

HOW TO BUILD A BETTER LUNG CANCER SUPPORT GROUP: BEST PRACTICES FROM AUSTRALIA, THE UNITED KINGDOM AND THE UNITED STATES



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BACKGROUND

People diagnosed with lung cancer experience high levels of distress and greater unmet emotional needs than those diagnosed with other cancers. Most lung cancer patients prefer lung cancer-specific groups, however many facilitators report starting and maintaining these groups can be a challenge.

The primary goal of this study was to understand the issues faced in running lung cancer support groups and the ways in which successful facilitators have used to overcome those challenges. The information gained will be used to try to increase the number and sustainability of available lung cancer groups.

Secondary goals include the creation of a best practices guide and the implementation of a small trial of improved practices study to test the results.

METHODOLOGY

A 21 question online survey was sent to lung cancer group facilitators in Australia (AUS) by the Lung Foundation of Australia; the United Kingdom (UK) by The Roy Castle Lung Cancer Foundation and the United States (US) by Lung Cancer Alliance. Responses were collected between 29 August and 22 September 2013.

RESPONSE RATE

	SURVEYS SENT (#)	RESPONSES (%)
AUS	7	n=7 (100%)
UK	42	n=26 (62%)
US	82	n=41 (50%)
TOTAL	131	n=74 (56%)

FACILITATOR CHARACTERISTICS

	AUS/UK	US
Solo or co-facilitated?	79% co-facilitated	54% co-facilitated
Professional degree?	45% YES	76% YES
Social Work	7%	69%
RN	53%	19%
Lung cancer survivor?	0%	7%

GROUP CHARACTERISTICS

	AUS/UK	US
# Responded	33	41
Longevity	<1 yr - 14 yrs 8 groups > 5 years 1 group, same facilitator >14 years	3 mos - 27 yrs 8 groups > 10 years 1 group same facilitator > 17 years
Frequency	91% meet once a month	90% meet once a month
Participant number: > 6	10%	32%
6 - 10	45%	44%
11- 20	45%	24%
Composition	94% both patients and caregivers	88% both patients and caregivers
Setting Hospital/ca ctr	45%	53%
Cancer support center	15%	37%
Public place	40%	7%
Content	94% mix of support and educational	85% mix of support and educational
Ongoing vs. time limited	82% ongoing	90% ongoing
Open vs. closed	82% open	100% open
Is the group a success?	75%	71%

SUMMARY

The majority of facilitators say their groups are successful. As expected, the main challenge for groups in all countries is sporadic or poor attendance.

Most of the groups surveyed are:

- Once a month
- Composed of both people with lung cancer and those who love them (some groups in the UK also include thymic cancer and mesothelioma)
- Professionally led
- Co-facilitated
- A mix of support and education

Groups in AUS are most often held in cancer centers. Many in the UK are as well but in the US groups are equally as likely to be in a center that only provides support for people with cancer.

Groups in the US tend to have fewer participants per group. Three groups in the US are led by lung cancer survivors compared to none in the UK or AUS.

QUALITIES OF A SUCCESSFUL FACILITATOR

Person-focused
Community-centered
Positive
Respectful
Compassionate
Empathic
Dedicated
Tenacious
Enthusiastic
Patient
Passionate
Adaptable
Creative

[One must have] the will to ensure the group works for those patients/carers who attend whether there be 3 or 12 . – UK facilitator

INTERESTING CHALLENGES

One group in Australia includes people diagnosed with mesothelioma as well as lung cancer and reported tension between the groups as those with mesothelioma are seen as "victims" and receive financial compensation whereas those with lung cancer are seen as bringing the disease on themselves and stigmatized.

Many facilitators credited attendance by long-term survivors as helpful and a reason for the group's success but one facilitator is searching for a way to get them to "move along" out of the group.

