

**Title: Why don't Cancer survivors attend cancer support groups in Toronto**

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**Abstract**

**Background:** Cancer is the leading cause of death for both men and women in Canada.

Professionally or nonprofessionally led support groups have been recognized as a significant source of psychosocial support for cancer survivors. However, the participation rate was low and reasons for leaving a support group were not explored fully.

**Purpose:** to explore the reasons why Chinese cancer survivors left or did not attend a cancer support group in Toronto.

**Method:** In-depth individual qualitative interviews were conducted. Five Chinese cancer survivors participated in in-depth interviews. Colaizzi's phenomenological method was used to analyze the interview data.

**Results:** Four themes were extracted from the in-depth interviews: "not fit in", "not satisfied with the information provided", "tried to be a normal person", and "lack reliable transportation and convenient scheduling".

**Conclusion:** Cancer support groups can improve cancer survivors' physical and psychosocial outcomes. The services can also help cancer survivors to obtain health related information and connect with professionals and peers. In recognizing the reasons why cancer survivors left support groups, 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.

**Keywords:** Cancer, Cancer support group, Chinese, qualitative study, attendance

## Introduction

Cancer is the leading cause of death for both men and women in Canada. Nearly 50% of Canadians is expected to be diagnosed with 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]. 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]. Research has showed that 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]. Usually, a typical Canadian support group consists of eight two-hour sessions. Led by experienced professionals along with cancer survivors, these sessions are structured but also provide flexibility in format and topics [8]. Topics, such as information on all types of cancer, diagnostic tests, treatments, side effects, clinical trials and many other cancer-related issues are provided. Furthermore, peer-led, self-help groups can connect people living with cancer and caregivers with trained volunteers who offer encouragement and share ideas for coping from their unique perspectives [1, 9, 10]. Sometimes, professional persons, e.g. oncologists, surgeons, social workers, as well as psychologists are involved in the support program who seek to identify what they think would improve quality of life and what would meet the needs of the patients [11]. A variety of activities are served including information-based support program supplemented with relaxation, qi-gong, art therapy, music therapy, mindfulness,

aromatherapy, reiki, yoga, oncology-specific exercise programs, etc. [12]. These psychosocial activities benefit patients with cancer by engaging their personal interests and preferences in the treatment process [12].

Two studies examined men's participation in support groups and discovered that men with cancer **are** seeking connection and emotional support in their coping efforts [12, 13]. Their female partner plays a key role in providing supportive care. Men in both studies prefer mixed sex groups, and groups composed of mixed diagnoses.

To understand how often the support group services are used in clinical practice or the factors that influence participation, a study was conducted and concluded that **only a few** cancer survivors (5.4%) had participated in any type of cancer support group, although services **are** available to them. Those attended tend to be disproportionately white, female, middle-class, better educated, and younger. The major determinants of participating a support group include participants' perceptions of illness severity, perceived benefits, perceived barriers, and cues for action (i.e., recommendation by family/friends) [14]. **Although no data have been reported on the ratio of Chinese cancer patients participating in support groups, Leng and colleagues find that minorities are less likely to participate in such groups due to inappropriate social environments in America [15].**

A qualitative study examined the reasons for not attending a support group and revealed that reasons include 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].

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]. Researchers in Australia developed a culturally sensitive and linguistically appropriate support group program for Australian-Chinese cancer survivors and reported that the participants evaluate the program is useful, relevant and effective in providing informational support and psychosocial support for them. The program provide a sense of interconnectedness and thus minimizing the participants' feelings of isolation and helplessness [16].

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.

## **Method**

In-depth individual qualitative interviews were conducted from January to May 2016. A semi-structured guide (available upon request) posed questions to initiate conversations about participants' experiences of not attending a cancer support group.

## **Participants**

After obtaining ethics approval from York University's Research Ethics Committee, participants not attending a cancer support group were recruited through an outreach worker at South Riverdale Community Healthcare Centre (SRCHC). Eligibility inclusion criteria include adult cancer survivors whose age was 20 years or more, who can read and speak English or Mandarin, who approached the outreach worker for cancer support group information between 2012 and 2014, but not attend the support group or attended only once or twice. Potential participants were contacted by the outreach worker, who described the study to the participants

and emphasized that participation would be confidential, and privacy would be secured. They were informed of their right to disengage from the study at any time without risk. Participants who agreed to join the study signed a consent form and completed a questionnaire on demographic data at the time of the interview. Interviews were conducted by the first author and were carried out at times convenient to participants. Five participants were voluntarily to participate in in-depth interviews. The interview setting was the participants' home, or a location chosen by the participants for their comfort and safety. Interviews lasted from 60 to 90 minutes and were transcribed verbatim by a research assistant after removing all identifying information. To preserve the anonymity of the participants, we have limited the provision of demographic data, and participants are identified by a number.

