

Dimensions of Distress in Lung Cancer

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OBJECTIVES: To (a) compare the domains of distress between patients who were distressed and patients who were not distressed and (b) examine the relationship between the National Comprehensive Cancer Network Distress Thermometer and Problem List for Patients (DT-PL) and the Hospital Anxiety and Depression Scale (HADS) in individuals with advanced lung cancer.

SAMPLE & SETTING: Individuals with advanced lung cancer receiving chemotherapy were recruited from a comprehensive cancer center in the southeastern United States.

METHODS & VARIABLES: A cross-sectional, descriptive, exploratory design was used. Individuals with lung cancer completed the DT-PL and the HADS. Data were analyzed using descriptive statistics, t tests, and chi-square analysis.

RESULTS: Significant differences were found between the nondistressed group and the clinically distressed group in three domains of distress: family problems, emotional problems, and physical problems. There was no relationship between the DT-PL and the HADS anxiety subscale or the HADS depression subscale.

IMPLICATIONS FOR NURSING: Distress in individuals with advanced lung cancer goes beyond psychological stressors and includes family problems and physical problems.

After a cancer diagnosis, some individuals experience distress. For individuals with lung cancer, distress is a common experience (Chambers et al., 2015; Graves et al., 2007; Lashbrook et al., 2018). Previous studies report that 39% to 51% of individuals with lung cancer experience distress (Steinberg et al., 2009; Ugalde et al., 2012; Zabora et al., 2001). Despite advances in options for treatment and palliative care, individuals with advanced lung cancer continue to report a high physical symptom burden and unmet needs (Sung et al., 2017). Physical symptoms have been shown to have some associations with distress in patients with cancer (McFarland et al., 2018). In addition to coping with symptoms and unmet needs, individuals with advanced lung cancer must also cope with the diagnosis of a very serious, and potentially terminal, illness. Potential uncertainty about the future and the experience of physical and psychological symptoms may influence the distress experience for these individuals. Necessary to the effective delivery of psychosocial interventions is the development of a treatment plan (Holland et al., 2013). Consequently, it is important to examine the differences in components of distress in those with high and low distress to further individualize interventions.

Background

Definitions of Distress

Ridner (2004) described psychological distress as a “unique discomforting, emotional state experienced by an individual in response to a specific stressor or demand that results in harm, either temporary or permanent, to the person” (p. 539). According to the National Comprehensive Cancer Network (NCCN, 2020), “distress is a multifactorial unpleasant experience of a psychological (ie, cognitive, behavioral, emotional), social, spiritual, and/or physical nature that may interfere with one’s ability to cope effectively with cancer, its physical symptoms, and its treatment” (p. 5). Distress is a negative appraisal of

KEYWORDS lung cancer; oncology; distress; depression; anxiety

ONF, 47(6), 732–738.

DOI 10.1188/20.ONF.732-738

life stressors. The NCCN (2020) definition of distress is more comprehensive than psychological distress alone and can incorporate other factors that may cause distress in individuals with lung cancer.

Distress in Individuals With Cancer

When distress among individuals with cancer is effectively managed, it leads to better outcomes: a decreased chance of developing anxiety or depression, fewer calls and visits to the clinic, improved treatment adherence, and improved communication (Holland et al., 2013). Several studies have addressed distress in individuals with lung cancer. Previous studies include a longitudinal study of symptom distress in patients with lung cancer (Cooley et al., 2002), a cross-sectional study of distress among individuals who had survived a lung cancer diagnosis for at least one year (Eichler et al., 2018), a cross-sectional study of individuals newly diagnosed with advanced lung cancer (Steinberg et al., 2009), and a cross-sectional analysis drawn from a randomized controlled trial of individuals receiving chemotherapy for lung cancer (Ugalde et al., 2012). Studies showed that variations in distress occur and may be related to the cancer trajectory, with distress being the highest at the time of diagnosis (Eichler et al., 2018; Musiello et al., 2017; Steinberg et al., 2009).

