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**Ethnic Experience of Cancer: A Qualitative Study of Chinese–
Australians in Brisbane, Queensland**

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Ethnic Experience of Cancer: A Qualitative Study of Chinese–Australians in Brisbane, Queensland

ABSTRACT. This paper reports on the findings of a recent study of cancer experiences of members in the Chinese community in Brisbane, the state capital of Queensland. Results of the study have shown that the belief in fate and luck, as well as stoicism about cancer is very common among cancer patients and their family members. Their general strategy for coping with cancer is often passive. Families play the most important role in determining the strategy for helping the cancer patients in coping with the illness. Most prefer to keep the illness secret and private within the family. Implications of the findings from this study will be discussed for the development of culturally appropriate programs for cancer prevention and treatment for the Chinese community.

KEYWORDS. Chinese–Australians, attitudes to cancer, social stigma, support systems, service delivery

INTRODUCTION

Social scientists agree that health and illness are not only a bio-medical incident, but also fundamentally a social and cultural phenomenon (Schou & Hewison, 1999; Shaw & Kauppinen, 2004). There are significant differences between cultures in the understanding and interpretation of illness. A patient's experience and response to symptoms are shaped by lay beliefs which are informed by a complex body of inherited folklore (Fitzpatrick, 1984; Helman, 2000). Cancer has long been a fertile ground for metaphorical thinking. Over the past hundred years, the disease had been used to signify cultural and ideological division and is associated with powerful notions of culpability, personal weakness and other moral themes in different societies (Sontag, 1979).

Cross-cultural studies of cancer experiences have revealed that there are major differences in the understanding of the disease and in ways of coming to terms with it (Ashing Giwa et al., 2003; Domino, Fragozo & Moreno, 1991; Domino & Regmi 1993; Kagawa-Singer, 1993; Kagawa-Singer, 1996; Kagawa-Singer, Wellisch & Durvasula, 1997; Mathews, Lannin & Mitchell, 1994; Ong, Michael & Jiade, 2002; Papadopoulos & Lees, 2002; Thorne & Murray, 2000). Specifically, there are cultural differences in belief of risk and participation in cancer screening services (Garcia & Lee, 1988; Navon, 1999; Vernon et al., 1992), decision making on life and death issues (Hosking et al., 2000; Kagawa-Singer & Blackhall, 2001; Kaufert, 1999; Klessig, 1995), practices of disclosure and communication (Blackhall et al., 1995; Butow, Tattersall & Goldstein, 1997; Gautam & Nijhawan, 1987; Goncalves & Castro, 2001; Gordon & Paci, 1997; Kagawa-Singer & Blackhall, 2001; Mitchell, 1998; Mullin, Cooper & Eremenco, 1998; Mystakidou et al.,

1996), as well as pain perception and quality of life of cancer patients (Garro, 1990; Gordon, 1997; Juarez Ferrell & Borneman, 1998; Meyerowitz et al., 1998; Pfefferbaum, Adams & Aceves, 1990). These findings have profound implications for healthcare professionals and social workers as their practices, both in terms of formulating intervention strategies and providing care, are expected to be culturally appropriate and sensitive (Berger, 1998; Chui, Donoghue & Chenoweth, 2005; Die-Trill, 1998; Sensky, 1996).

In recent years, the idea of inclusive and culturally ‘appropriate’ care has attracted much attention of policy-makers, health practitioners and social workers (Al-Krenawi & Graham, 2001; Berger, 1998; Blue, 2006; Koenig & Gates-Williams, 1995; Shams & Robinson, 2005; Shaw, 2005). There are widespread discussions on how to increase cultural sensitivity in a healthcare setting and to incorporate the patients’ folk practices and beliefs into daily care and treatment of cancer (Baldwin & Riley-Eddins, 2006; Delbar, 1999; Die-Trill, 1998; Ma et al., 2004; Macbeth & Shetty, 2001; Pierce, 1997; Simon, 2006; Tanjasiri et al., 2007; Thomas, 2001; Tu et al., 2006). However, much of these discussions are devoted to the identification of differences and problems among diverse populations whereby relatively little effort has been spent on finding culturally geared solutions for specific group of cancer patients. As Gotay, Muraoka and Holup (2001) pointed out in their review on cultural aspects of cancer prevention and control, the evidence base on how cultural factors affecting the development of supportive interventions remains very thin. This paper aims to help bridging up this gap by sharing the findings from a series of in-depth interviews with Chinese cancer patients, caretakers

and health workers as well as community leaders in Brisbane, Australia. The study provides not only personal accounts of how cancer patients in Brisbane's Chinese community manage their illness, but also discusses their implications for planning and administration of solution-focused and culturally appropriate interventions.