### **Data Collection and Analysis**

The interview began with a broad open-ended question: "Could you please tell me why you stopped participating in the cancer support group/never participated in the cancer support group?", then followed by more specific questions, such as "Thinking back to your entire cancer Journey, do you think you got enough support you wanted?" "Thinking back to your entire cancer Journey, what kind of support did you want the most during that period?" etc. Probing questions, such as, "Can you tell me more?" "What do you mean?" were used. Field notes were taken to facilitate the analysis. Data analysis began as soon as the interview was transcribed. The transcripts were analyzed using Colaizzi's phenomenological method [17]. 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. 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

All the participants were Chinese, two males and three females. Ages ranged from 40 to 70 years old. Their diagnosis includes colon, prostate, breast, and pancreatic cancer. Only one participant attended the cancer support group twice; the rest attended only once. Individual demographic data of the participants were listed in Table 1.

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

### Participants' experiences of not attending a support group

When asked why the participants stop attending a support group, four themes were identified from the in-depth interviews. Each of the four themes will be discussed in detail, illustrated with extracts from the interviews.

#### Theme 1: Not fit in

Participant #1 stated that she was introduced by a friend to join a support group after she learned her disease. However, most of the participants in her support group were diagnosed with

breast cancer. Although the group facilitator would invite professionals talking about how to reduce stress or anxiety after cancer or how to eat healthy, most of the topics were related to breast cancer. Since her diagnosis was colon cancer, she felt that she couldn't fit in the group. So, she discontinued her participation in that support group.

Although participant #2 also had colon cancer, his reason for not attending a support group was different from participant #1. He was confined to bed at home, describing his experience as follows:

*“I was very ill back then. I just did a colostomy surgery and couldn't have the normal bowel movement. I felt pain and discomfort. I thought about getting help from nurses or professionals, so I called the facilitator of the support group. However, I was too sick to go, so I asked my wife to go instead.”*

Participant #2 went a support group twice before his surgery and his wife went several times alone after his surgery to collect relevant information. However, she needed to take care of her husband at home. She was worried about her husband's devastating weakness and fatigue due to the side effects of cancer treatment and decided not to attend the group after a while. Participant #2 has never gone back to any of support groups after recovered from treatment due to personal reasons. He understood that support groups could connect him with other men who were facing similar issues; however, he was enjoying the company of his friends. They visited him at home, took him to hospital, and made phone calls. He would like to share his emotions with friends, but he expressed that he just felt discomfort to expose his own feelings in front of a group of people. His physical condition also played a role because he needs to eliminate his bowel every half hour. He needs to carry all the equipment with him which is kind of inconvenience for him to go outside.

*“Although I have regular bowel movement, I can’t control the timing of my elimination. I have to eat less if I plan to go outside, so I would rather stay home watching TV.”*

### **Theme 2: Not satisfied with the information provided**

Participant #2 felt the information provided from the support group was not enough for him or his wife to deal with the challenging care of the disease. General healthcare issues, such as nutrition, hair loss, diarrhea, or constipation were covered; however, more specific or sensitive topics; such as skin care for a stoma or sexuality after treatment were not. He found that there are many programs and services available online to help meet the needs of people living with cancer, so he turned to learn and got advices from the internet resources.

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. He described his concerns as follows:

*“They (women in the group) talked about their histories of getting cancer and how they finally found appropriate doctors to treat them. It’s all different from mine. I would like to hear some men’s talk. Something is directly related to my diagnosis.” “I am old enough not to be frightened by cancer. I am not worried at all. I am more interested in topics, such as how to practice Tai chi because my friends told me Tai chi is good for health.”*

### **Theme 3: Tried to be a “normal” person**

Participating a support group could create pressure to some of the cancer survivors. 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.

*“I had insomnia badly for an extended period because I was often thinking about my illness, my treatment and related outcomes. I couldn’t sleep every time after listening other’s story of cancer trajectory. I would reflect it to my own disease which made me depressed.” “I tried to live a life as normal as possible. I want to be a normal person not a cancer survivor.”*

Participant #5 had similar feeling. She attended once and didn’t go back to the group even though the facilitator of the support group called her several times. 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.

