

# LOOKING AT SUPPORT FOR CAREGIVERS IN A NEW WAY: THE GUIDES PROGRAM

## STATEMENT OF NEED

### LUNG CANCER CAREGIVERS WHOSE LOVED ONES ARE AT THE END OF LIFE HAVE UNMET NEEDS.

Studies show that caregiver support is lacking, especially for caregivers whose loved ones are at the end of life or have died. Lung cancer's high mortality results in many caregivers facing these challenges. In addition, lung cancer stigma impacts the likelihood caregivers will access the limited end of life and bereavement support that is available. To address this problem, Lung Cancer Alliance created the GUIDES program, which provides one-on-one peer-to-peer support by telephone.

## ABOUT THE GUIDES PROGRAM

The Grief and Understanding in Death and End of Life Support (GUIDES) Program provides end-of-life and bereavement support to caregivers of people with lung cancer.

Volunteer numbers:  
- 5 male  
- 25 female

Matches made based on:  
- Relationship to loved one  
- Sex  
- Age  
- Distance of caregiver to loved one  
- Hospice  
- Children living at home

Volunteers must be at least a year past the death of their loved one and fill out an extensive survey about their caregiving experiences. They are provided with a training manual and participate in a mandatory telephone orientation.

## STUDY GOALS

This study was conducted to explore the benefits of peer-to-peer telephone support for caregivers whose loved one is at the end of life or has died from lung cancer. Participants were asked to assess the helpfulness of the program and if being matched with a GUIDES volunteer met their support needs. Those willing to provide additional feedback then participated in an in-depth telephone interview.

## SAMPLE SIZE & METHODOLOGY

### Methodology

An online, anonymous 11 question survey was sent to 20 participants who were matched with a GUIDES volunteer in 2012 and 2013. The survey assessed if the program was helpful and met the needs of the participants through Likert scale and multiple choice questions.