Distress Thermometer and Problem List

The NCCN developed the Distress Thermometer and Problem List (DT-PL) to serve as a brief screening tool for distress (Hoffman et al., 2004). It can be used to screen individuals for distress at diagnosis and at key transitions in the cancer trajectory (Holland et al., 2013). The DT is a global measure of distress that asks individuals to rate their distress during the previous seven days on a scale ranging from 0 (no distress) to 10 (high distress) using a visual representation of a thermometer. In previous research, a score of 4 or greater indicated moderate to severe distress (Holland & Bultz, 2007; McFarland et al., 2018; Musiello et al., 2017; Steinberg et al., 2009; Ugalde et al., 2012). Through the 38 items on the PL, individuals indicate potential sources of distress in five domains: emotional problems (6 items), family problems (4 items), physical problems (21 items), practical problems (6 items), and spiritual/religious problems (1 item) (Hoffman et al., 2004).

The DT-PL has been used as a screening tool for emotional distress in patients with various types of cancer (Lynch et al., 2011; Musiello et al., 2017; Steinberg et al., 2009; Ugalde et al., 2012). Although some researchers have used the DT-PL to identify

physical problems (Robbeson et al., 2019) or clinically significant fatigue in newly diagnosed individuals with cancer (Abrahams et al., 2017), others have found emotional distress to be distinct from physical symptoms (Steinberg et al., 2009).

Hospital Anxiety and Depression Scale

The Hospital Anxiety and Depression Scale (HADS) has been shown to be an effective screening tool for depression and anxiety in individuals with lung cancer (Castelli et al., 2009). Like the DT-PL, the HADS is a self-report measure. The HADS consists of two subscales that measure the domains of anxiety and depression (Zigmond & Snaith, 1983); this is a distinctly different concept than the multidimensional understanding of distress measured by the DT-PL. The HADS has been previously used to measure psychological distress in individuals with advanced cancer (Diaz-Frutos et al., 2016). The current authors hypothesized that the narrow scope of measurement of the HADS would not capture an individual's complex distress experience.

Objectives

There were two objectives for this study. First, among individuals with advanced lung cancer, the current authors sought to describe domains of distress in those with high distress and those with low distress. Second, among individuals with advanced lung cancer, the authors sought to examine the association between the DT-PL and the HADS.

Methods

Sample and Setting

In the current study, a cross-sectional, descriptive, exploratory design was used. This study received approval from the appropriate institutional review boards prior to the initiation of study-related activities.

A convenience sample of individuals with advanced lung cancer receiving chemotherapy was recruited from Vanderbilt-Ingram Cancer Center in Nashville, Tennessee. Initially, inclusion criteria for study participation included a diagnosis of stage IV cancer. Inclusion criteria were later amended and broadened so that those with stage IIIB cancer could also participate. Inclusion criteria required individuals to be aged at least 18 years, have received chemotherapy at least once for lung cancer, and be able to speak or read English. Exclusion criteria required that individuals not be enrolled in hospice, have another active cancer diagnosis, or have a documented cognitive

impairment. Participants in hospice were excluded because they were no longer receiving chemotherapy and, therefore, were no longer being seen in the clinical setting.

Using the inclusion and exclusion criteria, the treating physician screened individuals with a regularly scheduled clinic appointment and introduced the study to those who met the inclusion criteria. To further determine eligibility, a nurse screened potential participants using a standardized inclusion and exclusion criteria form and the Short Portable Mental

Status Questionnaire. After screening was complete, individuals provided informed consent and then independently completed self-report study measures. Participants completed study measures in a private bay in the chemotherapy clinic or a private room in the medical oncology clinic. No compensation was provided for this study.