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

Language seems not a problem to all those five participants because they all went to Chinese-speaking support groups (either Cantonese or Madeiran or bilinguals). Four of the participants were bilinguals. The only one who speaks Cantonese fluently understands Madeiran well. However, the support group was user-friendly, but the outside world was not. The reason for them not attending a support group was not language but transportation and schedule of the program.

Children of participant #3 had to work and he can’t understand English. 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. Participant #3 stated that:

*“My son and daughter-in-law need to work. There is no one who can take me to the support group. I had to figure it out myself. I don’t know English and am not familiar with the bus and subway system. It’s just too difficult for me to go there.”*

Participant #3 couldn’t find other suitable support groups in his neighborhood; eventually, he gave up. A similar situation happened to Participant #1. Participant #4 explained how distance and difficulties in access the support group led her giving up attending by stating that *“They are nice people, but the location is just too far from my home. I felt exhausted and decided not to go.”*

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.”*

## **Discussion**

The findings drawn from the current study reveal that reasons for cancer survivors stop attending a support group were due to “not fit in”, “not satisfied with the information provided”, “tried to be a normal person”, and “lack reliable transportation and convenient scheduling”. Additionally, the current study findings suggest that family members or friends can play influential roles in participants’ decision on whether to attend a support group. Although there are some similar publications worldwide, our study provided a closer look at why Chinese cancer survivors decided to leave a support group.

Professionally led or peer led cancer support groups have grown in popularity in Toronto; however, most of them are led by English-speaking facilitators. The few Chinese-speaking

support groups limited the options the Chinese cancer survivors could participate. If they couldn't "fit in" one group, it would be hard for them to find another suitable one. Therefore, quitting became a fast option. This result was consistent with other researchers' finding that mismatches between the group and the individual was one of the reasons the participants in their study not attending the support group [3]. Another probable reason could be cultural factors. A study stated that those who are lacking a circle of family or friends for support can benefit from a peer support group, but not every cancer patient thrives in a group setting [12]. This statement holds very true for Chinese men. Chinese men usually don't share their emotions with others, sometimes not even with their wife. It's not surprising to find that participant #2 was reluctantly to rejoin the support group.

Part of the reasons for cancer patients use of support services was for information seeking, especially among patients with more intensive distress or illness-related concerns [14]. If the information provided was not what they expected, it's evitable that they would decline the services; especially when they could have sufficient resources from their physicians, family members, internet, or newspapers. It's worth pointing out although participants wondered the truthfulness of the web information; internet has become an effective tool for them to collect health-related information, especially for personal sex issues.

Cancer creates long-term impacts on one's identities [10]. Studies have indicated that difficulties in dealing with members' death was one of the reasons for cancer survivors leaving a support group [3, 10]. None of our participants experienced death of group members, but some of them dropped out of the cancer support group to avoid thinking about negative thoughts or death. They avoided seeing sick faces that presented in the group and strived for being with healthy people. It's not because they didn't identify themselves as a sick person; it's just that

they didn't prefer to be with someone who was ill. Being with someone who is ill or dying stirs up the ultimate discomfort. It seems to remind these cancer survivors of their own impending death. This result was consistent with the finding of a qualitative study, which reported that several participants in their study mentioned wanting to leave cancer behind, and not be reminded of it through the support group [3].

Transportation or distance is often barriers for people attending a support group, especially for those who relied on their family's assistance, e.g., participant #3 in our study [10]. To make support services more useful, a flexible schedule is important, e.g., nighttime or weekends, so family members who are employed at daytime can accompany with their loved ones to the group meetings.

Leng and colleagues suggest that healthcare professionals should develop culturally sensitive programs which can provide language-friendly information and easily communicate patients with their individual problems to educate and empower patients. Healthcare professionals should consider those patients' unique cultural needs to promote a more positive view towards support groups [15].

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.

## **Conclusion**

There has been universal agreement on importance of support groups on improving cancer survivors' physical and psychosocial outcomes. The services provide a great chance for

cancer survivors to obtain health related information and connect with professionals and peers.

These services, however, require active engagement from cancer survivors to be effective.

In recognizing the reasons why cancer survivors left support groups, 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. An online support group or chatroom may be developed for participants getting more information they need. In addition, further studies are needed as the sample size of our study is small.

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## CONSENT

Participants who agreed to participate in the study were asked to sign a consent form at the interview.

## ETHICAL APPROVAL

Institutional ethics approval was received from York University, Toronto, ON, Canada.

## COMPETING INTERESTS

Authors have declared that no competing interests exist.