UNDERSTANDING COMMUNITY BELIEFS OF CHINESE-AUSTRALIANS ABOUT CANCER: INITIAL INSIGHTS USING AN ETHNOGRAPHIC APPROACH

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SUMMARY

Ethnography was employed to investigate the hypothesis that the cultural meaning of cancer is one of the possible barriers to access of cancer services. The objectives were to identify indigenous terminologies, taxonomies and illness explanatory models of cancer in a community-based sample of 15 Chinese-Australians and a sample of 16 informants who had been recruited through two Sydney familial cancer clinics. Many of the informants included in their narrative terms that seemed to match Western biomedical explanations for cancer. The majority of informants also maintained traditional Chinese beliefs, despite high acculturation and beliefs in biomedical explanations about cancer. Explanations of illness including cancer, referred to the following concepts: (i) karma (*yeh*), (ii) retribution (*bao ying*), (iii) fate (*ming yun*) or Heaven's or God's will, (iv) geomancy (*feng-shui*), (v) touched evil (*zhong chia*), (vi) misfortune or bad luck (*shui wan, dong hark*); (vii) offending the gods or deities requiring prayers or offerings for appeasement; and (viii) *kong-tau* (spells invoked through human intervention). Taking into consideration the heterogeneity of the Chinese population, the findings provide an insight into Chinese illness conceptualization that may assist health professionals to develop an understanding of how the cultural explanatory models affect access to screening services, communication of diagnosis of cancer and management of treatment regimen. Copyright © 2004 John Wiley & Sons, Ltd.

INTRODUCTION

In the last decade, increased attention has been paid to cross-cultural aspects of cancer. Ethnographic studies on breast cancer and cervical cancer screening have identified a range of beliefs about cancer, which have implications for clinical contexts and screening strategies (Bottorff *et al.*, 1998; Chavez *et al.*, 1997; Gifford, 1994; Gregg and Curry, 1994; Johnson *et al.*, 1999). The findings from these studies suggest that there is a need to have health messages and practices

tailored to particular cultural communities, incorporating factors such as the influence of the family and community (Bottorff *et al.*, 1998). They also suggest that the cancer models held by the patient may differ from those held by the clinicians (Gregg and Curry, 1994).

Culture powerfully shapes the explanations for cancer and, therefore, what people believe can be done about it. For example, breast cancer among Latina has been attributed to sugar substitutes, bruises from being hit, microwave ovens, eating pork, eating spicy foods, breast-feeding, and antibiotics (Perez *et al.*, 1992), and as a consequence of fondling (Hubbell *et al.*, 1995). Cervical cancer has been attributed among Latinas to sex during menstruation (Hubbell *et al.*, 1996). Vietnamese have been reported as not knowing

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that a breast lump could be a sign of breast cancer, or that abnormal vaginal bleeding could be a sign of cervical cancer (Pham and McPhee, 1992). Cancer is viewed among some groups as getting a death sentence, God's punishment. It is uncomfortable to touch someone with cancer, and the person would rather not know if they had incurable cancer (Perez et al., 1992). Vulnerability to cancer among Italian-Australian working class women was seen as reflecting fear of social as well as physical death (Gifford, 1994). Misunderstandings clearly affect the use of clinical oncology services by patients of diverse cultural backgrounds (Brushin et al., 1997; Butow et al., 1997; Kelaher et al., 1999).

Among Chinese populations (Mandarin, Cantonese, and other major groups), however, there is a dearth of research on explanatory models for cancer (Facione et al., 2000; Koo, 1987; Wong-Kim et al., 2003). The study by Facione et al. (2000) on the critical factors associated with first generation Chinese-American women's help-seeking behaviour for breast cancer found three factors unique to this group, namely, their sense of invulnerability to breast cancer, their attribution of cancer to fate and their extension of this belief to an expectation of death should a person have cancer, with a powerlessness to influence their own survival. This could contribute to delay in help-seeking, which might be exacerbated by their preference for using Chinese medicine and delaying Western therapies because of modesty. The question arises as to the extent to which Chinese people understand and accept the Western biomedical model of cancer causation.

