Title: Why Don’t cancer survivors attend cancer support groups? A pilot study

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Research Team

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INTRODUCTION

• Cancer is the leading cause of death for both men and women in Canada. Nearly half of Canadians will get cancer at some point during their lifetime.

• In 2017, 206,200 new cases of cancer would be diagnosed in Canada. [1].

• The cancer experience for many persons in North America is marked by social isolation, loss of support networks, stigma and changes in patterns of intimacy among close others [2].
INTRODUCTION

• Professionally or nonprofessionally led support groups have been recognized as a significant source of psychosocial support for cancer survivors [3].

• Such group services have been demonstrated to be a means of reducing anxiety and depression, facilitating adjustment and coping, and enhancing self-esteem and quality of life [4, 5].
• There are other benefits of attending a cancer support group include increasing knowledge on cancer and its treatment, developing a sense of belonging to a cancer community, as well as increasing empowerment, hope, and confidence [6, 7].
A study was conducted to understand the factors that influence participation.

The researchers concluded that few cancer survivors (5.4%) had participated in any type of cancer support group, although services were available to them.
INTRODUCTION

• Those attended tend to be disproportionately white, female, middle-class, better educated, and younger.

• The major determinants of participating a support group included participants’ perceptions of illness severity, perceived benefits, perceived barriers, and cues for action (i.e., recommendation by family/friends) [14].
INTRODUCTION

- A qualitative study examined the reasons for not attending a support group and revealed that reasons included
  - resisting or leaving behind a cancer patient identity
  - presence of existing support,
  - mismatches between the group and the individual,
  - a problem with group members,
  - difficulties in dealing with death of group members,
  - and practical issues, such as transportation problems and the timing of meetings [3].
INTRODUCTION

• Cultural factors may play a role in constraining participation, such as
• illness related stigma,
• mistrust of conventional medical institutions,
• or norms about personal expression [14].
INTRODUCTION

- Two studies examined men’s participation in support groups and discovered that men with cancer were seeking connection and emotional support in their coping efforts [12, 13]. Their female partner played a key role in providing supportive care.

- Men in both studies preferred mixed sex groups, and groups composed of mixed diagnoses.
RATIONALE AND PURPOSE

• Being volunteers in a cancer support group at a community healthcare centre in Toronto for years, we find that some of our members disappeared after one or two group meetings and were reluctantly to rejoin the group.

• Therefore, we proposed this project to explore the reasons why Chinese cancer survivors left or did not attend a cancer support group in Toronto.
Methods

• In-depth individual qualitative interviews were conducted from January to May 2016.

• A semi-structured format was used to initiate conversations about participants’ experiences of not attending a cancer support group.
Participants

• Five participants were voluntarily to participate in in-depth interviews.

Table 1 Individual demographic data of the participants

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Data Collection

• The interview began with a broad open-ended question:

• “Could you please tell me why you stopped participating in the cancer support group?”
Data Analysis

• Colaizzi’s [16] phenomenological method was used.

• All interviews were read by the authors independently to develop an overall understanding of the reasons why people do not attend a support group.

• Each transcript was analyzed individually.
Data Analysis

• Colaizzi’s [16] phenomenological method was used.

• Significant statements were identified and coded. Coded data were grouped and transformed into themes, which provide the essential structure of the description.

• Final themes were agreed with all research team members.
Results
Participants’ experiences of not attending a support group

- Theme 1: Not fit in
- Theme 2: Not satisfied with the information provided
- Theme 3: Tried to be a “normal” person
- Theme 4: Lack reliable Transportation and convenient scheduling
Participants’ experiences of not attending a support group

• Theme 1: Not fit in

• #1 Most participants in the group were with breast cancer. Her diagnosis was colon cancer

• #2 Too weak to go

• #3 Female issues
Participants’ experiences of not attending a support group

• Theme 2: Not satisfied with the information provided

• Participant #3 mentioned that his son and physician would provide more detailed information related to prostate cancer to him.

• He himself would read newspaper’s Medical News column to get some of the information.

• He felt that most of the participants in his support group were women and the topics they were interested were different from his.
Participants’ experiences of not attending a support group

• Theme 3: Tried to be a “normal” person

• Participant #4 described her sadness, nightmare and sleepiness at night due to her negative imagination of cancer and cancer treatment.

• Her physician suggested her make friends with healthy people, so she stopped attending the support group.
Participants’ experiences of not attending a support group

• Theme 3: Tried to be a “normal” person

• Participant #5 had similar feeling.

• She mentioned that cancer topics made her feel stressed. Participants in her group were not always in good health. Their sick faces made her sad and worried about she might encounter similar situations someday soon.
Participants’ experiences of not attending a support group

- **Theme 4: Lack reliable Transportation and convenient scheduling**

- **Language was not a problem** to all those five participants because they all went to Chinese-speaking support groups (either Cantonese or Madeiran or bilinguals).
Participants’ experiences of not attending a support group

• Theme 4: Lack reliable Transportation and convenient scheduling

• Participant #3 said that it took him a lot of time and energy to find the support group he had visited once.

• He needed to take a bus to a subway station and from the subway to take another bus to the centre where the support group held. He almost got lost on his way to the centre.
Participants’ experiences of not attending a support group

• Theme 4: Lack reliable Transportation and convenient scheduling

• Most of the support groups have their meetings during the daytime.

• Although the participants were not employed, they had other errands need to be taken of.

• Participant #5 mentioned that: “It would be better for me to go if they can arrange nighttime meetings. I need to take care of my grandchildren while my daughter works.”
Limitations

• The **small sample size** was the limitation of the study.

• However, the study provided a greater insight into the reasons why cancer survivors decided not to attend a support group through in-depth interviews, this limitation does not substantially undermine the findings of the study.
Discussion

Comments?
Questions?
Conclusion

• Health-care providers need to evaluate and be aware of the needs and difficulties for cancer survivors to attend support groups.

• They should match cancer survivors with appropriate groups.

• More language-friendly groups need to be launched, so cancer patients can easily find a suitable one from their neighborhood.
References


