

The Experiences and Needs of Chinese Cancer Patients: Findings of an Ethnographic Study on BCCA's Chinese Cancer Support Group

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Introduction:

- Ethnic Chinese constitute 17% of the population of metropolitan Vancouver, BC
- Few culturally- and linguistically-specific resources and supportive services are available for Chinese cancer patients
- Much remains to be learnt about Chinese cancer patients' experiences of living with and beyond cancer

Objectives:

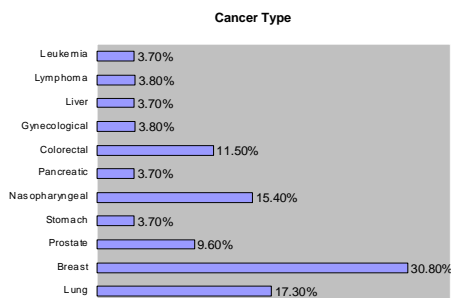
- Report results of an ethnographic study of BCCA's Chinese cancer support group
- Highlight experiences of Chinese cancer patients and functions that group serves for participants
- Forms part of a larger comparative study of cancer support groups

Research Design and Method:

- Ethnographic research design involving:
 - Participant observation** at Chinese cancer support group (Sept 2007-Apr 2008)
 - Monthly 2-hour drop-in group
 - Professionally-facilitated group in Cantonese
 - Psycho-educational format consisting of a lecture on a specific topic followed by open sharing and group discussion
 - In-depth interviews**
 - 7 participants; 6 patients and 1 family member
 - Interview questions on demographic information, personal experience of cancer, cultural issues for Chinese cancer patients and views on support group
- Field notes and interview data coded using Nvivo© software, beginning with open then focused coding
- Thematic analysis involving line-by-line scrutiny of data on the basis of topics that emerged as of particular interest

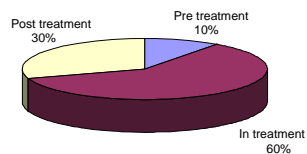
Results and Discussion:

Cancer Type and Treatment Stage



- Extremely diverse in composition, covering patients with many types of cancer, including lung, breast, prostate, stomach, nasopharyngeal, pancreatic, colorectal, gynaecological, liver, lymphoma and leukemia cancers
- Most commonly represented cancers in the group during the fieldwork period: breast (30.8%), lung (17.3%) and nasopharyngeal (15.4%) cancers

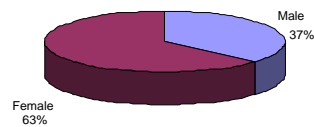
Treatment Stage



- All stages of the cancer diagnosis are represented in the group, from stage I to IV
- Patients in the group were largely in treatment (60%), with a third post treatment (30%)

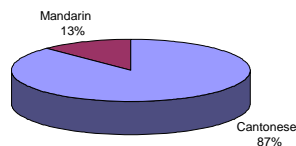
Attendance Patterns

Sex Composition



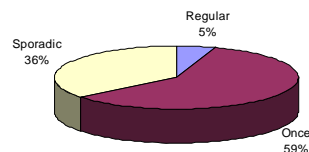
- 96 participants between Sept 07-Apr 08, averaging 21 attendees per meeting
- Females constituted almost 2/3 (63%) of total participants, with 37% male participants

Language Composition



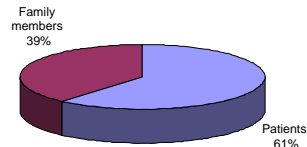
- Participants with Cantonese as first language constituted 87% of the group, with Mandarin-speakers 13% of the group
- Noticeable presence of people with Mandarin as their first language within group for Cantonese-speakers highlights the pressing information needs of Chinese cancer patients from diverse linguistic backgrounds

Attendance Composition



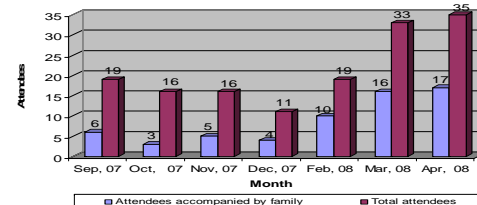
- 59% (N=56) one-time attendees; 5% (N=5) regular attendees/core members
- In light of the lack of linguistically appropriate resources, a certain proportion of one-time participants may attend the group as an information resource rather than because of a specific interest in attending a support group per se

Role Composition



- Almost 40% (N=37) family members among participants

Presence of Family Members



- Often more than 1 family member was present at group meetings, averaging 4 families per meeting
- Family members in attendance included spouses, children, parents-in-law, siblings
- This is very uncommon in other BCCA cancer support groups
- Family members are integral to Chinese group, reflecting the importance of family relationships and family ties for many Chinese cancer patients

Most Common Topics of Group Discussion

- Interactions with healthcare professionals
 - Language barriers
 - Quality of healthcare services
- Coping with cancer treatment and recovery process
 - Exercise (qigong, yoga)
 - Importance of information
 - Being 'self-reliant'
- Relationship with family and friends
 - Support from family
 - Worries about family
 - Impact of illness on family
- Treatment side effects
 - Pain
 - Eating and diet issues
- Fear and anxiety surrounding diagnosis and treatment
 - Fear of unknown, lost control
 - Anxiety about asking for help
 - Anxiety while waiting for treatment
- Content shared in meetings covers spectrum of physical and emotional issues
- Temporal dimension to group discussion, beginning with practical concerns and moving towards emotional issues
- Expressing emotional issues, especially to non-family members, is an unfamiliar phenomenon among many Chinese cancer patients
- Thus, such issues need to be approached indirectly rather than exclusively

Identified Benefits of Group

- Increased knowledge leading to reduced fear and anxiety, as ways of coping with cancer are shared
- Social function, interaction with others
- Understanding environment, with mutual support among patients
- Role of group in providing information, acceptance and understanding in the process of coping and recovery
- Function that group serves is dependent on patients' stage in cancer treatment trajectory:
 - In treatment – information and support
 - Post treatment – social function, support, 'giving back' to others

Limitations

- Generalisability of findings are limited as study is based on a single support group
- Views represented are predominantly from patients, requiring further research on the family's perspective

Conclusions

- Language-specific groups are attractive to patients as well as their families
- However, cultural background may influence content of meetings and how such discussions unfold
- Group appeared to benefit some patients more than others, particularly patients in the 'survivorship' phase
- Perceived benefits include information, acceptance and understanding, with changing motivation for attending group over time through the treatment trajectory
- Inclusion of educational or informational component may draw more culturally diverse participants than groups based solely on informal sharing
- Lack of linguistically and culturally appropriate resources for BCCA Chinese cancer patients is reflected by the large size of the group



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