

SURVIVOR GUILT: THE SECRET BURDEN OF SURVIVORSHIP

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BACKGROUND AND PURPOSE

The 5-year survival rate for a stage IV non-small cell lung cancer patient is 1%. What if you are a stage IV lung cancer patient who has beaten those odds? Society implies that these “outliers” should feel relieved; lucky; ecstatic. Negative emotions toward survivorship are commonly associated with depression or fear; however, many survivors feel a deep-seated sense of guilt.

Survivor guilt was first documented among Holocaust survivors, but is rarely discussed in the field of psychosocial oncology. Little research has been conducted to correlate survivor guilt as the mediating factor of depression and anxiety among cancer survivors.

The study goal is to identify the prevalence of survivor guilt among lung cancer patients and pinpoint themes among those affected.

METHODOLOGY

A total of 108 lung cancer survivors completed a 40 question survey via Survey Monkey on their lung cancer experiences and survivor guilt.

Procedure

- Respondents first provided demographic information: gender, type and stage of lung cancer, age at diagnosis, smoking history, and how long they have been in or out of treatment.
- Next, The Survivor Guilt subset (22 questions) of the IGQ-67 Interpersonal Guilt Questionnaire (O'Connor, et al) was used to measure survivor guilt. Questions included:
 - “I sometimes feel I don't I deserve the happiness I've achieved”
 - “I conceal or minimize my success”
 - “It makes me very uncomfortable to receive better treatment than the people I am with.”
- Respondents indicated their agreement with each question on a 5-point scale ranging from “Very true of me OR strongly agree” through “Very untrue of me OR strongly disagree,”
- Lastly, respondents were given a definition of survivor guilt with an open-ended question on their feelings toward that emotion.
- 20 respondents were also interviewed via telephone on their experience with survivor guilt.

DEMOGRAPHICS

Of the 108 respondents, the majority were female lung cancer patients between the ages of 50-59 years-old. Caregivers were excluded from this study.

Gender: Female: 93 (86%)
Male: 15 (14%)

	Male	Female	Total Population
Type of lung cancer:			
• Non-small cell lung cancer (NSCLC)	93%	85%	86%
• Small cell lung cancer (SCLC)	7%	11%	10%
• Unknown	0%	4%	4%
Stage:			
• Stage I-IIIa (Limited stage)	40%	64%	61%
• Stage IIIB-IV (extensive stage)	60%	27%	32%
• Unknown	0%	9%	7%
Smoking history:			
• Current smoker	0%	4%	4%
• Former smoker	93%	66%	69%
• Never smoker	7%	30%	27%
Currently in treatment:	20%	24%	23%
Years in treatment:			
• <1 year	0%	18%	16%
• 1-2 years	34%	23%	24%
• 2-3 years	33%	23%	24%
• 3-4 years	0%	4%	4%
• 4-5 years	33%	0%	4%
• >5 years	0%	32%	28%
Currently out of treatment:	80%	76%	77%
Years out of treatment:			
• <1 year	8%	22%	20%
• 1-2 years	17%	27%	25%
• 2-3 years	17%	6%	7%
• 3-4 years	8%	8%	8%
• 4-5 years	17%	6%	7%
• >5 years	33%	31%	33%