THE CHINESE COMMUNITY AND CANCER EXPERIENCE IN AUSTRALIA

As a culturally diverse society, a substantial proportion of Australia's population were born overseas. Figures of the 2006 Census shown that, 29.1% of Australians were born in a foreign country (Australian Bureau of Statistics, 2007). The Chinese population is an important component of the Australian society. By 2006, there were 302,760 Chinese in Australia. Brisbane, the third largest cities in the country alone attracted 25,762 or 8.5% of the Chinese population (see Table 1).

Table 1 Chinese Population in Australia 2006

| Place of Birth | Brisbane | Australia |
|----------------------------------|-----------------|------------------|
| People's Republic of China (PRC) | 11,417 | 206,589 |
| Hong Kong | 6,036 | 71,802 |
| Taiwan | 8,309 | 24,369 |
| <i>Subtotal</i> | <i>25,762</i> | <i>302,760</i> |
| Total Population | 1,763,135 | 19,855,287 |

Source: Australian Bureau of Statistics. *Census of Population and Housing 2006*.

One of the characteristics of the Chinese community is that a significant proportion of its members arrived in Australia only in the past decade. This is a direct result of the recent change in immigration policy of the Australian Government (Lui, 2006). In the 2001 Census, 39.1% of the Taiwanese in Australia were found to arrive in the country after

1996. Similarly 31.7% of PRC and 22.6% of Hong Kong migrants settled in Australia during the same period.

According to figures of the Queensland Cancer Registry, the Chinese community had a lower cancer incidence and mortality rates compared to the Australia-born population and Queensland residents between 1996 and 2000 (see Table 2).

Table 2 Cancer Incidence and Mortality Rates by Place of Birth, Queensland 1996 – 2000

| Place of Birth | Incidence | | Deaths | |
|----------------------|-----------|-------------------|--------|-------------------|
| | No | ASR/100,000/Year* | No | ASR/100,000/Year* |
| China-Born | | | | |
| Males | 109 | 229.5 | 37 | 71.5 |
| Females | 101 | 179.5 | 36 | 54.9 |
| Persons | 210 | 203.2 | 73 | 62.9 |
| Australia-Born | | | | |
| Males | 27,669 | 348.9 | 13,180 | 160.0 |
| Females | 24,208 | 273.5 | 9,714 | 97.1 |
| Persons | 51,877 | 305.9 | 22,894 | 124.9 |
| Queensland Residents | 42,275 | 370.9 | 17,728 | 147.4 |
| Males | 34,751 | 289.1 | 12,660 | 91.3 |
| Females | 77,026 | 325.8 | 30,388 | 116.7 |
| Persons | | | | |

* ASR/100,000/Year = age-standardized rate per 100,000 population per year.

Sources:

1. Queensland Cancer Fund.
2. Australian Bureau of Statistics. *Census of Population and Housing 1996 and 2001*.

The lower cancer burden among the Chinese population may be explained by the younger age structure and lifestyle of the Chinese community. But there is also the problem of report or registration. The Queensland Cancer Fund estimated that the country of birth of 13% of new cancer cases, and around 1% of cancer deaths were not recorded in the

Registry during this period. As country of birth is seldom recorded for foreign-born patients, this may have resulted in an underestimate of cancer rate for the Chinese population.

In recent years, there were a number of studies that examined specifically behavior and responses of Chinese–Australians to cancer. Kwok and Sullivan (2006; 2007) studied how traditional health beliefs affected cancer screening behavior of Chinese women. The study conducted by Huang and colleagues (1999) focused specifically on the information and communication needs of Chinese patients and their relatives. Yeo and colleagues (2005) examined the narrative accounts and cancer conceptualization of Chinese people. Chui and colleagues (2005) focused on culturally specific strategies that Chinese patients used to cope with advanced cancer. These are all valuable studies in understanding the needs and specific problems encountered by the Chinese patients in adapting to the cancer experience in Australia. However, they had not systematically explored how the experiential perspective of Chinese patients and their carers could inform the development of effective and culturally appropriately interventions and social work practices catering specifically for this group of migrants.

HEALTH BELIEFS, STIGMA AND THE ROLE OF FAMILY IN HEALTH CARE IN CHINESE CULTURE

In traditional Chinese culture, health is considered ultimately as a matter of balance or harmony. Maintaining good health is to strike a balance between ‘yin’ (represents femininity, the moon, cold, darkness, material forms and submission) and ‘yang’ (represents masculinity, the sun, heat, light, creation and dominance) as well as internal

and external factors that can pull one towards excesses in many different ways (Chen & Swartzman, 2001; Hui 1999a). Becoming ill thus stands for a loss of equilibrium, failure of the sick person in following a positive path of life, or simply lack of self-discipline. It is a matter that has direct relationship to moral uprightness and is often perceived as caused by neglecting one's filial duties or breaking down in interpersonal networks. Protracted diseases like cancer and mental illness are particularly stigmatized in the Chinese culture for not only causing great disability and suffering but representing moral defects and sins committed in a past by the ill person (Papadopoulos et al., 2007).

