

ASSESSMENT TO PROGRAMMING: RESPONDING TO THE NEEDS OF THE US LUNG CANCER COMMUNITY

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BACKGROUND

Research has shown that people diagnosed with lung cancer have greater unmet supportive care, physical and emotional needs compared to those diagnosed with other types of cancer.

Much of the research is older and primarily focused on small numbers of newly diagnosed patients. Some articles have only focused on the lack of treatment options, not the practical and psychosocial needs of those in treatment and long-term survivors.

Our goal was to more fully understand the needs of those diagnosed with lung cancer in order to develop services and programming to address unmet needs.

METHODS

An online Community Needs Assessment survey was distributed to lung cancer patients and loved ones 11/9/2015 to 2/8/2016.

820 people responded, including 471 patients/survivors and 349 loved ones, 181 of whom identified as primary caregiver.

The overall completion rate was 72.6%.

Respondents were specifically asked to identify the most prevalent and problematic symptoms and side effects experienced:

- During treatment
- Shortly after treatment ended
- 5+ years post-diagnosis

Respondents were also asked to identify which were most problematic during each time period as well as unmet needs for each period.

In addition to other questions, respondents were asked about discussions and plans for palliative and survivorship care,

DEMOGRAPHICS

Patients and survivors:

83% female, 17% male

Most were:

- Older (78% aged 50+ at diagnosis)
- **White (94%)**
- **Urban/suburban (77%)**
- Retired (53%)
- Current or former smokers (65%)
- Less educated (56%= no college degree)
- In active treatment (52%)
- Diagnosed with NSCLC (86%)
 - Adenocarcinoma (80%)
 - Stage III or IV (64%)

5+ year survivors = 21%

RED = atypical for lung cancer

REPORTED SYMPTOMS AND SIDE EFFECTS

DURING TREATMENT: **PATIENT REPORTED**

- **Fatigue (62.9%)**
- **Hair Loss (48.2%)**
- **Anxiety/Worrying (47.9%)**
- **Constipation (45.1%)**
- **Shortness of Breath (42.5%)**
- **Nausea (40.5%)**

AFTER TREATMENT: **PATIENT REPORTED**

- **Anxiety (43.1%)**
- **Shortness of Breath (37.8%)**
- **Fatigue (35.1%)**
- **Stress (28.7%)**
- **Peripheral Neuropathy (27.7%)**

AFTER 5+ YEARS: **PATIENT REPORTED**

- **Shortness of Breath (39%)**
- **Fatigue (28.0%)**
- **Memory Problems (26.8%)**
- **Anxiety (24.4%)**
- **Stress (22.0%)**

BLUE = also the most PROBLEMATIC in time period

UNMET NEEDS RESULTS

“Side effects” was in top 6 phrases and >50% of responses related to side effect management.

I wish there was more concern for side effects and quality of life; the focus is on treatment and survivorship but the physical and emotional cost is enormous and it is hard for others to understand the daily struggle.

When 1st diagnosed I feel that I was not fully informed of long term physical side effects...common with [surgery].

The severe side effects of [targeted therapy] was never discussed, nor was the option of lowering dosage, until I was hospitalized with severe issues.

RESULTS → PROGRAMMING

A webinar series was developed to meet the unmet need of assistance managing the most common and challenging sx and s/e:

- Immediate, post-treatment and long term
 - Shortness of breath
 - Anxiety
 - Fatigue
- During treatment
 - Constipation
 - Diarrhea
 - Nausea

COPING WITH...SERIES

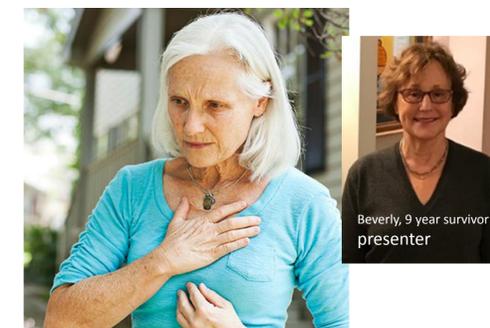
- Webinar-based
 - Live
 - YouTube archived
- Comprehensive
- Holistic
- Expert, multidisciplinary presenters (including survivors)
- Create and distribute accompanying educational materials

COPING WITH...SERIES

Pre-launch work

- Funding
- Peer consultation
- Research (uniqueness)
- Considered partnerships
- Developed project management tools

COPING WITH SHORTNESS OF BREATH:
JANUARY 2017



COPING WITH GI TOXICITIES: APRIL 2017



COPING WITH ANXIETY: JULY 2017



COPING WITH FATIGUE: NOVEMBER?

NEEDS ASSESSMENT STRENGTHS

- Significant response
- High completion rate
- Majority of respondents = pts//survivors

NEEDS ASSESSMENT LIMITATIONS

- Respondents were mostly white
- Respondents were mostly female

COPING SERIES CHALLENGES

- Significant learning curve
- Experts are willing to help but busy
 - Overall low live attendance
 - Significant use of YouTube archives
- Post-webinar survey attempts unproductive

CONCLUSIONS

As a national organization, we are obligated to understand and work to meet the unmet needs of our community. This assessment revealed multiple gaps in the receipt of palliative care by patients, survivors and their loved ones. The *Coping with...* series is the first of many steps Lung Cancer Alliance will initiate to help meet identified needs.

CONTACT

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