

# What should a support program for patients with lung cancer look like? Differing attitudes of patients and support group facilitators.

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## Introduction

- High levels of psychosocial distress and support needs among patients with lung cancer
- General literature supports benefits of support groups – improve psychosocial well-being
- Extensive range of support groups and programs exist in Victoria eg Cancer Connect, Cancer Helpline, Living with Cancer
- Uptake by patients with lung cancer is low
- Support group participants more likely female, younger, more educated, have existing supports

## AIMS of Lung Cancer Support Program Project

- To determine the support needs of patients and their families with lung cancer
- To find out why existing services are being under-utilized
- To develop more appropriate models of support

## Data Collection Method

Self-completed surveys of:

A convenience sample of 101 lung cancer patients from the Peter MacCallum Cancer Centre (East Melbourne and Bendigo).

All support group facilitators affiliated with the Cancer Council Victoria.

Respondents of both the patient and facilitator surveys were asked about a lung cancer support program and:

- preferred content
- preferred location
- preferred facilitators
- potential barriers to attendance of a support program for people with lung cancer

## Patient Survey

101 lung cancer patients completed patient survey (response rate 58%)

265 patients screened

91 (34%) patients ineligible

- Non-English speaking 61
- Cognitive impairment 10
- Too unwell 4
- Participating in another study 16

174 eligible patients

- 34 (20%) patients declined to participate in survey
- 39 (22%) patients consented but did not complete survey
- 101 (58%) completed survey

Patient Demographics

- Current smoker 12 (12%)
- Self-rated ECOG
  - ECOG 0-1 56 (56%)
  - ECOG 2 – 3 44 (44%)
- Non-small cell lung cancer 80 (79%)
- Small cell 16 (16%)
- Mesothelioma 5 (5%)
- Metastatic disease 42 (42%)
- Receiving active treatment 35 (35%)
- Median time since diagnosis 10 mo (0-97)

## Facilitator Survey

145 eligible support group facilitators

52% response rate (75 surveys)

General Support Group Facilitators

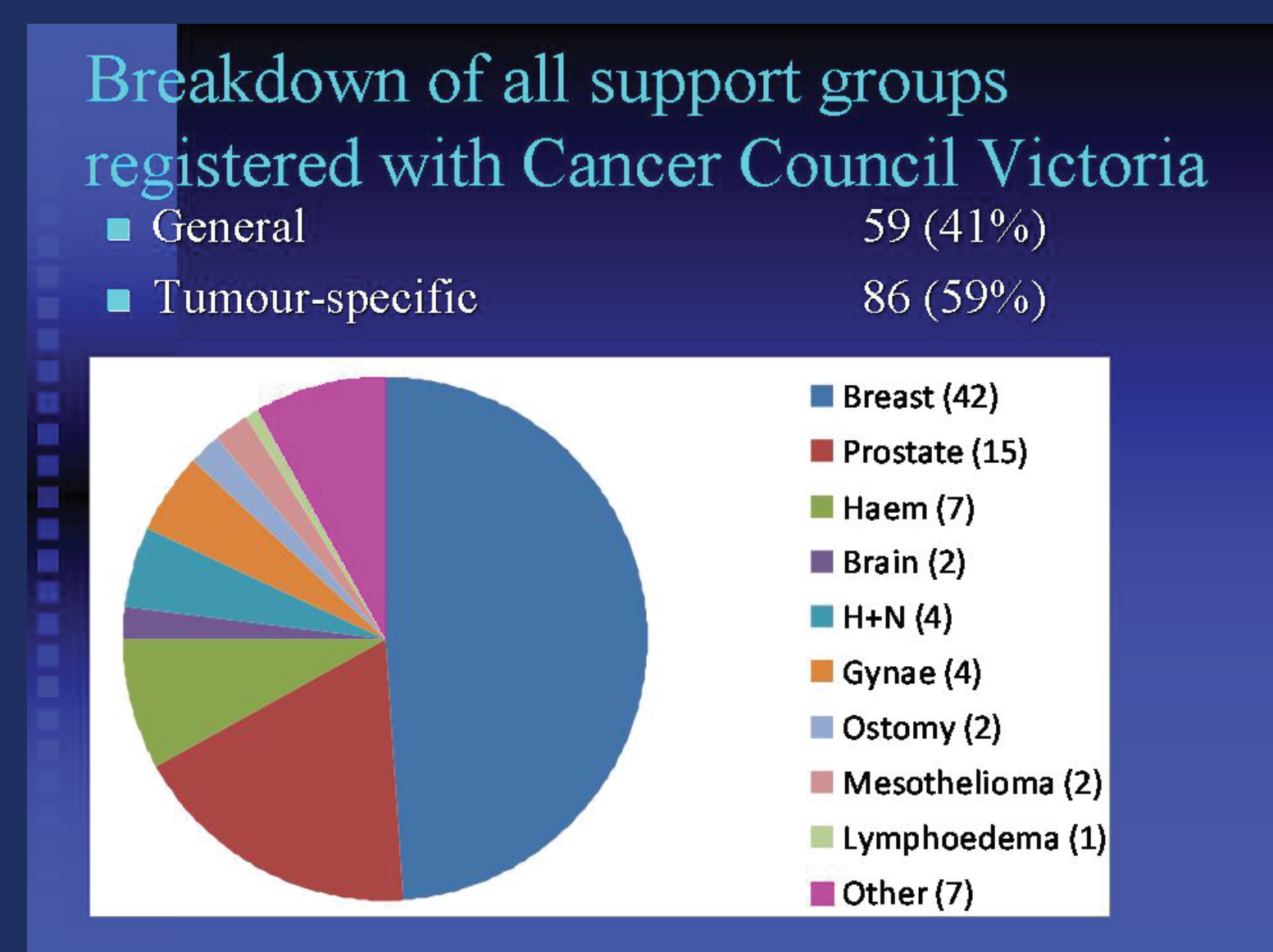
41% of eligible support group facilitators were from general support groups (59 surveys)  
61% response rate in “General Support Group” subset

Tumour Specific Support Group Facilitators

59% of eligible support group facilitators were from tumour specific support groups (86 surveys)  
45% response rate in “Tumour Specific Support Group” subset

Facilitator Demographics

- Median age (range) 57 (35-79)
- Female 58 (78%)
- Health professional 31 (42%)
- Cancer survivor 26 (35%)
- Volunteer 17 (23%)
- Completed facilitator training 38 (51%)



Patients and facilitators agreed that a lung cancer support group should be small and include information about lung cancer treatment, side effects and self-care strategies

## Facilitators Preferred

- Support program to be held in a community building
- Involvement of a cancer survivor
- Predominant focus on social and emotional support

## Patients Preferred

- Support program to be held at a hospital
- Involvement of a health professional
- Predominant focus on information about lung cancer treatment and self-care

53% of patients responded they would be likely or very likely to attend a support program if it suited their needs.

## Results



## Biases in results

- Patients from a centre with good supports
- Missing the views of the non-responders

## Conclusion

Disparities in the views of patients and facilitators about the preferred location, type of facilitator and content of a lung cancer support program may in part explain the poor uptake of existing support programs by lung cancer patients and should be considered in the design of future programs.

Existing peer support models do not suit the needs of the majority of lung cancer patients.

New models and existing services need further investment and development.

Patient preference for ‘support through information’ needs to be considered in the design of future models.

## Areas to consider

- Specialist lung cancer nurse coordinators
- Accessing lung cancer patients and families through telephone, internet and multi-media resources
- Accessing the non-English speaking lung cancer patients and families.

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