The Chinese society is a hierarchical system based on family and kinship networks where personal identity is clearly differentiated and defined in terms of the system of interpersonal relationships in which an individual is involved (Fei, 1992). The Chinese culture held this wider network responsible for the individual's behavior and welfare. As a result, social stigma caused by illness can quickly move from the affected individual to his or her family group and bring extreme shame and guilt to the group as a whole or even to the ancestors. This 'family-oriented' stigma can devastate the reputation of a family group and result in a kind of social death that threatens the group's perpetuity (Bedford & Hwang, 2003; Bedford, 2004; Yang et al., 2007). For fear of being ridiculed and 'losing face' and to protect the family, it is not uncommon that the Chinese tend to deny the existence of or disguise the seriousness of cancer suffered by themselves or their family members.

At the same time, the Chinese family does play a quintessential role in accommodating needs and channeling health care services and making medical decisions on behalf of the patients (Chen & Swartzman 2001; Hui, 1999b). It is a traditional belief that the family has the responsibility to take good care of its members. A sick person is thus expected to seek help from immediate and extended family before turning to professionals and the government. This family-centered model of health care service is significantly different from the patient autonomy model that prevails in the western societies (Ong, Michael & Jiade, 2002).

The brief discussion in this section demonstrates that reaction of the Chinese to illness is ground in its own cultural framework where Chinese social norms may shape the way physical symptoms are reacted to and the degree to which support or services utilized if at all. As research has revealed, many of these health care beliefs and practices were preserved in the Chinese migrant communities and survive into contemporary western societies (Green et al., 2006; Jovchelovitch & Gervais, 1999; Lai & Chappell, 2007; Lee et al., 2001; Wong-Kim, Sun & DeMattos, 2003).

METHODS

The researchers employed the method of in-depth interview to collect information from the Chinese community in Brisbane. A total of eight cancer patients, five carers and eleven stakeholders were interviewed in the study to canvass their experiences, problems and needs in coping with cancer or in helping cancer patients. While the patients were invited to share their personal experiences of cancer, the carers and stakeholders further

articulated their needs for services that could support the care they offer to their loved ones. The information gathered provides valuable insight in the design and delivery of culturally appropriate interventions for this migrant group.

The cancer patients and carers were recruited through personal contacts or referrals by ethnic community associations and health workers. The snowball technique was used in recruiting participants because a reliable sampling frame of the Chinese population is not readily available. This lack of an adequate research infrastructure within minority ethnic groups is commonly acknowledged (Sin, 2004). As an attempt to broaden the source of informants, the investigators also appealed to the Chinese community members to contact them through the local ethnic radio program. Table 3 indicates the demographic profile of the patient and carer samples in the study.

Table 3 **Profile of Cancer Patients and Carers**

| | Patient (N=8) | Carer (N=5) |
|-------------------------|----------------------|--------------------|
| Age | | |
| 30-45 | 4 | 2 |
| 46-60 | 3 | 2 |
| 61-75 | 1 | 1 |
| Gender | | |
| Male | 4 | 2 |
| Female | 4 | 3 |
| Marital Status | | |
| Married | 7 | 5 |
| Divorced | 1 | 0 |
| Religion | | |
| Catholic | 3 | 2 |
| Christian | 3 | 3 |
| None | 2 | 0 |
| Cancer Diagnosis | | |
| Colorectal | 1 | - |
| Liver | 1 | - |
| Lung | 2 | - |

| | | |
|--------------------------------|---|---|
| Nasal | 1 | - |
| Stomach | 1 | - |
| Breast | 2 | - |
| Relationship to Patient | | |
| Spouse | - | 4 |
| Children | - | 1 |

The eleven stakeholders interviewed in this study were service providers and community leaders who have direct contact with cancer patients within the Chinese communities in Brisbane. They include general practitioners catering for Chinese clientele, medical social workers in local hospital who worked closely with Chinese cancer patients, leaders and community social workers from community and religious organizations, and selected Chinese herbalists who are experienced in treating cancer cases. Table 4 summarizes characteristics of these key informants.