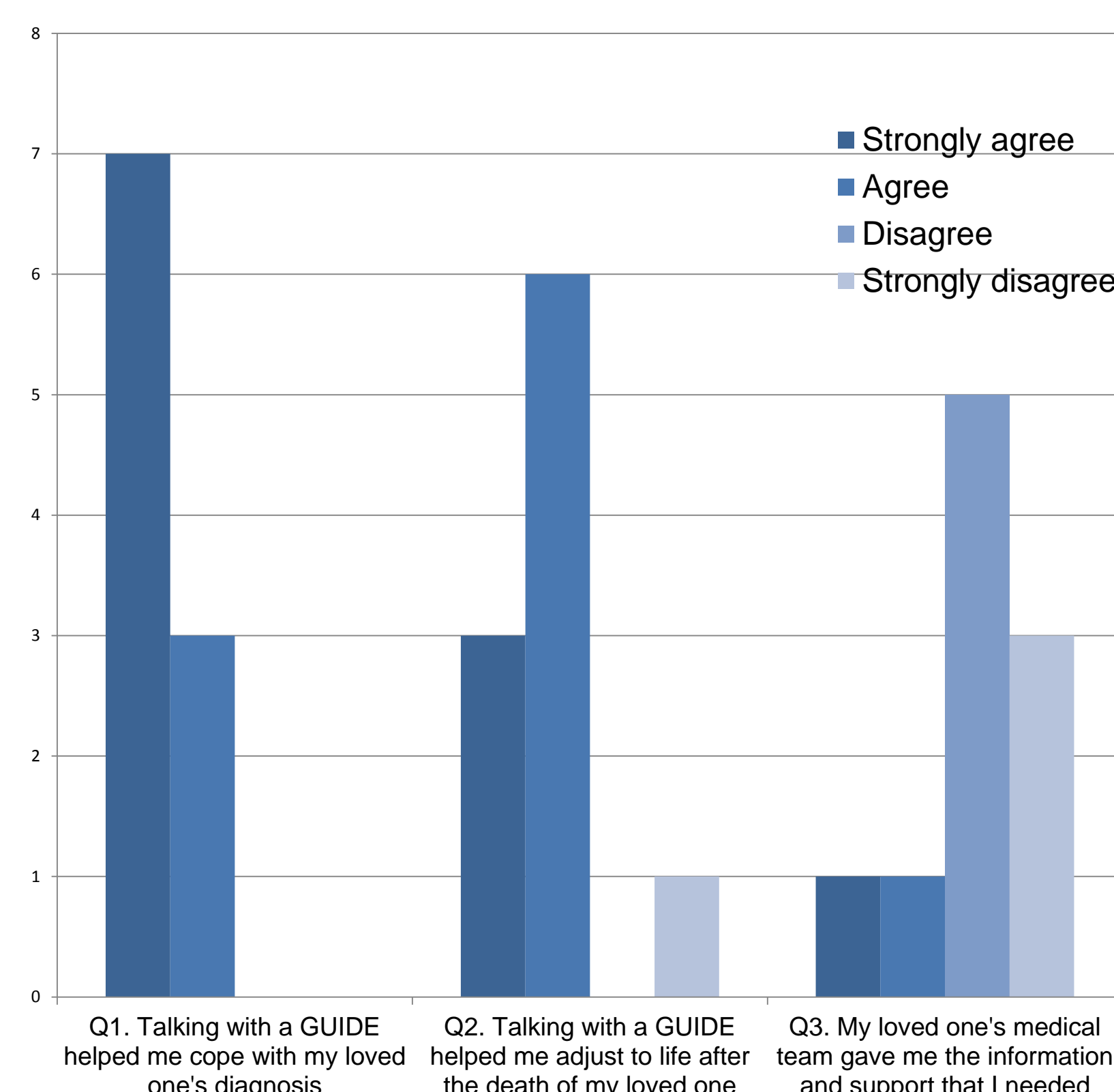
### Response

10 participants completed the survey for a 50% response rate, 2 men and 8 women. 4 were spouses of people with lung cancer, 6 were adult children.

9 of the 10 respondents included contact information and participated in an in-depth telephone interview to further explore their experiences. Telephone interviews focused on the depth of their connection with a GUIDE and what made it unique versus other forms of grief support. An average of 60 min was spent per call.

## GUIDES HELPS TO COPE

GUIDES helps people cope by letting them know that they are not alone. GUIDES offers continuous support from making difficult decisions to empowering people beyond the death of their loved one.



### 100% of participants

- Would recommend the GUIDES Program to others
- Strongly agreed or agreed that talking with a volunteer helped them to cope with the diagnosis
- Felt empowered that someone else understood their unique situation

*When someone you love is diagnosed with a terminal disease, you just don't know what direction to lead. If you don't make the right decision, this person that you love's life could go in the wrong direction. The worst part was my siblings making different 'right decisions' and us not being able to agree. My mind was ready to explode and I needed unbiased support and advice.*

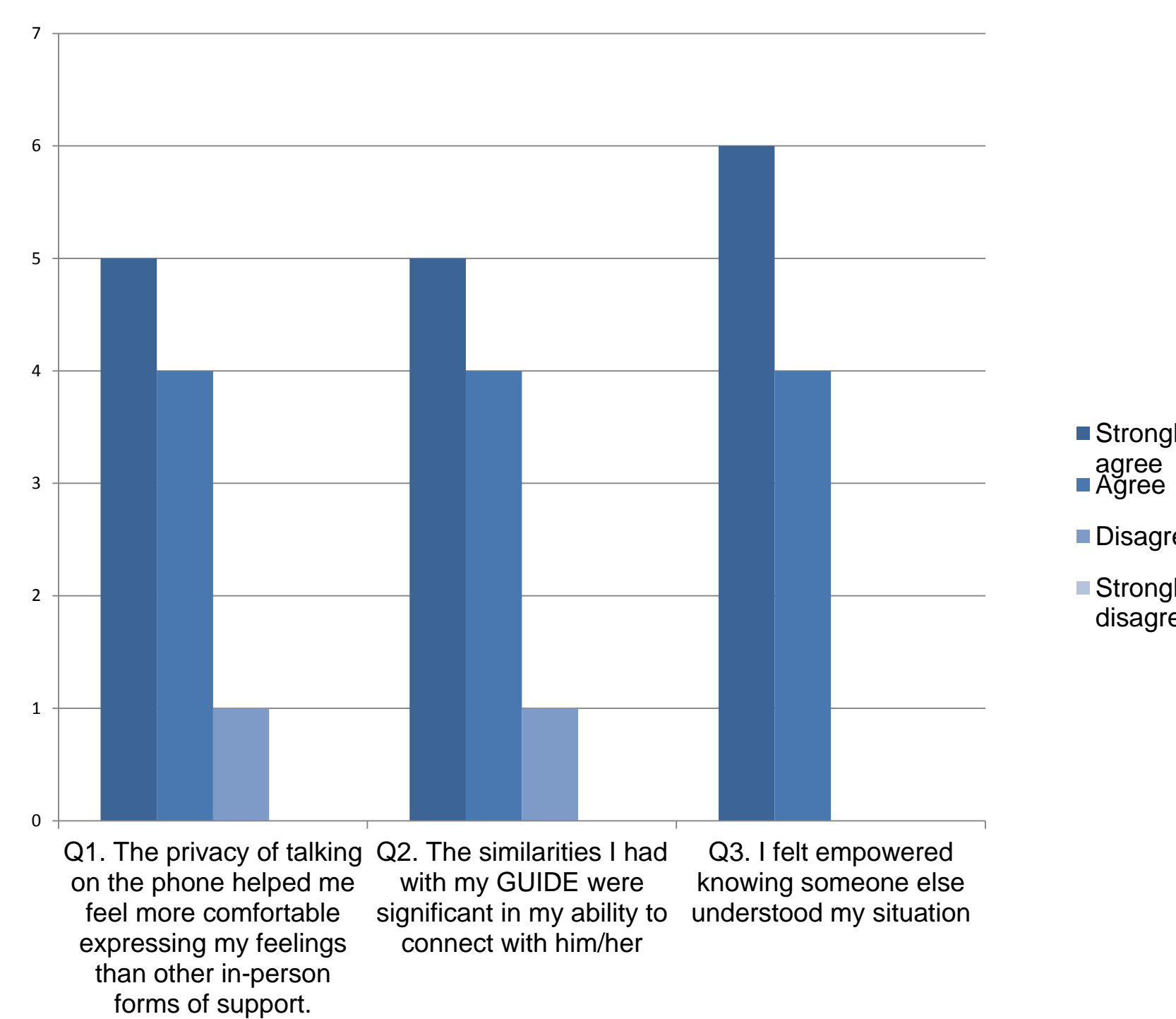
*I called my GUIDE 9 months after my dad passed away because I still cried when I looked at pictures of him. The first holidays without him made me physically sick. She always answered the phone and told me that I wasn't crazy and things would get better.*

