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Scan-Associated Distress in Lung Cancer: Quantifying the Impact of “Scanxiety”

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Abstract

Objectives—Diagnostic imaging may be a major source of cancer-related distress, a condition known as “scanxiety”. Scant scholarly work has been performed to evaluate scan-associated distress in cancer. We sought to characterize risk factors for scan-associated distress among patients with Non-Small Cell Lung Cancer (NSCLC), and to evaluate the impact of scan-associated distress on quality of life.

Materials and Methods—We conducted a cross-sectional survey study of patients with recurrent/metastatic NSCLC treated at an academic medical center. Clinical and demographic variables were obtained through chart abstraction and patient self-report. We used a modified version of the Impact of Event Scale 6 (IES-6) to specifically assess distress associated with scans, and quality of life was measured using the Functional Assessment of Cancer Therapy – Lung (FACT-L).

Results—Among 103 participants (survey response rate 76.3%), median age was 67, 61.2% were women, and 82.5% were white. At the study visit, 72.8% of subjects discussed a recent scan, and

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83% reported some scan-associated distress. Scan-associated distress was not associated with whether the patient had a recent scan, progressive disease or time from diagnosis. Scan-associated distress was associated with impaired quality of life ($p=0.004$); each unit increase in IES-6 corresponded to an approximately one-unit decrease in FACT-L score.

Conclusion—Scan-associated distress is a common problem among patients with NSCLC, and is associated with impaired quality of life. Scan-associated distress severity was not associated with time since diagnosis or whether a recent scan was discussed at the study visit, which implies scan-associated distress may be a persistent problem.

Keywords

Scan-Associated Distress; Scanxiety; Quality of Life; Lung Cancer; Cancer Distress

Introduction

Screening for cancer-related distress, termed the “6th vital sign,” has been recommended by multiple certifying agencies.[1–3] Cancer-related distress is associated with impaired quality of life, reduced satisfaction with care, and worse overall survival.[4] In addition to symptomatic distress from therapeutic toxicity, cancer progression and co-morbid illness, patients may also experience distress as a result of the diagnostic scans they undergo.

In a piece for *Time* magazine in 2011, Bruce Feiler coined the term “scanxiety” to describe this scan-associated distress.[5] “Scanxiety” refers to the often-debilitating anxiety patients with cancer experience in the period surrounding imaging studies for their cancer. While no study to date has formally evaluated the association of scan-associated distress with quality of life among patients with cancer, multiple studies have shown that imaging can cause significant distress when healthy patients undergo cancer-screening scans.[6–9]

The primary objective of this study was to characterize the nature of scan-associated distress among a group of patients with recurrent or metastatic non-small cell lung cancer (NSCLC). Patients with NSCLC were selected because scans are frequently ordered in this disease.[10] We first aimed to identify demographic and clinical risk factors associated with scan-associated distress severity, and then evaluated the association of scan-associated distress severity with quality of life. Scans are ubiquitous in modern oncology; as such, having a deeper understanding of how these scans affect quality of life could have a significant impact upon clinical practice.

Materials and Methods

Study Design and Patients

We conducted a cross-sectional survey in a consecutive convenience sample of patients seen in the outpatient thoracic medical oncology clinics at the Abramson Cancer Center at the University of Pennsylvania from May to August 2015. Eligible participants were at least 18 years of age with a primary diagnosis of recurrent or metastatic non-small cell lung cancer. Additional inclusion criteria were approval of the patient’s oncologist to approach the patient and ability to understand enough English to complete the survey. Trained research

assistants approached potential subjects in the waiting room. After completing an electronic informed consent process, patients completed all surveys on a web-enabled tablet. The survey took approximately 10 minutes to complete. Each patient was eligible to complete the survey once. The Institutional Review Board of the University of Pennsylvania approved the study protocol.