Table 4 Profile of Stakeholders

| Case | Gender | Post | Type of Work/Organization | Year of Service in Brisbane |
|------|--------|----------------------|------------------------------|-----------------------------|
| 1 | M | General practitioner | Private practice | 9 |
| 2 | M | General practitioner | Private practice | 17 |
| 3 | F | Social worker | Medical social work | 2 |
| 4 | F | Social worker | Medical social work | 5 |
| 5 | F | Coordinator | Community care service | 12 |
| 6 | F | Coordinator | Community care service | 18 |
| 7 | M | Chairperson | Community organization | 11 |
| 8 | M | Priest | Religious service (Catholic) | 40 |
| 9 | F | Coordinator | Religious service (Buddhism) | 4 |
| 10 | M | Chinese herbalist | Private practice | 36 |
| 11 | F | Chinese herbalist | Private practice | 28 |

The reasons for involving these stakeholders as research participants are two-fold. First of all, they are key informants that play a quintessential role in providing social and medical support, cultural activities, and welfare as well as care services to the Chinese community in Brisbane. By doing so, they have accumulated vast experience in

interacting with Chinese cancer patients in different stages of their illness. These experiences are invaluable for understanding needs and problems of the Chinese patients as well as for designing culturally appropriate care service for them. Secondly, the observations of these stakeholders could complement, enrich, and at times, verify accounts provided by the cancer patients and their carers. As cancer remains taboo in the Chinese community, it was not uncommon that patients declined to talk about or to explain their illness and experiences in detail. It is also important to note that the patients and carers whom agreed to participate in the study were usually those who had had some successes in overcoming their illness and were thus more willing to share their experiences. In such a case, observations of the stakeholders help to fill the gaps and offer further information on ways of how Chinese patients and their families cope with cancer. To summarize, the inclusion of stakeholders in the study is an arrangement to negotiate the issue of cultural sensitivities in the recruitment and solicitation of information from under-represented populations (Pfeffer & Moynihan, 1996; Rawaf & Bahl, 1998).

Each interview ran for approximately an hour and a half and following a list of semi-structured questions to elicit personal, first-hand experiences of the interviewees. Table 5 outlines themes of discussion and guiding questions pertinent to each theme.

Table 5 Themes and Guiding Questions of the Interview

| Theme | Guiding Question (for stakeholders) | Guiding Question (for patients and carers) |
|--|---|---|
| Attitude & Beliefs | <p>How is cancer perceived in Chinese culture?</p> <p>How do patients cope with the prognosis of cancer?</p> <p>Are Chinese patients open to talk about their illness and problems?</p> | <p>How would you describe cancer?</p> <p>What do you think are the causes of cancer?</p> <p>Do your friends know you have cancer? Did you have any reservation about telling them?</p> |
| Support System | <p>Who are the carers of Chinese cancer patients?</p> <p>What is the role of family members/relatives in caring for the patient?</p> | <p>How did you come to terms with your illness? Whom did you turn to for support?</p> <p>How did your family react to your condition? How does/did your illness affect your family?</p> |
| Access to & Quality of Care | <p>Do Chinese patients receive adequate medical treatment and care in Brisbane?</p> <p>What are the main obstacles preventing patients from accessing quality care and support services?</p> | <p>What difficulties did you face and what services did you find helpful in assisting you in coping with the problems you had?</p> <p>What do you think about the care you have received from the health service?</p> |
| Intervention & Empowerment | <p>What are the best ways to empower/support Chinese patients?</p> <p>What should be done to better disseminate information about cancer prevention, care and supportive services for cancer patients within the Chinese communities?</p> | <p>Not applicable.</p> |
| Service Needs | <p>Not applicable.</p> | <p>What could be done on a community wide basis to help to improve the quality of life of those who have cancer and their carers?</p> <p>What experiences did you have in participating in support group or counseling (if applicable)?</p> |

The researchers followed the grounded theory tradition in the process of data analysis (Glaser & Strauss 1967; Strauss & Corbin 1998). According to Strauss and Corbin (1998: 158), the grounded theory approach is ‘a *general methodology* for developing theory that is grounded in data systematically gathered and analyzed’ (original emphasis). The approach aims to develop a comprehensive account of a phenomenon that identifies the major constructs, their relationships, and the contexts and processes in which the phenomenon emerged. All of the interviews were taped and transcribed. The transcriptions were checked by each of the researchers to ensure information was correctly recorded. The researchers then coded the transcriptions separately to identify underlying concepts and ideas. These observations and notes were later put together and compared. The practice of separate coding minimized individual bias in interpreting the data. The use of stakeholder interviews to complement and verify accounts of the cancer patients and their carers was another device used to increase the validity of the study.

RESULTS

The interviews revealed that among the Australian Chinese cancer as illness is conceptualized and grounded in a traditional cultural framework. Not only is the illness perceived as something extremely unfortunate and negative, it is stigmatized as a social disgrace for both the sick individual and his or her family. As a result, the Chinese tend to keep the news of cancer within the family and may decline to seek external help until the burden of care is no longer manageable. Family thus played a quintessential role in the provision of care of Chinese cancer patients. Supportive services targeting cancer patients or their carers thus have to take into consideration these cultural practices and norms.

