

Optimising clinical practice in cancer genetics with cultural competence: lessons to be learned from ethnographic research with Chinese-Australians

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Abstract

Hereditary cancer is about families, and clinicians and genetic counsellors need to understand the cultural beliefs of patients and families about cancer and inheritance. In the light of their kinship patterns Chinese-Australians were chosen for the present study, which aims to determine the explanatory models of inheritance, cancer, and inherited cancer, with a view to identifying the relationship between these culture-specific lay attributions and help-seeking behaviour, and to identify possible barriers to genetic counselling and testing.

Qualitative ethnographically informed methodology involving semi-structured interview was used as a method to uncover latent beliefs held by the families who are represented by the subjects. In-depth interviews were conducted with 16 informants of Chinese ethnicity, who had been recruited through two major Sydney familial cancer clinics.

We report the attributions of cancer in general, then on inheritance, kinship, genes and genetics and then focus on the way in which these beliefs come together around hereditary cancer. The majority of informants, despite high acculturation and belief in biomedical explanations about hereditary cancer, also acknowledged the influence of traditional family Chinese beliefs, where ‘inheritance’ and ‘genetics’ were related to retribution for ancestral misdeeds and offending ancestors. Extensive mismatch of attributes and beliefs were identified in those who attended the clinic and senior family members, creating barriers to optimal service utilisation. Three traditional patterns of beliefs were identified: (a) father and mother contributed in equal share to one’s genetic makeup, linked to the *ying-yang* theory; (b) the dominance of life force (*yang chi*) and the shaping of genes were transmitted through the paternal line; and (c) natural and supernatural forces operated in the cause of hereditary cancer.

The study provided guidance for clinical practice. Exploration and acknowledgement of family beliefs, regardless of cultural background and therefore avoiding stereotyping, can enable the clinician to work with the whole family—those who hold Western attributions, those who maintain traditional notions of genetics and inheritance, and those who incorporate both into their belief systems—and provide effective clinical services. Further ethnographic studies are needed, focusing on the Chinese groups who do not attend the clinic and those with lower acculturation and educational levels.

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In the famous 18th century novel the Hong Lou Meng (The Dream of the Red Chamber), the old grandmother has her daughter’s beautiful daughter described to her in the following terms: ‘Her whole bearing, madam, is such that she seems to be not a

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granddaughter on your daughter's side, but rather your granddaughter by your son'

Introduction

Hereditary cancer is about families. Up to 5% of all breast and bowel cancers are associated with germline mutations in the BRCA1 and BRCA2 genes and several mismatch repair genes (Dunlop et al., 1997; Whittemore, Gong, & Itnyre, 1997). The cloning of these genes has made possible the use of diagnostic testing for affected individuals and predictive testing of their unaffected blood relatives. Such testing, where appropriate, is usually conducted within the confines of familial cancer clinics. These clinics provide a comprehensive service that includes information, support, risk assessment, genetic testing if appropriate and advice regarding early detection and prophylactic strategies.

Genetics needs to focus on the whole family, not only the individual counsellor (Van't Spijker & Ten Kroode, 1997) and therefore family involvement is essential to the provision of an optimal service. Currently, categorisation into a high-risk group for susceptibility to cancer is dependent upon a family history of cancer that meets internationally accepted criteria. Clinicians and the family members who attend the clinic rely on the identification of relatives who have or had cancer. When family history has been confirmed and judged to be appropriate, genetic testing can be offered to unaffected at risk family members if a blood relative with cancer is willing to participate in the testing. Identification of a mutation in that relative means that predictive testing will then be available for other family members. Access to testing is thus very much a family affair and relies upon good communication.

The client profile of familial cancer services is most often from the dominant culture in Australia (Anglo-Saxon/Anglo-Celtic), from high socioeconomic groups, with high education levels and—if they are of a culturally diverse background—acculturated. Even if the latter do attend, their senior family members will likely be less acculturated and hold beliefs that may be incompatible with information provided at the family cancer clinic. In fact, our clinical experience suggests that, per capita, few people of culturally diverse backgrounds attend familial cancer clinics in Sydney, Australia, where 30% of the patient profile at health services are of culturally and linguistically diverse background (South East Area Health Service, 1997). Given the reliance upon family communication, awareness of the cultural diversity, beliefs and attributes of the whole family are essential to the provision of an optimal service.

The cultural construction of beliefs about genetics and inheritance is important because these beliefs shape the

clinical presentation of problems and normative health behaviours. It has been suggested that the difference in explaining the causes of health and ill health is a key cultural barrier in the application of Western medical explanations to Southeast Asian communities (Eisenbruch, 1991). It is very likely that patients explain genetic disorders such as inherited cancer susceptibility in terms which may reflect strong religious conviction, societal beliefs, and lay concepts of disease and biomedicine (Cohen, Fine, & Pergament, 1998; Handelman, Menahem, & Eisenbruch, 1989). Mismatches between the biomedical facts about genetics and the cultural assumptions held by individuals that may cause management problems is not uncommon even in the dominant culture (Richards, 1997) but where families are from culturally and linguistically diverse backgrounds; in particular, if their belief systems are, with the best of intentions, discounted and discredited (Weil, 2001), such problems may be magnified.