CREATIVE SOLUTIONS

Groups in all countries participate in lung cancer awareness events which build cohesion

US

- In one group where many people live in another part of the country in the summer, participants keep in touch via email and Facebook
- An issue with parking was resolved when a patient and his family started a fund to pay for it
- One group has two participant-suggested rituals: beginning with all reading aloud something written by one of them and when someone is ill or has died they discuss it at the start of the group so they can process
- One group is streamed live with a chat component so anyone in the world can join in

UK

- Some participants are "welcomers" who go out of their way to make those new to the group feel part of it
- One group is facilitated by a multi-disciplinary team
- Participants bring goodies and when someone dies, they all attend the funeral
- One group has three facilitators who rotate to help with burnout

AUS

- An agreement with the cancer council to co-facilitate gives the group more credibility and authenticity
- Facilitators are volunteer health professionals

KEYS TO SUCCESS

Participants

Nearly all cited the participants as the primary reason their group is successful.

- Foster a core group that consistently attend
- Include long-term survivors to give hope
- Engage active participants to make new attendees feel welcome and part of the group
- If appropriate, encourage contact outside between formal meetings

Monthly groups need a 'core' of survivors to be a success and we are fortunate to have several participants who...come as the core.– US facilitator

Remember the basics

Many of the keys to making a group a success seem intuitive but may be overlooked.

- Snacks or a meal draw people in
- Ensure the setting is conducive to sharing
- Send emails or make calls to remind participants
- Consistency matters

Our group has been running for six years with the same two facilitators and never a month has been missed, very important to patients and carers as they know who to expect at the group and [that] builds up trust. – UK facilitator

Don't go it alone

Successful groups capitalize on support, both within the organization or institution and from the community at-large.

- If possible have at least one co-facilitator with complementary skills
- Involve participants in the planning and determining focus
- Utilize outside speakers and presenters
- Foster relationships with doctors

[One reason for our success is that] we have earned the trust of several key physicians and oncologists. – UK facilitator

Be bold

Difficult topics can be hard for even professionals to discuss. Find ways to do it and to keep the mood informal and positive.

- Address poor health status and death straight on
- Don't be afraid to use humor
- Consider developing rituals to remember those who die
- Persevere even when attendance is low

When there are only a couple of people there I feel that even if one person gets benefit that is successful. – UK facilitator

Be creative and flexible

Think outside the usual "support group" box.

- Adapt the group to the changing needs of the participants
- Find creative ways to market -- people can't attend if they don't know about it.
- Personally invite people to join, don't just rely on signs and flyers

We don't call it a support group as we find that this can put people off. – UK facilitator

CONCLUSION

Each year, many lung cancer support groups fail and the reason most often cited is lack of attendance.

Before the survey, it was expected that professionally facilitated groups and those that meet more often than once a month would be the most successful. This survey shows that with thought, attention and participant involvement, monthly lung cancer groups can be very successful. It also revealed that facilitation by a professional does not guarantee success, given that 100% of facilitators without a professional degree consider their groups to be a success.

The results bring confidence that we will be able to assist struggling groups to become more successful and to help those starting groups understand what to consider prior.

[My support group] is one of the most rewarding aspects of my career. – US facilitator

LIMITATIONS

It is possible that the most motivated and successful facilitators participated in the survey.

Specific geographic information was not gathered to assess if particular strategies are more successful in urban or rural settings.

TROUBLESHOOTING GUIDE

Creation of the Lung Cancer Support Group Troubleshooting Guide is underway to make the information gathered from the survey available to anyone in the world interested in starting or improving a group. The guide will be suitable for facilitators at all skills levels and address the various challenges that may be faced in starting or maintaining a group, using the knowledge and expertise of experienced facilitators of successful lung cancer support groups.

NEXT STEPS

Twelve US facilitators responded their group is not successful or that they are unsure. We are currently engaged in a small trial of improved practices to help facilitators of four of those groups to test real-world implementation of the suggestions gathered from this study and the research on support groups.

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