While few studies specifically focus on culture-specific beliefs about cancer amongst the Chinese, a larger body of literature is available that explores psychosocial aspects of a cancer diagnosis and treatment amongst Chinese patients (Fielding et al., 1998; Ho et al., 2003a, b; Huang et al., 1999; Lam and Fielding, 2003; Yu et al., 2000). Some of these studies also provide some insights into culture-specific beliefs about cancer causation. For example, previous studies have mention beliefs that cancer is contagious (Huang et al., 1999; Wong-Kim et al. 2003), the result of God's will or due to bad luck (Ho et al., 2003b), or that it reflects punishment as a result of ancestor's conduct (Wong-Kim et al., 2003). In a study of 202 members of a Hong Kong hereditary cancer registry, participants were found to be more concerned about the well-being of their significant others than their own, in their decision-making about genetic testing (Ho et al., 2003b), which is consistent with the well-established finding that Chinese people are more interdependent and relationship-oriented compared to their Western counterparts (Ho et al., 2003b).

Andersen's Behavioural Model of Health Services Use offers a theoretical framework that can guide research in this area (Aday and Andersen, 1974; Andersen and Newman, 1973). According to this model, while the need for health care (e.g. symptoms) is the primary factor determining use of services, sociodemographic background variables and beliefs and values concerning health and illness are considered predisposing factors, and financial and community resources, enabling factors (Aday and Andersen, 1974; Andersen and Newman, 1973). In particular, culture-specific illness beliefs and values are acknowledged to impact on help-seeking behaviour as strongly as social relationships (Aday and Andersen, 1974; Andersen and Newman, 1973). Findings from empirical studies are largely consistent with this model and provide evidence for culture-specific differences in help-seeking behaviours mediated by beliefs and attitudes (Abe-Kim et al., 2002; Alberts et al., 1998; Takeuchi et al., 1988).

The current study aims to examine the cultural meaning of cancer as a possible barrier to access cancer screening and treatment, using ethnography. The objective was, using Chinese-Australian community members and Chinese-Australians who had attended a familial cancer clinic as the case, to identify indigenous terminologies, taxonomies (illness classifications) and illness explanatory models of cancer.

In Chinese culture, family affairs are traditionally confined to within the family and it is considered shameful for the family members to discuss with outsiders family matters such as illness, including cancer (Leung and Lee, 1996). Within this environment, eliciting accurate family beliefs and personal fears regarding illness cannot occur using an impersonal 'objective' form of data collection (Kleinman and Kleinman, 1999). Ethnography was selected as the most appropriate methodology as it is the most effective way of obtaining accurate data on cultural beliefs and an understanding of the traditional practices that impact on daily functioning (Denzin and Lincoln, 1994).

Qualitative studies establish the range of beliefs and attitudes, which can then be taken further

using quantitative methodologies to determine the extent to which beliefs are endorsed. The important advantage of a qualitative data collection strategy such as ethnography is that dimensions of lay beliefs are not assumed beforehand. When dimensions are predetermined by the researcher, the ensuing results are more likely to reflect professional rather than informants' standards leading to decreased internal validity. Hence, a systematic investigation of culture-specific beliefs and attitudes using ethnography can minimize the risk of ethnocentricity (Sensky, 1996). The disadvantage of the inductive purity of methodology advocated by ethnography and its emergent approach to interviewing is that it tends to yield very large amounts of information, is time-consuming and does not yield data that lends itself to undertaking comparisons between individual or groups of informants, unlike a more structured approach with an upfront conceptual framework and instrumentation (Denzin and Lincoln, 1994).

METHODS

Participants, procedure and analysis

Encounters with informants were carried out by a Chinese psychologist with training in family therapy and qualitative methodology (SSY), in Mandarin, Cantonese, Hokkien or English, as appropriate. Some encounters with informants whose primary language was English were also in the company of KBS (three encounters) or ME (one encounter), who contributed to these particular interviews. Informants were recruited through two sources: Community- and clinic-based. For the community-based sample, a 'participant observer' approach by building up a personal relationship with the participant first, consistent with our ethnographic method, was used (Spradley, 1979). A more formal approach (recruitment of a consecutive sample of patients who had attended familial cancer clinics) was used for the clinic-based sample. Clinic-based recruitment appeared the only feasible way to recruit informants with a family history consistent with a hereditary cancer syndrome due to the low prevalence of these syndromes. Our rationale for including informants from families with a hereditary cancer syndrome (many of whom include

multiple relatives affected with cancer over several generations) was that for such informants the experience of cancer was particularly salient and might impact on culture-specific beliefs and attitudes about cancer. Comparisons with the beliefs and attitudes of the community-based sample would therefore indicate whether or not coming from a cancer-dense family impacted qualitatively on beliefs and attitudes.

