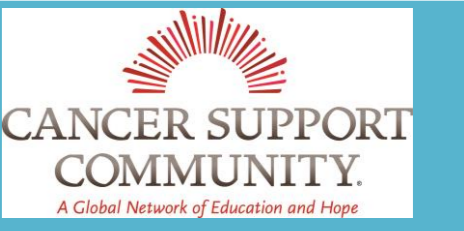


# EVALUATION OF LUNG CANCER SUPPORT GROUP PARTICIPATION: PRELIMINARY RESULTS



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## BACKGROUND

In-person support group attendance can address the greater unmet physical and emotional needs and high rates of distress experienced by those diagnosed with lung cancer. While survivors tend to prefer lung cancer-specific groups, these can be challenging to start and maintain. As a result, there are <100 groups currently active in the United States, inadequate to serve the 224,000 people diagnosed annually.

The National Lung Cancer Support Group Network was established in 2015 to connect current facilitators, strengthen existing groups that are struggling and establish seven new groups in areas of high need. The new groups include a research component to assess group impact on quality of life and satisfaction to better understand the value of participation and engagement.

Enrollment and follow-up evaluation are ongoing for this project. We present initial results of the first new group at Gilda's Club Nashville, analyzed by Cancer Support Community's Research and Training Institute.

## METHODS

Using a pre/post test design, group members completed pencil-and-paper questionnaires.

The baseline questionnaire included:

- CancerSupportSource@CSS-15 Distress Screening Tool
- Positive Affect Scale of PANAS
- UCLA 3-item Loneliness Scale

Follow-up questionnaires, administered after six months of attendance, included:

- CSS-15 Distress Screening Tool
- Positive Affect Scale of PANAS
- UCLA 3-item Loneliness Scale
- Additional self-efficacy measures
- 14 questions on group helpfulness

## DEMOGRAPHICS

Groups include lung cancer survivors, spouses/partners and other family members.

Twenty participants completed the baseline questionnaire. Half (n=10) also completed the six month follow-up questionnaire.

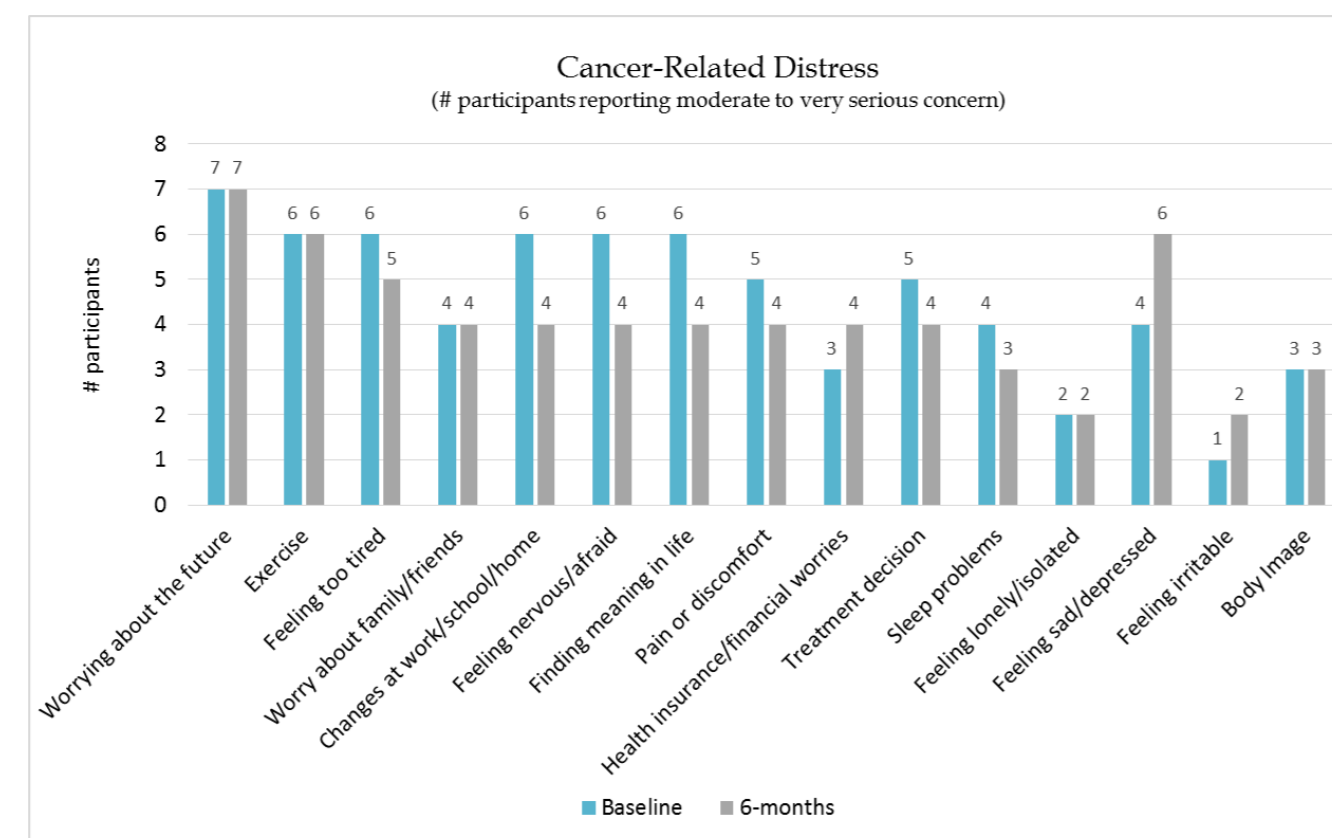
Demographics of those who completed baseline and follow-up questionnaires (n=10):