Study Variables

To measure scan-associated distress we used the Impact of Event Scale 6 (IES-6) instrument, an abbreviated form of the Impact of Event Scale-Revised (IES-R). The IES-R is one of the most widely used instruments to measure the psychological impact of a specific event. This 22-item scale has been validated in the setting of a wide variety of stressors, ranging from cancer diagnosis to sexual assault. It has a 3-factor structure, mirroring the diagnostic criteria for post-traumatic stress disorder (PTSD): intrusion, avoidance and hyperarousal. [11–14] The IES-6 is an abbreviated 6-item survey that was designed to maintain the same factor structure. The IES-6 has very good internal consistency (Cronbach's Alpha=0.8) and correlates strongly with IES-R across a wide variety of traumatic events. The heading for the survey stated "Below is a list of difficulties people sometimes have after stressful life events. Please read each item, and then indicate how distressing each one has been for you during the past 7 days with respect to your most recent scan (i.e. CT, PET, MRI).",. This heading was used to focus questions on scan-associated distress, rather than generalized distress. Scores ranged from 0–24, with higher scores indicating more severe scan-associated distress.[15]

To measure quality of life, we used the Functional Assessment of Cancer Therapy – Lung (FACT-L) instrument. The FACT-L is an extensively validated 36-item instrument to measure quality of life using a 4-factor structure (Physical, Social, Emotional, and Functional Well-being). Scores range from 0–136, with higher scores indicating improved quality of life.[16]

Demographic variables including age, sex, race, educational level, marital status and household income were obtained through patient self-report. We determined clinical factors, such as original tumor stage, time since diagnosis and molecular profile through chart abstraction. We also utilized chart abstraction to determine if each patient was receiving information about a new scan at the study visit, and if they were experiencing progressive disease leading to a change in treatment.

Statistical Analyses

The sample size was based on an expected effect size of 0.3 in the IES-6 (IES-6 score equivalent, 1.59). With 103 patients, we would have 82% power to detect such a difference, assuming a 2-sided Type I error rate of 0.05.[17] Descriptive statistics were utilized to characterize our sample. To compare risk factors for scan-associated distress severity between groups we used Student t tests and analysis of variance tests (ANOVA) as appropriate. To evaluate the association of scan-associated distress with quality of life, we fit a linear regression model using IES-6 as the independent variable and FACT-L as the

dependent variable. All tests were 2-sided, and a p value of less than 0.05 was considered significant.

Results

We screened 144 patients to identify 135 eligible subjects, of whom 106 consented to participate in the study. Each subject completed the survey once. Three patients were subsequently dropped from analysis due to not meeting eligibility requirements. This yielded a 76.3% rate of study participation. The median age of survey participants was 67, with a range of 35–84 and standard deviation (SD) of 10.4. In this cohort, 61.2% of patients were women, 82.5% were white, 72.8% were currently married, and 53.4% had completed at least a college degree. Former and current smokers made up 67.8% of the sample. At the study visit, 72.8% of subjects discussed a recent scan and 27.2% experienced progressive disease leading to a change in treatment. (See Table 1)

The distribution of IES-6 scores is presented in Figure 1. The mean score (SD) was 6.39 (5.29), with a range of 0–21. Among patients surveyed, 83% experienced some degree of scan-associated distress. None of the demographic or clinical variables was significantly associated with scan-associated distress severity. There was some indication that women, never smokers, and those with high household income had more severe scan-associated distress, but those differences were not statistically significant. Scan-associated distress severity was not associated with whether a patient was attending the visit to discuss a recent scan, time from diagnosis, or if there was progressive disease. (See Table 1)

More severe scan-associated distress was significantly associated with impaired quality of life, as measured by FACT-L total score ($p=0.004$); each unit increase in IES-6 corresponded to an approximately one-unit decrease in FACT-L score. We performed a series of linear regressions to evaluate which of the FACT-L subscales drove the impact of scan-associated distress on quality of life. We found a statistically significant association between greater scan-associated distress and impaired emotional well-being ($p<0.001$), but not for any of the other subscales. (See Table 2)

Discussion

Cancer-related distress is a major problem for the growing population of cancer survivors.[1, 18, 19] Emerging literature about financial toxicity, issues with employment, and long-term health behaviors has clearly shown that the indirect effects of a cancer diagnosis and its treatment can have a profound impact on a patient's life.[20–22] “Scanxiety” represents another potential cause of cancer-related distress not directly related to the underlying disease or its treatment.

