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# Chinese Cancer Support Group Study: Key Findings

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**Kirsten Bell, PhD**  
**Joyce Lee, MA**

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## 1. INTRODUCTION

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Over the past few decades, cancer support groups have emerged as a key mechanism for addressing the psychosocial needs of cancer patients and their families, and provide an important means of helping patients cope with life during and after cancer diagnosis and treatment. Such groups have produced “remarkably positive effects on the psychosocial functioning of their members” (Gottlieb & Wachala 2007: 396). A meta analysis of randomized controlled trials (Zabalegui *et al.* 2005) evaluating support groups for cancer patients found evidence that they improve emotional states, diminish depression and anxiety, and improve quality of life and marital relationships.

Although cancer support groups have demonstrable benefits for those who participate, available evidence indicates that they enroll only a small minority of patients (Mathews 2000; Coreil, Wilke & Pintado 2004; Butow *et al.* 2007; Avis *et al.* 2008). Moreover, participants tend to be white, middle-class females (Gottlieb & Wachala 2007; Mathews 2000; Cella & Yellen 1993; Grande, Myers & Sutton 2006; Magen & Glajchen 1999; Taylor *et al.* 1986; Docherty, 2004). While cancer support groups are not universally attractive contexts for addressing psychosocial issues (Gottlieb & Wachala 2007), the white, middle class composition of existing groups may serve to limit the participation of people from minority ethnic and racial backgrounds who might otherwise be interested in attending. Indeed, US studies of breast cancer support groups have found that black women perceive such groups to privilege white women’s experiences with the disease at the expense of their own (Mathews 2000; Moore 2001).

For immigrants from non-English speaking backgrounds, language issues also pose a barrier to participation in cancer support groups (Avis *et al.* 2008; Bui *et al.* 2002). However, even if patients are fluent in English, language and communication issues can still occur. Avis *et al.* (2008) found that participants from non-English speaking backgrounds felt that using English to discuss their experiences led to misunderstanding. Although support groups for specific linguistic and ethnic groups might increase their participation, it is unclear whether people from these communities wish to be segregated in this way (Butow *et al.* 2007).

This report will examine the key findings from a qualitative study of the Vancouver Cancer Centre’s Chinese Cancer Support Group – one of the few available support services explicitly tailored to meet the needs of Chinese cancer patients, who constitute the largest visible minority in Vancouver, Canada.

## 2. METHODS

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### Research Design

This study applied a qualitative design utilizing participant observation and in-depth interviews as the primary data collection methods. This methodological approach is consistent with a number of prior studies of cancer support groups (Mathews 2000; Coreil, Wilke & Pintado 2004; Cope 1995; Arrington, Grant & Vanderford 2005; Ussher *et al.* 2006; Oliffe *et al.* 2008).

### Setting

The setting was a professionally-facilitated drop-in support group for Chinese cancer patients and caregivers held in the Vancouver Cancer Centre at the British Columbia Cancer Agency (BCCA). The group was created in September 2006 and meets on a monthly basis; the 2-hour meetings consist of both psycho-education and support. Meetings begin with a round of introductions, whereby participants take turns introducing themselves by identifying their name, role (patient or family member), cancer type and treatment stage.

In the first half of the meeting, the facilitator leads participants in the discussion of a set topic by means of a reflective question. Participants' responses are noted on a flipchart. Participants are also invited to share about challenges and coping skills stemming from their experience of cancer, as well as other concerns they might wish to raise. Following a 15-minute break, generally a guest speaker is scheduled for the second half of the meeting (see table 1 for summary of presentation topics during fieldwork period).

**Table 1. Guest presentation topics between September 2007-April 2008**

Month	Topic
September 2007	Support – no scheduled presentation
October 2007	Guest speaker on library services
November 2007	Guest speaker on palliative care
December 2007	Support – no scheduled presentation
January 2008	No scheduled meeting
February 2008	Support – no scheduled presentation
March 2008	Guest speaker on homecare services
April 2008	Guest speaker on stress and mindfulness meditation

### Data Collection & Analysis

The BCCA ethics board provided approval for this study. Prior to conducting the fieldwork, approval was obtained from Sandy Kwong, the Chinese support group facilitator, and Kirsten Bell and Joyce Lee attended a support group meeting in order to explain the goals of the project to the group and ascertain their level of interest in taking part in the study. The group members present at the meeting were very enthusiastic about the project and provided verbal consent for the research; based on this positive response, fieldwork was initiated. Bell, a medical anthropologist, provided Lee with training in ethnographic methods and Lee conducted the fieldwork and interviews under

Bell.'s supervision. Lee is of Chinese origin, and is proficient in English, Cantonese and Mandarin.

As the support group has a drop-in format, obtaining informed consent from the group participants was an ongoing challenge. In order to facilitate the consent process, a number of measures were undertaken. First, prior to each scheduled meeting the facilitator attached an addendum to her emailed reminder notice providing information regarding the project and requesting members to contact her if they were uncomfortable with Lee's presence at the meetings. Second, Lee approached new members at the beginning of meetings to explain the project and give them written information (in Chinese) about the study. Third, during each meeting Lee introduced herself and reminded participants of her presence in the group.

