# Tailoring genetic information and services to clients' culture, knowledge and language level

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## Summary

This article discusses approaches to dealing with transcultural care. Patient treatment can be improved by considering various cultural differences, establishing empathy, and focused listening. Scenarios, points for reflection and suggestions for non-judgemental language are provided.

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## Keywords

**Culture and religion; Genetic counselling; Genetic disorders; Transcultural nursing**

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JUST AS a handshake in the UK tends to be firm, a handshake in the Middle East tends to be gentle – firm would be perceived as aggressive. In Islam and Orthodox Judaism, a handshake between members of the opposite sex is forbidden. No handshake is 'more correct' than another; they are just different. This article discusses the implications of cultural differences for nursing practice.

The *Code of Professional Conduct* specifies that nurses must 'promote and protect the interests and dignity of patients and clients', irrespective of 'race', culture, and religious beliefs (Nursing and Midwifery Council (NMC) 2002). Some of these terms are explained briefly in Box 1. In this, the second article of seven on competency standard statements in genetics, the skills associated with transcultural nursing are emphasised as being as important in genetics as they are in any other area of practice (Box 2).

The article aims to raise awareness about how ethnicity and cultural differences may influence care and nurse-client communication. It also considers the process of translating complex genetic information into lay language, with attention given to the importance of language.

## Influence of cultural differences and ethnicity on caregiving

Cultural difference not only applies to religion or ethnicity, it also reflects difference between groupings. It is sometimes helpful to consider the ways in which people differ in terms of 'culture'. For example, a consultant obstetrician who arranges a termination of pregnancy for fetal abnormality might have very different values, beliefs and attitudes from a pro-life activist.

**BOX 1**

**Glossary**

**Culture**
A population of people characterised by common habits, rules, beliefs, traditions or other behaviours passed within and between generations.

**Ethnicity**
Used to denote a particular group of people who share a common cultural heritage, religion, language, place of origin, or ancestry.

**Race**
This term is now discredited as a means of describing different groups of people, because it has no biological basis. Its use is confined to terms such as 'racism' and 'race relations'.

**Stereotype**
An over-simplified or untrue generalisation about a particular group of people.

(Adapted from Husband and Hoffman 2004)

**BOX 2**

**Second of seven competency standard statements**

Appreciate the importance of sensitivity in tailoring genetic information and services to clients' culture, knowledge and language level, recognising that ethnicity, culture, religion and ethical perspectives may influence the clients' ability to use these.

(Kirk *et al* 2003)

Although both people may be white and middle class, their values and belief systems would make them 'culturally different' (Box 3). Because we are all individuals and have different life experiences, most interactions between health professionals and clients will have an element of cultural difference to them. A fundamental step in transcultural nursing is to be able to acknowledge cultural differences appropriately, without fearing a charge of 'political incorrectness'. All models of transcultural nursing have their basis in recognising and valuing diversity and, at the same time, embracing individuality and disregarding stereotypes (Wilkins 1993).

## Acknowledging cultural differences

Husband and Hoffman (2004) say that the fear of stereotyping patients makes 'some of the most caring and sensitive nurses deny themselves the possibility of recognising difference. Yet being comfortable with difference is at the heart of transcultural care' (Box 4).

**Learning about culture** The focus on transcultural nursing has suggested that it is helpful to become familiar with the client's cultural orientation and his or her social context, that is, the position of the individual in the larger social environment (for example, Leininger 1996). However, it would be impractical to suggest that the only way to do this involves learning facts and figures about different cultures. It is more useful to know what questions to ask oneself about culture and be aware of the differences between people. Sensitive work involves focused listening, establishing empathy and reflecting on the links between personal issues and social context (Box 5).

**Ethnic groups and vulnerability to specific diseases** It is important to consider effective communication cross-culturally, and it is also vital to be aware of the link between ethnic groups and vulnerability to particular diseases. As many ethnic groups remain geographically and culturally separate, people have tended to marry within the same ethnic group. As a result specific gene alterations became more common in certain groups, for example, sickle cell anaemia is common in the black African population, cystic fibrosis is common in the northern European white population, thalassaemia is common in the Mediterranean population and Tay-Sachs disease is common in the Ashkenazi Jewish population (Box 6).

It is recommended that clients of the relevant ethnic groups are offered testing for

**BOX 3**

**Points for reflection**

What factors would you use to describe your own identity? Think of people you know who identify with cultural groups different from the one to which you belong. What factors make them similar to you, and what factors make them different? How would you describe them to a colleague who you identify as belonging to the same cultural group as you? Would you shy away from remarking on the factors that make them different from you?

**BOX 4**

**Scenario 1**

A young, pregnant Pakistani woman has learned through her culture that medical doctors are important professionals. In Pakistan her local doctor was a wise, paternalistic figure who gave advice to his clients. A female client would show her respect by listening quietly and not maintaining eye contact. When the woman comes to see the midwife for the first time in the UK, she is nervous and frightened. She wants the midwife to tell her what to do – her cultural stereotype about what doctors should do.