The present study, aimed to explore the diversity of beliefs and attributes within families, to assess how culture shapes a family's beliefs about cancer and inheritance, concepts of kinship and how these combined beliefs shape their cultural construction of hereditary cancer. This has been well documented in the dominant culture in the United Kingdom, Finland, the United States and the Netherlands (Chapple, May, & Campion, 1995; Richards, 1997; Visser & Bleiker, 1997; Weil, 2001) where lay knowledge about inheritance is closely related to ideas about kinship and the social relatedness of family members (Richards, 1997). e.g. 'real' fathers, unlike step-fathers, are distinguished as a biological parent (Richards, 1997). Using Chinese-Australians as the case, this study aimed to extend these observations to a group who must reconcile Western views with all their diversity with traditional beliefs and explanations. Chinese-Australians are the best group to study, for several reasons: (i) they are the largest non-English-speaking background group in New South Wales (Public Health Division, 1997); (ii) data have become available to show that mutation rates in BRCA1 and mismatch repair genes in Hong Kong Chinese are present in approximately the same proportion as in any number of populations previously studied (Chan et al., 1999; Tang et al., 1999); (iii) anecdotal evidence shows that those of Chinese background are increasingly attending familial cancer clinics; and (iv) clinical observation suggests that Australian-Chinese people hold beliefs concerning kinship and its role in the transmission of disease that impact on clinical presentation. Our research is built on insights by our group into understanding the cultural attitudes to cancer among Greek and Chinese informants (Goldstein, Thewes, & Butow, 2002; Huang, Butow, Meiser, & Goldstein, 1999). To our knowledge, no previous research is

available that has examined the relationship between Chinese culture, cancer, genetics and kinship.

The classical writing on kinship in China suggests that there used to be fundamental differences from Western concepts. To give some examples, Chinese kinship could be 'fictive' as well as based upon biologically related family membership (Potter, 1978; Topley, 1978). There are also complex grades of relationship in the family. The male and female kin are different, with a large spread of kinship terms for the father's side, and distinct kin terms for one's father's elder brother and his younger brother, and their wives were similarly distinguished (Baker, 1979, p. 23). Even the traditional definition of family was a composite of three institutions: the *ke* (the people who share one stove), the descent line, and what Margery Wolf called 'the uterine family' (Wolf & Huang, 1980, p. 59). The term 'generation' suggested 'inheritance (*ch'uan*, transmission), 'history' and 'rivalries' (*tieh*, family pedigree) and 'descendants' (*tso*, posterity or offspring) (Chao, 1983, p. 29). It seemed possible that such deep structures might influence those of Chinese origin who resettled in Australia.

Another point of departure highlighted in this study concerned the cultural construction of inheritance held by the Chinese-Australians as compared to the professionals working in the field of genetic counselling. The professionals in this area in Australia, medical geneticists and genetic counsellors, are largely from the dominant culture (Lobb, Butow, Meiser, Tucker, & Barratt, 2001). Similarly, the membership of the US National Society of Genetic Counsellors in 1998 was approximately 93% white American and 96% female (Schneider & Kalkbrenner, 1998; Weil, 2001). These professionals have been trained in a 'Western' milieu (Harper, 1998), embracing Mendelian principles of inheritance, and the concept that an individual's genetic makeup is equally derived from both parents in the background of a random segregation of genes.

However, incompatibility between the counsellors' and the counselees's beliefs is not uncommon in the dominant culture where the occurrence of a disorder is often held linked to other phenotypic characteristics (I look like my mother [who had breast cancer] so I must 'take after her' and so I will probably get breast cancer too) (Richards, 1996). Lifestyle causes of illness, as opposed to a genetic basis, is often cited (Chapple et al., 1995). The lack of compatibility between counsellors' and counselees' beliefs is also often cited in regard to understanding of inheritance of breast cancer susceptibility through the male line. There is widespread, cross-cultural misunderstanding of this concept but it may simply be the difficulty in associating men with diseases which are almost entirely female rather than a basic misunderstanding about inheritance (Richards, 1997).

So while it is generally accepted in the dominant culture that each 'side' of the family contributes to the genetic makeup of a child, one 'side'—maternal or paternal—can appear to have more influence (Davison, 1997). Nevertheless, even with the incompatibility with the concept of random segregation, British kin reckoning still tends to be bilateral (Davison, 1997), in contrast to kinship beliefs and inheritance held by others from different cultures. Among patrilineal cultural groups, including the Chinese, it was believed that the father places his seed in the womb which is merely the receptacle, and that as such the 'genetic' material is derived from the father alone (Inhorn, 1994; Parkin, 1997). Similar ideas are found among Cambodians (Eisenbruch, 2000). In other patrilineal societies, however, e.g. in Malaysia, it was believed that the mixture of the seed of their father with the mother's menstrual blood becomes the child; that people can become kin by living and eating food together, and siblings by sharing breast milk, so that milk and blood together make up kinship (Carsten, 1995). Inheritance is a complex of biology and social meaning. Heredity in Western society was rooted in the Galenic theory that semen nourished the blood and the womb and it was not until the eighteenth century that it was realised that a child could resemble its mother, not only its father (Finkler, 2000).

It is widely acknowledged that those providing clinical services and genetic services should achieve competence in dealing with individuals from diverse cultural backgrounds and should recognise the impact of ethnicity and culture on the genetic counselling interaction (Dixon, Dang, Cleveland, & Petesron, 1992; Punaless-Morejan & Rapp, 1993; Wang & Marsh, 1992; Wang, 1998a, b; Weil & Mittmann, 1993). Developed countries have undergone dramatic shifts in their cultural and ethnic makeup since World War II. Multicultural Australia is a suitable setting in which to study the cultural influences on the understanding of inheritance, and subject to environmental and evolutionary influences and social factors such as continued migration and marriage patterns (Brady, 1996). Clinical genetics services need to keep pace with the moving target of this changing picture, with successive waves of immigration. For example, there are several aspects of a number of Asian cultures that may be culturally incompatible with the way in which genetic services are currently being delivered. The belief in compliance with authority and elders and the doctor's treatment decisions in regard to elders is in contrast with Western individualism and the associated current emphasis on patient autonomy and shared decision-making (Huang et al., 1999). In this study, respect and concern for elders has priority over a parent's autonomy in regard to extensive information about cancer and specifically about the implications of hereditary cancer.