- Average age: 56.3
- Most were:
  - Patients/survivors (70%)
  - Diagnosed at stage IV (70%)
  - White (90%)
  - Female (60%)
- Attended an average of 10 groups

## RESULTS

### Cancer-related Distress

There was a significant decrease in overall distress (p=0.007) following group participation.

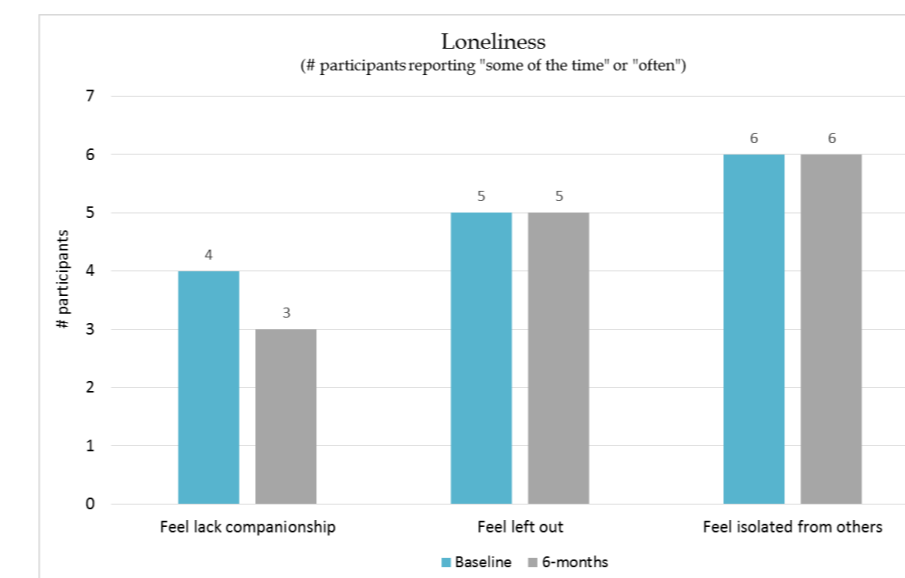


***"It's reassuring to be around others...in similar situations to share and hear what someone else may have experienced..."***