Community-based informants of Chinese ethnicity were directly approached by the interviewer from personal contacts developed through networking with the community or following recommendations from leaders of various Chinese community groups. Purposive sampling (i.e. targeted sampling for heterogeneity to allow the determination of the full range of beliefs and explanations from as many different perspectives as possible) was used to select potential participants (Patton, 1990). Steps toward forming a relationship built on acceptance and trust included participation in various activities such as drinking tea, or health talks, new migrants information sessions and cookery classes in the case of community members. For the community-based sample, interviewing was discontinued once no additional information appeared to be forthcoming, i.e. once informational redundancy had been reached, in accordance with standard qualitative methodology (Patton, 1990).

Clinic-based informants were recruited through two major Sydney familial cancer clinics. These clinics provide a comprehensive service to people at high risk of developing cancer according to National guidelines, which includes risk assessment, genetic testing and advice regarding early detection and prophylactic strategies (Kirk and Tucker, 1997). The medical records of two major Sydney familial cancer clinics were reviewed to identify all those of Chinese ethnicity who had attended since 1995. The staff specialist involved in the patients' 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. Ethics approval was obtained from three institutional ethics committees.

The interviewer introduced the study as aiming to describe Chinese beliefs and attitudes about cancer. All the informants identified themselves to be of Chinese ancestry, and care was taken to note with which dialect or other cultural group they

identified. The majority of the interviews were conducted in the informants' homes.

If consent was given, encounters were tape-recorded. They lasted between 1 and 3 h. A majority of the interviews were conducted informally, covering several sessions over 2 to 6 days, with notes taken by the interviewer. The following information was elicited: Sociodemographic and cultural background data; family history of cancer; perceived communication preferences for receiving a cancer diagnosis; perceived causation of cancer; and terminologies for cancer and causes of cancer. The narrative was structured in part by an adaptation of an Explanatory Model Schedule. This instrument was originally in English (Eisenbruch, 1989) and in Khmer (Eisenbruch and Handelman, 1989), and was translated by SSY into Mandarin and Cantonese. ME worked with SSY on successive piloting and testing of Cantonese and Mandarin terms and adapting the trigger situation to diseases such as cancer. In this way, the attributions of cancer were documented. The Explanatory Model Schedule was used to elicit the attributions by informants according to the Murdock Ethnographic Atlas (Murdock *et al.*, 1978). The respondents indicate the strength of their beliefs that a particular disease or affliction is caused by a series of possible causes. These spanned natural and supernatural causes, which were further broken down into mystical, animistic, or magical.

Data on language preference and proficiency and acculturation were used for descriptive purposes and to provide the basis for comparisons and contrasts undertaken as part of data analyses. The *Rissel Acculturation Scale* was employed as an estimate of English language preference and proficiency (Rissel *et al.*, 1998). This eight-item scale has demonstrated high internal consistency and criterion-related validity in a sample of 851 Sydney general practice patients. Although the *Rissel Acculturation Scale* was developed to measure the degree of acculturation, it is, however, based on the traditional linear theory that assumes that as people adapt and acculturate to their new cultural surroundings, they necessarily strip off their old culture. Acculturation is, however, a complex and multi-dimensional construct, and the present study used the scale as an estimate of language preference and proficiency. Scores range from 0 to 35. Informants were categorized into those with low and those with high English language proficiency using a median split, to enable comparisons of beliefs and attitudes between those with low and those with high levels of acculturation.

The conceptual qualitative research framework of Miles and Huberman (1994) was chosen to guide data analysis. One of the strengths of this framework lies in the explicitness of its description of qualitative data analysis, which includes the use of highly structured data displays to tease out relationships and synthesize findings.

Detailed synopses of approximately 1000 words each were prepared by SSY for each informant, summarizing each account as a narrative in English to enable multiple analysts to participate in the analysis. Several follow-ups by the interviewer occurred in order to clarify or expand on some of the topics. To facilitate analyses of data, tapes were listened to repeatedly by SSY and difficult passages were checked. BM also listened to approximately 50% of the taped English language interviews to verify the accuracy of the synopses. The first 15 interview synopsis were coded by SSY and BM in order to develop an agreed upon set of codes, and SSY continued with coding. Data analyses were iterative and SSY, BM, ME and KBS participated in this process, using the synopses to identify and agree upon emergent themes, and discuss their face validity. In addition, conceptually clustered matrices, a form of visual display described by Miles and Huberman (1994), were prepared to facilitate analysis both within and across cases. These tables cross-tabulated emergent themes by type of sample (clinic- or community-based) and level of acculturation (low versus high), and were examined by SSY, BM and DG to identify potential differences. Three informants' comments were obtained by going through the draft report with them to ensure accuracy of the data collected and check the validity of findings.

