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## Survivor guilt: The secret burden of lung cancer survivorship

Tara Perloff<sup>a</sup> , Jennifer C. King<sup>a</sup>, Maureen Rigney<sup>b</sup>, Jamie S. Ostroff<sup>c</sup>, and Megan Johnson Shen<sup>d</sup>

<sup>a</sup>Department of Science and Research, Lung Cancer Alliance, Washington, DC, USA; <sup>b</sup>Department of Support Initiatives, Lung Cancer Alliance, Washington, DC, USA; <sup>c</sup>Department of Psychiatry & Behavioral Science, Memorial Sloan Kettering Cancer Center, New York, NY, USA; <sup>d</sup>Department of Medicine, Weill Cornell Medicine, New York, NY, USA

### ABSTRACT

**Objectives:** Historically, long-term survival following diagnosis of lung cancer has been a rare occurrence. An overall poor prognosis and the low likelihood of long-term survival are thought to precipitate survivors experiencing what is referred to as survivor guilt. This study explored the prevalence and nature of survivor guilt among lung cancer survivors.

**Methods:** Lung cancer survivors ( $n=108$ ) completed an online survey through a national organization's online community platform. This survey included a commonly used measure of survivor guilt targeting lung cancer and a single item that asked about whether they had experienced survivor guilt associated with lung cancer. Additionally, survivors were asked to provide open-ended descriptions of survivor guilt. In-depth thematic analysis was used to analyze these in-depth responses from those with the highest guilt scores on the survey measure (top quartile).

**Results:** Survey responses revealed a majority of study respondents endorsed survivor guilt with 55% reporting an experience of survivor guilt associated with lung cancer. In addition, 63.9% of respondents scored above the mean on the survivor guilt scale. Qualitative analysis revealed five recurring themes among respondents with the highest survivor guilt scores (top quartile): 1) mentioning the death of others, 2) questioning "why not me?" 3) the role of the passage of time on emotions experienced, 4) the role of demographic and clinical characteristics' on survivor guilt, and 5) strategies for coping with survivor guilt.

**Conclusions:** This study identifies survivor guilt in lung cancer survivors and raises clinical awareness that managing survivor guilt is a psychosocial challenge for lung cancer survivors. Results highlight the need for addressing this critical issue.

### KEYWORDS

guilt; lung cancer; psychosocial; survivor guilt; survivorship; quality of life

## Introduction

Approximately, 402,326 Americans living today have been diagnosed with lung cancer at some point in their lives.<sup>1</sup> Despite recent advances in treatment and screening for early detection,<sup>2</sup> lung cancer remains the leading cause of cancer death across every ethnic group in the United States, killing an average of 433 people per day and 168,000 people per year.<sup>1</sup> With such high mortality and poor prognosis, estimated as an overall 5-year survival rate of only 18.0%,<sup>3</sup> lung cancer survivorship has historically been a rare occurrence. It is often assumed that someone diagnosed and successfully treated for lung cancer should simply be “grateful to be alive.” However, extensive experience working with survivors of lung cancer led to the realization that many survivors expressed feelings about the burden of guilt. This led to the hypothesis that survivor guilt may be an undescribed psychosocial challenge in lung cancer survivorship.

The traditional psychoanalytic view of guilt is based upon a subconscious desire to harm others from feelings such as jealousy, vengeance and contempt. Research prior to the 1980s has highlighted feelings of guilt as a primary contributor to psychopathology and emotional distress.<sup>4–9</sup> In the 1980s, Joseph Weiss explored guilt as a derivative of altruism.<sup>10–12</sup> According to Weiss, the person suffering from guilt may in some cases have intentionally harmed or hoped to harm another, but more often the person is suffering from an irrational fear of potentially hurting others caused by the attempt to further his or her own cause.<sup>11</sup> Weiss held that people are highly motivated by altruism and a deep-seated need to help or at least do no harm to others as part of their adaptive need to preserve interpersonal relationships with those who are closest to them.<sup>10–12</sup> The type of guilt which is based on a person’s fear of harming others in the pursuit of his or her own goals may be divided into several different though associated forms of guilt which exhibits an exaggerated sense of responsibility for others, such as survivor guilt.<sup>13</sup>