To be evidence-based, recommendations for achieving cultural competence in dealing with families from diverse cultural backgrounds should be based on systematic research on the perception, social construction and cultural meaning of genetic testing and counselling. We recently undertook a systematic literature search on empirical research on the inter-relationship between culture, cancer and genetics, and found a limited number published. On the basis of our review of the cultural context of hereditary cancer (Meiser et al., 2001), a research paradigm was proposed, to furnish the evidence base for the provision of culturally competent familial cancer clinic services.

Methods

The working assumption was that Chinese-Australian perceptions of genetics and cancer are influenced by *emic* perceptions of causes of cancer, kinship and family. We take *emic* to mean the understanding of cancer and genetics from within the specific culture's frame of reference, rather than being adapted from a universal, or *etic*, understanding (Fetterman, 1998; Ramirez, Bogdanovic, & Jasovic-Gasic, 1991). These perceptions are likely to affect family communication regarding hereditary cancer. Rather than developing a matched-comparison design, we chose to focus on one ethnic group to obtain in-depth data with greater cultural validity and to unpack the underlying cultural construction of genetics. Clinically informed ethnography was selected as most appropriate for this study as its focus is on the description and explanation of attitudes, values and beliefs as they are shared by a cultural group or subgroup as a consistent whole (Peters, McAllister, & Rubenstein, 2001). It has depth (reflecting the prolonged time spent interviewing) and power to tap explanatory models. It is appropriate as an effective means to gain understandings otherwise elusive to quantitative or pencil-and-paper methods (Yelland & Gifford, 1995).

Sample

The medical records of two major Sydney familial cancer clinics were reviewed to identify all those of Chinese ethnicity who had attended since 1995 for advice about their or their children's risk of having inherited susceptibility to cancer. Thirty-one individuals of Chinese ethnicity were identified as eligible. The staff specialist (clinical geneticist or oncologist) involved in the patient's care contacted patients by letter and invited them to participate. Letters were in English and Chinese. Individuals were asked to contact the familial cancer clinic regarding their wish to participate.

Fifteen were not included: five could not be contacted; four said they were too busy; one did not identify with

the Chinese community; one was deceased; and four reported being afraid of the consequences of participation. We also compared sociodemographic and family history variables of those individuals who participated in interviews and those who did not. There were no statistically significant differences in age, sex and type of family history. However, non-participants were significantly more likely to have been affected with cancer (67%), compared to participants (33%), with chi square = 5.74 and $p = 0.017$.

The 16 informants who were included in the study were approached by the research assistant, a Chinese psychologist with training in family therapy and qualitative methodology (SSY), between 6 months and 5 years following attendance at the familial cancer clinic. A face-to-face meeting was arranged at which time informed consent was obtained. Meetings were conducted at the informant's preferred location by SSY (and sometimes with ME or KBS), in a mixture of Mandarin, Cantonese or English, as appropriate. In the course of these meetings, the narrative for the study was informed by these principles

- To permit free shifting of focus between their beliefs and those held by senior members of the family.
- To uncover attributions about non-threatening illnesses in general and move to a focus on more serious and evocative illnesses such as cancer.
- To explore and record the local or indigenous terminologies for kinship, inheritance, or cancer, and interpret their meaning.
- To assemble the local cultural logic and classification (i.e. cancer = inner/outer; hard/soft).
- To explore the local rules of kinship and descent (e.g. patrilineal descent, bilateral descent, combinations of biologically and non-biologically related individuals).
- To explore the attributions and explanatory models for illnesses including cancer, (e.g. aetiology = natural/supernatural = mystical–animistic–magical).
- To record the concepts (e.g. non-verbal techniques such as the use of outline diagrams of humans drawn by the informants, onto which they 'draw' the illness, its cause and effects).

The meetings were tape-recorded when consent was given. Each lasted between 1 h and 2.5 h, and some informants were visited on several occasions. An aide-mémoire was used to structure the narrative, outlining the major topics to be covered. The local cultural meaning—and the logic—of cancer, genetics, and hereditary cancer was explored using an adaptation from an *emic* Explanatory Model Schedule, first developed in a Cambodian version, than in a 46-item international version which has been used with people of various ethnic backgrounds in Australia (Eisenbruch, 1990).

Analysis

Detailed synopses were prepared for each participant, summarising each participant's account as a narrative in English with Chinese terms preserved as far as possible. To facilitate analysis of data, tapes were listened to repeatedly and difficult passages were checked. Data analyses were iterative and SSY, ME, BM, and KBS participated in this process.

Results

Demography

Sociodemographic, family history and acculturation characteristics of the sample are shown in Table 1. Fourteen were female, two male. Informants were aged 28–69 years at first contact. Eleven were married and had children. Fourteen had post-school qualifications. Informants had been born in Australia (3), Burma (1), Canton (2), East Timor (1), Hong Kong (2), Malaysia (3), Shanghai (1), Taiwan (2), and Vietnam (1). Amongst overseas-born informants, time since migrating to Australia ranged between 11 and 26 years. About 56% of the sample described themselves as Christian, 13% Buddhist and 31% did not identify themselves as of a religious group (notably those from Communist China). This seems to be representative of the Chinese-Australian population (Australian Bureau of Statistics, 1996).

Family history was consistent with hereditary breast cancer for 11 informants, with hereditary non-polyposis colorectal cancer for three, and with Von Hippel Lindau disease for two. Familial cancer clinic staff categorised individuals into those whose family history was either consistent or not consistent with a dominantly inherited susceptibility to cancer to provide an objective measure of risk. Eleven participants were classified as having a family history consistent with a 'dominantly inherited susceptibility', and five as having one suggestive only of a 'moderately increased risk' respectively. All had received genetic counselling according to National guidelines (National Health and Medical Research Council, 1999).

We report the attributions of cancer in general; then on genes and inheritance, genetic testing, genetics and kinship; and then focus on the way in which these beliefs come together around hereditary cancer.

