

Review article

Cultural aspects of cancer genetics: setting a research agenda

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Abstract

Background—Anecdotal evidence suggests that people from non-Anglo-Celtic backgrounds are under-represented at familial cancer clinics in the UK, the USA, and Australia. This article discusses cultural beliefs as a potential key barrier to access, reviews previous empirical research on cultural aspects of cancer genetics, draws implications from findings, and sets a research agenda on the inter-relationships between culture, cancer genetics, and kinship.

Methods—The CD-ROM databases MEDLINE, PsychLIT, CINAHL, and Sociological Abstracts were searched from 1980 onwards.

Results—Cultural aspects of cancer genetics is the focus of an emerging body of publications. Almost all studies assessed African-American women with a family history of breast cancer and few studies included more diverse samples, such as Americans of Ashkenazi Jewish background or Hawaiian- and Japanese-Americans. Our analysis of published reports suggests several directions for future research. First, an increased focus on various Asian societies appears warranted. Research outside North America could explore the extent to which findings can be replicated in other multicultural settings. In addition, control group designs are likely to benefit from systematically assessing culture based beliefs and cultural identity in the “majority culture” group used for comparative purposes.

Conclusion—More data on which to base the provision of culturally appropriate familial cancer clinic services to ethnically diverse societies are needed. Empirical data will assist with culturally appropriate categorisation of people from other cultures into risk groups based on their family histories and provide the basis for the development of culturally appropriate patient education strategies and materials.

(J Med Genet 2001;38:425-429)

Keywords: hereditary cancer; kinship; culture; family history; cultural competence

Ethnic differences in cancer incidence and mortality are well documented. Cancer incidence varies by ethnicity as a result of environmental and genetic factors. In Australia, for example, people born in Asia have a lower incidence and mortality from colorectal and breast cancer compared to those born in Australia.^{1 2} The belief that geographical differences in the incidence of some cancers is attributable to dietary factors is supported by the changes observed in the incidence rates in migrants who move from areas of low risk for particular cancers to countries where the risk is higher. For example, data on the migration of Japanese and Chinese men and women to Hawaii and to the mainland United States, whose risk of developing prostate or breast cancer was previously low, show that it increases to match that of the indigenous population within a few generations.³

Ethnic differences in cancer incidence may also be a function of genetic factors. An emerging body of publications is examining the prevalence of mutations associated with hereditary breast cancer or hereditary non-polyposis colorectal cancer (HNPCC) in non-western people, in particular in Chinese and Japanese patients with breast or colorectal cancer.⁴⁻⁶ Until recently, the assumption has been that the lower incidence of breast and colorectal cancer in those of Chinese origin, for example, would translate into a lower incidence of mutations in breast and bowel cancer predisposition genes.¹ However, data have become available that show that mutation rates in *BRCA1* and HNPCC associated mismatch repair genes in Hong Kong Chinese are present in approximately the same proportion as in any number of populations previously studied.^{5 6} Moreover, the proportion of familial cases and incidence of early onset cancer are similar.⁵ Importantly, one study of young Hong Kong Chinese affected by colorectal cancer showed a fourfold excess when compared with studies carried out in western countries.⁷ The excess in the younger age group suggests a higher proportion of heritable mutations, which is masked by the lower absolute incidence figures. If clinical care is to be appropriately extended to this community, then it is imperative to study the biomedical facts of mutation

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rates. In this respect, the Chinese are an important paradigm for other Asian immigrant groups in multicultural societies. However, in addition to biomedical factors, the cultural context of inherited cancers among the Chinese may be of equivalent importance.

