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Emotional Distress in Patients Newly Diagnosed with Late Stage Cancers

Elizabeth Ercolano[1*], Mei Bai[2], Mark Lazenby[3], Tony Ma[4] and Ruth McCorkle[5]

[1]Associate Research Scientist, Yale School of Nursing, USA
[2]Doctoral Candidate, Yale School of Nursing, USA
[3]Assistant Professor, Yale School of Nursing, USA
[4]Database Manager, Yale School of Nursing, USA
[5]Florence Wald Professor of Nursing, Yale School of Nursing, USA

Abstract

A new diagnosis of cancer and a recurrence after a disease free interval are recognized as times of high emotional distress for patients. These crisis periods are known as the existential plight occurring within the first 100 days. This time of emotional distress may be extended beyond 100 days for those patients who have late stage and progressive disease at diagnosis.

Keywords: Emotional distress; Cancers

Introduction

There is a growing body of literature related to the needs of patients living with late stage cancer documenting that these patients seem to be the most vulnerable for prolonged physical problems and psychological distress [1-3]. Multiple physical problems, intense emotional distress manifested by anxiety and depression, and complex needs are identified issues in these patients [4,5]. Evidence suggests that the prevalence of significant distress in cancer patients is between 33-45% [6]. There is growing support to address psychosocial needs of cancer patients by incorporating timely assessment of distress into routine clinical care [7,8].

We were particularly interested in identifying characteristics of patients who may need more intensive monitoring of their distress throughout their illness trajectory. The purposes of this secondary analysis were to: describe the demographic, clinical, and quality of life variables of patients newly diagnosed with late stage cancers; Identify characteristics of patients with high and low emotional distress; and determine factors related to high emotional distress in patients newly diagnosed with late stage cancers.

Methods Design

This study was a secondary data analysis from a parent study in which 153 patients with late stage cancer were recruited from the disease-specific oncology clinics of Smilow Cancer Hospital at Yale-New Haven between February, 2010 and December, 2012. Criteria for entry of patients into the parent study included: 1) a diagnosis of Stage 3 or 4 gastrointestinal (including pancreatic and esophageal), gynecological, head-and-neck, or lung cancers within 100 days; 2) post-surgical (including biopsies) with a physician's order for ongoing oncologic treatment; 3) life expectancy of at least six months as confirmed by a medical oncologist; 4) age of 21 years or older; and 5) living within the State of Connecticut. Potential eligible patients were identified at weekly disease specific tumor boards. We had originally planned to recruit only late stage patients within the first 100 days of diagnosis but it became challenging given the referral networks associated with requests at the disease specific tumor boards. As a result, we expanded our criteria to include newly diagnosed patients referred for their primary treatment at our cancer center and patients who had been previously treated and had a recurrence after at least a year disease free interval. The inclusion of patients with varying lengths of time since diagnosis allowed us to test whether the period of existential crisis extends beyond 100 days. Patients' oncologist or a designate asked if they were interested in learning about the study. For those patients who agreed, research staff

met with patients in the hospital or at their clinic visit to explain the study, answer questions, and obtain consent. Demographic, clinical, and quality of life outcome questionnaires were collected at that time as baseline data. Once data collection was completed, patients were randomized to an intervention or attention control group. The parent study was designed as a translational study of an advanced practice nursing intervention to improve clinical outcomes, including quality of life, function, symptoms, and health care use.

Data collection

Outcome data in the parent study were collected at three times: baseline within the first 100 days after diagnosis, 1- and 3-months later. Only data collected at baseline were included in this secondary analysis. The Yale School of Medicine Human Subjects Institutional Review Board approved the current study.

Measures

Patient history and clinical form: An investigator developed form was used to obtain data related to sociodemographic, health history, insurance, cancer treatment, and clinical information. Non-participants were asked their reason for not participating. There were no differences on demographic information between those who participated and those who declined.

Comorbidity was assessed as the number of other medical diagnoses adapted from the Co-morbidity Checklist used by Satariano [9] and associates and by the Human Population Laboratory (HPL) in the Alameda County Survey [10,11].