Cancer

Naturalistic explanations

All the informants attributed causes of cancer in their family in Western biomedical language and content such as faulty genes and mutations (not necessarily inherited),

reflecting information they had received at genetic counselling. Yet they also attributed causes to (i): psychological factors (personality, being unhappy, inability to express emotions or holding them in); (ii) stress (e.g. migration, unpleasant experiences, many deaths in the family); (iii) foods, diet (low fibre, high salt, pork, high fat, too much meat, salted fish); (iv) drugs, alcohol, smoking; (v) chemicals or radiation (e.g. dry-cleaning chemicals, pesticides, petrol fumes, greenhouse gases, genetically modified foods); (vi) hormonal factors (pregnancy); (vii) breast feeding (milk getting stuck) or not breast feeding; and (viii) physical strains (wearing tight-fitting brassieres, lifting). Group vii (breast feeding) was the least attributed by the informants.

Whether or not the informants used Western 'content', many also used underlying Chinese idioms; these idioms however were most notable when speaking of the senior family members' attributions. While most attributed ill health to the result of an imbalance of the positive and negative life force (*ying-yang*) in the body, others attributed it to beliefs which can be classified according to the three supernatural groups of traditional attribution of illness, including cancer, developed by Murdock (Murdock, Wilson, & Frederick, 1978): mystical (mediated by impersonal cause); magical (caused by angry, envious agent); and animistic (mediated by personalised supernatural agent). Mystical explanations of illness, including cancer, referred to the following concepts: (i) Heaven's or God's will, (ii) karma, (iii) bad luck or fate, (iv) offending the Gods or deities requiring prayers or offerings for appeasement, and (v) *feng-shui*. Magical explanations included *kong-tau* (spells invoked through human intervention). Animistic (mediated by personalised supernatural agent) explanations referred to evil spirits and loved ones seeking reunion with the living in the other world.

A belief that cancer is contagious coloured the behaviour of some of the informants, as well as those who did not participate in the study. Four declined participation specifically because they felt that talking about cancer may either aggravate it in those already affected or cause cancer to start growing even if they were unaffected. Even simply attending the familial cancer clinic and touching objects such as the newspaper in the clinic, could cause cancer to break out. The clinic was too near the oncology clinics for their liking.

Inheritance and heredity (genetics)

Concepts of genes and inheritance

Most informants expressed western biomedical explanations for inheritance of health problems and used terms such as 'genes' and 'chromosomes', seemingly with the same meaning as in Western genetics. It was

Table 1
Sociodemographic and family history summary data for informants

Type of family history	Degree severity family history ^a	Number of relatives with cancer	Affected vs. unaffected	Age	Country of birth (self)	Year of migration to Australia	Educational level (post-school vs. no post-school)	Language(s) of interview	Language proficiency	Acculturation score	Religion
Breast cancer	High risk	2	Affected/breast	47	Taiwan	1985	Post school	Mandarin	Mandarin	9(L)	No religion
Breast cancer	Moderate risk	3	NOT/A ^b	60	East Timor	1976	No post school	Mandarin	Mandarin, Hakka	10(L)	Buddhist
Breast cancer	High risk	2	NOT/A	49	Canton	1982	Post school	English	English, Cantonese	20(M)	No religion
HNPCC ^c	High risk	4	NOT/A	33	Hong Kong	1990	Post school	Cantonese	Cantonese	10 (L)	Baptist
Breast cancer	Moderate risk	4	NOT/A	36	Canton	1990	Post school	English, Mandarin	Mandarin, English	30	No religion
Breast cancer	High risk	6	Affected/breast	46	Malaysia	1970	Post school	English	English	29	Protestant
Breast cancer	Moderate risk	2	Affected/breast	54	Malaysia	1975	Post school	English	English	28	Catholic
Breast / ovarian cancer	High risk	5	NOT/A	49	Malaysia	1979	Post school	English	English	28	Catholic
VHL ^d	High risk	2	NOT/A	30	Australia	Nil	Post school	English	English	30	Christian
Breast cancer	High risk	4	NOT/A	48	Hong Kong	1977	No post	Cantonese	Cantonese, English	13	Baptist
HNPCC ^c	Moderate risk	1	Affected/bowel	26	Vietnam	1980	Post school	English	English	30	Buddhist
HNPCC ^c	High risk	3	NOT/A	27	Taiwan	1989	Post school	Mandarin	Mandarin, English	12	No religion
VHL ^d	No cat	2	NOT/A	28	Australia	Nil	Post school	English	English	29	? Christian
Breast cancer	High risk	3	NOT/A	46	Burma	1977	Post school	English	Burmese, English	15	Catholic
Breast/ ovarian cancer	Moderate risk	4	Affected	69	Australia	N/A	Post school	English	English	32	Christian
Breast/ ovarian cancer	High risk	4	Affected/ovary/uterus	47	Shanghai	1979	Post school	English	Mandarin, English	21	Christian

^aTo provide an estimate of objective risk, clinic staff were asked to make a judgment on whether a participant's family history was either consistent or not with a dominantly inherited predisposition to cancer, and participants were thus classified as being at 'high risk' or 'moderate risk', respectively (National Health and Medical Research Council. Familial aspects of cancer: A guide to clinical practice. Canberra: National Health and Medical Research Council, November 1999).

^bNOT/A = Not affected.

^cHNPCC = Hereditary non-polyposis colorectal cancer.

^dVHL = Von Hippel Lindau Disease.

generally stated that ‘genes’ and other ‘biological matter’ passed equally from each parent to the child at conception; and that mutated or faulty genes could pass to descendants. In explaining the flow of ‘genes’ from mother and father, some viewed this as an expression of ying-yang balance theory. The traditional Chinese usage of the term ‘genes’ had indigenous constructs crafted onto it, e.g. the essence of life force (*yang chi*) is transmitted from the father.