Culture specific presentation of a family history of cancer

Consensus guidelines on the care of subjects with an inherited susceptibility to hereditary breast cancer or HNPCC or those at risk of having inherited a susceptibility have been published in several countries, including Australia.⁸⁻¹² The Australian guidelines were designed to assist with the categorisation of subjects into one of three risk groups based on their family history of breast or colorectal cancer, that is “At or slightly above average risk”, “Moderately increased risk”, and “Potentially high risk”, and to provide appropriate advice about early detection strategies and referral to familial cancer clinics.⁸⁻¹² However, the surveillance and referral recommendations, and ultimately access to genetic testing, are dependent upon the correct categorisation based on family history using an Anglo-Celtic concept of kinship. Anecdotal evidence suggests that most patients attending familial cancer clinics are of Anglo-Celtic backgrounds. The assumption that categorisation into risk groups is also working successfully for people of non-Anglo-Celtic background is yet to be confirmed. From ethnographic research it is understood that many cultures have a profoundly different understanding of kinship and this may have a substantial impact on the way in which a family history of cancer is understood and presented.¹³ For example, it has been suggested that Mendelian modes of inheritance (which largely correspond to western bilateral kinship systems) are incompatible with non-western (patrilineal) kinship concepts.¹⁴ Western kinship systems are based on the idea that any person belongs to a family with different “sides”, and beliefs about inheritance are conceptually organised around these sides.¹⁵ Such bilateral kinship systems largely correspond to the descent models of clinical genetics and contribute to the relatively effortless assimilation of knowledge about genetics by patients from western cultures.¹⁵ By contrast, patrilineal kinship systems provide a blueprint largely incompatible with established modes of inheritance. In many Asian and Middle Eastern cultures, a kindred is defined chiefly by the male line of descent from a common ancestor.¹³ A disease “running in the family” may be construed as being derived directly from a common ancestor and this belief may impact on help seeking behaviour.¹³

Underuse of familial cancer clinic services by people of diverse cultural backgrounds

To our knowledge no published data are currently available that allow statistical inference of differences in use of familial cancer services by ethnicity. Despite this, clinical experience in familial cancer clinics around

Australia, for example, is consistent with data showing the lowest proportion of women reporting having had mammographic screening or pap smears is among Asian born women.¹⁶ Among Vietnamese-Australian women, recent immigration and low levels of acculturation were associated with low participation rates in cervical cancer screening.¹⁷

Factors contributing to underuse are likely to be complex and may include: language and literacy barriers; possible failure of the multicultural media to report on genetic issues and thus a lack of awareness of genetic services; lower than expected risk for hereditary cancers^{18 19}; lack of referral to genetic clinics by general practitioners and specialists for a number of reasons including misinterpretation or misreporting of a family history of cancer; incomplete family histories because of migration or a lack of access to medical records to confirm family history; culturally determined attitudes to genetic testing and counselling may be incompatible with current genetic service provision.

Cultural beliefs may serve as a key barrier to access to familial cancer clinics in several ways. In many Asian and Middle Eastern cultures, the family remains the central organising structure.^{20 21} In these cultures, the emphasis on family reputation, privacy, and culture based strategies of solving problems within the family may be particularly hard to reconcile with consulting a counsellor.^{22 23} Counselling is likely to be a less than acceptable strategy as it is based on disclosure of private information to strangers. Genetic disorders may be perceived as particularly shameful since they are likely to be construed as reflecting adversely not only on the individual person but on the family as a whole.²² Assistance outside the family may be seen as a public admission of this shame and therefore is not to be condoned.²² The concept of predictive testing may also be imbued with cultural meanings, given the dominant role played, for example, by astrology in many cultures and the associated notion of averting ill fate through precautionary measures.²⁴⁻²⁶ For example, Cambodian explanations for cancer have been described as centring around the role of astrology, karma, and fate.^{27 28} If counselling is offered in a way that is incompatible with patient beliefs built on the logic of astrology, karma, and fate, it is not culturally competent and is thus likely to be jettisoned.

In addition, there are several ways in which culturally determined beliefs about cancer in particular may serve as a key barrier to use of familial cancer clinic services. First, in some cultures, the degree of stigma associated with cancer is considerable. Westbrook *et al*²⁹ found significantly higher degrees of stigma in Arabic-, Greek-, and Chinese-Australians compared to Anglo-Celtic Australians. It is unclear to what extent these differences are the result of the well documented fear of cancer or beliefs that cancer is incurable by western biomedical treatment.²⁷ Associated with this stigma is the notion that patients should not be told their diagnosis if the cancer is incurable or not