RESULTS

A previous article reports on explanatory models of inheritance and *inherited* cancer amongst the clinic-based sample (Eisenbruch *et al.*, 2004), while this article describes how the method helped to elicit explanatory models for cancer in general amongst both the clinic- and the community-based samples. A total of 51 informants were approached for an interview, 31 of whom

consented, 6 male and 25 female informants. Sociodemographic and cultural background data of the sample interviewed are shown in Table 1. Informant age ranged from mid-20s to mid-80s. Nineteen informants had post-school qualifications, and 12 did not. Only three community-based informants had some degree of a family history of cancer. All of the clinic-based informants had a family history consistent with hereditary breast cancer, hereditary non-polyposis colorectal cancer (HNPCC) or Von Hippel Lindau disease, more fully described elsewhere (Eisenbruch *et al.*, 2004).

Five clinic-based patients could not be contacted and one was deceased, and a total of 14 individuals declined participation. Of those who declined participation, four said they were too busy, one did not identify with the Chinese, and seven reported being fearful about talking about cancer. Amongst those reporting being fearful, one felt that speaking about cancer could bring on the illness and two felt that talking about cancer would increase their anxiety that could result in their falling ill. The individuals who declined being interviewed were similar in age range and country/region of origin to those who participated. However, as reported previously, amongst the clinic-based sample, non-participants were significantly more likely to have been affected with cancer compared to participants (Eisenbruch *et al.*, 2004).

Table 1. Sociodemographic and acculturation characteristics ($N = 31$)

Variable	Level	Clinic sample ($N = 16$)	Community sample ($N = 15$)	Total sample	
		N	N	N	%
Sociodemographics					
Sex	Female	14	11	25	81
	Male	2	4	6	19
Age	< 30	3	1	4	13
	30–39	3	1	4	13
	40–49	7	3	10	32
	50–59	1	4	5	16
	60 +	2	6	8	13
Marital status	Married	11	8	19	61
	Not married	5	7	12	39
Biological children	Yes	11	13	24	77
	No	5	2	7	23
Educational level	Post-school educ	14	5	19	61
	No post-school educ	2	10	12	39
Acculturation					
Country of birth	Australia	3	0	3	10
	Burma	1	0	1	3
	China	3	5	8	26
	East Timor	1	0	1	3
	Hong Kong	2	4	6	19
	Malaysia	3	4	7	23
	Taiwan	2	0	2	6
	Vietnam	1	0	1	3
	Indonesia	0	1	1	3
	Singapore	0	1	1	3
Religion	Christian	10	5	15	48
	Buddhist	2	4	6	19
	Taoism	0	1	1	32
	No identified religion	4	5	9	29
Years since migration	Nil	2	0	2	6
	0–9	0	5	5	16
	10–19	5	6	11	73
	20 +	8	4	12	39

Differences in beliefs by type of sample and acculturation levels

No qualitative differences were observed between attitudes and beliefs of community members and those who had attended a familial cancer clinic towards any of the issues examined as described below. Likewise no differences in the range of attitudes and beliefs were found by level of acculturation.

Cancer

Indigenous terminologies. All data on explanatory models of cancer were taken into account in the analysis. A glossary of the Chinese terminology informants used is provided in Appendix A with transliterations into English, corresponding Chinese characters and their English translations. Seven informants, regardless of their country of origin, used their local terms to differentiate between the benign *liang xing lau* and malignant *auk xing lau* tumours. In another local classification, *auk xing lau* referred to cancers that are poisonous and spread to various parts of the body, whereas the *liang xing lau* are non-spreading and curable. It was believed that the benign tumours, rather than being a distinct category, have the potential to change to the malignant tumours.

It was noted that younger informants from Hong Kong often included the English term 'cancer' in their narrative. All the informants from Hong Kong included other terms based principally on the physical appearance of the tumour, regardless of its location, but in this case referring to the breast. In their narrative, the informants used terms such as '*san ye* (grow things)', '*san lau* (grow tumour)', '*san yat lup* (grow a lump)' and '*san yat gau* (grow a mass)', when talking about cancer. Older Hong Kong informants, however, used terms with different visual connotations, such as *san lau*, which means 'growing a swollen tumour' and *san auk zhong* or *san tok zhong*, which means that the cyst is full of pus and blood. *San lau* refers to the visible swellings such as those that occur in cancer of the breast or face. One informant reported the use of *gu chiam*, meaning 'swollen drum' to refer to stomach and liver cancer.