However, when asked about the indigenous terminology used by senior family members to describe inheritance, the terms used were *wai chuen* in Cantonese, and *y chuan* in Mandarin (transmission from the generation above passed down to the generation below).

No matter what the sex of the embryo, it derived its energy from the father’s *yang* as the male has more *yang* than *ying*. A good man was more likely to have male descendants whereas if he had been wicked in his current life, or in his previous incarnation, he would end up with no male offspring, his line effectively broken, with no succour in old age. Traditional thinking meant that if a woman gave birth to a boy, she would consider that her husband gave her a son. However, if she gave birth to a daughter she would believe that she was responsible in fashioning the child to become a girl and indeed, the family would blame the mother for not giving birth to a boy. It is her duty to give birth to sons.

One informant who discussed inheritance using ‘genes’, ‘mutations’ and ‘faulty genes’ pointed out that the use of the latter terms that had been used in the genetic counselling session had the potential to put shame on to a family. She said that telling her that she had a faulty gene which predisposed her to cancer meant that, in Chinese society, she must not have behaved well (if you are not good, you get cancer). She suggested that it would be much better if, at the start of a session, it was pointed out to family members that everyone had faulty genes for something.

Genetic testing

Another indigenous idiom suggested by one informant to describe genetic matter or stock is *zhung*. The term is also applicable to plants and animals. [The Anglo-Celtic will say, e.g. ‘chip off the old block’ and the Chinese will say that it must be from the same *zhung* (SSY)]. This informant suggested that testing for a gene could be equated to testing for the *zhung*. If the faulty gene is not identified, and the person is therefore no longer at risk for inheriting a particular illness, this would be equivalent to saying that the *zhung* is not there. She said that the explanation that the *zhung* is not there will alleviate anxiety in the traditional Chinese as this is acceptable and understood by them.

Where the family believes that the illness has been caused by bad luck, the informant said testing for *zhung* may also be used to explain a negative result on genetic

testing. The finding that there is no identified gene flaw in the family (i.e. the *zhung* is not there), will reduce anxiety for some traditional Chinese in regard to the illness, but not overall. It does not mean for them that the bad luck has stopped here but simply that the bad luck that results in that illness has not been inherited. For others, the informant suggested that if the test shows that a family member has not inherited the faulty gene or the bad luck, they may believe that the bad luck (or the risk of the illness) stopped there. In her own case, the informant said that the fact that her mother’s cancer is in remission and her youngest sister who has breast cancer has been living for more than 10 years after diagnosis is very reassuring for her mother who now feels that the bad luck may be dissipating.

Kinship issues and impact on eliciting family history

All informants depicted kinship in the idiom of genetic material that was equally contributed by both biological parents. When asked about the relatives that should be included in a family history, all responded that relatives on both the mother’s and father’s side should be included. One informant specifically said that her brother’s wife’s family would not be considered as a close relative since she is outside the family. However, the narrative analysis revealed that underlying this view is the local definition of ‘close relatives’ due to a patrilineal view of kinship. Male related cousins were considered to be more strongly linked genetically than female siblings: paternal cousins are called sisters and brothers as they share the same surname. In addition, an uncle on the paternal side is considered closer than an aunt who has married because of the change in surname. While marriage to a cousin on the father’s side was not allowable in cultural terms (*it would be considered as incest*), the same did not apply to cousins on the mother’s side.

All informants stated that traditionally the Chinese consider the males as more significant and to have high ranking in the family hierarchy as the females do not have a position in society. Thus, within a Chinese family, the eldest son will rank first, then the second son and so forth. All the males from the eldest son’s children and children’s children will still rank higher than any female in the family.

Differentiation between blood relatives and other relatives was clearly delineated by all informants. Two informants said that it meant that we are from the same ancestors, indicating that we are related through the blood lines. Two other informants from the one family said that their mother had an adopted brother and an older sister. The uncle was not considered a blood relative and would not be at risk for having the faulty gene in the family. Indigenous terminology also clearly delineated blood relatives as ‘family, from other relatives’ (*huet tong*).

However, in one family, traditional thinking senior family members believed that misfortune including cancer could be introduced into a family by someone in the kinship network who was not necessarily related by blood. It was believed that ‘bad luck’ (*shui wan*) was introduced into the family following marriage to the ‘wrong’—as perceived by the husband–wife. She was blamed as the cause of many instances of misfortune affecting her husband’s siblings. Equally, her rare cancer syndrome was blamed on ‘bad luck’ rather than simply involving faulty genes.

Non-penetrance of mutations—concept of ‘skipping generations’

Several informants accurately described the concept of non-penetrance by stating that a faulty gene inherited from an affected grandparent could be passed to a child from an unaffected parent. When asked how this concept would be described by senior family members, one referred to the phrase *gat doi wai chuen*. In the Chinese lay language this usually refers to a third generation having some traits or even illnesses inherited from the first generation. However, it embraces both biological genetic material transmission and other factors such as retribution, bad luck, feng-sui, etc. So in Chinese traditional thought, while an illness can be inherited and even skip generations, the cause of the illness (bad luck, etc.) is simultaneously inherited.

Concept of spontaneous mutations followed by inheritance through the generations

It was recognised by all informants that an inherited illness in the family started with a family member in the first instance developing a faulty gene—a spontaneous mutation. The illness was then passed to subsequent generations as the faulty gene was inherited. The cause of the original mutation was variously described as God’s will, ancestral retribution or bad luck depending on whether they were Christian, Buddhist or non-religious. Most also felt that these factors governed which family member inherited the faulty gene rather than the biomedical explanation of random segregation (‘It is just unlucky to be born in the family’, ‘it was God’s will that she got cancer and her sister didn’t’)

Hereditary cancer

All the informants were familiar with biomedical explanations about hereditary cancer, e.g. having a family history of cancer would increase their risk, reflecting the information they had received at genetic counselling. For example, one informant stated: ‘genes have a big part in us having cancer. My family has a higher chance of getting cancer compared to other families as many of our family members had cancer’.

