

South Asian Communities and Infertility



A resource for health care
professionals

What is 'South Asian'?

The term 'South Asian' refers to members of those communities, including East African Asians, whose ancestral roots can be traced to the Indian subcontinent, i.e. India, Pakistan or Bangladesh. It does not include people whose families originate in other Asian countries such as China, Philippines and Singapore.

Although the term 'Asian' is often used in the health service this term masks a tremendous diversity of national origins, cultures, religions and languages.

Older people may feel more strongly about traditional aspects of South Asian culture than young people born in Britain, but individual views vary a great deal. It is never possible to predict what is important to individual people and so it is important never to make assumptions about cultural differences. Always ask the patient and listen sensitively.

How big is the South Asian population?

Asian and Asian British groups in the 2001 census

Ethnic group	Count	% total population	% minority ethnic population
Indian	1,054,311	1.8	22.7
Pakistani	747,285	1.3	16.1
Bangladeshi	283,063	0.5	6.1
Other Asian	247,664	0.4	5.3
Total	2,332,323	4.0	41.4

Half of all South Asians were born and educated in the UK and are the children and grandchildren of people who migrated in the 1960s and 1970s. Some Bangladeshi women will have moved here more recently to join their husbands. Inter-continental marriage still occurs and some spouses therefore will be more recent arrivals.

What languages do South Asians speak?

Everyone born in the UK speaks English. There are also speakers of Punjabi (including the Mirpuri dialect); Urdu, Hindi, Tamil, Gujarati (including the Kutchi dialect), Pashto, Bengali (including the Sylheti dialect). Many South Asians can speak or understand several languages, some East Africans also speak Swahili and some people brought up in the UK may not speak any South Asian language (DOH 2004).

When organising interpreters it is very important to check the dialect, especially for those who say they speak Punjabi or Bengali or Gujarati (see above). Confidentiality is very important and patients may want to know the name of the interpreter. Working well with an interpreter requires conscious and careful management. Guidelines are available in Henley and Schott (1999).

Evidence shows that using informal interpreters (relatives and friends) often leads to translations which are inaccurate and unreliable. Misunderstandings, mistranslations and omissions are alarmingly high, even when health professionals think the interview has gone reasonably well. Bias and distortion can occur and embarrassment is common. This is especially likely in discussions of infertility. In some cultures, husbands and wives may not feel able to discuss these issues together and may not know the relevant words either in English or their first language.

Confidentiality is very important. This is especially the case in small communities where many people know each other and news travels fast. Breaches of confidentiality can have serious consequences.

Is religion important?

Religion is likely to be important to many South Asian people, though individuals vary considerably (just as in the white 'Christian' population) in terms of how religious guidelines influence behaviour. This can never be assumed.

South Asians in the UK are religiously very diverse. The 2001 census asked a question on religion for the first time, so there is now more reliable data on ethnicity and religion (see www.statistics.gov.uk/census2001).

- **Indians** are religiously diverse - 45 % are Hindu, 29% Sikh and 13% Muslim.
- **Pakistani and Bangladeshi** groups are more homogenous – 92% are Muslims

It is not possible here to give specific details of the characteristics of each South Asian religion or culture. For an excellent resource on cross-cultural healthcare see: Henley and Schott (1999). For issues specific to nursing see: Culley & Dyson (2001). Information on South Asian religions is available on the websites listed below.

It is important to consider that culturally and religiously, certain aspects of care may be important to people. There are different cultural conventions about:

- Modesty and privacy
- Body space
- Clothing and Jewellery
- Washing and cleanliness
- Food and diet
- Family structure and relationships
- Naming systems and forms of address
- Religious beliefs and practices (e.g. Muslims are *culturally* diverse)

However, we cannot predict individual behaviour based on group membership. The only person who can tell you what is important for them is the patient. If we want to find out, we have to ask. This is not always easy. Henley and Schott (1999: 21) suggest the following guideline for working well across cultures:

When working with someone whose culture differs from your own, it is always necessary to:

- be aware of your own cultural values and norms and how these may be affecting your thinking and judgements
- notice any assumptions you're making about the other person and try to suspend them
- listen with respect, set aside any defensiveness, and be willing to understand this person on their terms
- ask them about their needs – they are the expert - and respond flexibly and sensitively
- accept that cross-cultural encounters can be difficult and confusing for both sides

Family and marriage

- Most South Asian adults prefer to be married. Cohabitation, separation and divorce are relatively rare compared with white groups.
- Family size of Indian women is broadly the same as white women, but Bangladeshi and Pakistani women marry younger, start families earlier, complete them later and have more children than is now typical in Britain.
- Most Indian families live in small families - mum, dad and two children is the norm. Pakistani and Bangladeshi households are more likely to contain more adults, including many two-generation households
- Most Asian elders live with their son or daughter.
- Formal, parentally arranged marriages are in decline, especially in the Hindu and Sikh groups, though parents' views are still very important in most cases.

What is the health status of South Asians?

The health status of different communities is very closely related to their socio-economic standing. As in all populations there are divisions of wealth and income within each group.

- **African Asians** and **Indians** have reached a position of broad parity with the white population in economic status and in overall health status
- **Pakistanis, and especially the Bangladeshis** continue to be severely disadvantaged with high levels of male unemployment and severe poverty. These communities report much higher levels of general ill health.