*Survivor guilt* is a phenomenon linked to the interpersonal process of “surviving” harm while others do not.<sup>14</sup> The term “survivor guilt” was coined by Drs. Stanley Cobb and Erich Lindemann in 1943.<sup>15</sup> They defined survivor guilt as the presence of tension, loneliness, or mental pain that was precipitated by visits from loved ones, by mentioning the deceased, and by receiving sympathy.<sup>15</sup> Robert Jay Lifton further explored survivor guilt, noting “psychic numbing,” or the cessation of feeling, as a dominating lifestyle characteristic experienced by those who suffered feelings of death guilt.<sup>16</sup> Although survivor guilt was initially applied to surviving tragedies such as the Holocaust or Hiroshima, the term was later applied to refer to suffering guilt for surviving HIV+ during the AIDS epidemic.<sup>17</sup> Unlike survivors of war and natural disasters, survivors of the AIDS

epidemic had to deal with their conflicted emotions in the presence of others whom they presumed would die. Survivor guilt during the AIDS epidemic was described as a perpetuating feeling of “why *not* me” associated with difficulty recognizing and communicating emotional distress and a mediator of depression among this population.<sup>17,18</sup> Since its initial application to the AIDS epidemic, survivor guilt has continued to be studied among a broad range of individuals diagnosed and treated for serious life threatening medical conditions, including transplant survivors.<sup>19,20</sup> In these few studies, the commonality among those with survivor guilt was vulnerability in relation to his/her solidarity with others who died of the same disease.<sup>20</sup> Whereas research shows that people diagnosed with lung cancer experience higher levels of distress than those diagnosed with other types of cancer,<sup>21</sup> survivor guilt has been an overlooked psychosocial challenge for lung cancer survivors. Although the number of survivor guilt commentaries has been increasing in the medical and psychology literature,<sup>22–26</sup> the majority are focused on surviving events such as war, mass shootings and suicide.<sup>27–30</sup> Few empirical studies have yet to examine survivor guilt quantitatively among cancer survivors. The goal of the present study was to explore the prevalence and nature of survivor guilt experienced by lung cancer survivors as assessed by both a validated measure of survivor guilt that has been used with other populations as well as individuals’ perceptions of experiencing guilt attributable to surviving lung cancer. Additionally, the present study sought to explore common narrative themes experienced by lung cancer survivors suffering from high levels of survivor guilt. We hypothesized that survivor guilt would be prevalent among lung cancer survivors.

## Methods

Participants were recruited via weekly e-mail newsletters and Facebook posts, through the Lung Cancer Alliance’s online community of approximately 50,000 people broadly affected by lung cancer. Participants were recruited between April 27 and June 3, 2016 and participation was completely voluntary with no incentives offered. Only those identifying as survivors of lung cancer were eligible to complete the survey. Of the 159 individuals who started the survey, 108 complete online surveys were obtained (68%). Survey responses were anonymous, except for an optional item to allow re-contact for follow-up studies.

## Measures

Data were collected online via Survey Monkey.<sup>31</sup> The online survey included both quantitative and qualitative questions focusing on

demographics, survivor guilt, and general feelings toward surviving lung cancer when others did not. Quantitative measures were rated on Likert-type scales. Qualitative measures included an open-ended question eliciting survivors' experience of survivor guilt.

**Demographic and clinical information.** Demographic and clinical information was assessed via patient self-report. Items included: gender, age at diagnosis, type and stage of lung cancer, smoking history, and length of time since treatment completion.

**Survivor guilt.** Because no prior empirical studies have examined survivor guilt in a lung cancer population, we chose the 22-item *Survivor Guilt* subscale of the Interpersonal Guilt Questionnaire (IGQ-67 SGS)<sup>13</sup> in order to ensure that validated measure was utilized. The previously published healthy comparison group consisted of 199 college students of 133 females and 66 males, ranging in age from 18 to 68 years ( $M = 65.4$  for males and  $M = 68.9$  for females).<sup>32</sup> We modified survey questions so as to focus on lung cancer survivorship. Participants were asked to rate their level of agreement with items assessing the degree to which they feel guilty about surviving their cancer (e.g., "It makes me uncomfortable to receive better treatment than the people I am with") on 5-point Likert scales ranging from either 1 = very untrue of me to 5 = very true of me OR 1 = strongly disagree to 5 = strongly agree. A total sum score was created with possible scores ranging from 22 to 110, with higher scores indicating greater survivor guilt. The IGQ-67 SGS responses were found to be internally consistent (Cronbach's  $\alpha = .76$ ), which is similar to that observed in prior research conducted with other survivor samples.

**Endorsement of survivor guilt.** After completing the IGQ-67 SGS, individuals were given the following brief definition of survivor guilt: "When people survive lung cancer, they often experience a feeling known as survivor guilt. Many patients feel guilt when thinking about why they survived lung cancer and others did not." They were then asked, "Have you felt this way during your lung cancer journey?" (yes/no) and were then asked to explain (open-ended question). Survey responses were anonymous to mitigate bias toward the theoretical view of survivor guilt and lung cancer survivors.