Emotional Distress was measured by the Emotional Distress Thermometer, which is a rapid method to evaluate whether patients indicate they have distress on a scale of 0 to 10 with a mark of 4 or above indicating a need for further evaluation [12-14].

Patient Problem List was developed by the Distress Management

Guidelines Panel of the National Comprehensive Cancer Network to accompany the thermometer [12]. The original list comprised problems categorized in six conceptual domains: illness-related, family, emotional, practical, spiritual, or other. After implementing routine screening with two disease- based groups of patients at our cancer center, the Psychosocial Advisory Committee revised the problem list based on the results. This list contains 35 problems classified in five conceptual domains. Patients were asked whether they had experienced any of the problems in the past week and were asked to check those items that applied yes or no on the tool.

Functional Status was measured by the Enforced Social Dependency Scale (ESDS). The ESDS, developed to measure functional abilities of patients with cancer, consists of two components: personal and social competence. Personal competence includes six daily living activities of eating/feeding, dressing, walking, traveling, bathing, and toileting. Dependency in each activity was reported by the patient and rated by the interviewer on a 6-point scale. Scores for personal competence were summed and ranged from 6 to 36. Social competence consists of home, work, and recreational activities, which were rated on 4-point scales, and the category communication, rated on a 3-point scale. Scores for personal and social competence are summed to generate a total dependency score ranging from 10 to 51, with higher scores reflecting greater dependency. The ESDS has demonstrated reliability (Cronbach's alpha=0.72 to 0.96) and validity [15,16].

Health Distress was measured by a 4-item scale developed by the Stanford Patient Education Research Center [17]. The items ask patients how they feel and how things have been during the last month related to how much have you been discouraged by your health, how fearful you are about your future health, how much health is a worry in your life, and whether you are frustrated by your health? The scale is scored by the mean of the four items and ranges from 0 (none) to 5 (all of the time), higher scores indicating more distress. Internal consistency reliability is reported as 0.87.

Depression was measured by the Personal Health Questionnaire (PHQ-9). The scale consists on nine items and asks patients to circle the number that reflects whether they are bothered by the item over the last two weeks. The items include the person's interest in things, feeling down, sleep problems, tiredness, concentrating, moving slowly, and thoughts of hurting oneself. The scale ranges from 0 (none) to 3 (all the time). Higher scores reflect greater depression. The scale has strong psychometric properties [18,19].

Symptom Distress was measured by the Symptom Distress Scale (SDS) and contains thirteen cancer-specific symptoms: nausea (presence and intensity), mood, appetite, insomnia, fatigue, pain (presence and intensity), mobility, bowel patterns, concentration, and appearance (30). Each symptom is placed on a 5×7 card with a 5-point Likert-type format ranging from 1 (normal or no distress) to 5 (extensive distress). Total Symptom Distress is obtained as the unweighted sum of the 13 scales, a value that could range from 13 to 65. Both internal consistency and test-retest reliability estimates have indicated the scale's reliability [20-22]. Self-Rated Health was measured by the first item of the Medical Outcomes Study 36- Item Short-Form Health Survey (SF-36) [23]. The first item asks patients to rate their health on 5-point Likert scale ranging from excellent (5), very good, good, fair, or poor (1); with higher scores reflecting better health. The single item has demonstrated reliability and validity. An assessment of test-retest reliability demonstrated a score of 0.89 [24].

Analytic plan

Statistical analyses were performed with Statistical Analysis Software for Windows, version 9.2 (SAS 9.2). Means, standard deviations, and frequencies were used to obtain descriptive statistics of the patient population. Descriptive statistics of means and standard deviations were computed for five outcome measures (ESDS, Health Distress, PHQ-9, SDS and Self-rated health) as well as EDT. We also looked at the source of patients' distress related to five problem domains. To determine the degree and direction of relationship among EDT distress, problem counts and outcome measures, Spearman correlation coefficients were calculated due to skewed data distribution for problem domain variables. Difference of EDT distress, problem counts and outcome variables among subgroups were examined using Analysis of Variance (ANOVA) or Wilcoxon Sum Rank Test based on Levene's Test for the assumptions of ANOVA for homogeneity of variance. The relations of demographic and clinical characteristics with the dichotomous variable of distress (EDT $\geq$ 4 vs. EDT<4) were examined using chi-square analyses, and odds ratios with 95% confidence interval were computed. All of the potential predictor variables of distress as well as outcome measures were included in multiple logistic regression full model. Final regression model included only significant predictors which were selected using Stepwise model selection method. An alpha of .05 with a two-tail test was used for level of significance.

