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 dealt with them to overcome these challenges. The information gathered 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 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

<table>
<thead>
<tr>
<th>SURVEYS SENT</th>
<th>AUS (%)</th>
<th>UK (%)</th>
<th>US (%)</th>
<th>TOTAL (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>n=7</td>
<td>7 (100%)</td>
<td>n=28</td>
<td>n=41</td>
<td>n=74 (56%)</td>
</tr>
</tbody>
</table>

GROUP CHARACTERISTICS

<table>
<thead>
<tr>
<th>Australian and US</th>
<th>US</th>
</tr>
</thead>
<tbody>
<tr>
<td>AUS/UK</td>
<td>33</td>
</tr>
<tr>
<td>Longevity</td>
<td>&lt;1 yr - 14 yrs</td>
</tr>
<tr>
<td></td>
<td>1 group same facilitator /17 yrs</td>
</tr>
<tr>
<td>Frequency</td>
<td>91% meet once a month</td>
</tr>
<tr>
<td>Participant number</td>
<td>10%</td>
</tr>
<tr>
<td>E-10</td>
<td>45%</td>
</tr>
<tr>
<td>Composition</td>
<td>44% both patients and caregivers</td>
</tr>
<tr>
<td>Setting Hospital/hospital clinic</td>
<td>45%</td>
</tr>
<tr>
<td>Public place</td>
<td>15%</td>
</tr>
<tr>
<td>Content</td>
<td>49%</td>
</tr>
<tr>
<td>Ongoing vs. time limited</td>
<td>82%</td>
</tr>
</tbody>
</table>
| Open vs. closed   | 82% | 100%

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
- Encourage active participants to make new attendees feel welcome and part of the group
- If appropriate, encourage contact outside between formal meetings

Monthy 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

INTERESTING CHALLENGES

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 had a particularly suggested ritual: beginning with all reading aloud something written by one of them and whenever someone is ill they discuss it at the start of the group so they can process
- One group is offered free tea with a chef-mentor so anyone in the world can join in
- Some participants are “welcome” 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
- An agreement with the cancer council to co-facilitate gives the group more credibility and authenticity
- Facilitators are volunteer health professionals

CONCLUSION

Each year, 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 with more than one facilitator per group would be the most successful. This survey shows that with thought, attention and persistence, motivated 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 group as 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.

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.

CREATIVE SOLUTIONS

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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 based on facilitators’ 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 that 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 new word implementation of the suggestions gathered from this study and the research on support groups.

CONTACT

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