Palliative and Supportive Care

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Pain-related distress among patients referred to a community-based palliative care program

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Original Article

Cite this article: Riggs A, Breuer B, Patel V, Harounian J, Chen J, Dhingra L, Portenoy RK, Knotkova H (2019). Pain-related distress among patients referred to a community-based palliative care program. *Palliative and Supportive Care* **17**, 338–344. https://doi.org/10.1017/S1478951518000251

Received: 9 January 2018
Revised: 27 March 2018
Accepted: 2 April 2018

Key words:
Community-based palliative care; CMSAS; pain-related distress

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Abstract

Objective. Numerous studies have characterized the pain reported by patients with advanced illness in terms of descriptors such as severity, but few have measured pain-related distress. Distress may be important in the clinical approach to pain. To evaluate pain-related distress among adult patients with advanced illness and pain following enrollment in an urban, specialist-level, community-based palliative care program.

Method. In a retrospective cross-sectional analysis, data were extracted from the electronic health records of all patients who were able to complete the pain item from the Condensed Memorial Symptom Assessment Scale at the start of care. Bivariate and multivariate analyses evaluated the associations between distress and both sociodemographics and disease-related information.

Results. The 506 patients completing the pain item had a mean (*SD*) age of 70.7 years (13.8); 64.2% were women, 32.1% were Hispanic, 32.6% were white, and 27.7% were black. Of the 503 patients who indicated some level of distress on a 0–4 scale, 221 (43.7%) had high distress, defined as a score ≥3 ("quite a bit" or "very much"). Cancer diagnosis and poor performance status (unable to care for self) were predictors of high pain-related distress (both $p < 0.05$).

Significance of results. Among patients with advanced illness who reported pain at the start of care by a specialist palliative care program, high pain-related distress was common, particularly among those with cancer or poor physical function. Further studies are needed to explore the extent to which pain-related distress should inform the assessment and management of pain.

Introduction

Programs that provide specialist-level palliative care to homebound patients are slowly emerging in the United States and other countries, joining an array of home health programs that target the needs of the chronically ill. Patients referred to community-based palliative care usually have advanced illness and multiple sources of illness burden. Poorly controlled symptoms are common and pain is among the most prevalent and distressing (Blinderman et al., 2008, 2009; Dhingra et al., 2014). Effective pain management often is a key element in the relief of illness burden for both the patient and family caregivers (Andrews, 2001).

Although numerous studies have characterized the pain experienced by populations with advanced illness in terms of common descriptors such as severity, few have measured pain-related distress (Chang et al., 2004; Dhingra et al., 2011; Vallerand et al., 2016; Vowles et al., 2017). From the clinical perspective, the distress associated with chronic pain may influence the approach to assessment, the urgency of treatment, or the choice of first-line therapies. Studies of distress are warranted to explore the extent to which this descriptor may provide unique or actionable data. We evaluated pain-related distress in a large sample of patients who completed the pain item on a validated symptom measure at the time of enrollment into an urban, specialist-level, community-based palliative care program.

Methods

In a retrospective cross-sectional analysis, we evaluated electronic health record data from 506 adult patients who enrolled in a community-based palliative care program during 2010–2013. A patient was included in this analysis if he or she was able to complete the Condensed Memorial Symptom Assessment Scale at the start of care. This measure was administered by the physician or nurse conducting an initial comprehensive assessment, and scores were either entered directly by patients or elicited by interview and recorded by the clinician.

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Table 1. Demographic characteristics

Demographic characteristics ($n = 506$)		
		Mean ± *SD*, min-max, median
Age		70.7 ± 13.8, 18–98,73
		n (%)
Sex		
	Men	181 (35.84)
	Women	324 (64.16)
KPS		
	10–40: unable to care for self	72 (14.57)
	50–70: unable to work	417 (84.41)
	80–100; able to carry on normal activities	5 (1.01)
Language		
	English	302 (69.11)
	Spanish	93 (21.28)
	Other	42 (9.61)
Marital status		
	Not married	201 (64.84)
	Married	109 (35.16)
Living status		
	Lives alone	84 (25.53)
	Doesn't live alone	245 (74.47)
Poverty status below poverty		
	1 (<10%)	50 (10.25)
	2 (10–19.9%)	128 (26.23)
	3 (20–29.9%)	152 (31.15)
	4 (30–39.9%)	112 (22.95)
	5 (≥40%)	46 (9.43)
Primary payer		
	Medicaid	18 (3.56)
	Medicare	145 (28.66)
	Commercial	343 (67.79)
Disease diagnosis		
	Cancer	181 (40.58)
	CHF/cardiac	27 (6.05)
	COPD	37 (8.30)
	Neurodegenerative	117 (26.23)
	Chronic renal failure	18 (4.04)
	Cirrhosis	5 (1.12)
	Other	61 (13.68)
Race/ethnicity		
	Asian	12 (3.11)
	Black	107 (27.72)
	White	126 (32.64)
	Hispanic	124 (32.12)
	Other	17 (4.40)

(*Continued*)

https://doi.org/10.1017/S1478951518000251 Published online by Cambridge University Press

Table 1. (*Continued.*)

Demographic characteristics ($n = 506$)		
Pain distress		
	Not at all [0]	3 (0.59)
	A little bit [1]	92 (18.18)
	Somewhat [2]	190 (37.55)
	Quite a bit [3]	175 (34.58)
	Very much [4]	46 (9.09)

CHF, congestive heart failure; COPD, chronic obstructive pulmonary disease; KPS, Karnofsky Performance Scale.