## RESULTS

### Loneliness

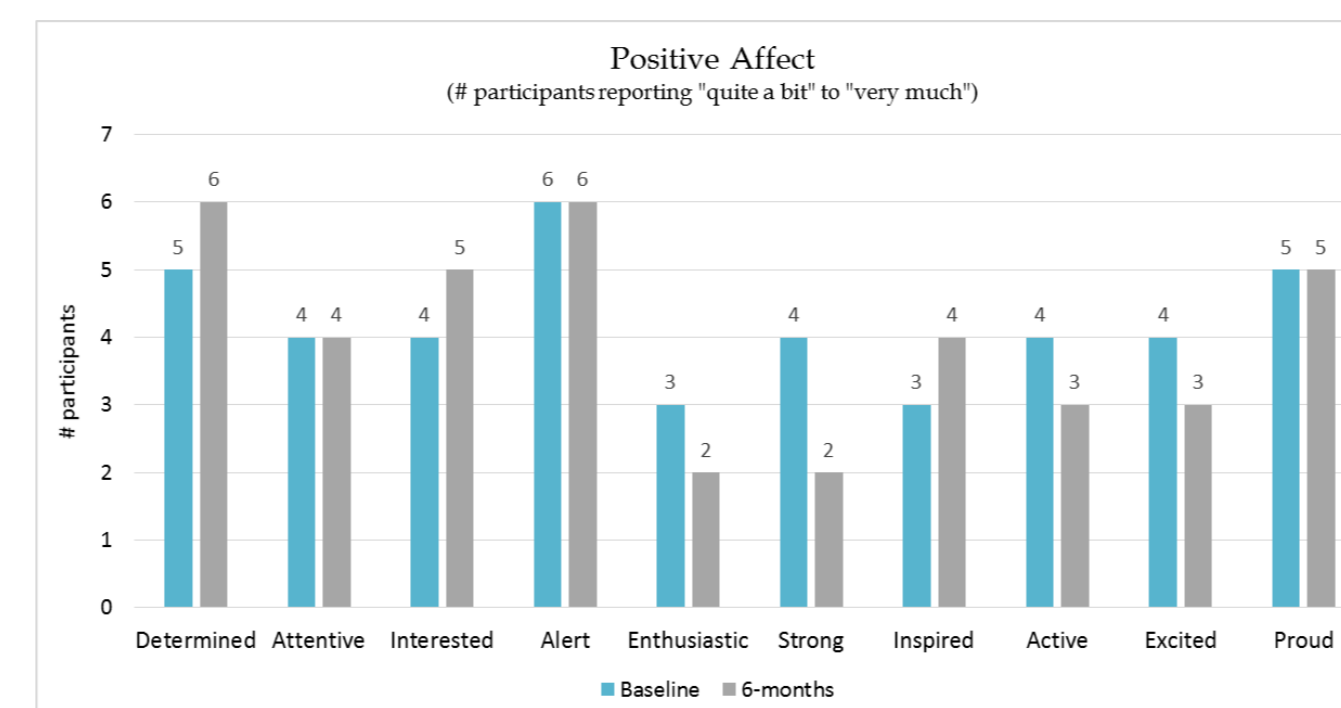
While not statistically significant, fewer completers reported lacking companionship.



***"It's the community that makes it work."***

### Positive Affect Scale

While not statistically significant, completers felt more interested, determined and inspired. They also felt less strong and enthusiastic at six months.



***"This is a loving, supportive, encouraging and inspiring group."***

### 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
- Making treatment decisions
- Accessing information and resources

