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

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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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.

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)
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...
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 2004). 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.
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.

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References


Further resources

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

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