responding to treatment,²¹⁻³⁰ and that the family should advise the doctor on what and how to tell the patient.²¹ A key issue in Chinese-Australian patients with cancer and their relatives, for example, is the importance of fully informing and involving the family, taking into account their own cultural norms.²¹ Finally, the diagnosis of hereditary cancer is established based on the family history of cancer. In Australia, predictive testing is only available to an unaffected subject in those families where an affected family member is willing to give a blood sample and a causative mutation has been identified. There is a need to reconcile, on the one hand, documentation and confirmation of an extended family history recognising the different systems of kinship as well as the necessity for a blood sample from an affected relative, versus, on the other hand, the cultural belief that those with an unfavourable prognosis should not be told their diagnosis of cancer.

Methods

Several strategies were used to conduct the publication search. The CD-ROM databases MEDLINE, PsychLIT, CINAHL, and Sociological Abstracts were searched from 1980 onwards using the following key words "culture" and "genetics" (both as nouns and adjectives) in combination. Searches were also conducted for key authors who published in this field. The reference lists of all publications identified were examined. A manual search of the following specialist journals was carried out for 1990 to 2000: *Genetic Counseling*, *Journal of Genetic Counseling*, *Genetic Testing*, and *American Journal of Human Genetics*.

Results

LAY REPRESENTATIONS OF GENETICS AND FAMILIAL CANCER

Several studies assessed lay understanding of inheritance in the general population in the UK and in families attending for genetic counselling for breast/ovarian cancer risk.¹⁵⁻³¹ Findings suggest widespread beliefs that cancer may skip a generation; that there will be a resemblance (physical or in character) between those in the family who are affected and those who are not; that a person is likely to develop the cancer at the same age as it developed in their nearest relative who had the disease; and a difficulty in appreciating inheritance of breast or ovarian cancer via male family members.¹⁵⁻³² All of these studies have been undertaken in the UK predominantly with people of Anglo-Celtic background. Lay knowledge about inheritance is closely related to ideas about kinship and social relatedness between family members.³² Kinship systems vary across cultures and thus lay knowledge about inheritance is also likely to be subject to cultural variation.

To our knowledge, with the exception of the following, no published data are available that document lay understandings of inheritance in other cultures. The use by paediatricians of Vietnamese traditional beliefs about inheritance of illness were used in counselling a family affected by mucopolysaccharidosis VI.³³

The second author's ethnographic observations in Cambodia have shown the underlying logic that links local notions of inheritance with the acquisition of illnesses.²⁸⁻³⁴ In some examples: (1) a forebear, through his or her actions, could create a disease that would be transmitted to the offspring, to emerge in the second or third generation; (2) men acquired "social" illnesses, women during pregnancy tended to acquire the capacity to transmit "paediatric" diseases such as measles or mental retardation to the fetus, and these illnesses could be propagated to further generations; (3) a disease in the forebear could be transformed into a series of unrelated diseases (such as leprosy in one descendant, furunculosis in another, lameness in another); (4) inherited diseases could be divided into those transmitted vertically (for example, from grandparent to parent to child) and horizontally (for example, across marriage or sibship relations); (5) a disease (such as TB) could include subtypes that were or were not inherited. There was no comprehension of genetic testing or genetic counselling. Such beliefs, if generalisable to other Asian cultures, violate the logic of genetics held by western health workers and need to be pinpointed for familial cancer clinic services. The third author has undertaken surveys of the Australian population since 1984, which show an increasing general understanding of the concepts of inheritance. However, the results also confirm the widespread belief that a resemblance (physical or in character) influences the likelihood of inheriting a genetic disorder affecting family members.³⁵

CULTURAL ASPECTS OF CANCER GENETICS

Cultural aspects of cancer genetics is the focus of an emerging body of publications.¹⁸⁻³⁶⁻⁴² Almost all studies assessed African-American women with a family history of breast cancer.¹⁸⁻¹⁹⁻³⁶⁻³⁷⁻³⁹⁻⁴² African-American women had lower levels of knowledge about breast cancer genetics,⁴⁰ and were less likely to have heard or read about genetic testing for inherited disease, even after controlling for educational level.³⁶⁻⁴⁰ African-American women also had lower risk perceptions of developing cancer than women in the majority culture.¹⁸⁻¹⁹ As these studies used matched group designs, the observed differences were unlikely to be because of differences in educational level, age, and income. Given previous evidence that documents an association between perceived risk and mammographic screening,⁴³ lower than expected risk perceptions may contribute to underuse of mammographic screening.¹⁸