The midwife senses her vulnerability and mistakenly believes the woman's silence means she does not understand what is being said – cultural stereotyping. The midwife talks more slowly and tries to simplify what she is saying; the client subsequently feels irritated that the midwife does not appear to be offering advice or wisdom and the midwife feels confused that the client is behaving so submissively.

The midwife's stereotypical view of the client and the client's stereotypical view of the midwife are inhibiting communication. The midwife could reconsider this type of consultation by first thinking about her own stereotypes of culture. She could ask the client what her expectations are of the consultation, and reflect more on the feelings she experiences in relation to the client. This might help to make communication between them more open.

**BOX 5**

**Scenario 2**

A young black man from Zimbabwe arrives at the accident and emergency (A&E) department in a largely white NHS hospital. He has recently left his home country, where racism was a part of everyday life. On meeting the white A&E nurse he feels uncomfortable and does not know who he can trust. He anticipates racism and becomes defensive and withdrawn.

The nurse is surprised at the man's lack of co-operation because she is trying to help him, but she realises that his responses to her are not personal: he is in pain and the alien environment is making him feel uneasy. The nurse is mindful that he may have different views and perceptions of her motives and the role of the organisation. She asks him gently about his fears and, gradually, she is able to establish clearer communication. She does not know all the nuances that relate to the customs and traditions of his culture, but she is able to see that he is culturally different from her and makes a special effort to listen carefully and not jump to conclusions.

**BOX 6**

**Scenario 3**

Hannah and Jacob are of Ashkenazi Jewish descent ('Ashkenazi' refers to the Eastern European roots of this section of the Jewish population). After several years of unsuccessful attempts to conceive, the couple are offered in vitro fertilisation (IVF) treatment, and are delighted when Hannah becomes pregnant after the first menstrual cycle. At that point, their obstetrician offers them testing for Tay-Sachs, a genetic disease carried by 1 in 25 Ashkenazi Jews. Infants born with the disease will develop progressive neurodegeneration and will invariably die before four years of age.

The tests reveal that the parents are both carriers of Tay-Sachs and thus there is a one in four chance that their child is affected by the disease. The couple are referred to the regional genetics centre and, after genetic counselling, opt to have chorionic villus sampling (CVS), although they are worried about the risk of miscarriage as Hannah is now 11 weeks' pregnant.

They understand the implications of the pregnancy if the fetus is affected, but Hannah is too traumatised to discuss the option of termination. Jacob says they will probably opt for termination if the test is positive. CVS shows that the fetus does not have Tay-Sachs. However, Hannah and Jacob are angry that appropriate testing and genetic counselling had not been offered to them before commencing IVF treatment.

haemoglobinopathies (sickle cell and thalassaemia) or Tay-Sachs testing, especially in the antenatal period. The Department of Health is targeting screening programmes at specific ethnic groups (Aspinall *et al* 2003), for example, universal screening for haemoglobinopathies in areas where there are many couples of West African origin.

Many health professionals do not have the 'ethnicity awareness' to ask about ethnic origin with confidence, and feel uncomfortable that the question may hint at an underlying racist agenda. Ethnic identification can be flexible and people may present different aspects of their identities in different contexts, for example, ethnicity can be viewed interchangeably with country of birth, religion, skin colour, language or nationality. Therefore, it is important to explain to the patient why knowing about genetic ancestry is helpful (Aspinall *et al* 2003). However, it should also be acknowledged that, as mixed ethnicity groups increase, the association between ethnicity and particular genetic conditions is becoming less distinct (Box 7).

## Communication

Communication is an essential component of care, yet interpersonal communication can be ambiguous and misunderstood. Communicating across cultural boundaries increases this risk, which is further compounded when dealing with complex scientific information.

**Explaining genetic concepts in lay language** It is usual for people to attach meaning to inheritance that may not necessarily relate to the science of inheritance (Richards 1996). For example, clients may assume that because they resemble a relative with breast cancer, they too will develop the disease. No matter how much scientific information is given to the contrary, it can be difficult to shift this emotional connection. Therefore, it is useful to elicit prior knowledge and assumptions that clients have about genetics during consultation (Lanie *et al* 2004).

People can sometimes have an 'illusion of knowing' about genetics terminology (Park 2001). They may have been exposed to genetics terms through the media and educational sources, and can use genetics terms freely in conversation; but their underpinning scientific knowledge may be limited. It is important to tailor genetic information to the clients' levels of understanding in a sensitive manner that respects their educational ability.

**Power of language** In addition to providing clear explanations, it is also important to remember that the language used in a consultation can be powerful. It is common in genetic counselling to discuss the 'risk of recurrence' of a genetic

condition for the next generation. This use of language assumes that the situation is 'risky' in some sense, and that passing on the genetic condition may not be favourable. While this may be a correct assumption in most cases, to talk in terms of 'risk' for some genetic conditions might be offensive.

One such condition is deafness. People who are culturally deaf – meaning they are positive and proud of their deafness and do not view it as a disability – may prefer to have children who are deaf (Middleton *et al* 2001). Therefore, in a genetic counselling consultation it would be more appropriate to talk in terms of there being a 'chance' of passing on deafness, with no judgement attached to whether this would be a good or a bad thing. Conversely, there are many deaf people who do not view deafness as a positive experience and this highlights the importance of asking about clients' cultural perspectives (Box 8).