Others used the term *san pui yoke*, which means 'grow a piece of flesh'. All the Mandarin-speaking informants from Shanghai and Malaysia used the term *ai zheng* to refer to cancer with reference to the organs where the cancer was located. For example, liver cancer was referred to as *gan yan* and lung cancer as *fei yan* in Mandarin or *koin ngaam* and *fai ngaam* in Cantonese, respectively.

Concepts of causes of cancer

Eleven informants included in their narrative terms that seemed to match Western biomedical explanations for cancer. Explanations included the following: (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). Amongst non-Western explanations, informants mentioned that ill health could be the result of an imbalance of the positive and negative life force (*ying-yang*) in the body.

The narrative also included supernatural explanations, referring to: (i) karma (*yeh*), (ii) retribution (*bao ying*), (iii) fate (*ming yun*), or Heaven's or God's will, (iv) geomancy (*feng-shui*), (v) touched evil (*zhong chia*), (vi) misfortune or bad luck (*shui wan*, *dong hark*), (vii) offending the gods or deities requiring prayers or offerings for appeasement or (viii) *kong-tau* (spells invoked through human intervention). Incompatible astrological signs (*pazi buhe*) and seeking reunion with a loved on in afterlife were also mentioned as possible explanations for cancer.

Karma (yeh). Four informants, mostly Buddhist, believed that cancer was the result of bad karma, which resulted from misdeeds done in the present or previous lives. One reported that bad karma resulted if, along the ancestral line, there are family members making a living by taking other beings' lives, such as being a butcher: 'There is blood on the hands of this generation and [this] will bring misfortune, bad luck, and illnesses to the future descendants.'

One informant who had attended a familial cancer clinic and whose eldest sister had died from breast cancer said:

> They must have done something wrong in their previous life, and in this life they get punishment or they have done something wrong in their early life...my sister who had breast cancer believes it, that she has done something, even minor things and that gave her the cancer.

Retribution (bao ying). Thirteen informants, regardless of religious beliefs and age, narrated that any misfortune including cancer could be due to retribution (*bao ying*). This could be due to the family or the previous generations having done bad things (*yun kong si*). About half, regardless of religious adherence or age, believed that it could be a form of retribution (*bao ying*) to have cancer, while the other half attributed these beliefs to other family members. Thirteen informants believed that past or current misdeeds could cause ill health for the present and future generations. According to one informant, it was a common thinking that previous generations who have accumulated lots of wealth may have acquired it through foul means such as dealing in drugs or blackmail. Any past or present deeds that harm other people would result in the descendants having ill health, shortened lifespan, premature deaths, bad luck or misfortune—such as cancer. In one case the informant linked bad karma and retribution, where the cancer was described as 'a pay back for having aborted a foetus years ago.'

Fate (ming yun) or Heaven's will, God's will. Six informants, regardless of religious background or beliefs, believed that what happened in one's life, including getting cancer, was one's destiny or it was Heaven's or God's will (*tien chi*). Those who identified as Christian referred to the same idea, as God had a purpose for them. Almost all who reported that cancer and misfortune could be attributed to fate (*ming yun*) identified with Buddhist and/or Taoist philosophy. A Buddhist informant explained that *ming* is life that is fixed, and *yun* means 'movement', therefore, *yun* can be changed by praying to the deities or doing good deeds (making merit). According to Buddhists, every action in daily functioning is attempting to change our *yun*, although this is not always possible. For example, although an informant was from a wealthy family and married a wealthy

man, she has had a life of poverty and hard work. She said that it was her fate to suffer as war came and from then onwards, she led a difficult life. As she could not change the *ming* and was fated to have cancer, she would accept it.

Two of the Protestant and Catholic Chinese informants expressed the view that cancer was God's will. Those with traditional Chinese beliefs of Confucianism, Taoism and Buddhism would use the term, 'Heaven's will' (*tian shu*). For example, one woman in her 40s affected with breast cancer who had a Christian background, indicated that God had allowed her to have cancer as He had a purpose for her, to understand in-depth the suffering of others and thereby increase her faith and do good works by becoming a volunteer for a breast cancer support group.

Geomancy (feng shui). Feng shui is also referred to as geomancy and refers to a body of belief which centres on the idea that the natural surroundings where people live are capable of influencing their fate (Baker, 1979). Six of the informants, regardless of religious faith, believed that bad *feng shui* could result in cancer. Most were in the younger age range. Of those who mentioned *feng shui* as a contributing factor to ill health such as cancer, half reported family and friends who believed in *feng shui*, while the remainder themselves held the belief. For example, one informant's mother believed that the family house was not facing the right direction; in particular the gods were not placed in the right location. Her younger sister had been diagnosed with breast cancer and believed that her house, which is next to a flyover bridge, may have blocked all the good *feng-shui* and could have caused her cancer.