Diabetes and thalassaemia are conditions more common in all South Asian populations. The incidence of many other major conditions varies considerably between South Asian groups. For example, a major national study of ethnic patterns of morbidity (sickness) shows that Indians and African Asians have similar rates of coronary heart disease to whites, but Pakistanis and Bangladeshis have much higher rates (Nazroo 1997).

Are there differences in infertility?

There is no available data to suggest any difference in the incidence of infertility in South Asian populations.

In comparison with 'white' women, South Asian women have:

- higher rates of Polycystic Ovary Syndrome
- higher rates of diabetes
- lower rates of sexually transmitted diseases
- lower rates of smoking and alcohol consumption
- lower rates of obesity in Indian and Bangladeshi women (aged 16-34)
- slightly higher rates of obesity in Pakistani women (aged 16-34)

(Erens et al 2001)

Are there differences in treatment outcomes?

This is under-researched. Currently, there is little evidence of ethnic differences in the outcome of fertility treatment. Lashen et al (1999) report a controlled comparative study of 108 women born in the Indian sub-continent and 216 'Caucasian' controls receiving IVF treatment in Birmingham between 1994-97. No significant differences were found in response to ovarian stimulation and IVF outcome for the two groups.

What is important for infertility services?

- In South Asian communities, children are highly desired and childlessness is socially unacceptable. Children are seen as essential for normal adult existence and infertility is a highly stigmatised condition.
- Infertility in South Asian communities is highly visible and is not regarded as simply a couple-centred concern. Childless couples are subjected to social scrutiny.
- Men do not escape the stigma of infertility, if this is publicly revealed. However, there is a veil of silence shrouding male infertility.

- Community understanding of infertility, especially among older generations, is very limited
- Use of donated gametes is socially disapproved of, but there is an awareness that this does occur.
- There is a considerable need for both information and emotional support for South Asian couples, and women in particular.
- There is, however, a lack of acceptance of formal counselling by many South Asians and alternative ways of providing emotional support may be needed
- Patients would like more information about their infertility ‘journey’ – an individualised plan of treatment, with broad timescales, will help to reduce the frustration of patients who perceive ‘delays’ in treatment.
- Confidentiality is a major issue. Infertility treatment may not have been disclosed to family. Check how patients prefer contact to be made. The consequences of breaches of confidentiality can be very serious for the couple and/or the wider family.
- Concerns with confidentiality may also mean that interpreters are refused. This is particularly sensitive where one partner offers to translate for a non-English speaking spouse. However, professionals need to consider carefully the implications of this for patient understanding, concordance and for informed consent. Mistranslations, misunderstandings and omissions are alarmingly high when informal interpreters such as this are used.
- Telephone based interpretation may be preferable to face-to-face interpretation, though training is required to use this effectively.
- Patients could be directed to quality websites on infertility – see below.

A leaflet and CD with basic information about infertility and treatment is available in Punjabi, Gujarati, Bengali, Urdu and English. For details contact nhduson@dmu.ac.uk

Sources of information for professionals:

Information about South Asian religions is available online at:

<http://www.ethnicityonline.net/>

Ethnicity Online website, created to address the need for understanding of ethnic differences in healthcare.

<http://www.sikhs.org/>

Information about Sikhism

<http://www.hindu.org/>

Information about Hinduism

<http://www.islamonline.net>

Information about Islam

Say 'hello' in Hindi? For useful phrases in South Asian (and other) languages see:

<http://www.elite.net/~runner/jennifers/>

When is Ramadan, Divali or the Birthday of Guru Nanak?

A calendar of all religious festivals is produced by Shap and available at:

<http://www.support4learning.org.uk/shap/>

Books:

Religions in the UK: Directory 2001-2003 (3rd edn) (2001) Weller, Paul.

Published by the Multi-Faith Centre at the University of Derby, in association with the Inter Faith Network for the United Kingdom

ISBN: 0 901437 96 4

Culture, Religion and Patient Care in a Multi-Ethnic Society. A handbook for professionals (1999) Henley, A. & Schott, J. London: Age Concern

Useful sources of information for patients:

NHS Direct online: <http://www.nhsdirect.nhs.uk/>

CHILD: The National Infertility Support Network. Providing high quality support and information to those suffering from infertility in Great Britain.
<http://www.child.org.uk/>

Department of Health (2004) Guidance on Developing Local Communication Support Services and Strategies. Department of Health: The Equality and Human Rights Group.

ISSUE: ISSUE's support includes counselling and telephone counselling; putting you in touch with support groups locally; online support including a 24hours a day newsgroup. <http://www.issue.co.uk/>

The Daisy Network: A registered charity and support group for women suffering premature menopause. <http://www.daisynetwork.org.uk/>

Empty Arms: This site is for women dealing with Endometriosis and Infertility. <http://www.emptyarms.co.uk/>

ACeBabes: Site/ organisation for families following assisted conception.
<http://www.acebabes.co.uk>

Good American sites include:

RESOLVE: The National Infertility Association. Provides timely, compassionate support and information to people who are experiencing <http://www.resolve.org/>

FertilityPlus: Information written by patients for patients. A non-profit website for patient information on trying to conceive. The site owners are not professionals, but are rather providing information that is written by patients for patients.
<http://www.fertilityplus.org/>

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The information in this leaflet is based on the study: *Informing Policy and Practice: A Study of the Provision of Infertility Services to British South Asian Communities*, which was conducted by researchers in the Faculty of Health & Life Sciences at De Montfort University, Leicester. If you would like to know more about this research project, please contact Nicky Hudson on 0116 2078766, email: nhudson@dmu.ac.uk

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