**Explaining consanguineous marriage**

Consanguineous marriage, particularly between cousins, is common among some ethnic groups. It can be part of a traditional way of life, and may be considered beneficial to the family concerned, through a perception of shared tradition, closeness and family knowledge (Bennett *et al* 2002). The chance of both parents being carriers for the same recessive condition is increased if they are related, so recessive genetic conditions may have a higher prevalence in consanguineous unions (Figure 1).

**BOX 7**

**Scenario 4**

Julie worked in a district general hospital and had not been long qualified when she was asked to prepare a room for a young black man in sickle cell crisis. She knew about sickle cell disease from her training but, because she had never nursed anyone with the condition, she went to double check with a new staff nurse who had come from a large city hospital. Julie was shocked by her colleague's response: 'Black is he? I know the sort, they come in shouting for diamorphine, and as soon as they've had their fix, they want to go home.'

**Points for reflection** The example above diminishes the importance of pain management and identifies a case of racial stereotyping. How would you deal with a colleague who you felt was being racist?

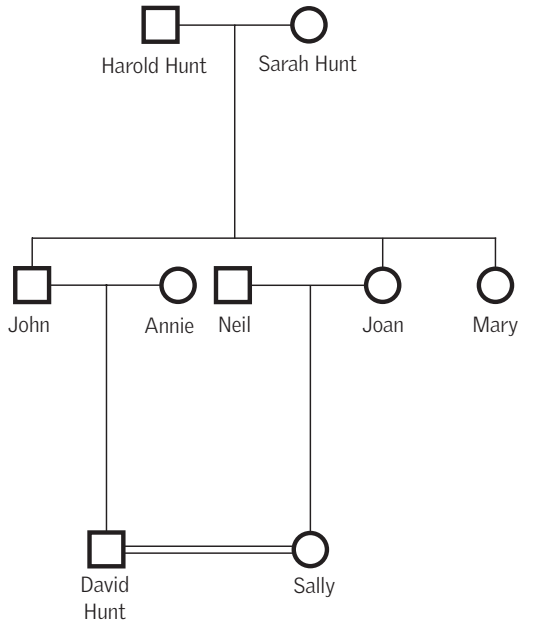
Do you know the ethnic demography of your local area, and the health needs of such groups? Consider the health information resources available in your local area for people from different ethnic groups.

**FIGURE 1**

**Consanguineous marriage**

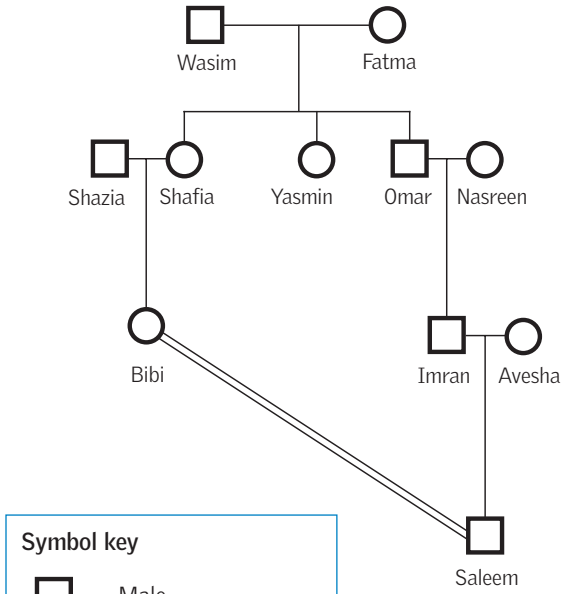
**A. First cousins**

Sally and David will have one eighth of their genes in common




**B. First cousins once removed**

Bibi and Saleem have one sixteenth of their genes in common



**BOX 8**

**Points for reflection**

How confident are you at communicating effectively with an adult from a different cultural background? How do you feel when the adult is also of a different linguistic background? What issues do you think need to be considered if you are communicating with – or through – a child from such a background?

Consanguineous couples are seen frequently for genetic counselling; the language used in such consultations is carefully considered. It would be insensitive to talk of there being a higher chance of having a disabled child 'just because the parents are first cousins'. The cultural tradition of consanguinity should never be 'blamed', because this may cause offence and the parents may lose confidence in the health professional (M Ahmed, registered genetic counsellor, St James's University Hospital, Leeds, 2004, personal communication).

Instead, the focus should be on the genes and not on the marriage. It is common to hear consanguineous couples say that they have been hurt by the insensitivity of health professionals suggesting they are to blame for their children's medical problems (Darr 1999).

## Conclusion

Delivering genetic information sensitively, when the health professional and the client are of a different cultural background, can be achieved if cultural differences are recognised and respected. Cultural difference can exist in many contexts and does not only relate to religion and ethnicity. By focusing on listening skills, establishing empathy and by preventing stereotyping, it is possible to communicate sensitively and effectively. Considering the language used and appreciating the power it has is also important in promoting best practice **NS**

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## Further resources

RCN resource on Transcultural Health Care Practice www.rcn.org.uk/resources/transcultural