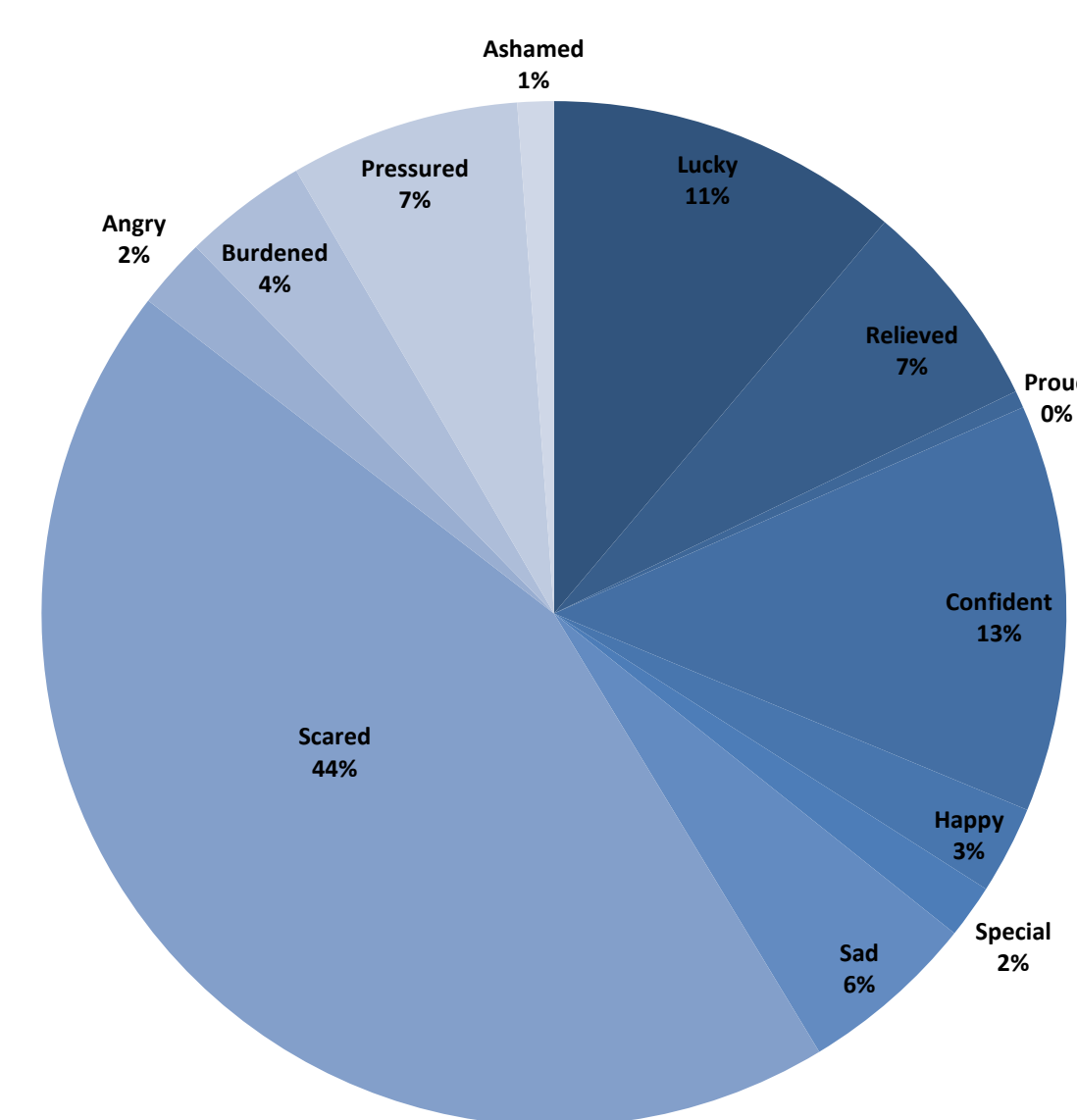
QUANTITATIVE RESULTS

55% of respondents identified with survivor guilt when asked if they felt guilty thinking about why they survived lung cancer and others did not.

63.9% of respondents scored above average on the IGQ-67 Survivor Guilt Scale. The average survivor guilt score for this study was 70.2 compared to the published control group averages of 65.4 for males and 68.9 for females.

44% of respondents said they feel scared when asked about feelings toward their next CT scan.

How do you feel when thinking about your next CT scan?



31% of respondents volunteer with an advocacy organization

79% of respondents who volunteer feel that volunteering helps them cope with their survivor guilt.

“It validates my having survived when others have not. It always feels good to be able to give something back.”

“It has empowered me and provided a vehicle to “fight back” against this devastating disease. It has also provided structure for my advocacy to improve lung cancer awareness, increase research funding and end the stigma of lung cancer.”

QUALITATIVE RESULTS

Recurring themes in the qualitative data include, but are not limited to: **self-reported depressive symptoms, denial and the question “why me?”.**

“I’m always told how lucky I am but I don’t feel lucky. I feel unsure, the word Cancer changed my life.”

“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. Have a couple friends who are very sick with lung cancer. It’s hard to see them. I feel like they hate me.”

“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.”

“Yes and no, I still can’t accept the fact that I had lung cancer. I underwent upper right lobectomy 9 months ago, isolated tumor, no chemo, no radiation, 14 lymph nodes were negative. My first CT scan was Feb. 2015 which was negative and my first PET scan is June 11th, 2015 and I am petrified. I feel for all who suffer lung cancer and pray that one day there will be a cure for all. For now, I have to learn to deal with my depression and anxiety.”

“I had a friend that had the exact same kind, same time, same treatment. I lived, but she didn’t. I still have a crippling amount of guilt over it. I lost my mother to lung cancer last year, and the guilt I feel from losing her and me still not only living, but thriving is very overwhelming.”

“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.”

“My Grandmother did not survive and my father did not survive so how come I survived. I read about people going through all the pain and chemo and radiation including surgery and do not survive make it so why me. Then there are times I am glad I survived because of my family. “

“My cancer was stage 1 so my journey did not entail chemo or radiation one thinks they will know how you would feel but the reality is I didn’t have to deal with those issues.”

“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. I cry when I read of someone dying. It especially bothers me when it is a child.”

“My sister was diagnosed 3 months after me with same lung cancer. She died after 11 months. Why did I survive and she did not?”

IMPLICATIONS

For Future Research

This study develops the basis for future research directions in creating tools to identify and assess patients for survivor guilt. This research will extend far beyond the lung cancer population.

For Clinicians

This study will help health care professionals recognize survivor guilt as a problem and develop interventions to treat it.

LIMITATIONS

- The control group for this study was borrowed from another study using the IGQ-67 scale
- Convenience sample
- Disproportionately female ratio
- Lack of data analysis to further develop themes

CONCLUSION

Little research has been done to identify survivor guilt in cancer patients and its effects on survivorship. The quantitative results of this study demonstrate a strong prevalence of survivor guilt among lung cancer patients and the qualitative results further support survivor guilt as a psychosocial challenge. Further research on survivor guilt across all cancer-types must be explored in order to identify effective coping mechanisms for patients who suffer with the burden of survivor guilt.

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