

**Parallel Session 4: Cultural Identity Implications in Genomics Research and
Communication**

CULTURAL COMPETENCE IN GENETICS EDUCATION

Mona Saleh and Kristine Barlow-Stewart

*The Centre for Genetics Education, PO Box 317 St Leonards, NSW 1590,
Australia. Tel: +612 9926 7324, FAX: +612 9906 7529 E-mail:
msaleh@med.usyd.edu.au*

Abstract

There is increasing awareness of the importance of genetic information in determining family members' current and future health. The Centre for Genetics Education, in close collaboration with providers of genetic counselling services, aims to provide accessible and relevant genetics knowledge to members of the public. In order to do so, resources are developed in a variety of formats to convey information and engage the public in a discussion of genetics and its implications. The challenge of communicating genetics information in Australia requires attention to cultural diversity and the way in which it affects the dissemination of scientific knowledge.

Key Words: Culture, Genetics, Communication.

Genetic counselling is a multidisciplinary approach to providing diagnosis, risk assessment, education and support to individuals and families affected by genetic conditions. It is also a process that delves into the foundations of a family. For effective communication in genetic counselling, it is essential to understand how individuals translate genetic information within the context of their own belief systems. The fundamental tool used during the first stage of genetic counselling is the documentation of a detailed family health history (pedigree). This inevitably involves addressing issues such as hereditary, kinship and personal beliefs about characteristics of certain family members. Cultural diversity plays a major role in determining people's beliefs and opinions about such issues.

The completion of the Human Genome Project in 2003 brings with it the promise of health benefits and an improved understanding of genetic conditions. Accompanying these benefits comes the impact of the knowledge and the choices regarding the utilisation of genetic technologies. Addressing these issues is optimally done within a genetic counselling context. Issues of informed consent and communication of the consequences of gaining personal genetic information has never been more crucial. The ability of providers of genetic counselling services in Australia to address these issues is challenged by a culturally diverse population. If the new technology is to be used responsibly, and made accessible

to all Australians, it is vital that genetic counselling service providers attain cultural competence and practice within a model that embraces, rather than excludes cultural diversity.

The impact of cultural beliefs on the uptake of genetic counselling and the ensuing technologies has been studied internationally^{1,2} and to a lesser degree in Australia³. It has been documented that health providers can categorise individuals from specific cultural backgrounds and may make assumptions about their needs and opinions^{3,4}. This can lead to incorrect perceptions and may jeopardise optimal communication between provider and client.

Genetics education has historically been enmeshed in the genetic counselling process. As genetic counselling is primarily a communication process, it is affected by the skills of the practitioner in conveying complex principles at an appropriate level to the client. The challenges faced when communicating across cultures impacts on the genetic counselling process.

Why is culture so important in genetics?

A person's background, in terms of their ethnicity or cultural practices, can be a predictor of their genetic health.

During genetic counselling, information is collected from clients regarding their ancestry in order to predict the potential gene mutations present in their DNA. This can be a powerful tool in risk assessment, particularly where consanguinity is the reason for seeking genetic counselling.

Gathering what may be deemed "basic" family health history information can be challenged by cultural beliefs.

When collecting a family history, simply extracting from a client the details regarding their siblings or other kinship relationships may not be as "basic" as it seems. The documentation of a family health history in genetic counselling is governed by an understanding of biological inheritance within an Anglo-Celtic-Saxon concept of the family tree. Particularly in cultures where child rearing is viewed as a community role, rather than exclusively that of the biological parents, the definition of a sibling by the genetic counsellor may be in conflict with the understanding and beliefs of the client.

New technologies may target certain population groups as being at risk of ethn-specific genetic conditions.

In the case of the genetic condition hypercholesterolaemia, the Lebanese population has been identified as being at increased risk. This condition is one of the growing number where pharmacogenetics will be used in targeting pharmaceuticals to the genotype of affected individuals. The challenge of informing this community about the issues related to genotyping such as informed

consent, insurability and privacy must not be overlooked as the promise of better treatment arrives.

Genetic counselling practitioners in Australia often use educational tools and resources to assist in communicating complex issues to their clients. These tools may be in written form, either produced by the practitioner, obtained from the Centre for Genetics Education or other sources. It is important to know whether these educational tools, when used as resources to aid the genetic counselling process, do meet the needs of a culturally diverse population. The production of culturally inappropriate resources may result in the limitation of access to quality genetic counselling and enabling informed choice about the utilisation of new genetic technologies by a large proportion of Australians.

Genetics education resources must therefore reflect a diverse population and be validated by the community it serves.

References

Lewis, L.J. (2002) Models of genetic counseling and their effects on multicultural genetic counseling. *Journal of Genetic Counselling*. Vol11, No.3, 193-212.

Weil, J. (2001) Multicultural education and genetic counseling. *Clin Genet*. 59, 143-149.

Barlow-Stewart, K., Yeo, S.S., Eisenbruch, M., Meiser, B., Goldstein, D., Tucker, K. (*manuscript in preparation*) Exposure of stereotyping: community beliefs about kinship learnt from Chinese-Australians that may impact on optimal utilisation of cancer genetics services.

Wang, V.O. (2001) Multicultural genetic counseling: then, now and the 21st century. *Am J Med Genet*. Fall, 106(3), 208-215.

Kessler, S (1997) Psychological aspects of genetic counseling. IX. Teaching and counseling. *J Genet Couns*. 6(3), 287-295.

PCST International Conference - www.pcst2004.org