Immersion in the research setting involved participation in and observation of the monthly cancer support group meetings (N=7) held over the fieldwork period. Interaction with the group participants included informal conversations prior to and after meetings, and during tea breaks. Because of the group's drop-in format, the researchers and the facilitator decided it would not be appropriate to audio-tape the meetings. Rather, observational data were recorded in a notebook during the group meetings and written up into full field notes following the meetings.

Aside from the participant observation at the support group meetings, key informant interviews ranging from 1 to 2 hours were conducted with 7 group members (6 patients and 1 family member to seek further "clarification, explanation and validation" (Cope 1995: 473) of the fieldwork data (see table 2). Participants in the groups were invited to take part in an interview after fieldwork had been underway for several months. This helped to maximize the validity of the research because interview questions were generated through the participant observation itself, rather than in a laboratory or office (Sanjek 2000). It also served to reduce participants' anxiety about being interviewed, as they were familiar with the researchers by the time of interview (*cf. Ussher et al. 2006*).

Key informants received a nominal honorarium (a \$20 gift card) to acknowledge their time and contribution to the study. With the written consent of the informants, notes of all interviews were taken; only 4 of the 7 interviews were recorded, in keeping with the stated preferences of the interviewees. All interviews were conducted in Cantonese and covered basic questions including demographic information, personal experience of cancer, cultural issues for Chinese cancer patients, and participants' views on the support group itself.

**Table 2. Overview of key Informants**

Informant	Sex	Age range	Treatment stage	Time elapsed since diagnosis	Time in group <sup>b</sup>	Frequency of attendance group	of in
1 <sup>a</sup>	Female	20s	n/a	n/a	5 mths	Sporadic	
2	Female	60s	Post	2.5 yrs	1.25 yrs	Regular	
3	Female	60s	Post	2.5 yrs	1.33 yrs	Regular	
4	Female	70s	Post	4.5 yrs	1.5 yrs	Regular	
5	Female	40s	Post	1 yr	1 yr	Sporadic	
6	Female	50s	In	6 mths	1 mth	Sporadic	
7	Male	50s	In	3 mths	3 mths	Regular	

<sup>a</sup>Caregiver

<sup>b</sup> These numbers are based on informants' own estimates and it is unclear how accurately people remembered their date of entry to the group as there were some discrepancies in the dates estimates several informants gave.

Qualitative data analysis software was used in the initial stages of analysis to facilitate coding of the data. Under Bell's supervision, Lee coded the data using ethnographic coding processes (Emerson, Fretz, & Shaw 1995), involving open coding to identify any and all ideas and themes in the material and focused coding as the fieldwork progressed, whereby the transcripts and field notes were subjected to a line-by-line scrutiny on the basis of topics that had emerged as of particular interest. Field notes and interview transcripts/notes were then analyzed using ethnographic content analysis techniques (Altheide 1987). Ethnographic content analysis draws on numerical and narrative data to develop a systematic and analytic understanding of the data. Like grounded theory (Strauss & Corbin 1990), it is embedded in the *constant discovery* and *constant comparison* of situations, settings, images, meanings and nuances (Altheide 1987).

### 3. KEY FINDINGS

#### Composition of Group

During the fieldwork period 96 participants attended the group in total: 36.5% (N=35) were male and 63.5% (N=61) were female (see table 3). Sixty-two percent (N=59) of the group were patients and 38.5% (N=37) were family members. The range of cancer sites represented in the group was diverse, including lung, breast, prostate, stomach, nasopharyngeal, pancreatic, colorectal, gynecological, liver and blood cancers. Breast (30.8%), lung (17.3%) and nasopharyngeal (15.4%) cancers were the most commonly represented cancers in the group during the fieldwork period and participants with a range of prognoses attended, from people in active curative treatment, to those in palliation, to people who defined themselves as “recovered” (*hong fook jie*).

**Table 3. Characteristics of support group participants**

Characteristic	N	% <sup>a</sup>
First language		
Cantonese	84	87.5
Mandarin	12	12.5
Sex		
Male	35	36.5
Female	61	63.5
Role		
Patient	59	61.5
Family member	37	38.5
Attendance		
Regular <sup>b</sup>	5	5.2
Once <sup>c</sup>	57	59.4
Sporadic	34	35.4
Cancer type <sup>d</sup>		
Lung	9	17.3
Breast	16	30.8
Prostate	5	9.6
Stomach	1	3.7
Nasopharyngeal	8	15.4
Pancreatic	1	3.7
Colorectal	6	11.5
Gynecological (cervix, uterus)	2	3.8
Liver	1	3.7
Blood	3	7.5
Treatment stage <sup>e</sup>		
Pre treatment	5	10
In treatment <sup>f</sup>	30	60
Post treatment <sup>g</sup>	15	30

<sup>a</sup> All calculations based on N = 96, unless otherwise stated.

<sup>b</sup> Present at each meeting, missing no more than 2 consecutive meetings.

<sup>c</sup> One-timers included people who had not attended the group prior to the fieldwork period (this information was obtained from Sandy Kwong) and who only came once during the fieldwork period.

<sup>d</sup> Cancer type % based on N = 52.