Prior studies to assess the severity and impact of scan-associated distress among patients with cancer are very limited. Thompson et al performed a series of qualitative interviews among 80 patients with lymphoma.[23] The vast majority of patients reported some element of scan-associated distress. They found that more severe generalized anxiety was associated with a worse doctor-patient relationship and a history of prior relapse. They did not specifically quantify scan-associated distress or quality of life. Multiple studies have shown

that performing screening scans in healthy patients can be associated with significant distress. Scans with indeterminate results that required further testing, patients with anxious personality types, and waiting a long time for results were associated with the greatest amount of distress.[8, 9, 24–26] The impact of scans is not all negative, however. In a prospective study of women with breast cancer, more frequent scans were not associated with a decrement in quality of life, and patients actually said they wanted more frequent imaging.[27] Of note, this study did not measure scan-associated distress or generalized anxiety.

In our study we found that approximately 83% of patients experienced some degree of scan-associated distress. We were unable to identify clinical or demographic risk factors for scan-associated distress severity. Scan-associated distress severity was associated with impaired overall quality of life, driven largely by a decrement in a patient's emotional well-being.

In prior qualitative descriptions of “scanxiety,” patients have reported that the distress is most severe in the period leading up to a scan and is ameliorated by then having a reassuring scan result.[5, 23] We had further hypothesized when we designed the study that during the course of a patient's disease scan-associated distress severity would diminish as patients adjusted to the process of managing the disease. Surprisingly, in this pilot study scan-associated distress severity was not associated with receipt of a recent scan, progressive disease, or time from diagnosis. In other words, for the large group of patients who experience “scanxiety” the distress from a scan may last well beyond the scan itself. Being told that a scan shows no evidence of disease progression might not be as reassuring as previously assumed. Scan-associated distress thus has the potential to have a significant and lasting impact on overall quality of life.

Our study has a number of important limitations. First, the IES-6 was not specifically designed to assess scan-associated distress. That being said, the IES has been validated with concordance across a wide variety of stressful episodes, including the diagnosis of cancer. [12, 15] We did not use a generalized anxiety scale in order to account for the fact that anxiety is common and multi-factorial in a population of patients with cancer.[28] Use of a generalized anxiety tool would thus not provide focused data on scan-associated distress. Next, the cross-sectional nature of our study prevents us from assessing the longitudinal impact of scan-associated distress. Our limited sample size prevented a more comprehensive assessment of subgroups. We were unable to explore several potentially relevant clinical variables (e.g. line of treatment, patient-physician relationship, and use of internet portals to learn about scan results). Our research team is actively pursuing a larger, prospective study to address these limitations. Finally, our sample included patients with recurrent or metastatic NSCLC. Patients with metastatic NSCLC represent a notably heterogeneous group; overall survival in this population ranges from 6 months to 3 years.[29] Future studies should evaluate scan-associated distress in a more homogenous population to confirm our findings. Despite these limitations, we believe that our study adds significant knowledge to the field. This is the first study to formally quantify the severity and impact of “scanxiety” among patients with cancer. We showed that scan-associated distress is common among patients with NSCLC, can be severe, and is associated with a significant decrement in quality of life. Scans are ubiquitous in modern oncology care, and represent a significant

cost to our healthcare system.[10, 30] Scans may exacerbate “scanxiety” and may contribute substantially to cancer-related distress. We believe our findings, once confirmed, could have significant public health impact.

