

Original Research Article

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

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

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

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

UNDER PEER REVIEW

27 **Introduction**

28 Cancer is the leading cause of death for both men and women in Canada. Nearly 50% of
29 Canadians is expected to be diagnosed with cancer at some point during their lifetime.
30 In 2017, 206,200 new cases of cancer would be diagnosed in Canada [1]. The cancer experience
31 for many persons in North America is marked by social isolation, loss of support networks,
32 stigma and changes in patterns of intimacy among close others [2]. Professionally or
33 nonprofessionally led support groups have been recognized as a significant source of
34 psychosocial support for cancer survivors [3]. Such group services have been demonstrated to be
35 a means of reducing anxiety and depression, facilitating adjustment and coping, and enhancing
36 self-esteem and quality of life [4, 5]. Research has showed that other benefits of attending a
37 cancer support group include increasing knowledge on cancer and its treatment, developing a
38 sense of belonging to a cancer community, as well as increasing empowerment, hope, and
39 confidence [6, 7]. Usually, a typical Canadian support group consists of eight two-hour sessions.
40 Led by experienced professionals along with cancer survivors, these sessions are structured but
41 also provide flexibility in format and topics [8]. Topics, such as information on all types of
42 cancer, diagnostic tests, treatments, side effects, clinical trials and many other cancer-related
43 issues were provided. Furthermore, peer-led, self-help groups can connect people living with
44 cancer and caregivers with trained volunteers who offer encouragement and share ideas for
45 coping from their unique perspectives [1, 9, 10]. Sometimes, professional persons, e.g.
46 oncologists, surgeons, social workers, as well as psychologists were involved in the support
47 program who sought to identify what they thought would improve quality of life and what would
48 meet the needs of the patients [11]. A variety of activities were served including information-
49 based support program supplemented with relaxation, qi-gong, art therapy, music therapy,

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

53 Two studies examined men's participation in support groups and discovered that men
54 with cancer were seeking connection and emotional support in their coping efforts [12, 13]. Their
55 female partner played a key role in providing supportive care. Men in both studies preferred
56 mixed sex groups, and groups composed of mixed diagnoses.

57 To understand how often the support group services are used in clinical practice or the
58 factors that influence participation, a study was conducted and concluded that few cancer
59 survivors (5.4%) had participated in any type of cancer support group, although services were
60 available to them. Those attended tend to be disproportionately white, female, middle-class,
61 better educated, and younger. The major determinants of participating a support group included
62 participants' perceptions of illness severity, perceived benefits, perceived barriers, and cues for
63 action (i.e., recommendation by family/friends) [14].

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

69 Cultural factors may play a role in constraining participation, such as illness related
70 stigma, mistrust of conventional medical institutions, or norms about personal expression [14].
71 Researchers in Australia [15] developed a culturally sensitive and linguistically appropriate
72 support group program for Australian-Chinese cancer survivors and reported that the participants

73 evaluated the program was useful, relevant and effective in providing informational support and
74 psychosocial support for them. The program provided a sense of interconnectedness and thus
75 minimizing the participants' feelings of isolation and helplessness.

76 Being volunteers in a cancer support group at a community healthcare centre in Toronto
77 for years, we find that some of our members disappeared after one or two group meetings and
78 were reluctant to rejoin the group. Therefore, we proposed this project to explore the reasons
79 why Chinese cancer survivors left or did not attend a cancer support group in Toronto.

80 **Method**

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

84 **Participants**

85 After obtaining ethics approval from York University's Research Ethics Committee,
86 participants not attending a cancer support group were recruited through an outreach worker at
87 South Riverdale Community Healthcare Centre (SRCHC). Eligibility inclusion criteria include
88 adult cancer survivors whose age was 20 years or more, who can read and speak English or
89 Mandarin, who approached the outreach worker for cancer support group information between
90 2012 and 2014, but not attend the support group or attended only once or twice. Potential
91 participants were contacted by the outreach worker, who described the study to the participants
92 and emphasized that participation would be confidential, and privacy would be secured. They
93 were informed of their right to disengage from the study at any time without risk. Participants
94 who agreed to join the study signed a consent form and completed a questionnaire on
95 demographic data at the time of the interview. Interviews were conducted by the first author and

96 were carried out at times convenient to participants. Five participants were voluntarily to
97 participate in in-depth interviews. The interview setting was the participants' home, or a location
98 chosen by the participants for their comfort and safety. Interviews lasted from 60 to 90 minutes
99 and were transcribed verbatim by a research assistant after removing all identifying information.
100 To preserve the anonymity of the participants, we have limited the provision of demographic
101 data, and participants are identified by a number.

102 **Data Collection and Analysis**

103 The interview began with a broad open-ended question: "Could you please tell me why
104 you stopped participating in the cancer support group/never participated in the cancer support
105 group?", then followed by more specific questions, such as "Thinking back to your entire cancer
106 Journey, do you think you got enough support you wanted?" "Thinking back to your entire
107 cancer Journey, what kind of support did you want the most during that period?" etc.
108 Probing questions, such as, "Can you tell me more?" "What do you mean?" were used. Field
109 notes were taken to facilitate the analysis. Data analysis began as soon as the interview was
110 transcribed. The transcripts were analyzed using Colaizzi's [16] phenomenological method. All
111 interviews were read by the authors independently to develop an overall understanding of the
112 reasons why people do not attend a support group. Each transcript was analyzed individually.
113 Significant statements were identified and coded. Coded data were grouped and transformed into
114 themes, which provide the essential structure of the description. Final themes were agreed with
115 all research team members.