Yet not all applied their thinking about genes and inheritance of faulty genes to genes and cancer. A few, despite coming from cancer-dense families or having been advised at the clinic that their cancer risk was increased due to presence of a familial cancer syndrome, did not believe that cancer could be inherited. One woman who came from a family at moderately increased risk only said that breast cancer could not be inherited in her family because not all of her sisters had developed breast cancer. She said:

If it was genetic then everyone would get it since they had the same parents. Some toxins got into the body and the body reacted resulting in cancer cells. If the cancer is lodged in the stomach, then there will be stomach cancer.

Another believed that personality (i.e. unhappiness, pessimism), rather than genes, are responsible for the development of cancer. Another informant who did not have a family history of cancer but had been referred for genetic counselling because of a diagnosis of colon cancer at a very early age, did not believe that cancer can be inherited. This informant said that no one in his family believed that cancer could be inherited. Instead, this informant expressed the view that having cancer was God’s will.

Where the informants had accepted that the cancer in their family was due to the inheritance of a faulty gene, several said that this explanation was not accepted by their senior relatives or other members who held Chinese traditional thoughts. They believed that the previous generations’ misdeeds could result in *bao ying* (literally, ‘pay-back’) and adversely affect the future generations. For example, one informant reported her mother as believing:

Something the ancestors did that would cause her to suffer, e.g. did something bad, led a very bad life, did evil things to people, might have murdered people... they ‘re not punished for what they did but their children and future children will suffer... will see their children suffer, will see their children or grand-children die...

Another explanation was given by one Hong Kong Chinese informant who said that if a Chinese family has the misfortune of giving birth to a stillborn, they would consider their own conduct or the past misdeeds of the previous generations as an explanation. The view was expressed that it is not unusual for Chinese families who have children with birth defects such as blindness, mutism, etc. to attribute these birth defects to the ancestors’ past misdeeds or to reason that the present generation have been unfilial to them and have offended the ancestors. In this same vein, another informant said that his mother and his aunt both stated that his

mother's cancer was due to something that she or her ancestors had done: 'what have I done wrong?' Other informants said that older relatives believed that ill health can be due to fate (*mian wan* in Cantonese, *ming yun* in Mandarin) or the deities (*shen*), Buddha or Jesus, depending on one's religious beliefs. Another informant with a strong family history of breast cancer reported on her sister's beliefs. When her sister had advanced breast cancer, she believed her deceased mother-in-law, who when she was still alive disliked her, wanted to harm her and was responsible for her unremitting illness.

Screening and surveillance

While the majority of informants were accessing, or proposed to access, recommended screening and surveillance, several mentioned that they or their relatives simultaneously believed that paying respects to the ancestors and making offerings would ensure the protection from ill health and good fortune of descendants. In particular, attending to the ancestral graves, including non-disturbance of the ancestral graves or burial site and an auspicious burial time are important for the good health, fortune and prosperity of the future generations. For example, one informant believed that the ancestral graves must be maintained and cared for by the younger generations. If there were a show of disrespect or negligence of making offerings, this would offend the ancestors (*fan ju xin* or *tak choy ju xin*), resulting in bad luck and sicknesses such as cancer for future generations. She said that her grandfather's bones were dug out and relocated elsewhere so as to make it convenient for the family to offer prayers to him. This relocation and disturbance of her grandfather's bones had offended him and resulted in a death in the family every 2 years. This was also given as an explanation for the number of cases of cancer that had occurred in the family.

One informant said that she and her family believe that if one is fated to have cancer because of a faulty gene, there is nothing that one can do to change the fate. 'I feel that if it happens, it happens'. However, she said that the older generation may go to the temples to create fortune (*chok fook*), or changing the luck (*chui wan*) by praying and making offerings to the Goddess of Mercy (Kuan Yin).

Discussion

The findings reported in this paper demonstrate the power of cultural beliefs concerning inheritance and cancer. The discussion covers cultural notions of inheritance, kinship and descent, the cultural determinants of 'risk' of cancer, and traditional beliefs in the face of modernisation.

Notions of inheritance

Studies have shown lack of recall about genetics and medical information (Michie, McDonald, & Marteau, 1997) and differences have also been reported in what information counsellors believe should be provided at a counselling session and what counsellees want (Michie, Axworthy, Weinmann, & Marteau, 1996). Other studies have shown that misconceptions, discordant beliefs and fears may not always be recognised or resolved during the process of genetic counselling (Chapple et al., 1995).

However, the informants in this study, highly acculturated and educated, all reflected the information they had heard at the familial cancer clinic in regard to genes and inheritance. All reported that a child received an equal share of the parent's genetic material and that faults or mutations in genes could contribute to problems expressed as illness or physical disability. Yet, the underlying *logic*, of this 'inheritance', however, had to do with balance achieved through the passage of the *yin* and *yang* from each parent.

Risk and danger

The attributions and understanding about genetics, in general, however, did not necessarily apply to cancer and hereditary cancer; it depended upon whether the informants held the notion that cancer was due to having inherited a faulty gene. Deeper probing revealed that some, despite articulation a Western 'genetic vocabulary', believed that it could not be genetic if not all members of a generation developed cancer and that cancer has a myriad of causes, not necessarily genetic. Here is a clinical implication, for there is a mismatch between the biomedical and Chinese notion of 'risk'. These findings tell the clinician about the cultural differences between the Western view of 'risk' which lies at the heart of genetic testing and counselling—see Lock (1998) on the philosophy of risk in breast cancer. In the present study, the Chinese women, in attributing the genetic risk to action of ancestral spirits, seem to regard the clinical label of 'genetic risk' in terms of 'danger'. The findings of 'all or nothing' or binary principle of inheritance, is not uniquely Chinese as has also been observed among Anglo-Celtic people (Lippman-Hand & Fraser, 1979; Parsons & Atkinson, 1992).

