SURVIVOR GUILT: THE SECRET BURDEN OF LUNG CANCER SURVIVORSHIP

Tara Perloff[1], Megan Johnson Shen PhD[2], Kate Abramson LICSW[1], Jennifer C. King PhD[1], Kay Bayne[1]

[1]Lung Cancer Alliance, [2]Weill Cornell Medicine

LUNG CANCER ALLIANCE

Weill Cornell Medicine

INTRODUCTION

With a 5-year survival rate of only 18.0%, lung cancer survivorship has historically been an all too rare occurrence. It is often assumed that someone who was diagnosed with lung cancer should be grateful to experience survivorship. A more common, though often unnoticed, aspect of lung cancer survivorship is the burden of guilt experienced for simply being a survivor of the disease. This feeling of objective guilt is a phenomenon known as *survivor guilt*.

The goal of the present study was to explore the prevalence of survivor guilt among lung cancer survivors as assessed by both a validated measure as well as individuals' perceptions of experiencing survivor guilt.

METHODOLOGY

108 lung cancer survivors completed an online survey via Survey Monkey of their experience with lung cancer survivor guilt. Outcomes assessed focused on examining demographics, survivor guilt, and general feelings toward surviving lung cancer when others did not.

MEASURES
1. Demographic and clinical information was assessed via patient self-report.
2. Survivor guilt was assessed using the 22-item "Survivor Guilt" subscale of the Interpersonal Guilt Questionnaire (IGQ-67).[1] This 22-item subscale asks participants to rate their level of agreement with questions assessing the degree to which they feel guilty about surviving their cancer.
3. A single-item question was used to assess whether an individual felt as if he/she experienced survivor guilt. Individuals were first given a brief definition of survivor guilt and then asked to explain (open-ended).

DATA ANALYSIS
- Descriptive statistics were calculated for demographic variables and measures of survivor guilt. T-tests and Analysis of Variance (ANOVAs) were conducted to examine if there were group differences in the levels of survivor guilt across demographic variables.
- Qualitative analysis of open-ended responses was conducted for 25% of respondents with the highest measured survivor guilt.
- A theoretically derived preliminary coding guide was created
  - Three authors of the study coded text
  - New codes were added if both coders agreed on the necessity of the code
  - After initial coding, coders discussed and resolved coding discrepancies

DEMOGRAPHICS

The majority of those who completed the survey were females (86%) between the ages of 50-59 years old when diagnosed with lung cancer (47.2%), had been diagnosed with non-small cell lung cancer (85%), and were former smokers (69.4%).

CHARACTERISTIC	NUMBER	PERCENTAGE
Age (in years) when diagnosed		
30-39	5	4.6%
40-49	16	14.8%
50-59	51	47.2%
60-69	31	28.7%
70-79	5	4.6%
Gender		
Female	93	86.1%
Male	15	13.9%
Lung Cancer Type		
Non-small cell lung cancer	93	86.1%
Small cell lung cancer	11	10.2%
I don't know	4	3.7%
Stage of Lung Cancer (When Diagnosed)		
Stage I-IIIA (Limited)	66	61.1%
Stage IIIB or IV (Extensive	34	31.5%
I don't know	8	7.4%
Smoking history		
I am a current smoker	4	3.7%
I am a former smoker	75	69.4%
I have never smoked	29	26.9%
Currently in Treatment for Cancer		
Yes	25	23.1%
No	83	83.1%
Length of time in treatment		
Less than 1 year	4	3.7%
1-2 years	6	5.6%
2-3 years	6	5.6%
3-4 years	1	0.9%
4-5 years	1	0.9%
More than 5 years	7	6.5%
Length of time out of treatment		
Less than 1 year	17	15.7%
1-2 years	21	19.4%
2-3 years	6	5.6%
3-4 years	7	6.5%
4-5 years	6	5.6%
More than 5 years	26	24.1%

RESULTS

- **63.9% of survivors scored above average** on the IGQ-67 Survivor Guilt Scale
- **55% of lung cancer survivors reported experiencing survivor guilt** as indicated by the single-item measure
- **Survivor guilt did not vary by any of the demographic or clinical** characteristics as indicated by T-tests and ANOVAs

QUALITATIVE ANALYSIS

Five themes emerged in the open-ended text analysis of individuals with the highest measured survivor guilt:

Theme 1: Death of others. Survivors repeatedly referenced the death of someone known to them which caused feelings of guilt.

"It's hard to explain. I have lost a few friends to lung cancer in the last year and I had a hard time when they died. Felt guilty. Still feel guilty around their loved ones."

Theme 2: Why not me? Survivors reported negative feelings toward why they did not die of lung cancer rather than why they survived.

"I have a hard time understanding why I am still alive and others have to die. Lots of people have more to offer the world than I do."

Theme 3: Effect of the Passing of Time on Emotions Experienced. Survivors' feelings changed from grateful to guilty throughout their survivorship journey.

"I feel some guilt, and at the same time, being grateful, that my cancer was detected early and that I have had great medical care. I do feel guilty when I see others not have the medical benefit that I have had."

Theme 4: Effect of Demographic and Clinical Characteristics' on Survivor Guilt. Survivors' validated their guilt by comparing themselves to others known to them with similar or unique demographic and clinical characteristics.

"A simple question of why I am still alive and others are not. I feel I did this to myself because I was a smoker."

Theme 5: Coping with Survivor Guilt. Survivors' found comfort by being part of a cancer community.

"I feel that my diagnosis brought this disease into my life and I will do everything in my power to help others that are suffering from lung cancer."

CONCLUSIONS

The rates of self-report of survivor guilt are high (55%), and these rates are even higher when utilizing a valid, reliable measure (63.9% above average). These combined results indicate that experiences of survivor guilt are common among lung cancer survivors.

Thematic analysis of open-ended qualitative data indicates that lung cancer survivors are suffering from feelings of despair as a result of survivor guilt. Though little research has been done on survivor guilt among any group of cancer survivors, the five themes that emerged through the qualitative analysis are consistent with survivor guilt research that has been studied in other populations.

FUTURE RESEARCH

Larger studies need to be done to confirm findings of survivor guilt, as well as to allow further insight into demographic and clinical correlates of survivor guilt. Survivor guilt should also be measured across multiple cancer types to determine whether survivor guilt is a unique experience of lung cancer survivors.

Thematic results indicates that experiencing survivor guilt is associated with psychosocial burdens on patients, calling for future research to understand survivor guilt better and to target the psychosocial distress experienced so that effective coping mechanisms may be developed for individuals who suffer.

References: 1. O'Connor LE, Berry JW, Weiss J, et al. Interpersonal guilt: The development of a new measure. Journal of clinical psychology 1997;53(1):73-89.