Variables

Demographic information, including date of birth, gender, race, years of education, marital status,

TABLE 1. Sample Characteristics by Group

Characteristic	Nondistressed (N = 38)		Clinically Distressed (N = 23)		χ^2	p
	n	%	n	%		
Education					3.53	0.473
Less than high school	12	32	9	39	-	-
High school	14	37	4	17	-	-
College	8	21	5	22	-	-
Master's degree	3	8	3	13	-	-
Doctoral degree	1	3	2	9	-	-
Gender					0.59	0.444
Female	21	55	15	65	-	-
Male	17	45	8	35	-	-
Insurance status					1.31	0.727
Medicare	17	45	10	43	-	-
Medicaid	2	5	-	-	-	-
Private	15	39	10	43	-	-
Other	4	11	2	9	-	-
Missing data	-	-	1	4	-	-
Marital status					4.23	0.376
Single	4	11	1	4	-	-
Single with partner	-	-	1	4	-	-
Married	29	76	18	78	-	-
Widowed	5	13	2	9	-	-
Other	-	-	1	4	-	-
Race					2.07	0.558
White	33	87	20	87	-	-
Black	2	5	2	9	-	-
American Indian	2	5	-	-	-	-
Asian	1	3	-	-	-	-
Missing data	-	-	1	4	-	-

Note. Because of rounding, percentages may not total 100.

Note. Participants were divided into the 2 groups based on National Comprehensive Cancer Network Distress Thermometer score. This tool asks individuals to rate their distress during the previous 7 days on a scale ranging from 0 (no distress) to 10 (high distress). The cutoff score of 4 or greater indicates clinical distress.

income, employment status, area of residence, and insurance status, was self-reported by participants.

The DT-PL was used to measure distress and problems experienced by participants. This measure was previously found to be acceptable by individuals with lung cancer (Lynch et al., 2011) and has been used in individuals with lung cancer (Musiello et al., 2017; Steinberg et al., 2009; Ugalde et al., 2012).

The HADS is a validated instrument that measures depression and anxiety (Zigmond & Snaith, 1983), and it has been used in studies involving individuals with lung cancer (Ugalde et al., 2012). The HADS has two subscales (anxiety and depression), each with 7 questions for a total of 14 questions. Participants answer questions related to symptoms of anxiety and depression that have occurred in the previous two weeks. To indicate possible clinical depression or anxiety, a cutoff score of 8 or greater on the HADS subscales has been established (Bjelland et al., 2002). A score of 8 on the HADS depression subscale was found to be correlated with the Montgomery-Asberg Depression Rating Scale and is an appropriate cutoff score for depression (Castelli et al., 2009). In the current study, the Cronbach's alpha for anxiety was 0.86 and 0.84 for depression.

Data Analysis

Data analysis was completed using IBM SPSS Statistics, version 26.0. Continuous variables that were normally distributed were summarized using mean and standard deviation. The total number of items reported by each participant within each of the five PL domains was summed. Frequency distributions were used to summarize nominal and ordinal variables. Two groups were created using the DT cutoff score of 4 or greater: a clinically distressed group (score of 4 or greater) and a nondistressed group (score of 3 or less). Differences between the distress groups were determined using independent sample t tests. Chi-square analysis was used to test for associations between distress and depression and anxiety. Effect sizes were calculated using eta squared.

Results

The mean age of the sample ($N = 61$) was 65 years. Most participants were White ($n = 53$), married ($n = 47$) and has received a college education or a graduate degree ($n = 22$). About an equal number of participants had private insurance or Medicare. Demographic characteristics of participants are summarized in Table 1. The nondistressed group consisted of 38 participants, whereas the clinically distressed group consisted of

23 participants. No differences in demographics were found between the two groups.

Analysis of Group Differences in the Problem List Domains

The data were analyzed to determine if there were group differences in the five domains of the PL. Results are presented in Table 2. Analysis revealed significant differences between the two groups in three domains: (a) family problems ($p = 0.002$, $\eta^2 = 0.145$), (b) emotional problems ($p \leq 0.001$, $\eta^2 = 0.234$), and (c) physical problems ($p \leq 0.002$, $\eta^2 = 0.157$). No differences were found in two domains: practical problems and spiritual/religious problems.