Results

The demographic and clinical characteristics of 153 patients enrolled in the trial as measured at baseline are presented in tables 1 and 2. The average age of the sample was 60.4 (12.6) years, with a range of 27 to 87 years. The sample was predominately female, white, highly educated, married, and living with others. Over a third of the sample were patients with gastrointestinal cancers (n=53, 35%), followed by lung cancer (n=46, 30%), gynecological (n=27, 17.5%), and head and neck (n=27, 17.5%). Overall patients had two or more comorbidities. Patients with lung cancer had the highest average of numbers of comorbidities. Diagnosis was confirmed by biopsy for 35% of participants (n=54); the remaining were confirmed and treated with major surgery (n=99). The majority of the sample were newly diagnosed (n=139, 90.8%); the remaining had experienced a recurrence after a one year disease free interval (n=14, 9.2%).

There were no significant differences on mean distress scores for any of the demographic characteristics, but patients with a high school education or less reported greater distress, although the difference was not significant (F(2)=2.81, p=0.063). Patients' emotional distress was significantly higher with higher number of co-morbidities (F(3)=3.58, p=0.015). Also patients diagnosed with late stage cancers continued to report high emotional distress after three months, significantly more than those that were diagnosed after a year (χ^2(2)=6.35, p=0.042). Those with recurrent disease (F(1)=7.19, p=0.008) reported significantly more problems than others.

Spearman correlations were conducted between emotional distress, the number as well as domains of problems and outcome variables and are described in table 3. The strongest relationships were between emotional distress scores and health distress (0.52), depression (0.49), and symptom distress (0.50), all were significant at p=0.0001 level. These same moderate correlations continued with the number of problems, and the emotional and physical domains. Means, standard deviations, and Cronbach's alphas for patients' emotional distress, ability to perform activities of daily living, health distress,