Touched evil (zhong chia). A common theme mentioned, regardless of religious beliefs, was that when one is unlucky, or one's spirit is low and one had inadvertently offended some spirits, illnesses could occur by spirit possession. Both informants with Taoist and Christian identification mentioned that illnesses could be an outcome of one's having inadvertently offended certain spirits by walking over someone's grave, urinating on the graves or saying inappropriate things about the dead.

A similar belief was reported by another informant who said she was given *fu tchui* (charm water) to get rid of the evil spirits as her illness was caused by *tiak lar suap* (touched evil). She had made offerings of food and candles for the spirits

(*kuei*) to appease them. Another informant from the clinic sample believed that her uncle had touched evil spirits as his spirit was low, which resulted in his having cancer.

Misfortune and bad luck (shui wan, dong hark). One informant reported misfortune and bad luck as possible explanations for having cancer but did attribute the belief to someone else. All of these informants, regardless of age, appeared to identify with Taoist philosophy. One reported a belief commonly held by Chinese in Hong Kong according to which bad luck could cause ill health including cancer. Some of this bad luck could be due to the family having been cursed by others who are usually jealous of the family's wealth and good fortune. In order to change their luck and improve their fortune, some would consult monks, nuns or temple masters.

Offending the gods or deities. Three informants reported their older relatives believing that the illness could be the result of offending the gods or deities such as the earth god, kitchen god or the Monkey God. Chinese people would consult the fortune-teller who would identify the source of the problems and incantations and offerings required to appease the deities. For example, one informant reported that her deceased uncle's wife believed that they could have offended one of the spirits, which led her uncle to having cancer.

Black magic (kong tau). Six informants reported *kong tau* (black magic) as a possible explanation for ill health including cancer. A large proportion of these informants were in the younger age range, and born in Malaysia and Christian. These informants had dual religious beliefs, as they were also inclined towards Taoism and Buddhism. A third believed that rivalry or jealousy would make a person cast a charm (*kong tau*) on another, thus inducing illness. One said:

> My friend's husband was having an affair and this mistress used *kong tau* in an attempt to make him sick but it ended up that her friend's brother got sick instead. Her friend has a servant who recognized the practice and suggested that they consult a *dukun*, a type of Indonesian black magic practitioner.

Another belief reported by one informant included incompatible astrological signs (*pazi buhe*) as a cause of serious illness; and one clinic attendee believed that her sister had died of cancer because her husband's spirit sought reunion with her in the other world.

Comments on using ethnography with the Chinese community

As part of undertaking this study, we encountered many challenges and hence had the opportunity to gain insights into undertaking ethnographic research with Chinese informants. These may be useful to other researchers wishing to explore sensitive topics, such as beliefs about cancer, amongst Chinese people.

The English word 'communication' has no single equivalent Mandarin or Cantonese word as many Chinese equate communication with talk. For example, those who are skilful in talking (*hui shuo*) are deemed good communicators. Therefore, employing an ethnographic approach in studying the Chinese community's beliefs about illnesses in general and cancer in particular requires engaging this community in informal discussions. In undertaking ethnographic research, it is important that these verbal exchanges be based on culturally determined mutuality and interdependency.

We found it essential that the interviewer form mutual good feelings (*gan qing*) with informants. This *gan qing* is the basis for cultivation of mutual aid (*hu xiang bang zhu*) and mutual care (*hu xiang guan xin*) in Chinese interpersonal relationships. Networking within the Chinese community appears an important ingredient in the successful recruitment of informants in a community study. Socially coded preparatory steps must occur prior to engaging the informant as any verbal exchange cannot occur in a vacuum. For example, we found that recruitment of informants was often facilitated through social events such as drinking tea together. While the researcher aimed to develop a close relationship with the interviewees, this was based on the mutual understanding that the aim was to learn more about Chinese beliefs about cancer, rather than develop a long-lasting friendship.

Flexibility on the part of the interviewer also appeared important as elderly Chinese in particular may not wish to answer questions directly and there may be a need to reiterate questions over a number of meetings. The 'interview' really became an 'encounter', in the course of which friends and visitors rightfully take precedence to the interview process. The interviewers needed to recognize that the numerous interruptions are part of the process

and must not be interpreted as signifying a lack of respect.

We also observed that some Chinese informants might seem to give informed consent to be interviewed but have done so to 'save face' when in reality they do not wish to be interviewed. On the other hand, it became evident that it was socially acceptable to refuse an interviewer's request if there is no pre-existing relationship (guanxi). Therefore, in order to secure an interview, it was vital that there is an opportunity to establish the veracity of the good character of the interviewer at the first contact with the interviewer. It was therefore not unusual for the informants to seek more personal information about the interviewer, such as their country of origin, occupation and place of residence of family members.

