

“WE ARE AMBASSADORS FOR SURVIVORS”: EXPERIENCES OF LUNG CANCER SUPPORT GROUP ATTENDEES AND FACILITATORS



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BACKGROUND

Annually, an estimated 1.8 million people are diagnosed with lung cancer globally. Lung cancer patients have greater unmet physical and emotional needs and higher levels of distress than those with other cancers. In-person support groups can address unmet social support needs and may increase feelings of control and decrease distress.

While people with lung cancer prefer lung cancer specific groups over those for all cancers, such groups can be particularly hard to start/maintain. The number of lung cancer support groups in the world is unknown. In the US, where over 230,000 are diagnosed annually, fewer than 100 groups exist at any given point.

METHODS

We solicited, compiled and analyzed real-world perspectives of lung cancer support group attendees (patients, survivors and loved ones) and facilitators in order to provide direction to new groups and help improve those that are struggling.

Attendee perspectives were gained through:

- 10 focus groups, questions included motivation for group attendance, group format preferences and group benefits
- Analysis of 17 pre-and post support group attendance questionnaires to measure group impact
- A review of current literature

Attendee perspectives will be formally collected through 31 October 2018 with further data analysis through year end.

Facilitator perspectives were gained through:

- A 21 question online survey, sent to 7 facilitators in Australia, 42 in the United Kingdom and 82 in the United States
- In-depth interviews with three successful facilitators
- A review of relevant literature

The Lung Cancer Support Group Troubleshooting Guide was created based on the online survey and literature review. It is being updated to include new suggestions and tips gained from later polls and interviews.

ATTENDEE PERSPECTIVES

Attendee perspectives were analyzed and categorized into major themes, some of which are included here.

THEME: COMMUNITY

There is great value in connecting with others who truly understand.

- *It helps to be in the company of fellow travelers*
- *I go to church a lot but I don't want to talk about [my lung cancer] there*
- *The stigma made me feel uncomfortable going to [an all cancer] support group*
- *I don't feel judged here*
- *Every lung cancer patient needs this*
- *Come for the community, stay for the laughter*

THEME : LEARNING

Many enjoy educational presentations and learning from each other.

- *I like getting information from speakers, I feel it's a good use of my time and [this is] a good place to learn*
- *I've learned some new coping skills*
- *I read a lot of stuff but it's nice to hear about [new advances] directly from someone*
- *[I come for] the opportunity to learn and ask questions*
- *I like sharing things from when I went through treatment that could help other people too*

THEME: GIVING BACK

Attendees feel a responsibility to help one another.

- *As long timers, we are ambassadors for survivors*
- *I feel useful, which has helped me to feel better*
- *I am dedicated to being here to help others*
- *I want to be able to reach out to other survivors and show they are not alone*
- *I like being able to show...that people do survive lung cancer*
- *[The group] provides...a place for me to give back*

ONE WORD DESCRIPTIONS

Attendees were asked to describe their group in one word.

QUESTIONNAIRE RESULTS

Results of 17 completed baseline + 6-month follow up questionnaires.

Self-Efficacy

- 100% agreed or strongly agreed that after attending the group, they felt confident in asking their healthcare team questions about treatments and side effects
- 94% (n=16) agreed or agreed strongly that after attending the group, they felt confident in making treatment decisions and accessing information and resources

Helpful Group Experiences

Highest scores were reported for:

- Feeling a sense of belonging
- Receiving support and encouragement
- Developing new friendships

Lowest scores were reported for:

- Feeling as though they could confront difficult problems
- Talking about fear of recurrence

100% said they would recommend the group to others.

FACILITATOR PERSPECTIVES

Facilitator perspectives have been analyzed and categorized into challenges and solutions. The greatest challenge is getting the word out and maintaining attendance.

ATTENDANCE SOLUTIONS

- Get local radio coverage to spread the word
- Call it something other than a support group may draw in more people
- Hold raffles for small prizes anyone can use keeps people coming back
- Build personal relationships and stay in touch to help attendees feel invested
- Personal invitations to join the group makes new attendees feel special
- Schedule a fun activity like a ball game or walk to help the group bond in different ways
- Have a plan in place to manage the death of members, which can fell even the strongest group
- Offer food of some kind, whether a full meal, coffee and pastries, organizing a pot luck or even just providing chocolate
- Keep going, even when no one comes

WHAT IS “SUCCESS?”

Successful groups may have 20+ attendees or 3 strong, consistent members. In a discussion about what success is, facilitators were asked: Is it really JUST about the numbers?

YES: *It's not a group if no one comes.*

NO: *I feel that if even one person gets benefit, that is success.*

MAYBE: Attendance waxes and wanes...one month no one shows, the next several people attend.

SURPRISES

None of the three facilitators interviewed had run a lung cancer support group before. Things that surprised them included:

- Time burden to launch and pre-group prep
- Attendees with just lung nodules or diagnosed with other cancers
- Difficulty getting RSVPs

NEXT STEPS

Polling of current and prospective lung cancer support group facilitators indicate an interest in a webinar series, to include:

- Starting a lung cancer group
 - Troubleshooting a struggling group
 - Educational presentations on topics of interest
 - A discussion series to allow facilitators to support each other and share tips on group management
- We will continue to connect facilitators through a quarterly newsletter and are examining online forum options.

CONCLUSION

Only through listening to both lung cancer support group facilitators and attendees can we identify indicators of group success. The results of this project are disseminated to help leaders of new groups consider factors known to foster successful groups, provide direction to facilitators of struggling groups and offer emotional support through identification of universal issues and connection to other facilitators.

The information gathered from this project can help any kind of support group, not just those for lung cancer, anywhere in the world.

THANKS

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