Age, Mean ± SD	60.4 ± 12.6 years	Distress score Mean ± SD	F	p	Problem Counts Mean ± SD	F	p
	N (%)	Mean (SD)			Mean (SD)		
Age							
Under 50 years	**31 (20.3)**	4.35 (3.14)			8.23 (6.29)		
50-59 years	**45 (29.4)**	4.00 (2.73)	1.27	0.288	7.62 (4.72)	5.36†	0.148
60-69 years	**43 (28.1)**	4.23 (2.66)			6.44(4.07)		
Over 70 years	**34 (22.2)**	4.18 (2.55)			5.53 (4.29)		
Gender							
Male	**67 (43.8)**	3.60 (2.74)	2.00	0.160	6.19 (4.82)	2.88	0.092
Female	**86 (56.2)**	4.23 (2.78)			7.53 (4.87)		
Marital status							
Single	**24 (15.7)**	3.96 (2.54)			**8.92 (5.88)**		
Married	**86 (56.2)**	3.67 (2.78)	1.83	0.145	**6.66 (4.66)**	3.31	**0.022**
Widowed	**14 (9.1)**	3.50 (2.18)			**4.07 (3.54)**		
Divorced/separated	**29 (19.0)**	5.00 (3.01)			**7.55 (4.57)**		
Race/Ethnicity							
Caucasian/non-Hispanic	**131 (85.6)**	3.99 (2.82)	0.17	0.679	6.78 (4.78)	1.09	0.297
Other˙	**22 (14.4)**	3.72 (2.47)			7.95 (5.47)		
Education							
Graduate School	**21 (13.7)**	3.48 (2.87)			6.29 (5.05)		
College	**76 (49.7)**	3.58 (2.66)	2.81	0.063	6.87 (4.65)	0.35	0.706
High School or less	**56 (36.6)**	4.64 (2.78)			7.30 (5.18)		
Religion							
Protestant	**26 (17.0)**	3.12 (2.18)			5.19 (3.43)		
Catholic	**76 (49.7)**	4.04 (2.83)			6.89 (4.74)		
Jewish	**6 (3.9)**	5.00 (3.22)	1.09	0.364	5.83 (4.36)	2.10	0.083
Other	**21 (13.7)**	3.76 (2.86)			7.24 (5.74)		
None	**24 (15.7)**	4.50 (2.92)			9.04 (5.48)		
Employment status							
Full-time/part-time working	**51 (33.3)**	3.59 (2.89)			**7.00 (4.97)**		
Sick leave/disabled/unemployed	**40 (26.2)**	4.88 (2.93)	2.05	0.109	**8.50 (5.98)**	7.57†	0.056
Retired	**49 (32.0)**	3.63 (2.40)			**5.37 (3.38)**		
Homemaker/other	**13 (8.5)**	3.77 (2.77)			**7.92 (4.19)**		
Household Income							
<$30,000	**22 (14.4)**	3.59 (2.30)			6.50 (4.86)		
$30,000-59,999	**23 (15.0)**	3.61 (2.87)			6.87 (5.34)		
$60,000-89,999	**17 (11.1)**	3.59 (2.60)	1.90	0.113	5.24 (4.16)	0.85	0.494
≥$90,000	**24 (15.7)**	3.04 (2.71)			6.88 (5.14)		
not reported	**67 (43.8)**	4.61 (2.85)			7.58 (4.82)		
Living conditions							
with other families	**122 (79.7)**	3.89 (2.81)			7.19 (4.91)		
alone	**29 (19.0)**	4.14 (2.67)	0.23	0.792	5.52 (4.33)	3.01	0.052
not reported	**2 (1.3)**	5.00 (2.83)			13.00 (5.66)		
Cancer Diagnosis							
Head & Neck	**27 (17.6)**	4.22 (2.68)			7.41 (5.52)		
Gastrointestinal	**53 (34.7)**	3.64 (2.77)	1.97	0.121	6.28 (5.13)	1.49	0.221
Gynecological	**27 (17.6)**	5.00 (2.87)			8.52 (4.28)		
Lung	**46 (30.1)**	3.54 (2.66)			6.57 (4.42)		
Co-morbidities							
0-1	**50 (32.7)**	**3.16 (2.71)**			6.24 (5.72)		
2	**30 (19.6)**	**4.37 (2.65)**	3.58	**0.015**	6.27 (4.44)	1.71	0.167
3-4	**33 (21.6)**	**3.61 (2.87)**			6.91 (4.56)		
5-12	**40 (26.1)**	**4.93 (2.58)**			8.38 (4.11)		
Time since Diagnosis							
< 3 months	**100 (65.4)**	**4.10 (2.65)**			6.72 (4.84)		
3-12 months	**40 (26.1)**	**4.18 (3.15)**	6.35†	**0.042**	7.35 (5.42)	0.31	0.731
> 12 months	**13 (8.5)**	**2.15 (1.68)**			7.46 (3.38)		

Table 1: Distress and Problem Counts by Demographic and Clinical Characteristics (N=153).

depression, symptom distress, and self- reported health as measured at baseline in the parent study are reported in table 4. The mean distress score of the overall sample was 3.95 (SD=2.8). The sample reported mild to moderate functional dependency (Mean=20.81, SD=10.1), a little to some health distress (Mean=1.79, SD=1.3), little to no depression (Mean=5.17, SD=4.1), moderate symptom distress (Mean=23.86, SD=6.95) and good to fair health Mean=3.61, SD=1.1). Although not significantly different, patients with gynecological cancers reported the highest levels of distress (Mean=5.00, SD=2.9). When comparing patients who scored 4 or higher on the distress thermometer; we found significant differences on all outcome variables except self-reported health. Patients with higher distress reported significantly more personal limitations (F(1)=5.47, p=0.0206), social dependency (F(1)=4.65, p=0.0326), health distress (χ^2(1)=28.05, p<0.0001), depression (χ^2(1)=20.46, p<0.0001), and symptom distress (χ^2(1)=25.37, p<0.0001).