In addition, in a randomised trial, Lerman *et al*⁴² found that African-Americans showed increases in intention to be tested and provision of a blood sample as a proxy measure of testing if they were given the opportunity to discuss personal concerns and familial issues about testing. These findings suggest that African-American women may benefit especially from genetic counselling that includes a discussion of familial issues and perhaps reflect

African-Americans' greater family orientation.⁴² Cohesiveness within African-American families also appears to influence attitudes to confidentiality and informed consent issues. Benkendorf *et al*⁴⁴ found that African-American women were more likely than women in the majority culture to agree that health care providers should be able to disclose the results of genetic tests to spouses or immediate family without written consent, and that parents should be able to decide whether to test their minor children for genetic susceptibility to breast or ovarian cancer.

Our systematic search of published reports showed just three previous studies that assessed more diverse samples, such as Americans of Ashkenazi Jewish background,^{36, 45} and Hawaiian- and Japanese-Americans.³⁸ Ashkenazi Jewish women were significantly less likely to believe that they are candidates for genetic testing, compared with women in the majority culture.³⁶ About half the Ashkenazi Jewish women surveyed indicated that the potential to improve the health of the Jewish community strongly influenced their decisions to participate in genetic testing.⁴⁵ Glanz *et al*³⁸ investigated first degree relatives of colon cancer patients included in a Hawaiian tumour registry. Compared to people in the majority culture and Hawaiian-Americans, Japanese-Americans reported the lowest levels of interest in obtaining genetic testing for colon cancer susceptibility, after controlling for socio-demographic variables. However, Japanese-Americans did not differ from other ethnicities in terms of their interest in genetic counselling.

DIRECTIONS FOR FUTURE RESEARCH

Our analysis suggests several directions in which previous studies could be built upon and extended. First, an increased focus on various Asian societies appears warranted, given their particular notions of kinship including some societies with strong patrilineal descent systems, as the likely links between folk notions of inheritance and kinship have more obvious clinical relevance. Any study in this area must, however, take into account the heterogeneous nature of the immigrant Asian communities. Also, to our knowledge, all previous research on cultural aspects of cancer genetics has been undertaken in the United States. Similar research outside North America could explore the extent to which findings can be replicated in other multicultural settings. In addition, control group designs are likely to benefit from systematically assessing culture based beliefs and cultural identity in the "majority culture" group used for comparative purposes. The assumption that the majority culture is a homogeneous group has been criticised and it has been suggested that it is as ethnically diverse as any other culture.^{32, 46} Beyond that, there is a place for research to be carried out in developing countries, in particular the parent countries of recent arrivals, where traditional beliefs and practices concerning kinship, inheritance, and illness are most plain to see.

Finally, all previous studies used quantitative measures originally developed and validated

with people acculturated to a western society. Such measures may fail to capture the full complexity of the relationship between culture and inheritance. The degree to which these measures are valid is unclear, as culture can affect the perception and interpretation of health and illness and may thus affect responses to questionnaire items.⁴⁷ We believe that research on the relationship between culture and cancer genetics would benefit from a more extensive use of qualitative methodologies as few validated measures of culture specific, health related beliefs and schemas are available.

Data on which to base the provision of culturally appropriate familial cancer clinic services to ethnically diverse societies are needed. Empirical data will assist with culturally appropriate categorisation of people from other cultures into risk groups based on their family histories, and provide the basis for the development of culturally appropriate patient education strategies and materials. Moreover, such research will inform evidence based training of genetic services staff in culturally appropriate family history taking and cultural competence.

Bettina Meiser is supported by Public Health Australia Fellowship 007079 from the National Health and Medical Research Council of Australia. The authors would like to thank Associate Professor Michael Friedlander for his valuable contribution.

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