<sup>e</sup> Treatment stage % based on N = 50.

<sup>f</sup> In treatment group included 9 palliative and 21 non-palliative patients.

<sup>g</sup> Post treatment group included 1 palliative and 14 non-palliative patients.

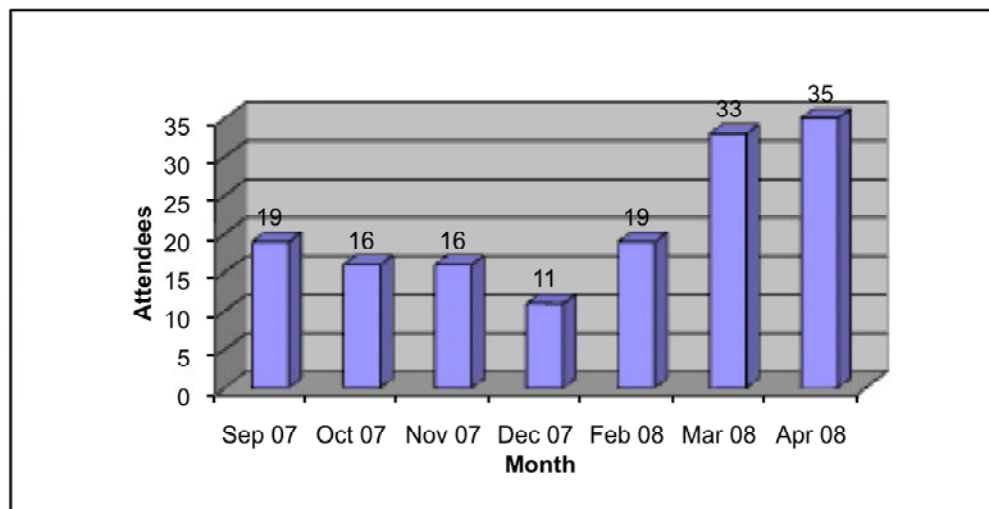
Interestingly, although the meetings were facilitated in Cantonese, the group also attracted a number of people whose first language was Mandarin (N=12, 12.5%). The presence of a substantial minority of Mandarin-speakers clearly highlights the lack of culturally- and linguistically-specific resources for such patients and the importance of the group as a resource and forum for ethnic Chinese in Vancouver, regardless of their linguistic background.

### Attendance Patterns

#### *Regulars vs. one-timers*

During the eight-month fieldwork period (September 2007-April 2008), there was an average attendance of 21 participants per meeting (range: 11-35) (see Figure 1). Interestingly, although the attendance at each group meeting was disproportionately large in comparison to other BCCA support groups, there were fewer regular attendees (N=5) than was evident in other drop-in groups. More than half (59.4%) of the people who attended the group came only once. There was one significant difference between the group regulars and one-timers: the majority of the regulars were “recovered” (*hong fook jie*) cancer survivors, while the majority of the one-timers were presently in-treatment.

**Figure 1. Attendance over Study Period**



As the majority of one-timers were in treatment when they attended the group, their failure to return may, in some cases, be explained by the difficulty of committing to a support group while undergoing cancer treatment. Indeed, observational evidence indicates that people are more likely to attend a support group after they have completed primary treatment than while they are undergoing it (Schippner 2001; Stanton *et al.* 2005).

Another possible explanation for the large number of one-timers is that a certain proportion of people may have come to the group not because they were seeking a support group per se, but because they were seeking *information* and there are few culturally and linguistically appropriate resources available for Chinese cancer patients (Chan, Law & Leung 2000). Thus, these participants may have been using the group

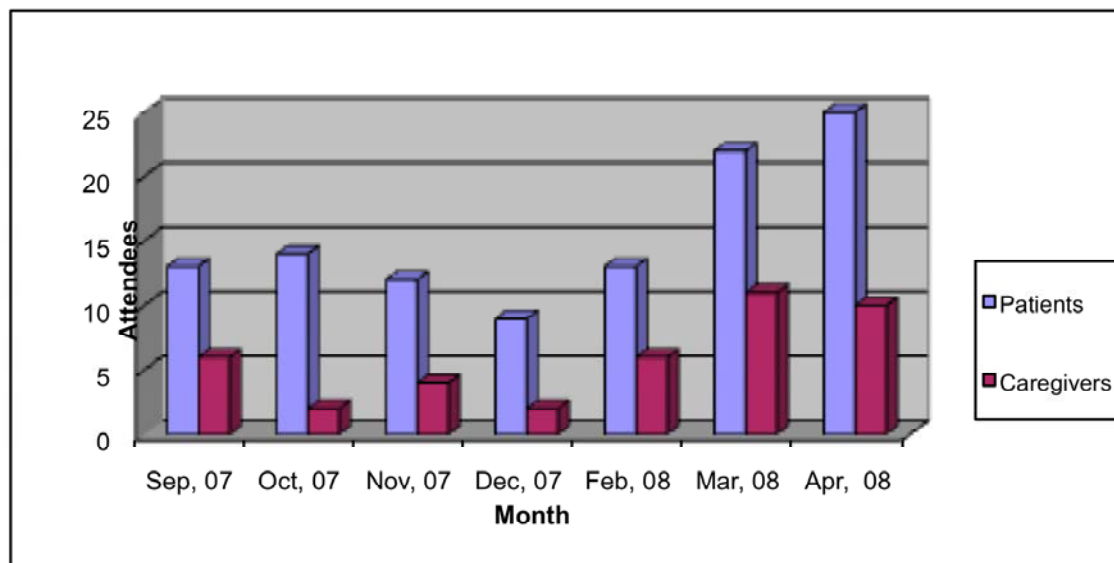
differently from how a 'traditional' support group is understood: as a one-off *resource* rather than as an ongoing support mechanism.