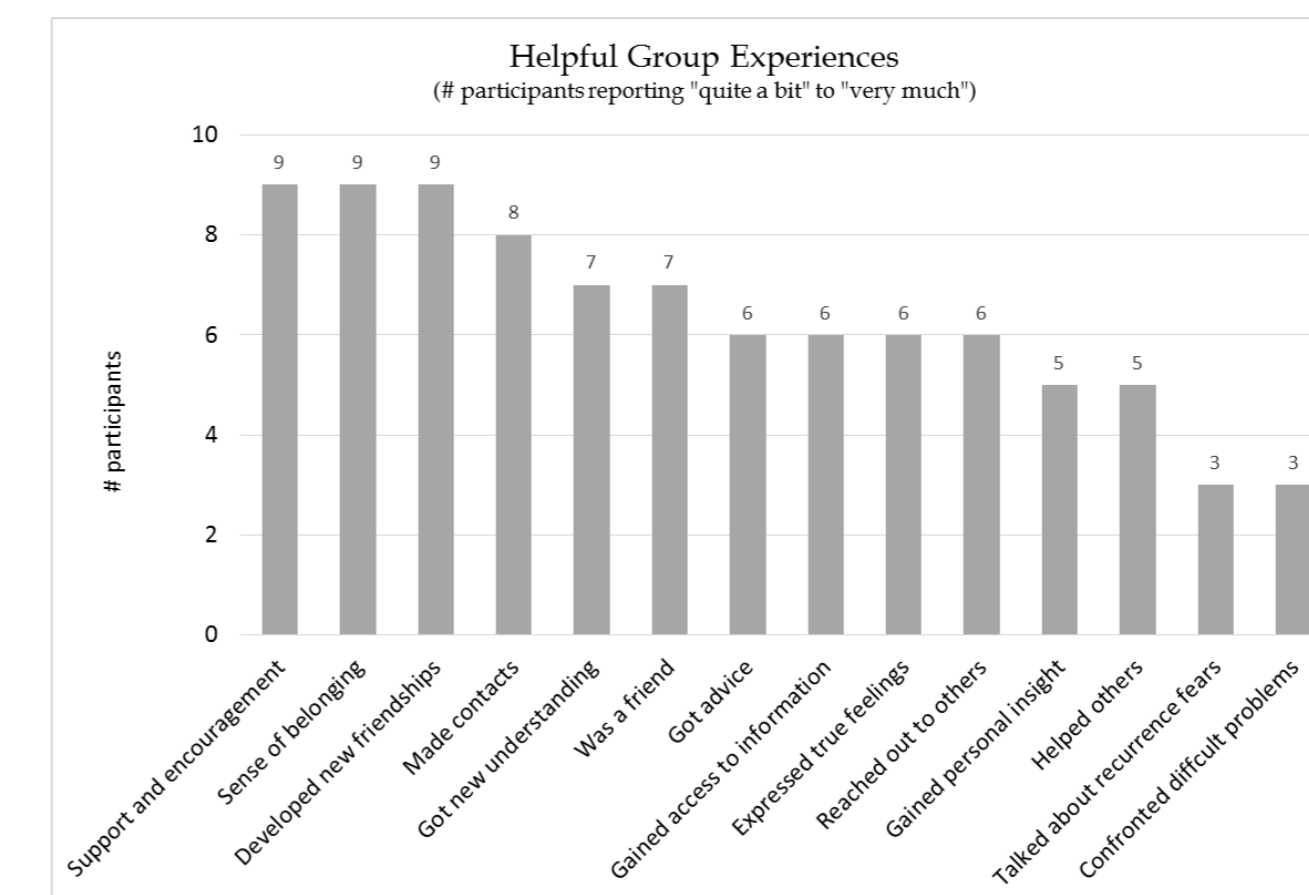
## RESULTS

### Helpful Group Experiences

Highest scores were reported for:

- Receiving support and encouragement
- Having a sense of belonging
- Development of new friendships

***"It helps to be in the company of fellow travelers."***



Lowest scores were reported on:

- Being able to talk about fear of recurrence
- Confronting difficult problems and fears

***"I am concerned my husband [the patient] feels he can't express himself in the group."***

**All participants said they would recommend the group to others.**

***"Every lung cancer patient needs this."***

## STRENGTHS

- 70% survivors
- 40% male
- High representation of late stage diagnosis reflects the overall disease

## LIMITATIONS

- Very preliminary results (n=10)
- Mostly White
- Single setting

## CONCLUSIONS

Although preliminary, these results suggest positive potential impact and benefit of lung cancer support groups, particularly with regard to improving quality of life through reductions in distress.

Six of the seven groups have launched and the next analysis of participant experiences will be available mid-2017.

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