The results of the multivariate logistic regression are found in table 5. Age, marital status, and cancer site were not significantly associated with distress. Women reported significantly more distress than men (χ^2 (1)=9.011, p=0.0027). Time since diagnosis and comorbidity (# of medical conditions) had a significant effect on distress in both bivariate and multivariate analyses. Patients diagnosed within the first three months and patients diagnosed between four and twelve months had similar levels of distress which were significantly more than those diagnosed beyond one year (χ^2(1)=9.809, p=0.0074). Those who were unemployed, disabled, or on sick leave due to their illness had the highest distress (χ^2(1)=7.037, p=0.0080). Patients with higher numbers of comorbidity had significantly more distress than those with fewer number of comorbidities (χ^2 (1)=5.239, p=0.0221). Health distress (χ^2(1)=14.926, p=0.0001) and symptom distress (χ^2(1)=13.577, p=0.0002) were significantly related to distress in both bivariate and multivariate analyses.

Discussion

In this sample of 153 patients diagnosed with late stage cancers, we found no differences in mean distress scores on any demographic

	N (%)	Distress score Mean ± SD	F	p	Problem Counts Mean ± SD	F	p
		Mean (SD)			Mean (SD)		
Disease Status							
Recurrent	**14 (9.2)**	5.14 (3.32)	2.88	0.092	**10.21 (4.51)**	7.19	**0.008**
New	**139 (90.8)**	3.83 (2.69)			**6.62 (4.81)**		
Treatment							
Surgery	**99 (64.7)**	4.24 (2.89)	3.08	0.081	7.32 (5.22)	1.67	0.199
Biopsy	**54 (35.3)**	3.43 (2.48)			6.26 (4.14)		
Family cancer history							
Yes	**110 (71.9)**	4.03 (2.82)			6.98 (4.73)		
No	**27 (17.6)**	3.78 (2.55)	0.14	0.874	6.70 (5.66)	0.05	0.955
Not reported	**16 (10.5)**	3.75 (2.91)			7.13 (4.81)		

Other race/ethnicity includes African American (n=12), American Indian (n=1), and Latino/Hispanic (n=9)
†χ^2 value in Wilcoxon Sum Rank test

Table 2: Distress and Problem counts by Demographic and Clinical Characteristics (N=153) (Cont').

	EDT	Problem counts	Practical problem	Family problem	Emotional problem	Spiritual problem	Physical problem
ESDS_personal	**0.24****	0.09	0.14	-0.06	-0.01	0.10	0.11
ESDS_social	0.19*	0.02	**0.18***	-0.04	-0.09	0.07	0.06
ESDS total	**0.23****	0.07	0.15	-0.06	-0.05	0.08	0.11
Health Distress	**0.52*****	**0.49*****	**0.23****	0.19*	**0.51*****	0.19*	**0.35*****
PHQ-9	**0.49*****	**0.51*****	**0.24****	**0.21****	**0.41*****	0.12	**0.42*****
SDS	**0.50*****	**0.55*****	**0.24****	**0.20***	**0.32*****	0.07	**0.54*****
Self-rated health	-0.13	**-0.16***	**-0.18***	-0.08	-0.02	-0.12	**-0.18***

†Spearman correlation
EDT=Emotional Distress Thermometer; ESDS=Enforced Social Dependency Scale; PHQ= Patient Health Questionnaire; SDS=Symptom Distress Scale
* p<0.05, ** p<0.01, ***p<0.001

Table 3: Correlations among EDT, Problem Counts and Outcome Measures† (N=153).