Perception of and Stigma attached to Cancer

All Chinese patients and carers interviewed agreed that when diagnosed having cancer, it was generally taken as a sign of ‘imminent death’, or *xung do ji shao* (‘more evil than good’). Not surprisingly when interviewed, many informants, particularly cancer patients, avoided using the word ‘cancer’ altogether and euphemism was regularly employed in describing their condition,

When I went for a checkup, my doctor found that I had a ‘lump’ in my body, and that was the first time when I found out that I had this illness.

I have been struggling with this ‘malignant tumor’ for quite a while – sometimes it gets the upper hand on me but in other times, I feel quite well.

When I found out that my wife had some ‘abnormal cell’ growth in her body, of course I felt very distressed.

While most patients had a basic knowledge of the causes of cancer, folk or mythic accounts continued to play a role in their understanding of the disease. A wide range of explanations was given by the patients about the possible causes of their illness. One patient, for example, decided he had cancer because he had hurt himself during a fall some years ago. In his view, ‘I have not been well since then – my body fluids are out of balance and everything else seems to go wrong too.’ Another patient who is still struggling with his stomach cancer similarly came to the conclusion that an unhealthy diet was the main cause,

it was all because too frequently I had *char-siu* [barbecued pork] for lunch when I was young. You know, it was convenient and easy just to get that for lunch, and it was delicious. I just didn’t know that barbecued stuff is carcinogenic.

Along the same line, a patient suffering from lung cancer attributed her problem to the frequent contacts she had with asbestos when she was growing up in China. But then, she also believed that bad *feng-shui* [geomancy] had contributed to her illness as well,

I was told where I put my bed in my bedroom was problematic because it was not facing the right direction, and it attracted bad *feng-shui* for my health.

The above examples illustrate that myths about the cause of cancer do prevail in the Chinese community. Overall, the Chinese patients interviewed did not consider the ways folk and medical interpreted causation of cancer were incompatible and they would shift from one explanation to the other with conviction according to the context of communication.

As the Chinese patients treated cancer with fear and considered it as something incurable and related to improper deeds or practices, most felt emotionally overwhelmed, and experienced a mixture of feelings of shame, guilt, uncertainty, fear, doom and anxiety. Many were worrying about how cancer would alter the way they look as well the way they would be received by others. Specifically, concerns about the side effects of chemotherapy such as massive hair and weight loss that would make them look visibly different, had caused them much anxiety. As a patient admitted to the interviewer,

I don't want to look different. People will start asking me why I look different than before and they will treat me differently. I just want to be treated as a 'normal' person. If my friends find out I have cancer, they will stop seeing me. They all fear that will catching this incurable disease from me. Or, they just think people with my condition couldn't do anything except for being seriously sick....

Most importantly, they believed that the illness also stigmatized their family publicly. As one breast cancer patient put it,

I felt guilty about my illness because I felt I must have done something wrong and I was dragging my family members into looking after me... I just couldn't help thinking I had disgraced my family because my illness must have some relation to whatever I did wrong previously to people.

Indeed, most of the patients and carers indicated that they felt uneasy to speak openly about the illness with people outside of their family circle or close friends. As another patient indicated,

[Having cancer] makes me feel shameful about my condition, and that I have caused my family to lose face [being sentenced to death]. I just don't want to talk about it with anyone outside my family in most circumstances.

For many of the interviewees, the practice of preventing others from finding out about their illness was a matter of self-protection,

When people found out I was not well, some were very sympathetic and considerate, but there were others who felt otherwise and said things that were very hurtful. Like, this illness is a punishment for some horrible things I did before to people, and I deserve what I get... My husband and my children heard the gossips and they felt equally hurt.

This is my way of protecting my family and myself. The Chinese migrant community in Brisbane is so small that as soon as someone finds out about your illness, everyone in the community will know about it. They'll start gossiping and soon people will even avoid you and your family as if they will catch something from you. I just don't want to be treated this way.

Observations of the stakeholders confirmed that cancer was a taboo subject in the Chinese community. A priest at a local church noted that even within the fellowship of a church, people were still reluctant to be open,

You'll see from time to time in the church's newsletter, there are notices requesting members of the church to pray for certain church members who are suffering from cancer or some serious illness. Yet you'll be hard pressed to find a single Chinese name in there. Even they [the patients and their family members] belong to this church, they still don't want others to know about their identity, and they want to keep it a secret.