Analysis of Individual Items on the Problem List

Next, the current authors sought to determine if there were group differences on individual items of the PL. In the practical problems domain, a significant difference was found for the insurance and financial concerns item ($p = 0.045$, $\eta^2 = 0.093$). Likewise, in the family problems domain, a significant difference was found for the family health issues item ($p = 0.002$, $\eta^2 = 0.148$). In the emotional problems domain, a significant difference was found for the following items: depression ($p = 0.001$, $\eta^2 = 0.159$), fears ($p = 0.019$, $\eta^2 = 0.089$), sadness ($p \leq 0.001$, $\eta^2 = 0.214$), worry ($p \leq 0.001$, $\eta^2 = 0.212$), and loss of interest in usual activities ($p \leq 0.001$, $\eta^2 = 0.182$).

Analysis of Physical Symptoms on the Problem List

The prevalence of physical symptoms within participants was assessed. Significant group differences were found in the following items: eating ($p = 0.019$, $\eta^2 = 0.089$), getting around ($p = 0.015$, $\eta^2 = 0.097$), memory/concentration ($p = 0.115$, $\eta^2 = 0.18$), pain ($p = 0.047$, $\eta^2 = 0.065$), and dry, itchy skin ($p = 0.019$, $\eta^2 =$

TABLE 2. Group Differences on Problem List Domains

Domain	t	p	η^2
Emotional problems	4.25	<0.001	0.234
Family problems	3.17	0.002	0.145
Physical problems	3.32	0.002	0.157
Practical problems	1.97	0.053	0.062
Spiritual/religious problems	1.29	0.201	0.028

Note. Significant differences were found for emotional problems, family problems, and physical problems.

0.09). When comparing the two groups, no individuals in the nondistressed group reported nausea, whereas 26% (n = 6) in the clinically distressed group reported nausea. For memory/concentration, 8% (n = 3) in the nondistressed group reported problems, whereas 35% (n = 8) in the clinically distressed group reported problems.

Analysis of Tools

Participants were categorized according to the established threshold score of 8 or greater on the HADS anxiety subscale and the HADS depression subscale, and the relationship with distress was explored. There was no relationship between the DT-PL and depression (p = 0.206) or anxiety (p = 0.896) in this sample.

Discussion

In this sample, 38% (n = 23) experienced clinical distress, similar to previous findings in which as many as 51% of individuals with lung cancer experience high levels of distress (Graves et al., 2007; Lashbrook et al., 2018; Steinberg et al., 2009; Ugalde et al., 2012; Zabora et al., 2001). The purpose of the current study was to further explore the concept of distress in individuals with advanced lung cancer. More specifically, the current authors sought to explore the sources of distress among those who met the threshold for clinical distress as compared to those who did not. In addition, the authors explored the association between the DT-PL and the HADS to examine whether the DT-PL captured psychological distress, depression, and anxiety in this sample. Identifying which items on the PL differ between those considered to be nondistressed and those considered to be clinically distressed contributes to the growing body of knowledge about distress in lung cancer by providing information that can further individualize interventions targeting distress. Among individuals with clinically significant distress, findings from the current study show that three domains may contribute to the overall distress experience: family problems, emotional problems, and physical problems. The experience of distress for individuals with lung cancer may be the cumulative effect of all the problems (stressors) identified in the PL. Those in the clinically distressed group did not report more PL items related to practical or spiritual problems. What is notable in these findings is the use of the PL to identify sources of distress.

It is worth noting that only individuals in the clinically distressed group reported family health issues as a concern. When considering the home-based care needs of those undergoing chemotherapy for lung cancer,

KNOWLEDGE TRANSLATION

- Common sources of distress for patients with advanced lung cancer include family problems, emotional problems, and physical problems.
 - Although oncology nurses focus on symptom management, it is important to use the National Comprehensive Cancer Network Distress Thermometer and Problem List to identify all sources of distress and refer patients to appropriate social, financial, and psychological care.
 - Patients with advanced lung cancer sometimes identify family health problems as a significant source of distress, and nurses should include assessment of caregiver distress when caring for these patients.
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family health concerns have the potential to greatly influence patient outcomes throughout the disease trajectory. As an individual experiences more symptoms or side effects of treatment, family caregivers with poor health may not be able to provide optimal care at home. Research has demonstrated that the early introduction of palliative care improves quality of life for individuals with advanced lung cancer (Temel et al., 2010). Future research can investigate whether the early introduction of family-centered palliative care, which specifically addresses the health concerns of family members, is beneficial in a population with advanced lung cancer.