**80% (8) respondents** did not feel that their loved one's medical team gave them enough support and information

*I never had contact with my mom's doctor, so it was a big shock when they released her into hospice. We never had anything explained to us until the hospice team came in and treated my mom like a real person.*

## GUIDES IS UNIQUE

GUIDES is the only personalized end-of-life support program for lung cancer caregivers. Through the GUIDES Program, caregivers are connected with someone based on their individual expressed needs.



*I was in Ohio and she was in Colorado, but I knew that I could call her when I was having a bad day. I could call her to ask things like, 'Is it normal that I still cry when his favorite song comes on, even though it's been 3 months since he passed?.' And she would tell me she still does the same thing, 5 years later.*

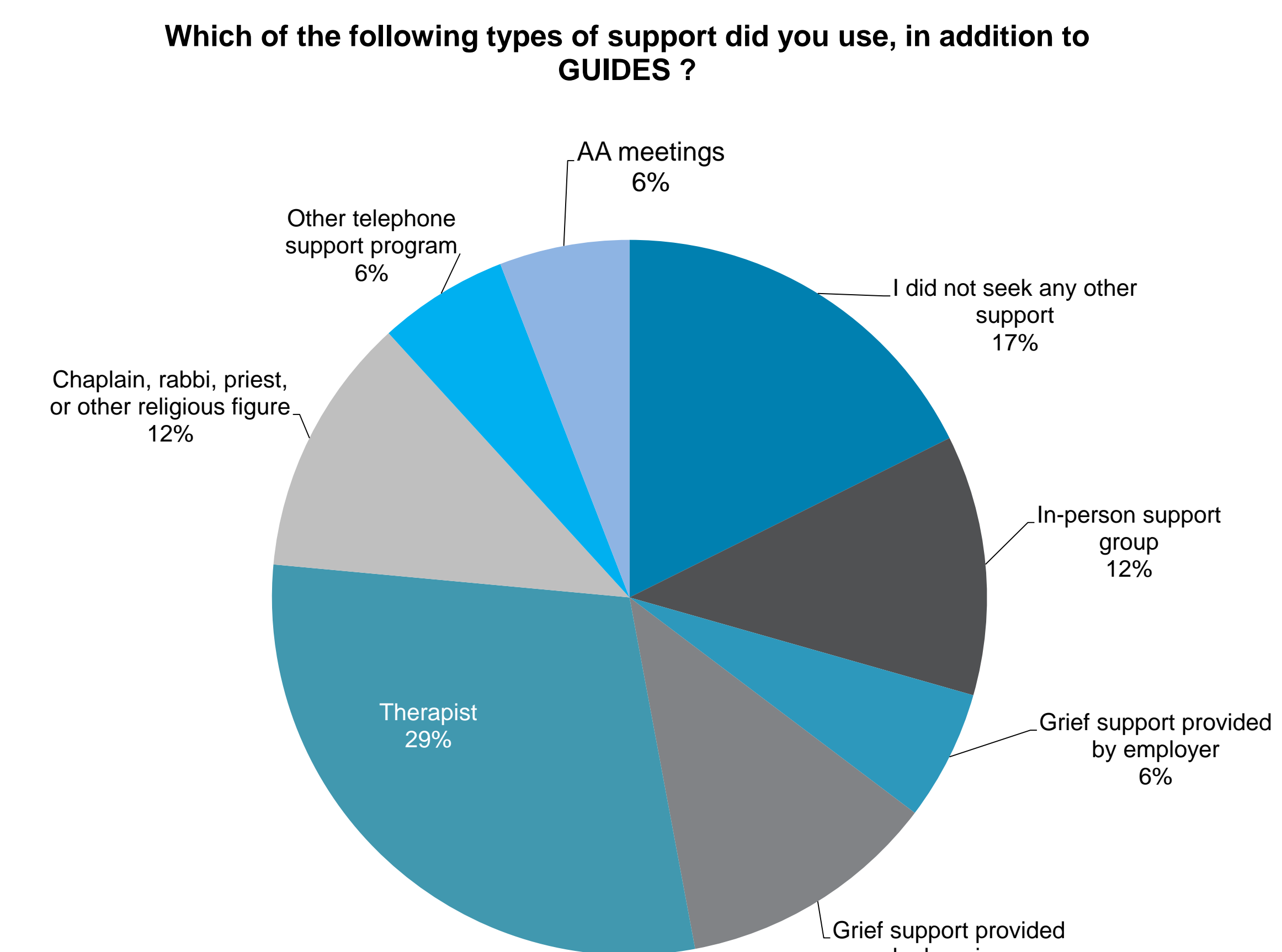
*I didn't have time for support groups with my full-time job and giving my own family attention. Knowing that support was only a phone call away was the most reassuring thing for me in my grief process.*