	Mean	SD	Cronbach's α	EDT ≥ 4 (n=81) Mean ± SD	EDT<4 (n=72) Mean ± SD	F value	p value
EDT	3.95	2.77	--	6.09 ± 1.87	1.56 ± 1.20	115.07*	**<0.0001**
ESDS_personal	12.48	7.33	0.93	13.77 ± 7.65	11.03 ± 6.71	5.47	**0.0206**
ESDS_social	7.33	3.12	0.90	7.84 ± 2.97	6.76 ± 3.20	4.65	**0.0326**
ESDS total	20.81	10.08	0.93	22.60 ± 10.28	18.79 ± 9.53	5.62	**0.0190**
Health Distress	1.79	1.27	0.90	2.31 ± 1.30	1.21 ± 0.94	28.05*	**<0.0001**
PHQ-9	5.17	4.13	0.76	6.62 ± 4.38	3.54 ± 3.14	20.46*	**<0.0001**
SDS	23.86	6.95	0.77	26.46 ± 7.11	20.94 ± 5.48	25.37*	**<0.0001**
Self-rated health	3.61	1.08	--	3.47 ± 1.16	3.78 ± 0.97	3.14	0.0784

EDT=Emotional Distress Thermometer; **ESDS**=Enforced Social Dependency Scale; **PHQ**=Patient Health Questionnaire; **SDS**=Symptom Distress Scale
*χ^2 value in Wilcoxon Sum Rank test

Table 4: Descriptive Statistics for EDT and Outcome Measures (N=153).

	Full Model[a]			Final Model[b]			
	Coefficient	Std Err Wald χ²	p	Coefficient	Std Err Wald χ²		p
Age	-0.0143	0.0287	0.246	0.6199	-	-	-
Male Gender	-1.8002	0.6135	**8.611**	**0.0033**	-1.4567	0.4853	**9.011**	**0.0027**
Marital Status			**8.884**	**0.0309**				
Single vs. Divorced	-1.3267	0.5762	5.302	0.0213	-	-	-
Married vs. Divorced	0.3921	0.3735	1.102	0.2938	-	-	-
Widowed vs. Divorced	-0.4102	0.6852	0.358	0.5494	-	-	-
Time Since Diagnosis			**9.970**	**0.0068**			**9.809**	**0.0074**
<3 month vs. >12 month	1.1851	0.4728	6.282	0.0122	1.0424	0.4050	6.623	0.0101
3-12 month vs. >12 month	1.4895	0.5430	7.525	0.0061	1.1443	0.4540	6.353	0.0117
Cancer Site			3.498	0.3210				
Head & Neck vs. Lung	-0.7773	0.5041	2.378	0.1230	-	-	-
Gastrointestinal vs. Lung	0.3987	0.3963	1.012	0.3145	-	-	-
Gynecological vs. Lung	0.5797	0.5339	1.179	0.2775	-	-	-
Employment Status			**10.480**	**0.0149**			**8.432**	**0.0379**
Full time/part time working vs. homemaker/other	0.3525	0.4635	0.578	0.4470	0.3588	0.4044	0.787	0.3750
Sick leave/disabled/unemployed vs. homemaker/other	1.3857	0.4697	8.704	0.0032	1.0920	0.4116	7.037	0.0080
Retired vs. homemaker/other	0.1617	0.5132	0.099	0.7527	0.2031	0.3914	0.269	0.6038
Comorbidity	0.3300	0.1274	**6.711**	**0.0096**	0.2208	0.0964	**5.239 5.2395.239**	**0.0221**
PHQ-9	-0.0341	0.0981	0.121	0.7281	-	-	-
Health Distress	1.1104	0.2994	**13.752**	**0.0002**	0.8942	0.2314	**14.926**	**0.0001**
SDS	0.1851	0.0590	**9.839**	**0.0017**	0.1433	0.0389	**13.577**	**0.0002**
ESDS_personal	0.0583	0.0370	2.482	0.1152	-	-	-

Full Model[a] includes all potential predictors of distress in demographic and clinical characteristics as well as outcome measures.
Final model [b] includes only significant predictors which were selected using Stepwise model selection method.
EDT=Emotional Distress Thermometer; **ESDS**=Enforced Social Dependency Scale; **PHQ**= Patient Health Questionnaire; **SDS**=Symptom Distress Scale

Table 5: Factors Related to Distress (EDT ≥4) in Multivariate Logistic Regression* (N=153).