A proportion of these patients may also have been turned off by the reality of the supportive-expressive dimension of the group. As Mok (2001) notes, for many Chinese people, coping with illness is largely a private and family affair and such patients may have seen this as a public airing of their 'dirty laundry'. However, this is not to suggest that Chinese patients are 'culturally' incapable of finding benefit in support groups – indeed, support groups for Chinese cancer patients in Hong Kong have proven beneficial and effective (Chan, Law & Leung 2000; Mok 2000; Mok 2001).

#### *Family members/caregivers*

Another feature of the group attendance patterns was the prominence of family members in the group. Thirty-nine percent of group participants over the fieldwork period were family members – a proportion that remained reasonably consistent over the fieldwork period (see Figure 2). Also of note was the fact that often more than one family member of the cancer patient was often present at the meetings (e.g. a spouse and a child, or both parents, or both parents-in-law) – a phenomenon that is extremely rare in other cancer support groups. One extended family also attended the group, as several members of the family had cancer.

**Figure 2. Attendance breakdown by composition**



The composition of the group therefore appears to reflect the particularly important role of family in the lives of many Chinese cancer patients and survivors. However, despite their substantial presence in the group, family members generally did not appear to attend in their own right in order to receive support for their own needs, but rather to support the patient. This observation is congruent with one informant's comment that her role was to "stand by" her cancer-stricken loved one, citing the example of accompanying the patient on hospital visits as a means of rendering support. Thus, on the occasions when family members spoke, their contributions generally centered on clarifying ways to render instrumental support to patients.

### Content of Group Meetings

A diverse range of topics were covered in group meetings during the fieldwork period (see table 4).

**Table 4. Most common topics and subtopics of discussion in support group**

Topics	Subtopics
1. Interactions with healthcare professionals	- <i>Language barriers</i> - <i>Quality of healthcare services</i>
2. Coping with treatment & recovery	- <i>Exercise (qigong, yoga)</i> - <i>Importance of information</i> - <i>Being 'self reliant'</i>
3. Family & friends	- <i>Support from family</i> - <i>Worries about family</i> - <i>Impact of illness on family</i>
4. Treatment side effects	- <i>Pain</i> - <i>Eating issues</i>
5. Fear & anxiety	- <i>Fear of unknown</i> - <i>Anxiety re: asking for help</i> - <i>Anxiety while waiting for treatment</i>

### Topics and Themes

#### *Interactions with healthcare professionals*

By far the most common topic of discussion amongst support group participants was their interactions with healthcare professionals. For the most part, conversations on this topic focused on the language barriers participants' experienced, the issues this posed in receiving effective care, and heightened distress this caused them in coping with cancer and treatment. Group members regularly highlighted the limited availability of interpreters and the need for more Chinese healthcare professionals in the BCCA. These discussions echo the findings of previous studies of Asian-American cancer patients (Jin, Slomka & Blixen 2002; Ashing *et al.* 2003; Ashing-Giwa *et al.* 2004), which have similarly highlighted the importance of language in receiving quality care, and the need to be able to effectively communicate with healthcare providers in order to relay one's concerns and understand the advice received.

A second and related focus of discussion was the quality of care participants received from their GPs and staff at the BCCA. During the fieldwork period, many participants expressed gratitude for the care they received from healthcare professionals – which one person characterized as “first class”. Sandy Kwong (the facilitator of the support group and the only Chinese-speaking social worker in the BCCA) was often particularly singled out as a source of support and help for group members. However, a number of group members also highlighted deficiencies in the care they received, including long wait times to see specialists and for diagnostic assessment and treatment, a lack of promptness in healthcare professionals’ responses to their medical needs, and inadequate coordination and organization in their healthcare.

#### *Coping with cancer treatment & recovery process.*

Coping with cancer treatment and the recovery process were also a frequent source of discussion at group meetings. Although such discussions were facilitated by the structure of the group and the facilitator’s efforts to elicit sharing about coping strategies, many participants actively sought out such information in the group. The most commonly highlighted strategies for coping with cancer and the recovery process were exercise (especially *qigong* and yoga) and the use of Chinese medicine.

The value placed upon *qigong* and Chinese medicine amongst Chinese cancer patients has been noted in previous studies (e.g. Lui *et al.* 1997; Chui, Donoghue & Chenoweth 2005; Ferro *et al.* 2007). Chui, Donoghue and Chenoweth (2005) have argued that for Chinese patients, western medicine is seen as an active and aggressive approach to cancer, whereas Chinese traditions such as *qigong* and Chinese herbal medicine are seen to have a restorative affect on health. In discussing their use of *qigong* and Chinese medicine, several support group participants’ expressed similar views about the “nonlinear” approach to treating illness in Chinese medicine and the need to integrate western and Chinese approaches to treating cancer.