Individuals who were clinically distressed identified insurance and financial concerns as a problem more often than those who were nondistressed. Research suggests that financial distress is common among individuals with advanced cancer and may lead to poor quality of life (Barbaret et al., 2017; Delgado-Guay et al., 2015). However, the role of financial distress among those with advanced lung cancer is not well understood or documented.

The most noteworthy symptoms reported in the clinically distressed group were nausea and memory/concentration. No individuals in the nondistressed group reported nausea, and few reported difficulty with memory and concentration. One consideration for these differences is that symptoms are not as well managed among those who are clinically distressed, contributing to higher levels of distress. Although numerous pharmacologic interventions are available to reduce chemotherapy-induced nausea and vomiting (Tipton et al., 2007), 26% (n = 16) of individuals in this study still experienced nausea. Additional research is needed to explore the extent to which physical symptoms contribute to the overall distress

experience throughout the lung cancer trajectory. More specifically, longitudinal studies that examine distress from the time of a new diagnosis through the end of life are needed.

An additional objective of this study was to explore the relationship between the DT-PL and the HADS. The PL measures emotional problems, and in this study, more individuals in the clinically distressed group reported depression, fears, sadness, worry, and loss of interest in usual activities. Despite participants' endorsement of several emotional problems on the PL, the lack of association between the DT-PL and the HADS in this study may indicate that individuals undergoing chemotherapy for lung cancer have stressors that extend beyond psychological distress. Distress as a multifaceted concept (NCCN, 2020) may be the more appropriate way to conceptualize and measure distress within this population. The lack of association between the DT-PL and the HADS also may indicate that reporting these problems in a dichotomous format does not rise to the level of clinical significance in this population. Although the DT-PL measures the intensity of distress that a person experiences, the PL does not measure the intensity of the problem the individual has identified; it cannot provide any additional information about the stressor beyond screening for the issue. Individuals who indicate difficulty with emotional problems on the PL should receive additional screening with tools designed specifically to measure anxiety or depression, such as the HADS.

Limitations

Several limitations for this study should be noted. First, this is a cross-sectional study. Sources of distress and the association between the DT-PL and the HADS cannot be determined over time, and sources of distress may change throughout the disease trajectory. Second, the sample for this study was primarily White and highly educated. The sample may not be representative of all individuals with cancer, and results should be interpreted with caution and applied only to similar populations. No clinical data were collected other than self-reported information.

Implications for Nursing

The DT-PL has previously been used in the clinical setting as a screening tool. Because the PL cannot determine the intensity of the problem, nurses should provide additional patient assessment and determine the intensity of the problem identified through the PL. Given the finding that family problems were a source

of significant distress, assessment of caregiver role strain and caregiver health should be included in care. Options for respite care should be considered when the caregiver's health is compromised. Nurses can identify community support systems for families, as well as use the DT-PL to make appropriate referrals. For example, individuals with financial or insurance concerns can be referred to a social worker.

Conclusion

In the current study, the authors found that sources of distress differ between those who experience a clinical level of distress and those who do not. The sources of distress that differed between the two groups were found in family, emotional, and physical problems. Although the DT-PL captured emotional problems in the dichotomous PL and the clinically distressed group reported significantly more of these problems than the nondistressed group, the HADS was not associated with the DT-PL in this sample. Nurses can note the differences in distress experienced by individuals with lung cancer and tailor their approach to monitoring stressors.

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This research was funded by the American Cancer Society and the Vanderbilt University School of Nursing.

Johnson, Schreier, and Ridner contributed to the conceptualization and design. Johnson completed the data collection. Johnson, Schreier, and Swanson provided statistical support and analysis and contributed to the manuscript preparation.

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