116 **Results**

117 **Participants**

118 All the participants were Chinese, two males and three females. Ages ranged from 40 to
 119 70 years old. Their diagnosis includes colon, prostate, breast, and pancreatic cancer. Only one
 120 participant attended the cancer support group twice; the rest attended only once. Individual
 121 demographic data of the participants were listed in Table 1.

122 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

123

124 **Participants' experiences of not attending a support group**

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

128 **Theme 1: Not fit in**

129 Participant #1 stated that she was introduced by a friend to join a support group after she
 130 learned her disease. However, most of the participants in her support group were diagnosed with
 131 breast cancer. Although the group facilitator would invite professionals talking about how to
 132 reduce stress or anxiety after cancer or how to eat healthy, most of the topics were related to
 133 breast cancer. Since her diagnosis was colon cancer, she felt that she couldn't fit in the group.
 134 So, she discontinued her participation in that support group.

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

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

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

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

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

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

163 Participant #3 mentioned that his son and physician would provide more detailed
164 information related to prostate cancer to him. He himself would read newspaper's Medical News
165 column to get some of the information. He felt that most of the participants in his support group
166 were women and the topics they were interested were different from his. He described his
167 concerns as follows:

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

173

174 **Theme 3: Tried to be a "normal" person**

175 Participating a support group could create pressure to some of the cancer survivors.
176 Participant #4 described her sadness, nightmare and sleepiness at night due to her negative
177 imagination of cancer and cancer treatment. Her physician suggested her make friends with
178 healthy people, so she stopped attending the support group.

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

183 Participant #5 had similar feeling. She attended once and didn’t go back to the group
184 even though the facilitator of the support group called her several times. She mentioned that
185 cancer topics made her feel stressed. Participants in her group were not always in good health.
186 Their sick faces made her sad and worried about she might encounter similar situations someday
187 soon.

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

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

195 Children of participant #3 had to work and he can’t understand English. It took him a lot
196 of time and energy to find the support group he had visited once. He needed to take a bus to a
197 subway station and from the subway to take another bus to the centre where the support group
198 held. He almost got lost on his way to the centre. Participant #3 stated that:

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

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

207 Most of the support groups have their meetings during the daytime. Although the
208 participants were not employed, they had other errands need to be taken of. Participant #5
209 mentioned that: *"It would be better for me to go if they can arrange nighttime meetings. I need to*
210 *take care of my grandchildren while my daughter works."*

211

212 **Discussion**

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

220 Professionally led or peer led cancer support groups have grown in popularity in Toronto;
221 however, most of them are led by English-speaking facilitators. The few Chinese-speaking
222 support groups limited the options the Chinese cancer survivors could participate. If they
223 couldn't "fit in" one group, it would be hard for them to find another suitable one. Therefore,
224 quitting became a fast option. This result was consistent with other researchers' finding [3] that

225 mismatches between the group and the individual was one of the reasons the participants in their
226 study not attending the support group. Another probable reason could be cultural factors. A study
227 stated that those who are lacking a circle of family or friends for support can benefit from a peer
228 support group, but not every cancer patient thrives in a group setting [12]. This statement holds
229 very true for Chinese men. Chinese men usually don't share their emotions with others,
230 sometimes not even with their wife. It's not surprising to find that participant #2 was reluctantly
231 to rejoin the support group.

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

239 Cancer creates long-term impacts on one's identities [10]. Studies have indicated that
240 difficulties in dealing with members' death was one of the reasons for cancer survivors leaving a
241 support group [3, 10]. None of our participants experienced death of group members, but some
242 of them dropped out of the cancer support group to avoid thinking about negative thoughts or
243 death. They avoided seeing sick faces that presented in the group and strived for being with
244 healthy people. It's not because they didn't identify themselves as a sick person; it's just that
245 they didn't prefer to be with someone who was ill. Being with someone who is ill or dying stirs
246 up the ultimate discomfort. It seems to remind these cancer survivors of their own impending
247 death. This result was consistent with the finding of a qualitative study [3], which reported that

248 several participants in their study mentioned wanting to leave cancer behind, and not be
249 reminded of it through the support group.

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

255 The small sample size was the limitation of the study; however, the study provided a
256 greater insight into the reasons why cancer survivors decided not to attend a support group
257 through in-depth interviews, this limitation does not substantially undermine the findings of the
258 study.

259 **Conclusion**

260 There has been universal agreement on importance of support groups on improving
261 cancer survivors' physical and psychosocial outcomes. The services provide a great chance for
262 cancer survivors to obtain health related information and connect with professionals and peers.
263 These services, however, require active engagement from cancer survivors to be effective.
264 In recognizing the reasons why cancer survivors left support groups, health-care providers need
265 to evaluate and be aware of the needs and difficulties for cancer survivors to attend support
266 groups. They should match cancer survivors with appropriate groups. More language-friendly
267 groups need to be launched, so cancer patients can easily find a suitable one from their
268 neighborhood.

269 **poster presentation**

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274 <https://stti.confex.com/stti/congrs19/webprogram/Paper94886.html>

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