This observation is shared by other stakeholders interviewed in the study. In particular, they indicated that cultural taboo was one of the major barriers to accessing help and psycho-social

support among Chinese patients. The social workers and service coordinators of ethnic organizations had mentioned cases where patients simply denied having the problem or turned down their offers for help.

Social and Cultural Support System

Traditional Chinese culture places an exceptional value on filial piety and would expect the family to look after its own dependents. The experiences of the Chinese patients confirmed that this is also the case in Australia. All informants agreed that family support was essential in helping them fight cancer. During the interviews, patients described how their family had participated in both making medical decisions and providing care and managing almost every aspects of their life, from interpretation, transport and accompaniment to medical consultation, emotional support and day-to-day care. Women in particular, played an important role in care provision. One patient remembered,

When I had my first big operation, my mother and sister came to Brisbane to look after me all the way from China. They had prayed for me outside the operation theatre and they performed all the domestic chores for me when I returned home from the hospital. I couldn't come through the whole thing if it were not for their help and support. You couldn't expect others doing this if they weren't your family, could you?

Carers, on the other hand, admitted it was a 'natural' thing for them to take on the duties caring for their family members when they were ill. As the eldest son of a cancer patient, it was not an easy task but had to be done,

Yes... I have to make time to take my father to see the specialist and to receive treatment. This definitely made my work harder, but you've got no choice – he's my father and it is my responsibility to take care of him. My mother's English is no good and I'm the only family member who is most suited to take him to the hospital. It's not that I don't trust the medical

system in Australia. There are interpreting services available and I could request these services; but it really makes a big difference if a family member is there.

The stakeholders agreed that the family was the primary source of support for Chinese cancer patients in Brisbane and family members were willing to share the caring duties where possible. A social worker of a public hospital observed that,

the supports offered by Asian families to cancer patients are impressive. Every aspects of life of the patients are well look after with relatives and family members taking turns to share the burden. What they did is amazing!

The two medical practitioners interviewed concurred with this observation. They both agreed that the quality of family support a cancer patient received was one of the determining factors that affected the prognosis and life expectancy of Chinese patients.

However, reliance on relatives to take up most of the care duties did create tremendous pressure on family members. This might also cause delay on seeking for external support when the kinship network was no longer capable to cope with the demand of duties of care. A Chinese community worker commented that

Many patients think they can cope with cancer themselves or by relying on their own family without realizing that this will create a huge pressure on their family members and relatives. They won't seek external help until the situation is most desperate and this always makes things more complicated and difficult.

There were instances that cancer could help bringing the family together, however. For instance, several patients reported that they had relatives calling long distance from overseas to express their concerns and support. They also had relatives and friends travelling from their home countries to visit them. A patient indicated that his three daughters came home much

earlier when they finished work and spent much more time with him since they were told the prognosis. However, as the situation continued, conflicts and tensions within the family would also emerge, particularly when all members began to experience the mounting pressures of performing care duties. According to some stakeholders, disagreements on medical decisions were commonplace and it was not unusual to find a family began to break up immediately after the cancer patient died.

A related concern articulated by all interviewees was the lack of support offered by the health system to carers in Australia. They felt bitter that while there are many services provided for cancer patients, few were available readily to assist carers who are under extreme pressure in the course of looking after their family members. The wife of a Chinese cancer patient, for example, found it difficult to cope with the increasing demands both her husband and her family made on her:

To take care of a cancer patient at home is a very demanding job. I really hope that someone could help me out — getting shopping or simple household chores done. Having to care for someone full-time at home, it's virtually impossible to get anything else done without assistance. It's very hard.

For carers who had poor command of English, the situation was worse. This was illustrated by the account given by a cancer patient in the study,

When I had the operation [to remove part of the lung], my mother came all the way from Shanghai to look after me. She did not speak any English, was not familiar with Brisbane and did not know how to drive. I was too weak after the surgery to leave my bed and my mother had to look after everything. I had applied for home care service but my application was turned down because I was considered having a full-time helper at home. While this was the case, what people did not realize was that my mother had to do all the shopping and carrying the groceries home on foot twice a

week walking for 40 minutes. You could imagine how difficult it was for her. I felt very guilty about the whole thing.

While family remained the principal source of support for cancer patients, some also drew strength from religion or faith. Half of the patients interviewed in the study attributed that religious beliefs or spirituality had made it much easier for them to maintain a sense of optimism in dealing with their condition.

Methods of Intervention and Empowerment

As indicated earlier, fear and stigma associated with cancer along with the existence of relatively strong family ties could prevent or delay many Chinese patients and their families from seeking external help and support. It was understandable that likewise they were reluctant to talk about their sadness, sorrow and grief they had experienced with ‘strangers’ outside of their families. This made it very hard for social workers or community organizations to reach out to them, particularly at a strategic time when they were in their early stages of cancer. A community worker felt both frustrated and disappointed at the situation,

The patients and their family members want to keep the matter so much within the family that they did not want anyone else to help. It is not uncommon to hear patients tell you that they don’t have cancer and turn down whatever helps you offer them... Even when they accept the service you provide to them, they want you to keep it in the dark from other people they know; or else they would just break away from you.

