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 II lung cancer patient who has beaten those odds? Scarily 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 in conjunction with 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 experience 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 IGG-67 Interpersonal Guilt Questionnaire (O’Connor, et al) was used to measure survivor guilt. Questions included: "I sometimes feel I don’t deserve the happiness I’ve achieved” – 1; "I can’t help but feel guilty” – 1; "It makes me feel uncomfortable to receive better treatment than the people I am with.” – 1.

- Respondents indicated their agreement with each question on a 5-point scale ranging from “Very true of me” strongly agree through “Very untrue of me” 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.

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 IGG-67 Survivor Guilt Scale. "I sometimes feel I don’t deserve the happiness I’ve achieved” – 1; "I can’t help but feel guilty” – 1; "It makes me feel uncomfortable to receive better treatment than the people I am with.” – 1.

Qualitative results

- Of the 108 respondents, the majority were female lung cancer patients between the ages of 50-58 years old. Caregivers were excluded from this study.
- Male: 15 (14%)
- Female: 93 (86%)

Demographics

Type of lung cancer:
- Non-small cell lung cancer (NSCLC): 33% of respondents
- Small cell lung cancer (SCLC): 7% of respondents
- Unknown: 4% of respondents

Stage:
- Stage I (Limited stage): 40% of respondents
- Stage III-B (Intermediate stage): 27% of respondents
- Unknown: 9% of respondents

Smoking history:
- Current smoker: 33% of respondents
- Former smoker: 66% of respondents
- Never smoker: 7% of respondents

Current smoking status:
- 31% of respondents volunteered with an advocacy organization

- 31% of respondents identified with survivor guilt. 79% of those who volunteer feel that volunteering helps them cope with their survivor guilt.

- "It validates my having survived; others have not. It always feels good to be able to give something back.”
- "It has empowered me and provided me with a vehicle to “fight back” against this deadly disease. It has also provided structure for my advocacy to improve lung cancer awareness, increase research funding and end the stigma of lung cancer.”

- “I’ve had a hard time understanding why I’m still alive and others have to die. Lots of people have more to offer the world than I do.”
- “I had a friend that had exactly the same kind, same time, same treatment. I lost her, but I still feel like they have a sliding amount of guilt over it. I feel like they hate me.”
- “I have a hard time understanding why I’m still alive and others have to die. Lots of people have more to offer the world than I do.”
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How do you feel when thinking about your next CT scan? For Future Research

This study develops the basis for future research directions in creating tools to identify and assess 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.
- Conveniencesample
- Inconclusivelyfemale ratio
- Lack of data analysis to further develop themes

IMPLICATIONS

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CONCLUSION

Little research has been done to identify survivor guilt in cancer patients and its effects on survivorship. The qualitative 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. Future 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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