The origin of family lines and mutations

Several informants did not believe that cancer was hereditary in their families, in the absence of an extensive family history. Some also appeared not to appreciate the notion of a spontaneous mutation as leading to the emergence of a *de novo* familial cancer syndrome. The clinician needs to know what is the underlying belief about origins of family lines and of 'corruptions' in them—such beliefs are culturally determined both for ethnic minorities and for the dominant

culture. In the traditional Chinese view, a family line started in the distant past, so long ago that it really had no beginning—and this is consistent with the Buddhist non-linear cycles of time. Baker (1979) depicts the Continuum of Descent as a rope which began in the remote past and which stretches to the infinite future. A westerner, used to linear thinking about birth and death, could more easily make sense of a spontaneous mutation showing up as an illness in a particular family member, and perhaps continuing down the family line from that point onward. Many westerners would be hard-pressed however to explain why the mutation had arisen. What is different about the Chinese informants is that they may not understand what the mutation is but they certainly are alive as to why—it arose, some said, because of what had happened in some prior generation. Informants who described themselves as Christian labelled the mutation as ‘God’s will’ but it is unclear what this connoted. The clinician, in discussing mutations with patients of any cultural stripe, should encourage them to explore and give voice to their conjectures as to how the mutations have arisen.

Mismatch between explanatory models of clinician, family member and senior family members

The results of this study highlight the potential for serious mismatch between the beliefs of many of those who present to familial cancer clinics for advice about their risk and their family’s beliefs. This mismatch is a likely barrier to the necessary family involvement in the full assessment of risk. Typically, the patient is the conduit of information received at the clinic for the family. Where they are of a culturally diverse background, the difficulties in communicating this information may be compounded by cultural beliefs concerning cancer. If it is adduced that senior family members believe that the cancer is due to bad luck, the clinician can suggest that modern tests can detect the first signs of the bad luck (i.e. assuming the family would want to know about bad luck; in some cultural settings, learning about bad luck is tantamount to causing it). Learning about the family beliefs and culture and embracing the concepts rather than discarding them, will optimise the counselling and assist with family communication—this is towards cultural competence in cancer genetics and genetic counselling. Indeed, this imperative has challenged the way the clinicians and educators involved in this study have worked.

Fear of broaching risk of cancer—education and information is not the answer

Screening recommendations, or counselling, is not simply a matter of ‘educating’ and ‘informing’ people. There is good evidence, e.g. among Muslim (Underwood, Shaikha, & Bakr, 1999) or Chinese-American women (Yu, Kim, Chen, & Brintnall, 2001) that, despite

being fully informed about the benefits, they choose not to participate in available screening programs. This may be the result of well-established barriers to cancer screening, such as potential pain and cost (Rutledge, Hartmann, Kinman, & Winfield, 1988; Slenker & Grant, 1989), perceptions of radiation risk (Baines, 1984) or a lack of physician recommendation (Rutledge et al., 1988; Slenker & Grant, 1989). In addition, if screening programs are not structured in a manner consistent with the cultural beliefs and customs, this may also lead to under-utilisation of screening. Several people who declined participation in this study and several who were interviewed as part of this project drew attention to their reluctance to talk about cancer and where it comes from. Amongst both affected and unaffected individuals, despite the levels of acculturation and education, this reluctance may reflect magical thinking, and in particular a fear of contagion. Similar beliefs have been described for Italo-Australian women and South Asian women (Gifford, 1994; Johnson et al., 1999). Fear of cancer and the reluctance to discuss it are not exclusive to those of Chinese background. However, decliners and informants approached as part of the current study, from the very first contact to the last, repeatedly signalled their reluctance to talk about cancer and elaborated upon it. Perhaps the related clinical issue is whether patients should necessarily be told their diagnosis if the cancer is incurable or not responding to treatment and whether the family should advise the doctor on what and how to tell the patient (Benowitz, 1999; Huang et al., 1999). Many doctors would fervently believe that this is never an issue and that, no matter what the culturally diverse families believe, they must adhere to a professional duty of disclosure.

The findings suggest that communication about cancer needs to be mindful that talking about inherited cancer may trigger widespread fear, especially amongst those already affected by cancer. If a multigenerational family presents for counselling, it may be beneficial to explore in advance of clinic attendance what information and in what manner it should be conveyed to individual family members, especially those already affected. The individual who made the appointment may be most suited to adopt this role of a gatekeeper of information. Where needs of individual family members differ, individual genetic counselling sessions may be most appropriate, or alternatively a session with the whole family may be preceded by an individual session with the individual acting as gatekeeper.

Another finding of this study is the care which counsellors and clinicians need to take with clarification of the term ‘faulty gene’, particularly in relation to cancer. The association of having a faulty gene with damage to family honour and shame needs to be addressed very early in the genetic counselling session by emphasising that we all carry some faulty genes. The

message, too, is that counsellors from the dominant culture are not stigmatising the 'ethnic' clients as bearing bad genes.

Kinship and descent

Genetic counselling in a multicultural society cannot take place outside the exploration of the cultural significance of children, lineage and kinship system and consideration of ancestral lines (Handelman et al., 1989). The Chinese patrilineal descent system was recognised by all informants as a possible barrier to the elucidation of an accurate family history. Westerners simply use single terms for uncles and aunts. In his studies of Chinese kinship, Baker (1979) notes a huge imbalance in the number of people actively recognised as kin on the maternal and paternal sides of the family.

The Western physician or counsellor might start with the assumption that the patient understands genes as coming from the germline of each of the two parents. The results of the present study reinforce and enhance another view identified in the studies conducted in the dominant culture (Davison, 1997; Richards, 1997). In discussing the family pedigree, it is important to realise that kinship is not based on biological relations alone; that third parties may be introduced to cement relations with ancestors; and that some of these ancestors may be quite outside the compass of the person's biological gene material. This is suggested by the views in one family that 'bad luck' and misfortune exemplified by cancer, have been introduced into the family through marriage rather than exclusively down the 'blood line'.