We also found it essential that the interviewer take steps to show respect to the elderly. A common phrase is 'a home with an elderly person is like a home with a precious treasure'. For the first meeting, there is the Chinese custom of bringing a small gift as kin min lai (first meeting gift). Therefore, we found giving two (even numbers are good luck) mandarins or oranges to elderly informants helpful in establishing better rapport. Oranges symbolize good health and good fortune. Further, it is important to be mindful of elderly people's sense of fragility and vulnerability and to be sensitive to their ability to cope with any discussion of illness or other difficult matters. These discussions may serve as a reminder of mortality, particularly in the case of the aged who are situated closer to the end of their lifespan and current incarnation.

DISCUSSION

There is a growing recognition that health science research in multicultural settings should employ ethnographic research methodology (Denzin and Lincoln, 1994), which has been found to yield accurate and in-depth information on sensitive topics such as cancer, an illness often considered anxiety-provoking and shrouded in secrecy within the community (Forchuk and Roberts, 1993; Kleinman and Kleinman, 1999). In this study, ethnographic descriptions and personal accounts were employed to bring to the surface deep-seated Chinese traditional folk beliefs. Interviews were conducted informally, covering several sessions,

and led to the interviewer being perceived as a 'friend' and accepted as an insider (ziqi ren), regardless of the manner in which the informants were recruited, thus allowing for the cultivation of mutual aid (hu xiang bang zhu) (Kleinman and Kleinman, 1999).

The ethnographically informed method yielded results consistent with many observations in medical anthropology that show that people can believe simultaneously in biomedical concepts and folk and traditional Chinese beliefs in the explanation for the causality of illness (Koo, 1987). The findings showed how informants regardless of identified religious beliefs, age, educational level or estimated English language proficiency, subscribed to a wide range of traditional Chinese beliefs about illnesses in general and cancer in particular. Perhaps surprisingly, we found no differences in the range of attitudes and beliefs about cancer by level of acculturation and between clinic- and community-based informants, which underscores the salience of the beliefs described. However, only quantitative studies can ascertain the degree to which particular attitudes and beliefs are endorsed, and future quantitative studies may indicate differences by acculturation level and other sociodemographic characteristics. Such studies will also need to ascertain the differential impact of folk and traditional beliefs compared to Western medical concepts on screening and treatment behaviours amongst people of Chinese background.

The informants also reported Western biomedical explanations for cancer. People already affected by cancer, irrespective of cultural background, have previously been reported as describing the causes in terms of environment (pollution, chemicals, toxins), diet (meats, fast foods, additives), psychosocial factors (stress, depression), immune system ('weakening' and 'cells go haywire'), physical injury (damage from an accident, steady pressure on abdomen), and as a combination of these causes. The perceived role of stress in inducing cancer has also been described previously in those of Anglo-Celtic background (Payne, 1990). Deeper examination, however, reveals some key differences. The cluster of supernatural explanations derived from Confucian, Buddhist, and Tao cosmologies was also apparent. Confucian and Tao cosmology was reflected in the beliefs in 'Heaven's will' (tian shu); bad luck (shui wan) caused when the spirit may have happened to be low, or fate (ming yun); feng-shui, or geomancy;

kong-tau, or spells cast by someone who has been offended; and the deities being offended, for example, the door deity (*kwan ti*) or the monkey deity. Buddhist cosmology was reflected in the attributions of cancer to karma, or bad action in a previous incarnation, as well as that the spirit of a loved one was seeking reunion in the next incarnation. The fact that almost half of the informants held such beliefs is testimony to the power of Buddhist influence despite the high acculturation—and, in some cases, the nominal Christian faith—of the informants.

Benign *liang xing lau* and malignant *auk xing lau* tumours

The fairly widespread benign-malignant dimension is of interest. The general Chinese belief was that the benign tumours are of the non-spreading type that may change to the malignant spreading type of cancer. Informants in the present study divided cancer into benign and malignant forms, but these were not mutually exclusive, as they believed that the benign form could evolve to the malignant type. This distinction does not appear to be unique to Chinese culture, with similar beliefs identified, for example, in a study of low-income African-American women, where a third of the women distinguished between fatal and non-fatal cancer conditions (Gregg and Curry, 1994). The hallmark here is that Chinese informants believed that the benign tumours could transform to malignant tumours, whereas African-American women believed that the only 'real' cancer was a late-stage cancer. The implication for African-American women was that they did not consider having pap smears and mammograms to screen precancerous tumours. The transformation of benign to malignant tumours has implications for the promotion of early detection strategies for cancer among the Chinese community. It may be more culturally appropriate to couch preventative strategies in reference to identification of 'benign tumours' than to advertise screening for cancer, which may evoke fear and dread, as the concept of an incurable disease that can spread to various parts of the body. The Chinese target audience is more likely to take up the screening message if couched in the threatening identification of these *liang xing lau* (benign tumours) which could change into a spreading one (*auk xing lau*).