Aside from these strategies, other commonly mentioned ways of coping with cancer and the recovery process were the need to be informed about treatment and the disease and the value of “self reliance”. Studies of Chinese cancer patients (Mok & Martinson 2000; Mok 2001) have argued that fostering self-reliance is crucial in helping to empower Chinese cancer patients in dealing with the disease.

#### *Relationship with family & friends*

Another feature of support group discussions was the focus on family relationships. Issues raised reflected the interconnectedness between the care patients received from the family and the concern patients had for their family as they adjusted to the change in role from being a family caregiver to recipient of care. Thus, one female informant described the ways in which her illness had compromised much of her energy and her sense of helplessness in attending to the needs of family members. Another participant emphasized the importance of the woman’s role in the family, and how it impacts the family when the woman is found ill and unable to take care of other members. This inability to attend to family needs clearly provided a source of guilt and distress for several cancer patients and survivors in the group – particularly females. As Chan and Molassiat (2000: 22-23) note:

The Chinese concept of reciprocity (bao) may be linked to the participants' sense of role fulfillment, creating a network of role interdependency within Chinese society... a Chinese patient may feel detached and deprived when social functions are diminished or family activities unsatisfactory.

Overall, participants in the group also spoke very positively about the role of family in their experience with cancer and the importance of these relationships in helping them deal with the disease. Several members emphasized the sacrifices their children made in order to care for them physically and financially, and others mentioned the invaluable moral support their children and spouses provided. Indeed, the large proportion of family members in the support group provides testament to a widespread concern and strongly voiced desire to support cancer patients. However, participants highlighted that family relationships could hinder as well as help the cancer patient and several group members mentioned that Chinese professionals could be more helpful for cancer patients than family members. In some cases, people highlighted that the family might provide a barrier to care because of the stigma attached to cancer and their fear of letting others know, or not wishing to tell others because they assumed that help would not be forthcoming – thus effectively “shutting the door” on others.

#### *Side effects of treatment*

Treatment side effects of treatment were also a common focus of discussion at group meetings. First, participants commonly mentioned the pain connected with cancer and its treatment. Radiation therapy was particularly singled out as a cause of pain – which may be partially explained by the relatively high proportion of patients in the group with cancers that involve radiation as a central treatment (e.g., nasopharyngeal cancer). While some participants expressed that they could endure the pain as long as it helped in treating their cancer, others voiced considerable fears about pain in connection with advanced cancer – which some indicated they feared more than death itself.

It is well recognized in the anthropological literature that pain is a complex phenomenon and that the ways in which it is experienced and expressed are socially and culturally shaped (Kleinman 1988; Helman 1990; Delvecchio Good et al. 1992; Good 1994; Taussig 1980). Unfortunately, the experience of pain amongst Chinese cancer patients has not been well studied. One recent review of the literature on the pain experience of Chinese cancer patients (Edrington *et al.* 2007) found that Chinese cancer patients generally reported moderate to severe levels of pain and another study (Molassiotis *et al.* 2000) has found that pain is a strong area of concern for Chinese survivors of gynecological cancers in Hong Kong. However, few of the studies included in the review explored socio-cultural factors that might influence Chinese cancer patients' understandings and experiences of pain. This is clearly an area where substantial further study is needed.

Issues connected with food, eating and diet were also recurrent focus of discussion at support group meetings throughout the fieldwork period. Amongst ethnic Chinese, food is seen to be intimately related to health, and many foods are considered to have curative value (Chang 1977; Liu 2004) – views that are also dominant amongst Chinese migrants in western countries such as the UK (Jovchelovitch & Gervais 1999; Prior,

Chun & Huat 2000), North America (Liang *et al.* 2004) and Australia (Chui, Donoghue & Chenoweth 2005).

In the Chinese system, the notion of balance between the forces of yin and yang guides the classification and use of food for medicinal purposes; thus hot/cold, wet/dry and tonic/poisonous are categories ascribed to different foodstuffs on the basis of the effects they have on the human body (Koo 1984; Andersen 1988). In the case of cancer, certain foods are seen to 'cause' the disease, while other foods are beneficial in helping to 'fight' it (Mok & Martinson 2000; Simpson 2005; Papadopoulos *et al.* 2007). For this reason, eating ability has been found to be integral to quality of life (QoL) amongst Chinese cancer patients (Wong & Fielding 2008). A recent study of Chinese cancer patients in Hong Kong found that eating and appetite were significant predictors of QoL amongst patients enrolled in the study – an association found for all cancer sites. In light of these findings, it seems likely that the distress eating difficulties cause may be higher for Chinese cancer patients than for other cultural and ethnic groups.