*You have your regular family and your friends, but you don't have anyone who knows the feeling. My husband was supportive, but he just didn't understand why I was so grumpy all the time.*

*Her dad died in hospice, too, of the same type of lung cancer. I asked her to tell me what death would actually look like so that I could prepare myself. Because of her, I knew what to expect.*

## GUIDES FILLS GAPS

GUIDES offers support to caregivers who don't have access to other forms of support. It is convenient, offers privacy and is available as needed. While typical forms of grief support have an expiration date, GUIDES offers continuous support along the caregiver's grief journey.



*My insurance only covered 4 weeks of professional therapy. I worked full-time and the closest support group was 45 minutes from my house. When my therapy sessions were over, I was supposed to be better, but I had never felt so alone.*

*I tried using hospice grief therapy, but they came at it from a religious angle that was different than mine. My Church was supportive, but they didn't understand the lung cancer stigma aspect. I didn't think there was anyone else like me until I called LCA and they connected me with a GUIDE. We still talk, a year and a half later.*

*I had to attend AA meetings for the first time in 27 years just to not fall off the wagon.*

*My therapist focused on resurfacing issues from my childhood rather than how to deal with the loss of my wife.*

## SUMMARY AND CONCLUSIONS

Telephone based peer-to-peer support fulfills a missing component to end-of-life support for caregivers. It is much less resource-intensive than live support groups and other professionally-led forms of support.

- The similarities participants shared with their GUIDE allowed them to develop a profound connection.
- Most participants found the convenience and privacy of talking on the phone to be most significant in their satisfaction with the program.
- The assurance of ongoing support, even months beyond their loved one's death, was comforting for participants.
- Participants who sought additional psychosocial support identified a gap in availability, convenience and effectiveness

Though this study is lung cancer-specific, the results extend far beyond this disease alone.

## LIMITATIONS

- Small sample size
- Because of the need to get a sufficient sample size, participants who were matched up to two years ago were included and for some, memories of the program were not as fresh
- All participants were at different places in the process, ideally all would have been followed-up with at the same interval
- Information on if the match with a GUIDES volunteer was made before or after the loved ones death was not gathered

## FUTURE RESEARCH

Numerous studies have demonstrated disparities in end-of-life support for caregivers, yet there are few studies to offer a solution. Despite its limitations, this study was piloted to provide a more comprehensive understanding of caregiver support needs with attention to areas not previously considered in research. Future research on larger sizes is warranted to show that peer-to-peer end of life support is effective and results extend beyond lung cancer caregivers.

**70% of participants want to volunteer in the GUIDES Program to help others through the end of life process.**