Three informants cautioned that clinicians should specifically ask about relatives affected by illnesses such as cancer on the father's side as well as the mother's, rather than simply asking about close relatives, or talking about blood relatives, to ensure that the family history ascertained is accurate. Another informant suggested that clinicians should ask about illnesses affecting relatives who have the same ancestor. Both of these alternatives should be used rather than the term 'close relatives', brothers and sisters or blood relatives.

Ancestral spirits as a key factor in determining 'risk' of cancer

This link between the indigenous views of the provenance of illnesses and the intervention of ancestors has been supported in this study. They are central to clinical cultural competence given the reliance put on ascertainment of an accurate family history in categorising families as 'high risk' for cancer susceptibility.

The Chinese kinship system is linked with the ancestral spirits as shown in the ancestral rituals, particularly around geomancy following death. It is the ancestral spirits who, unlike those not related to the

person, may be affected by the conduct of the descendant (Chao, 1983). Descendants must continue their duty to the ancestors so as not to deprive them of food and became 'hungry ghosts'. Our study showed that the informants maintained their belief in elements of the Chinese kinship system: a person exists on a line that links their ancestors and their descendants, suggesting that any bad behaviour of one party could have a significant impact on the others. The findings of the present study show that perhaps there is another way in which Chinese informants view themselves, an idea in which the individual is their pedigree. Clinicians need to know about the role of ancestral spirits, and to feel comfortable in including these beliefs in their narrative discussion with the patients. It would not be appropriate that clinicians, however, prescriptively foist such explanatory systems onto any Chinese patient in the clinic.

Traditional beliefs in the face of westernisation

One has to ask whether the traditional Chinese beliefs about kinship and inheritance have survived enough to be of any relevance in modern genetic counselling. After all, even if kinship and patrilineal descent systems used to be 'a fundamental guide to conduct and belief in all areas of social life' (Fortes, 1970), what does it matter in a Western setting? The fact that the informants reported the classical idea that male kin had different rank and terms supports the conclusion that, at least in some sense, these acculturated informants retained some traditional thinking. A proportion of informants reported on culture-specific attributions of inheritance which, they said, were held by other family members. It is possible that these informants did indeed not hold the beliefs themselves, or alternatively, acculturated informants may have wished not to be typecast as 'superstitious', and thus were more comfortable attributing traditional Chinese beliefs about inheritance and illness to an older member of the family. It is also plausible that a relative lack of ownership of traditional Chinese beliefs facilitated these informants' decision to attend for genetic counselling.

However, it is essential that we do not stereotype 'Chinese' thinking. There is as much diversity in the beliefs and explanations held by those Australians of Chinese descent as those of Anglo-Saxon-Celtic origin (Visser & Bleiker, 1997). The study highlights the need for clinicians to ask about their patients beliefs and understand as they manage, treat and try to prevent illness (Chapple et al., 1995) utilising the new genetic technologies. The counsellees's receptiveness to genetic counselling explanations and services will be enhanced by the open-minded acknowledgement of these beliefs and recognition of any incompatibility (Weil, 2001). Working together with the families to reconcile these

incompatibilities can only lead to the enhancement of clinical genetic services.

Methodological considerations

The methodology used in this study—an ethnographically informed narrative analysis—can provide a lead for clinicians. In onion-skin fashion, it peels and probes beliefs and attributes of the informant and their family. Stripping the ‘acceptable Western face’ initially presented by those from diverse cultural backgrounds who attend the familial cancer clinic, it allows the informants to put into words beliefs that are inevitably influenced by the family culture and may be seen to be not as acceptable to Western thinking.

Evidence that individuals of Anglo-Saxon/Anglo-Celtic background attending familial cancer clinics have above-average educational levels is accumulating (Cull et al., 1999; Meiser et al., 2000). The high educational and acculturation levels amongst our sample of Chinese informants are in keeping with this observation and suggest that Chinese families attending familial cancer clinics may not be representative of Chinese families with hereditary cancer as a whole. By contrast, the relatively high rate of individuals who declined to be interviewed for fear of talking about cancer suggests that we may not have captured the full range of views about cancer and inheritance amongst clinic attendants. The high level of acculturation among the subjects is a limitation to generalisation of findings; the effects of acculturation on cancer screening should be separated from those due to social and economic conditions (Suarez & Pulley, 1995) and in further quantitative research the effects of acculturation should be examined.

Another limitation of this study is that the views of senior family members have been imputed from our informants. The disparity in beliefs between family members has been reported elsewhere (Weil, 2000) as has been our findings that individual family members may hold apparently disparate or conflicting beliefs (Rolland, 1994; Weil, 2001). We are currently addressing this limitation by undertaking a community-based study from which it will be possible to describe concepts about inheritance and cancer using a sample with diverse characteristics, which will make it possible to make comparisons with beliefs of individuals without a family history of cancer.

It has been suggested that there is no unitary ethnic Chinese population (Chan Kwok, & Tong Chee, 1993, 1995). The group in this study is ethnically and linguistically heterogeneous, of varied degrees of acculturation. Due to the qualitative methodology used, it has not been possible to study the effects of ethnicity and acculturation upon the beliefs about inheritance and cancer. Despite the considerable heterogeneity of the Chinese community as reflected by ours, the responses

are consistent. For example, the concept of blood relatives, for all ethnic and religious groups, all groups recognised notion of blood vs. non-blood relatives. Similarly, the concept of *yin-yang* was used by Christian as well as non-Christian. On the other hand, ancestral retribution was more obviously attributed by the non-Christian relatives of Christians and by the non-Christians.

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