## Data analysis

Descriptive statistics were calculated for demographic variables and measures of IGQ-67 SGS. *T*-tests and Analysis of Variance (ANOVAs) were conducted to examine if there were group differences in survivor guilt by

demographic variables. A subset of respondents ( $n = 27$ ) with the highest scores (top 25%) on the IGQ-67 SGS were selected for their text responses to the open-ended question about survivor guilt experiences to be examined. This was done to extract key themes from individuals who reported experiencing a relatively high level of survivor guilt. Consistent with prior qualitative work, the analysis of these open-ended narrative responses was performed using a thematic text analyses approach.<sup>32</sup> The coding team consisted of three of the co-authors (TP, JK, MS) of this paper. The coding team developed a preliminary code book consisting of descriptive and interpretive concepts identified during review of the open-ended data. Each team member independently coded the data. Upon completion of coding the data, the team met to review the coding and discuss discrepancies. The team mutually agreed to the addition of several codes based on perceived importance of themes. Consensus was reached on all codes and application of codes. This process continued, following an iterative process, until all open-ended responses were coded.

## Results

### *Sample characteristics*

Of the 108 participants in this study, the majority were female (86%), were 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%). [Table 1](#) reports all descriptive statistics for demographic and clinical characteristics.

### *Quantitative findings*

*Prevalence of survivor guilt.* The mean score on the IGQ-67 SGS ( $M = 70.2$ ,  $SD = 9.84$ ) was higher than that reported by the previously published healthy comparison group ( $M = 65.4$  for males and  $M = 68.9$  for females).<sup>33</sup> In fact, the majority (63.9%) of lung cancer survivors scored above this comparison group benchmark. The majority of respondents (55%) also reported survivor guilt as indicated by affirmative endorsement of the single-item question assessing perceptions of experienced lung cancer survivor guilt.

*Demographic and clinical correlates of survivor guilt.* *T*-tests (for analyses of two groups) and ANOVAs (for analyses of 3+ groups) indicated that survivor guilt did not vary significantly by any of the demographic (sex, age at diagnosis) or clinical (lung cancer type, stage at diagnosis, smoking history, treatment) characteristics.

**Table 1.** Demographic and clinical characteristics of sample ( $n = 108$ ).

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

### **Qualitative findings**

As summarized in Table 2, five themes emerged from the coding of open-ended text responses. A detailed description and discussion of themes are described below.

#### **Death of others**

When asked about their own attitude toward surviving lung cancer, most respondents referenced the death of another person. Many respondents noted that the death of a family member made them feel particularly guilty for surviving lung cancer. Specifically, respondents described feeling guilty about children dying, particularly when the child's death was related to cancer. Respondents frequently compared themselves to deceased persons, noting characteristics about him/her that made them feel less worthy to still be alive. If the deceased person had children, it made the survivor feel guilty that those children were left behind.

**Table 2.** Summary of qualitative results.

Theme	Summary of Theme	Exemplary Quotations
Death of Others	Survivors repeatedly referenced the death of someone known to them which caused feelings of guilt.	<i>I cry when I read of someone dying. It especially bothers me when it is a child. [16] My daughter in law's Mother from lung cancer and was a never smoker. I smoked and survived. It still makes me feel awful. I lost my mother, aunt and cousin from lung cancer too. [2] My sister was diagnosed 3 months after me with the same cancer in the same location. She died after 11 months. [7]</i>
Why not me?	Survivors reported negative feelings toward why they did not die of lung cancer rather than why they survived.	<i>A simple question of why I am still alive and others are not. [18] I just feel like why did I survive and they didn't? What makes me so special to be alive and not them? I still feel this way even after 6 yrs. [16] 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. [12] 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. [18]</i>
Effect of Passing of Time on Emotions Experienced	Survivors' feelings changed from grateful to guilty throughout their survivorship journey.	<i>I had surgery in October, started chemo in November and completed in January 2015, so I am relatively new at this journey. I wish I wasn't on this journey, but believe it all happens for a reason and have faith that since mine was caught in early stages my prognosis will be good, but it's always in the back of your mind. [11] There is no answer. There is only gratitude for being one of the lucky ones, for now anyway. Cancer does return, and with every scan, you prepare yourself to hear those dreaded words. And perhaps that is the reason we do feel guilt for feeling lucky. [3]</i>
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.	<i>I have met so many women same age as me - same everything as me - who have advanced and I have not. [13] I feel bad for those who are younger than me who do not survive, especially those with young children. My children are grown and on their own, but I do not have any grandchildren yet. [15]</i>
Coping with Survivor Guilt	Survivors' found comfort by being part of a cancer community.	<i>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. [19] When you are diagnosed with cancer, any cancer, you realize all too quickly that you are now part of something incredibly huge ... a community of people who regardless of type or stage of their illness are fighting the fight of their life. [3]</i>