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Highlights

- Scan-associated distress is a common problem for patients with lung cancer.
- Scan-associated distress is associated with worse quality of life.
- No clinical or demographic features are associated with scan-associated distress.

Figure 1.
Distribution of scores on Impact of Event Scale 6 (IES-6)
Mean (Standard Deviation) Score 6.39 (5.29)
Range 0–21

Table 1

Patient Characteristics and Association with IES-6

Variable	n=103 (%)	Mean IES-6 (SD)	p value
Median Age	67 (10.4 SD, 35–84)		
Sex ^a			0.17
Male	40 (38.8%)	5.47 (5.13)	
Female	63 (61.2%)	7.02 (5.34)	
Race ^a			0.68
White	85 (82.5%)	6.30 (5.48)	
Non-White	18 (17.5%)	6.93 (4.18)	
Smoking Status ^{**a}			0.09
Former/Current	61 (67.8%)	5.53 (4.86)	
Never	29 (32.2%)	7.59 (5.83)	
Household Income ^b			0.13
Did not answer	26 (25.2%)	6.08 (5.10)	
<\$60K	24 (23.3%)	5.85 (4.76)	
\$60–100K	24 (23.3%)	4.41 (3.76)	
>\$100K	29 (28.2%)	8.61 (6.21)	
Marital Status ^a			0.97
Married	75 (72.8%)	6.38 (5.45)	
Not currently married	28 (27.2%)	6.42 (4.93)	
Educational Status ^a			0.98
Less than College Degree	48 (46.6%)	6.41 (5.80)	
College Degree or More	55 (53.4%)	6.38 (4.85)	
Histology ^b			0.48
Adenocarcinoma	91 (88.3%)	6.36 (5.28)	
Squamous	7 (6.8%)	6.28 (4.46)	
Unknown	5 (4.9%)	7 (7.51)	
Initial Stage ^b			0.69
IIIa	12 (11.7%)	6.2 (4.37)	
IIIb	2 (1.9%)	6 (7.07)	
IV	89 (86.4%)	6.43 (5.42)	
Time Since Diagnosis ^b			0.41
Less than 1 year	50 (48.5%)	6.42 (5.45)	
1–3 years	33 (32.1%)	6.17 (5.78)	
Greater than 3 years	20 (19.4%)	6.65 (4.34)	
Actionable Mutation ^a			0.64
Positive [*]	34 (33.0%)	6.21 (5.07)	

Variable	n=103 (%)	Mean IES-6 (SD)	p value
Negative	69 (67.0%)	6.75 (5.75)	
Reviewing a New Scan ^a			0.82
Yes	75 (72.8%)	6.46 (5.05)	
No	28 (27.2%)	6.17 (6.09)	
Progressive Disease ^a			0.39
Yes	28 (27.2%)	7.15 (6.22)	
No	75 (72.8%)	6.10 (4.91)	

* Refers to the presence of a known activating genetic alteration in the Epidermal Growth Factor Receptor (EGFR), Anaplastic Lymphoma Kinase (ALK), or Proto-oncogene Tyrosine Protein Kinase ROS (ROS1)

** Not all patients responded to this item

^a Student t test was used

^b ANOVA was used

Table 2

Association of Scan-Associated Distress with Quality of Life Measurements

QOL Measurement	B Coefficient (95% CI)	p value
FACT-L Total	−1.02 (−1.72, −0.33)	0.004
<i>Physical Well Being Subscale</i>	−0.18 (−0.41, 0.05)	0.12
<i>Social Well Being Subscale</i>	−0.09 (−0.29, 0.11)	0.40
<i>Emotional Well Being Subscale</i>	−0.31 (−0.46, −0.16)	<0.001
<i>Functional Well Being Subscale</i>	−0.09 (−0.45, 0.03)	0.09

Abbreviations: FACT-L: Functional Assessment of Cancer Therapy – Lung, FACT-G: Functional Assessment of Cancer Therapy – General Linear regression used for this analysis