Likewise when interview, one of the informants, a Catholic priest, noted that their Chinese church members were not so different – cancer patients preferred to attend private services or engage in small prayer groups to prevent others from finding out they had cancer.

Understandably successful outreach work was hard to come by, and even when there were successful cases, it was rare to find Chinese cancer patients and their carers meeting openly in groups to share their experiences and offer each other support. A patient informant explained was blunt about his reason in declining to participate in a local support group,

When you have so many people giving you support at home, there is really no point to be part of a support group....

This has certainly frustrated service providers and led them to develop a certain stereotype about Asian cancer patients. A social worker interviewed, for example, had this to say,

This certainly is an Asian thing. People just don't get used to the idea of sitting down and sharing their emotional problems and personal feelings with one and another even among people from their own culture. I once organized a support group for carers with disabled patients at home and I found it extremely difficult to maintain the number of participants. A support group for cancer patients or their careers will have to face the same problem.

Another community worker concurred,

Perhaps this will happen someday, but for the moment, our understanding is that Chinese people are still not used to the idea of openly talking about their problems in front of strangers. I think we should respect that.

Nonetheless, based on their extensive experience in serving Chinese–Australians, some stakeholders did manage to develop strategies of intervention that are effective in empowering the patients in a culturally sensitively manner. A service coordinator of a voluntary group in the Taiwanese community reported that they had been experimenting with an intervention method that was now commonly accepted in Taiwan,

... without being too obvious about offering our supportive service, we just left the patient and his/her family members a pre-recorded video tape containing various people reflecting their own experiences dealing with the illness – you know, talking about their own fear, loneliness, depression as well as their hope and optimism – together with a number of publications... this is the best way to help the patients and their family members to get over the initial fear and shame, learning through the video that they are not alone suffering from the consequences of this debilitating illness and that others are willing to talk about it. We also leave them a contact number so that people can reach us later on.

Feedback from the informants have shown that Chinese patients and their carers felt less threatened by watching other people talking and sharing their cancer experiences on tape or disk and they confessed they were empowered by learning the information and ways for coping with the disease in this manner.

For most patients and carers involved in this study, most spoke positively about the quality of medical services they had received in Australia. However, they were less impressed by the long waits for medical treatment or examination, and the lack of interpretation service in hospitals had also become a major concern.

Certainly one can make an appointment for accessing services for language interpretation. However, in practice this is not always possible particularly when one doesn't know exactly whether or not one would have difficulties in understanding everything the doctor says. Sometimes it is not very practical to have Chinese interpreters involved in moments that are supposed to be very private... At the same time, information on many government medical or social services is simply not provided in the Chinese language and one has to spend much time locating them. For us who have only a basic level of English proficiency, the process is often very hard and time consuming.

This probably explains why many of the patients interviewed preferred to consult general practitioners who speak their own language or dialect. For them, this was not only practical but also psychologically reassuring.

I get to know more about my medical condition when my doctor explains things to me in Chinese. However, most important is that psychologically when you're seriously ill, being able to understand your situation in a language with which you are familiar is simply more comforting.

The problem of communication or interpretation also came to the forefront when patients were staying at home. Language barriers were one of the major contributing factors to the under-use of health care services among the Chinese, especially those who had arrived in Australia in more recent times. One of the community workers interviewed perceptively recalled her experience,

There are things that might appear trivial to us but they cause much inconvenience to these cancer patients and their family members. For instance, there were a couple receiving home care services and they had difficulties explaining to the Blue Nurse [home care service provider] worker that they wanted to move their bed to the other side of the living room. In another case, the family members of a terminal cancer patient were extremely anxious about the fact they couldn't even call an ambulance in case of emergency because they didn't speak much English.

In the end, the community worker intervened and offered the couple the number of one of her staff's mobile phone so that they could contact the community organization for emergency services. Although it was not a direct line and some delay was unavoidable, the arrangement did alleviate the anxiety of the patients and carers.

DISCUSSION AND CONCLUSION

The present study focuses on accounts of Chinese patients, their caretakers and community stakeholders on their experience of cancer or taking care of a cancer patient. Owing to limited

sample size and the use of non-random sampling method, caution is needed when generalizing findings of this study to the larger population or other ethnic groups. The information collected in this research does, however, throw light on the importance and urgency of devising culturally appropriate interventions for patients with an ethnic minority background.