variables, type of cancer, or family history of cancer. This is an important finding indicating that patients who are diagnosed with late stage cancers no matter the type of cancer or whether they have a family history of cancer report similar levels of distress. Previously, researchers have reported that emotional distress varies by type of cancer. In cross-sectional data describing the emotional distress of patients across cancer diagnoses, Zabora et al. [25] reported that lung, pancreatic, and brain cancer patients experienced the highest distress when compared to other cancer sites. However, in our sample, patients with more comorbidities reported significantly higher levels of distress without regard to cancer site ($\chi^2(1)$=5.239, p=0.0221). Hurria et al. [26] also found in a descriptive correlational study that cancer patients with more comorbidities experienced higher levels of distress. Recurrent patients in our sample reported significantly greater problems (F(1)=7.19, p=0.008), however, the difference of the level of distress between newly diagnosed and recurrent patients was not significant (F(1)=2.88, p=0.092). In review of the literature, earlier studies also found that the difference in mean levels of distress between the recurrent and newly diagnosed patients was not statistically significant [27,28].

For the subgroup of patient (n=81, 53%) with distress scores ≥ 4, they reported more functional limitations, health distress, depression, and symptoms. In this study we sought to determine what factors were related to high emotional distress with late stage cancers. The homogeneity of being diagnosed with late stage cancers and the heterogeneity of the types of cancer were central in testing our hypothesis that distress is a hallmark of being diagnosed with late stage disease and that distress extends beyond the established 100 days of the existential plight. We found that patients diagnosed within the first three months and patients diagnosed between four and twelve months reported similar levels of distress above the cut score of 4, indicating

a need for further evaluation during this time. Patients who were diagnosed over twelve months (n=13) reported significantly lower levels of distress [29]. The correlation between emotional distress and health distress was highest (0.55, p=0.001) of all the variables and the item among the 4 item scale reported the most frequently was 'fearful about your future health' representing existential concerns (Data not reported).

In the final model to explain the factors related to high distress, women reported significantly more distress than men. In addition, patients who were forced to leave their employment had greater distress. Patients with higher levels of health distress and symptoms reported greater emotional distress. Previous research has cited similar factors as predominant contributors to high emotional distress including; being female, loss of employment or financial security, greater number of cancer-related symptoms, and declining physical health and function [4,14,20,29]. We expected these patients to be sick and it was not surprising that those who had other comorbid diseases and were functionally impaired, depressed, and reported symptom distress were also emotionally distressed.

Studying a cohort of newly diagnosed patients with late stage cancers provided an opportunity for us to identify those at risk for ongoing emotional distress that might interfere with patients' ability to consider their range of treatment options and initiate recommended treatment. These patients are on a steep learning curve to learn how to take in all that is happening to them and need assistance in recognizing they are experiencing distress and reporting it. Our findings showed that high emotional distress occurs within the first 100 days of the existential plight and extended up to one year. Clinicians have a responsibility to screen patients as soon as possible for distress and to monitor patients over critical points in the illness trajectory [30]. Our results also suggest that women newly diagnosed with late stage cancers, which were forced to stop working, have multiple co-morbidities, high symptom burden,

and high perceived health distress need to be monitored frequently for distress.

Limitations

Our results show promise for identifying factors that may assist providers with recognizing emotional distress in patients diagnosed with late stage cancers, including those subgroups of patients who need to be monitored more frequently. Our results also demonstrate that distress extends beyond the existential plight for these patients. However, there are several limitations that must be acknowledged. Although the recruitment of our sample originally was limited to the first 100 days representing the existential plight, we expanded the sample to include patients diagnosed beyond a year and patients with recurrent disease occurring after at least a year disease free interval. The sample also included patients with different types of cancer and patients with late stage lung cancer were treated very differently than late stage ovarian or pancreatic cancers. In addition, data presented in this secondary analysis were cross-sectional and represented only one data collection point. Although there have been a number of interventions identified to assist patients [31,32], additional research is needed to see if it is applicable for patients newly diagnosed with late stage cancers who may be at risk for long-term distress [33].

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