aspects. *The British Journal of Diabetes and Vascular Disease* **1**(2)

Raleigh V, Clifford G (2002) Knowledge, perceptions and care of people with diabetes in England and Wales *Journal of Diabetes Nursing* **6**(3)

Shaikh S, James D, Morrissey J, Patel V (2001) Diabetes care and Ramadan: to fast or not to fast? *The British Journal of Diabetes and Vascular Disease* 1(1): 65–67

Simmons, Williams DR. Powell MJ (1992) Prevalence of diabetes in different regional and religious South Asian communities in Coventry. *Diabetic Medicine* **9**(5): 428–31

UK Prospective Diabetes Study (UKPDS) Group (1998) Intensive blood-glucose control with sulphonylureas or insulin compared with conventional treatment and risk of complications in patients with type 2 diabetes (UKPDS 33) *Lancet* **352**: 837–53

UKPDS (1998) Effect of intensive blood glucose control with metformin on complications in overweight patients with type 2 diabetes (UKPDS 34) *Lancet* **352**: 854–65

Vass A (2003) Health literacy and patients' understanding. *British Medical Journal* **326**:1339

Web P (1997) *Health promotion and patient education* Stanley Thornes Ltd, Cheltenham