#### *Fear & anxiety*

Participants in the support group also readily voiced fears and anxieties about cancer and treatments. As has been found in other studies of Chinese cancer patients (e.g., Lam & Fielding 2003; Papadopoulos *et al.* 2007), and, indeed, cancer patients more generally (Sontag 1990), cancer was commonly seen to be synonymous with death. Thus, participants often spoken of cancer as a “death penalty” and “time-bomb”, and the fear that the diagnosis generated. However, participants also spoke of the negative impact of harboring the “fear of death”, often using the phrase “scaring oneself to death” to emphasize that the fear of death would undoubtedly expedite one’s death. One informant specified overcoming fear as the greatest barrier among Chinese cancer patients, reiterating the need for a change in mentality in coping with cancer. In this vein, participants repeatedly commented on the importance of “letting go” (not ruminating about death), “accepting” dying as part of the life journey, and continuing with daily living while dealing with cancer.

#### *Summary*

Clearly, the meetings cover a wide array of topics, from physical symptoms to emotional concerns and support needs. Interestingly, there was a temporal dimension to the topics discussed in meetings: more pragmatic and practical issues (e.g. communication, coping) were raised initially and conversation moved towards discussion of more emotionally loaded topics over the course of the sharing. As Chan *et al.* (2000) have noted, expressing emotional issues to strangers is a phenomenon many Chinese cancer patients are unfamiliar with. Therefore, in the context of the support group these issues were broached indirectly, *after* the provision of information and practical coping tips. One informant made some interesting observations regarding this phenomenon, noting that participants in Anglo-Canadian cancer support groups tended to be more willing to talk about their emotions and spoke of a man in the Chinese group who took great courage to express his perspective on cancer only towards the end of the meeting. This structure also seemed to benefit newcomers to the group, whose affect tended to become calmer as the meetings progressed.

### **Role of post-treatment survivors**

In the Chinese cancer support group, the core members of the group were primarily female cancer survivors (*hong fook jie*). These women assumed a critical role in the support group, providing insights and comfort to newcomers who were wrestling with the fear and anxiety surrounding cancer diagnosis and treatment. Through their presence they served as testimony to the existence of “cancer overcomers”, instilling hope and confidence in other group members regarding the possibility of a life beyond cancer and the rigors of treatment.

However, in addition to sharing their experiences during group discussion, they also supported the group members in more concrete ways, initiating contact beyond the confines of in-meeting discussion to newcomers and extending practical advice and care (such as comforting, offering drinks/food, exchanging contact information) to distressed individuals. Several of these women explicitly highlighted their desire to help other patients and support the continuation of the group as an entity during key informant interviews. According to one:

When I remember [the difficulty of treatment], I will understand others' situation more. If I want to help others, this is very important... I am just a single person. If I don't care about the support group, and if everyone thinks in that way too, then, the group will be gone.

## 4. FEEDBACK ON MEETINGS

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### **Benefits of Group**

Overall, informants made very positive comments about the Chinese cancer support group. Two benefits were consistently highlighted in informants' and participants' discussions of the group: understanding and knowledge.

#### *Understanding environment*

Several informants noted that the common experience of cancer amongst participants in the group allowed them to be more empathetic to each other's pain than might be the case in other contexts and relationships (even those with friends and family). Often, informants spoke of "mutual support among patients" and "not feeling alone in the struggle when hearing of others' challenges" when commenting on the support group environment. One informant also noted that the supportive environment benefited family members as well as patients, and that it was particularly valuable for those patients and caregivers with little prior exposure to cancer.

Other informants highlighted the "relaxing" nature of the group because members are able to understand and empathize with each other. One informant commented that cancer patients can "understand each other precisely", even without the use of verbal expression to describe their experience. According to another woman:

A curious phenomenon is that when a cancer patient shares with another cancer patient, there is less concern, feeling that the person can understand him/her. Like, even now, when I talk to my family/relatives, they may not understand what I have said. But in the support group it will be understood. This is very important, the issue of understanding.

Informants felt that the relaxing environment allowed them to speak freely with other participants in the group "like friends", gaining understanding and mutual encouragement, which helped to reduce stress, anxiety and fear – "halving the burden" and allowing participants to feel "normal" again because of their similar and shared experiences. In a cultural context where cancer is stigmatized and some group members may not feel comfortable talking about their experiences in the community more broadly, this function of the group became a critical means of coping with cancer.

#### *Increased knowledge*

Informants also highlighted the informative nature of the group, noting that they learnt new ways of coping with cancer through discussion and more about the issues involving cancer through the various topics covered by the guest speakers. This had the consequence of reducing the fear of the unknown and the anxiety the disease induces. One informant highlighted that he found it particularly encouraging to hear from cancer survivors in the group on how they coped with the illness. In expressing empathy for caregivers, particularly the spouses of cancer patients, one informant said that the information that caregivers received through the group would better support them to care for their loved ones. In the words of one informant, "members need guidance through information as much as support", highlighting the importance of this aspect of the support group.

These perceived benefits are consistent with findings from other studies of support groups and seem to constitute a benefit of support group membership, regardless of the ethnicity of the participant (Avis *et al.* 2008) or whether the group is professionally-facilitated (Gottlieb & Wachala 2007; Cope 1995; Ussher *et al.* 2006) or peer-led (Coreil, Wilke & Pintado 2004; Docherty 2004; Gray *et al.* 2007; Arrington, Grant & Vanderford 2005; Yaskowich & Stam 2003). However, while these generalized benefits are connected with support group membership, participants' needs are likely to vary based on their stage in the treatment trajectory.

