



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].**

INTRODUCTION

- **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].**

INTRODUCTION

- **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 reluctant 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

Code	Age	Gender	Diagnosis	Times of participating support group
1	47	Female	Colon	1
2	40	Male	Colon	2
3	70	Male	Prostate	1
4	43	Female	Breast	1
5	67	Female	Pancreatic	1

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.

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