I cry when I read of someone dying. It especially bothers me when it is a child.  
[Survivor 16]

My sister was diagnosed 3 months after me with the same cancer in the same location. She died after 11 months. [Survivor 7]

### ***Why not me?***

Although common for those diagnosed with cancer to experience feelings of “why me?” lung cancer survivors with survivor guilt experienced a feeling of “why *not* me?” Many survivors compared themselves to others with the same type of cancer who did not respond to treatment or who died. The “why not me?” feeling was associated with survivors’ thinking negatively of themselves and their place in society.

I just feel like why did I survive and they didn’t? What makes me so special to be alive and not them? I still feel this way even after 6 yrs. [Survivor 16]

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. [Survivor 12]

### ***Effect of passage of time on emotions experienced***

Many respondents expressed feelings of both guilt and gratefulness that evolved throughout their survivorship experience. Survivors who were diagnosed at any early stage reported feeling grateful or lucky because of their early detection. These respondents noted that feelings of guilt increased from the time that they were initially diagnosed with lung cancer throughout the course of their survivorship journey. Many initially felt grateful for their exceptional medical care, but also felt guilty that someone known to them was not as fortunate. Conflicting, complex emotions of guilt and gratitude were frequently expressed.

Very early on while going through chemo, I felt sad for those who didn’t make it. They were known to me so I felt a loss. After 20 years being a survivor, I am grateful for my health. [Survivor 1]

There is no answer. There is only gratitude for being one of the lucky ones, for now anyway. Cancer does return, and with every scan, you prepare yourself to hear those dreaded words. And perhaps that is the reason we do feel guilt for feeling lucky. [Survivor 3]

### ***Effect of demographic and clinical characteristics on survivor guilt***

Respondents reporting survivor guilt frequently associated their guilt with individual characteristics such as having children, their smoking history,

and the stage at which their lung cancer was diagnosed. Those who mentioned having adult children expressed feeling guilty for surviving to see their children reach adulthood when others known to them with lung cancer had died before their children were grown. Respondents who had a history of smoking commonly expressed feelings of guilt and self-blame, while those with no smoking history expressed guilt for the perceived burden of lung cancer on their loved ones. Those who were diagnosed early or responded well to treatment expressed feelings of guilt for having a less extensive lung cancer experience than others.

I have met so many women same age as me - same everything as me - who have advanced and I have not. [13]

I feel bad for those who are younger than me who do not survive, especially those with young children. My children are grown and on their own, but I do not have any grandchildren yet. [15]

### ***Coping with survivor guilt***

For many survivors, being part of a cancer community provided comfort and support. Some respondents stated that being a lung cancer survivor added meaning and purpose to their lives. Many felt that helping other people was their responsibility and obligation as payback for beating the odds of lung cancer.

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. [Survivor 19]

When you are diagnosed with cancer, any cancer, you realize all too quickly that you are now part of something incredibly huge ... a community of people who regardless of type or stage of their illness are fighting the fight of their life. [Survivor 3]

## **Discussion**

This is the first study to measure survivor guilt among lung cancer survivors and the findings support our hypothesis that survivor guilt is prevalent in this population. The majority of respondents reported experiencing survivor guilt (55%–63.9% depending upon classification approach) following diagnosis and treatment for lung cancer.

Thematic analysis of open-ended qualitative data indicates that lung cancer survivors are suffering negative mood states attributable to survivor guilt. Consistent with Lifton's work with survivors of war,<sup>16,34</sup> the identified qualitative themes suggest that survivors who actively confronted their guilt in terms of taking responsibility became energized by guilt in a positive way. Lifton distinguished negative survivor guilt as "static," and positive

survivor guilt as “animated.”<sup>34</sup> Many respondents who were suffering with survivor guilt did not know how to cope with the “static guilt” they were experiencing. Theme three, *Effect of Passage of Time on Emotions Experienced*, demonstrates the manifestation of static guilt from one’s initial diagnosis with lung cancer throughout their journey becoming a survivor of the disease. While many survivors felt grateful and empowered at one point in their survivorship, many turned inward at a later point as a result of their survivor guilt.