#### *Emotional vs. practical sharing*

Newly diagnosed patients are primarily seeking information, whereas after patients have accepted their illness and made initial decisions regarding treatment options, they desire more emotional support and the development of specific coping skills (Krupnick *et al.* 1993). Thus, there was some difference of opinion regarding the primary focus of the group and whether it should be about emotional sharing or practical information and tips on how to cope with cancer. One male informant with metastatic cancer stressed that the medical care that a cancer patient receives is different from psychological care, and that the role of support groups is to render emotional support to cancer patients, rather than to disseminate medical-related information. Other informants and group members also emphasized the importance of allocating time for members to share their experiences in the group setting, and the importance of mutual encouragement.

However, some informants and participants, particularly those receiving curative treatment, did not appear to find emotional sharing helpful. According to one informant, she found it unhelpful to dwell on emotional pain through group sharing and she found the "resigned" (hopeless) attitude expressed by some people to be especially disagreeable. She observed that while some expressed their anxiety and fear, others spoke of being "at peace", resigned to their situation to the point of hopelessness. Clearly, these differing views regarding the central function of the group were connected to patients' prognoses and their stage in the treatment trajectory.

#### *Social dimension*

A final benefit of support group membership highlighted by several informants was its social function – providing an opportunity to interact with other people, allowing for the formation of friendships and thereby improving emotional well being. Specific highlighted benefits of interaction included: "sharing of experience", "learning from each other", and "expanding one's network". For example, one informant who had moved to Vancouver following her diagnosis said that she wanted to make more new friends in the city through the support group, which she believed would add to her positive emotions.

For those cancer patients and survivors who had become more isolated since their cancer diagnosis and treatment (whether through fatigue, or discomfort in talking about cancer) the group therefore provided an important opportunity for social interaction. However, it is important to note that it was primarily core group members in recovery who emphasized this feature of the support group. Mok (2000) also observed a similar phenomenon in a Chinese cancer support group in Hong Kong, noting, "the needs of the cancer survivors are different, depending on their stage of the illness. The old-timers,

instead of getting more information, treasure the friendship that has developed in the self-help groups”.

### **Suggested improvements**

Although informants were asked about their suggestions for improving the group, informants generally suggested improvements in relation to the delivery of services to Chinese cancer patients rather than specifically focusing on the support group itself. The few specific suggestions received were as follows:

1. Ensure that meetings end on time (especially for people catching buses and with transportation issues);
2. Ensure that sharing stays on track, and that people do not divert from talking about the identified topic;
3. Allocate more time for members to talk about their experiences;
4. Increase the frequency of meetings (this was noted to be especially important in light of the fluctuating condition of patients);
5. Schedule social activities/ special events (e.g. *qigong*/meditation exercises, games, summer outings).

In response to prompts regarding informants' preferences for future topics at support meetings, the following were suggested:

1. Combined Western and Chinese approaches in treating cancer;
2. Practical coping pointers
3. Financial support for patients
4. Diet
5. Connecting patients to helpful resources
6. Correcting myths and misconceptions about cancer.

## **5. REFLECTIONS ON THE SUPPORT GROUP**

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### **Large group size**

As previously noted, the Chinese cancer support group is substantially larger than other patient support groups in the BC Cancer Agency, with an average of 21 participants per meeting, and meetings occasionally drawing up to 35 people. The large group size is a clear reflection of the fact that Chinese cancer patients have considerable information and support needs and the group provides one of the few contexts where these needs can be at least partially satisfied. However, a range of issues arise in a support group with so many members. The primary issue concerns the emotional safety of both the facilitator and support group members. A secondary issue is the constraints the large group size places on the time available for sharing amongst group members – something key informants regularly commented on.

Bearing in mind staffing and resource issues in the BCCA, there are several possible ways the size issue might be dealt with. First, the agency might consider holding a regular series of lectures designed specifically for Chinese patients that provide information about cancer and practical advice on dealing with it (much along the lines of the present ‘psycho-educational’ component of the group). As it appears to be the case that some group members are more interested in this information than the sharing component of the group, this might serve to reduce the overall size of the support group itself while still meeting the needs of Chinese patients and their families. Another possibility might be moving the guest lectures to the first half of the group (and setting the room up in a lecture-style format for this part of the meeting) and then holding a clearly demarcated ‘support’ meeting in the second half. However, in this situation, it would be important to retain the coping skills and pointers dimension of the group as a way of leading into the supportive-expressive content. Another option might be to separate the existing group into several more specific sub-groups (see below).

### **Inclusive of patients of all cancer types and stages**

The existing support group caters to patients of all cancer types and treatment stages. Thus, the support group and facilitator face the considerable challenge of promoting group cohesion while seeking to adequately address the array of concerns which patients of diverse cancer types and stages encounter. There are several ways the group might be divided – based on cancer stage (e.g. a separate group for stage IV patients), cancer site, or role (e.g. patients vs. caregivers). All of these options have resource implications. The least financially feasible option seems to be separating the group based on cancer site, given the very diverse range of cancers represented in the group. However, it should be noted that even if we consider the three most represented cancer sites in the group (breast, lung and nasopharyngeal), the issues patients face are very different – unlike breast cancer, lung cancer has a very low survival rate, and people with nasopharyngeal cancers may experience issues relating to facial disfigurement and attendant stigma.