Specifically, this study has found that traditional Chinese health beliefs and practices have been preserved in the migrant community in Brisbane. This observation is in consistent with research findings on Chinese communities in America and Britain (Chen, 1996; Prior, Chun & Huat, 2000). Interviews with stakeholders, carers and patients of Chinese background in Brisbane highlighted a number of culturally-specific experiences of cancer. Key informants indicated that cancer was generally associated with fear, anxiety and dread in Chinese traditions. The matter remained taboo in diasporic Chinese communities and discouraged patients from seeking external help and voicing their feelings. The family did play a key role in looking after Chinese cancer patients. However, the reliance of patients on family members also imposed huge pressures on the familial network. Overall, these findings deepen our understanding of the situation and coping strategies of Chinese cancer patients in Australia. They also provide practical guidelines for devising culturally appropriate interventions for ethnic minorities. There is evidence that ethnic minority groups in many countries are under-using palliative care services or receiving inadequate information and support in the diagnosis and treatment phases (Ashing Giwa & Ganz, 1997; Brenner 1997; Free et al., 1999; Mandelbatt, Yabroff & Kerner, 1999). While there is a general recognition that health care services in Australia are of very high standard, a large majority also feel that service provision geared towards a hegemonic mainstream alone does not meet the diversity of needs within a multicultural society. There is increasing demand for a mosaic of culturally appropriate

services for cancer patients and their cares that have a culturally and linguistically diverse background.

Resnicow and his colleagues (1999) argued that cultural sensitivity of health intervention can be conceptualized in terms of two primary dimensions: *surface* and *deep structure*. Surface structure involves matching intervention materials and messages to observable social and behavioral characteristics of a target population (such as using language, music, brand names and clothing familiar to the target group). It refers to the extent to which interventions fit within the experience and behavioral patterns of a specific culture. In contrast, deep structure involves incorporating the cultural, social, historical, environmental and psychological forces that influence the target health behavior in the proposed target population. Paying attention to the deep structure thus involves appreciation for how social norms, family and society of the specific culture influence the target behavior. As Resnicow et al. (1999: 12) pointed out, whereas surface structure generally increases the ‘receptivity’, ‘comprehension’ or ‘acceptance’ of messages, it is the deep structure that determines program impact.

Findings of this research bring to light a number of issues pertinent for the delivery of care to cancer patients in the Chinese migrant community. These issues are important as they highlight critical points of interventions in this particular community as well as revealing how traditional values and practices may shape the utilization and reception of care services. In the course of interviewing patients and caretakers, it became apparent that the term ‘cancer’ has taken on added meanings and stigma in the Chinese culture, healthcare workers or service providers should be careful in communicating with the patients and their carers and be very sensitive to the demand of privacy and enclosure. Findings of the interviews indicated that an ‘indirect’ and sensitive approach using prerecorded videos and DVDs of testimonial seminars

was very effective means in empowering cancer patients of Chinese background. In the future, information on cancer screening and prevention can also be distributed through this channel (cf. Ma et al., 2004).

Given Chinese patients preferred to keep the news of cancer within the close family circle and rely on family members for help and support, it is not uncommon that the family only sought external help when they were no longer capable of providing care for the patient. The acute needs for intensive care demanded by cancer patients were often difficult to come by at short notice, especially when the patients were not in the queue for service. The reliance on family care had overloaded family members and created tension. For this reason, social work interventions should also target carers as clients requiring services and support.

In these contexts, a community-based strategy for easing the loads these patients and their families carry should be explored. Community organizations such as the church or traditional temples, women's groups or associations, and the social worker network should be a strategic starting point as they all have unique resources and approaches to develop social capital within the Chinese community. At present, although there is a range of services provided to members of the Chinese community, few are devoted to offer assistance most needed by cancer patients and their carers. Respite care, counseling, help lines, and home visits for cancer patients and their families are commonly not part of the services delivered by organizations in the ethnic community. Given that these services may require specialized training and resources, a community approach to establish and deliver these services would look most promising.

Regarding the lack of knowledge about cancer and the existing services among Chinese–Australians, findings of this study indicate that clinics and general practitioners were important locations for Asian migrants to learn about cancer. Information of the disease and services could be displayed and distributed in these venues. Education on cancer prevention should also be more effectively carried out through local ethnic community associations, ethnic media and service providers.

To conclude, the increasingly social and cultural diversity faced by the public health sector in western nations has seen a greater need for delivering mainstream health services in a culturally sensitive and appropriate manner. The cancer experience of the Chinese community in Brisbane has shown that in meeting the goals of providing public health for all in a nation of social and cultural diversity, a contingent and reflexive mapping and understanding of the needs and access of its minority populations is often enlightening (Green et al., 2006).

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