Cultural differences in expectations are likely to create incongruence and the greater the incongruence, the more difficult it will be to establish a trusting working alliance. For example, we found a shared belief that getting cancer was one's destiny, which has been described previously for Chinese-Americans (Facione *et al.*, 2000). If patients believe in retribution for a past deed or that many family members are fated to have cancer, accessing early detection services or treatment of the disease may seem pointless. It may be difficult to overcome this traditional belief in the central role of fate, but recognizing its importance as a potential barrier to utilization of early detection strategies is essential.

It is essential not to stereotype Chinese as homogenous, but to be constantly alert to the diversity among the Chinese population, for example in terms of countries or regions of origin and dialects. This has implications for both health professionals and interpreters. The present sample was diverse from several countries/regions of origin and various dialects/languages, including Mandarin, Cantonese and Hokkien, with associated differences in indigenous health terminology.

In conclusion, the findings shed light onto developing testable strategies for engaging the Chinese population in preventative services such as cervical and mammography screening, communication of the diagnosis of cancer and provision of services to the patients and their families. Additional ethnographic studies of more homogenous Chinese groups would allow an even greater understanding of the similarities and differences in attitudes between the various, quite diverse groups of Chinese origin. Strategies are more likely to be effective if they integrate the Chinese conceptual and explanatory models of illness including cancer, while taking into account the heterogeneity of such conceptualization among the Chinese population, influenced by factors such as country/region of origin, age and acculturation.

Explanatory models are personally and socially constructed and shaped by culture, not only among those from linguistically and culturally diverse backgrounds, but also in the Anglo-Celtic dominant culture. Some of our findings may not be unique to people of Chinese background, and future studies are needed to examine beliefs and attitudes about cancer amongst people of Anglo-Celtic background. Likewise, some of the beliefs and attitudes described may not be unique to cancer among the Chinese, and similar research

should be undertaken to compare these to beliefs about other illnesses.

The limitations of this study should be mentioned. First, the high educational and acculturation levels amongst the clinic-based sample suggest that Chinese families attending familial cancer clinics may not be representative of Chinese families with hereditary cancer as a whole, and is a limitation to generalization of findings. Furthermore, 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. Finally, the different recruitment strategies used for the clinic- and community-based sample may have impacted on the results.

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APPENDIX A

Glossary

Terms	Characters	Meaning
hui shuo	會說	Skilful in talking
gan qing	感情	Feelings/ interpersonal relationships
hu xiang bang zhu	互相幫助	Mutual aid
hu xiang guan xin	互相關心	Mutual care
guan xi	關系	Relationship
kin min lai/jian mian li	見面禮	First meeting gift
liang xing lau	良性瘤	Benign tumour
auk xing lau	惡性瘤	Malignant tumour
san ye	生嘢	Grow things
san lau	生瘤	Grow tumour
san yat lup	生一粒	Grow a lump
san yat gau	生一舊	Grow a mass
san auk zhong/san tok zhong	生惡瘡/生毒瘡	Cyst full of pus and blood
gu chiam	蠱脹	Swollen drum
san pui yoke	生配肉	Grow a piece of flesh
ai zheng	癌症	Cancer
gan yan/koin ngaam	肝癌	Liver cancer
fei yan/fai ngaam	肺癌	Lung cancer
yeh	孽	Karma
bao ying	報應	Retribution
ming yun	命運	Fate
feng-shui	風水	Geomancy
zhong chia	撞邪	Touched evil
shui wan, dong hark	衰運/當黑	Misfortune or bad luck
kong tau	降頭	Spells invoked through human intervention
ba zi bu he	八字不合	Incompatible astrological signs
yun kong si	陰功事	Done bad things
tien ci	天賜	Heaven's will
fu sui	扶水	Charm water
tiak lar suap (hokien)	斗到醒醒	Touched evil
gui/kuei (hokien)	鬼	Spirits
ziji ren	自已人	Insider
kwan di	關帝	God of war

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