Separating participants based on cancer stage (e.g. stages I-III vs. IV) seems more feasible than separating them based on cancer site, although it would still require additional resources. While early stage cancer patients and survivors may be optimistic about the possibility of life after cancer, patients with stage IV cancer are in a very

different situation, and coming to terms with death is a difficult but necessary part of the life of a metastatic cancer patient. Thus, while early stage cancer patients may be uncomfortable with proclamations of acceptance of death, late stage cancer patients may be equally uncomfortable in a context where their situation is substantially worse than others present and adequate recognition of this difference does not occur. In this vein, female informant with metastatic cancer commented that she was in a very different situation from a number of participants in the support group and she was therefore unclear on what sort of support (if any) she could receive in this context.

A final option might be to create separate groups for patients and family members. While this option might have some benefits (see section 6), it is unclear whether family members would come along to a separate group as many of them see their presence in the group as a way of supporting the patient, rather than themselves – having a separate group for them might defeat their perceived purpose of being in the group in the first place.

#### **Caters exclusively to Cantonese speakers**

The existing group caters explicitly to Cantonese speakers although there are clearly a number of Mandarin-speakers who desire group support – as witnessed by the substantial minority of Mandarin speakers in the group, some of whom are not fully fluent in Cantonese. However, it is likely that the majority of Mandarin speakers screen themselves out of the group and other English-language support groups offered in the BCCA. The options for dealing with this issue are straightforward (e.g. create a separate group for Mandarin speakers, employ a facilitator who is fluent in Mandarin), but are likely to require substantially more resources.

## **6. FUTURE DIRECTION OF THE GROUP**

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Following the completion of the fieldwork, in July 2008 a meeting was held with a subset of the support group members (N=11) in order to obtain their feedback on the study and their views on the future direction of the group. The following represents a summary of participants' responses.

### **Alternative delivery mechanisms**

Participants indicated that they would be open to other modes of support delivery, including the use of video conferencing to link participants from various agency sites and the creation of an online support group – which was seen likely to particularly benefit those in treatment who might be unable to attend the monthly group meetings as a result of their physical condition. However, participants stressed that these modes of delivery should be an add-on to the existing face-to-face support group as there was concern that personal contact would be lost if such delivery modes replaced the existing group. Some participants also raised concerns about confidentiality in the context of an online group and stressed that access to the online group would need to be restricted by a server administrator to protect the privacy of users.

### **Caregivers/Family Support**

Participants indicated that caregivers and family members do encounter stress alongside the patients, and as such would also benefit from support. Specifically, the identified needs of caregivers were:

1. Connecting with other caregivers for mutual support;
2. Expressing their distress without the need to censor themselves;
3. Education on how best to respond to the patient's physical and psychological condition.

While participants supported the notion of a separate group for caregivers/family members, they were of the view that it might not be as well attended as the current support group where family members accompany the patient. Suggestions to deal with this situation included:

1. Having a group for caregivers to voice their views/concerns, while allowing the patients to attend;
2. Participants meet as a combined group, split into two groups during the time allocated for sharing of views and concerns, and reconvene as a larger group for the guest speaker component of the meeting;
3. Conduct follow-up studies to solicit the views of family and caregivers regarding what their needs are in caring for the patients.

### **Peer Support Network**

Participants suggested having contact list of patients who are willing to share their experiences, so that newcomers could make contact with those who have a similar diagnosis and prognosis for peer support. The request that group members initiate contacts with newcomers by means of telephone calls or visitations was also presented. This was noted to be particularly helpful to singles undergoing cancer treatment, given their lack of family support.

### **Separate groups according to cancer types**

While participants were of the view that there may not be a great need for separate groups according to cancer types, they were in support of having specific cancer site groups in addition to the current Chinese support group. This was deemed to be helpful for those needing extra support beyond the monthly meetings of the present group.

### **Disseminating Information**

Participants felt it was important to disseminate cancer-related information to patients and their families – particularly regarding what to expect following diagnosis. GPs were thought to be a crucial mechanism for disseminating this information.

Participants also raised the possibility of disseminating a monthly newsletter to group members. In addition to a Q&A column to address participants' concerns about cancer, it was suggested that the newsletter include contact information of cancer survivors as part of the peer support network. However, the issue of privacy was raised and concerns were expressed about the public announcement of cancer that such a contact list would engender.

### **Exercise component in support group**

Participants expressed a keen interest in exercise targeted for cancer patients, such as a particular type of *qigong* or *tai chi* believed to be helpful in cancer recovery. It was suggested that an exercise component be incorporated in the present support group structure, combining the social aspect of the group with an exercise dimension. However, participants also queried the feasibility of adding more content to the existing support group meeting timeframe of 2 hours.

### **Dissemination of research findings**

Participants were of the view that the research findings be disseminated to funders, decision-makers/management and healthcare providers.

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