Theme five of the qualitative analysis, *Coping with Survivor Guilt*, strengthens Weiss’ notion that people are highly motivated by a fundamental need to help others.<sup>12</sup> Many survivors stated that being part of a community was an outlet for coping with the guilt of surviving lung cancer. This also supports Lifton’s theory that accepting “responsibility of anxiety” creates “animated guilt” which is what he believed helped sufferers to cope with survivor guilt.<sup>16,34</sup> Those who felt that helping others was their mission or responsibility for being a survivor, appear to be demonstrating “energized” or “animated” guilt similar to that observed by Lifton in war survivors.<sup>34</sup> Lifton also identified a *Death of Others* theme among survivor guilt sufferers, which he described as “an unpayable debt to the dead that can become permanent.”<sup>34</sup> Lifton held that sufferers needed to render the significance of the death of others to inform one’s sense of survivor mission.<sup>34</sup> Terence Des Pres further explored this theme in his extensive research with concentration camp survivors.<sup>35</sup> Des Pres recognized a sense of mission in many survivors, but he disagreed with Lifton and other psychiatrists regarding its causes.<sup>35–37</sup> Des Pres believed that survivors’ identification with the dead was directly related to one’s sense of camaraderie experienced in the camps and completely unrelated to one’s guilt.<sup>37</sup> Theme four from the qualitative analysis, *Demographic and Clinical Characteristics’ Influence on Attitudes toward Survivorship*, supports Des Pres’ theory. Many respondents focused on specific commonalities that they shared with others known to them who died or were more advanced than they were [of the same disease]. This theme supports Weiss’ theory that survivor guilt occurs when people believe that they are, simply by furthering their own cause, experiencing good things at the expense of others, and that their success will make others feel bad by comparison.<sup>10</sup> Many respondents also referenced a “cancer community” in theme two, *Why Not Me*. In this context, respondents referenced both the commonalities and differences of others known to them in an attempt to justify why they should *not* have survived

These findings have clinical importance for mental health providers providing psychosocial support and treatment for patients with lung cancer. The identified feelings associated with survivor guilt are consistent with

previous qualitative research examining psychosocial concerns of posttreatment and long-term lung cancer survivors.<sup>38</sup> Feelings of survivor guilt should be assessed to gain a greater understanding of the specific psychosocial challenges faced by lung cancer survivors. Psychoeducation regarding the prevalence and nature of survivor guilt may be helpful in preventing deleterious psychological and physical outcomes. There are also a number of promising psychological interventions such as Self-compassion interventions,<sup>39</sup> Acceptance and Commitment Therapy<sup>40</sup> and other “third-wave” cognitive behavioral therapy interventions targeting guilt, regret and other drivers of negative mood states which may be appropriate to consider for use with lung cancer survivors, particularly those experiencing survivor guilt.

There are limitations of the study including a small sample size (108 patients), lack of validated measurement for lung cancer survivors, an overrepresentation of female survivors (86%), and sampling from an online patient community which may not be representative of all lung cancer survivors. Larger studies need to be done to confirm these findings. Comparative studies of survivor guilt with patients with mixed cancer diagnosis are needed to determine whether survivor guilt is a unique experience of lung cancer survivors. For example, it is unclear if the very low survival rate in lung cancer increases the prevalence of survivor guilt compared to cancers with a better prognosis. A larger sample size would allow further insight into demographic and clinical correlates of survivor guilt to support theme 4 of the qualitative analysis, Effect of Demographic and Clinical Characteristics on Survivor Guilt. Upon expanding the sample size, correlates may become evident among lung cancer survivor’s smoking history, stage of diagnosis, and treatment history. Future work should also be done to examine the themes identified in the qualitative analysis to pinpoint causes and effects of survivor guilt. Additionally, survivor guilt must be examined in association with depression.

This work has identified survivor guilt as prevalent in lung cancer survivorship, as indicated by both validated measures of survivor guilt (IGQ-67 SGS) and self-reported endorsement of experiencing survivor guilt. Thematic results indicated that experiencing survivor guilt was associated with psychosocial burdens on patients, calling for the need to understand survivor guilt better among lung cancer survivors and to target the psychosocial distress they experience. The present study’s results and the growing number of lung cancer survivors calls for further research identifying psychosocial strategies to mitigate survivor guilt.

### **Disclosure statement**

No potential conflict of interest was reported by the authors.

## ORCID

Tara Perloff  <http://orcid.org/0000-0002-1876-6632>

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