Table 2. Pain-related distress scores upon enrollment to the palliative care program

Demographic characteristics	*n*		Pain distress mean (*SD*)	*p*
Age	506			
<70 years		218	2.76 (0.72)	0.012
≥71 years		288	2.60 (0.71)	
Sex	505			
Men		181	2.59 (0.74)	0.087
Women		324	2.71 (0.70)	
Race/ethnicity	386			
Asian		12	2.73 (0.87)	
Black		107	2.71 (0.66)	
White		126	2.81 (0.68)	0.005
Hispanic		124	2.56 (0.76)	
Other		17	2.31 (0.74)	
Language	437			
English		302	2.76 (0.71)	
Spanish		92	2.49 (0.70)	0.005
Other		42	2.65 (0.67)	
Marital status	310			
Not married		201	2.75 (0.66)	0.873
Married		109	2.76 (0.77)	
Living status	329			
Lives alone		84	2.69 (0.70)	0.986
Doesn't live alone		245	2.68 (0.74)	
Poverty status below poverty*	488			
1 (<10%)		50	2.83 (0.69)	
2 (10–19.9)		128	2.77 (0.75)	
3 (20–29.9%)		152	2.57 (0.64)	0.009
4 (30–39.9%)		112	2.63 (0.73)	
5 (≥40%)		46	2.42 (0.76)	
Primary payer	506			
Medicaid		18	2.71 (0.68)	
Medicare		145	2.76 (0.72)	0.138

(*Continued*)

https://doi.org/10.1017/S1478951518000251 Published online by Cambridge University Press

Table 2. (*Continued.*)

Demographic characteristics	*n*		Pain distress mean (*SD*)	*p*
Commercial		343	2.62 (0.72)	
Disease diagnosis	446			
Cancer		181	2.82 (0.71)	
CHF/cardiac		27	2.87 (0.78)	
COPD		37	2.53 (0.72)	
Neurodegenerative		117	2.37 (0.64)	<0.001
Chronic renal failure		18	2.76 (0.74)	
Cirrhosis		5	3.20 (0.98)	
Others		61	2.68 (0.70)	
KPS	494			
10–40 Unable to care for self		72	2.86 (0.73)	
50–100 Unable to work, able to carry on normal activities		422	2.63 (0.71)	0.012

Comparison of mean pain distress at enrollment using one way analysis of variance.
CHF, congestive heart failure; COPD, chronic obstructive pulmonary disease.
*Poverty was treated as a categorical variable for purposes of this analysis.

The study was exempted from a review by the New England Independent Review Board because of the aggregated and deidentified nature of the data. Patient consent was not required.

Variables

The Condensed Memorial Symptom Assessment Scale is a validated 14-item questionnaire used to evaluate the prevalence and distress associated with 11 physical and three psychological symptoms (Chang et al., 2004). The timeframe of assessment is "during the past week." If pain is experienced, pain-related distress is measured with the inquiry, "How much did the symptom bother or distress you in the past seven days?" The 5-point scale includes: 0 (no distress at all), 1 (a little bit), 2 (somewhat), 3 (quite a bit), and 4 (very much).

Other variables included sociodemographics, primary diagnosis, and performance status. To evaluate socioeconomic status, the ZIP code of patient residence was transformed into a poverty quintile (Q1–Q5) based on the percentage of individuals within that ZIP code living in poverty from estimates from the American Community Survey (US Census Bureau, 2012). ZIP codes with <10% of residents living below the federal poverty line were transformed to Q1; 10–19.9% to Q2; 20–29.9% to Q3; 30–39.9% to Q4; and ≥40% to Q5 (Riggs et al., 2017; US Census Bureau, 2012; Villanueva et al., 2013). Performance status was measured using the Karnofsky Performance Status (KPS) scale, which ranges between 0 and 100 and has anchor points 0 (death) and 100 (no complaints/no evidence of disease) (Schag et al., 1984).

Analysis

Statistical analysis was performed with SPSS, version 24 (IBM Corp., Armonk, NY) and SAS, version 9.3 (SAS Institute, Inc., Cary, NC). Pain-related distress was modeled as both a continuous and categorical variable that divided pain-related distress into low (0–2) versus high (3–4). KPS was categorized into scales of 10–40 (unable to care for self), 50–70 (unable to work), and 80–100 (able to carry on normal activity and to work) (Schag et al., 1984) for bivariate analyses, and dichotomized in the multivariate analysis into levels 10–40 versus 50–100 because of the small number of patients with KPS scores 80–100. Age was dichotomized at the mean (70 years) for some bivariate analysis. Bivariate analysis applied chi-square, Fisher's exact tests, t-tests, or analysis of variance as appropriate; logistic and linear regression with manual backwards elimination were used to determine predictors of pain-related distress.

Results

The 506 patients who provided pain scores had a mean (*SD*, range) age of 70.7 (13.8, 18–98) and 64.2% were women (Table 1). The sample was racially diverse, with 32.1% identifying as Hispanic, 32.6% as white, 27.7% as black, 3.1% as Asian, and 4.4% as other race/ethnicity. Sixty-nine percent of patients spoke English as their primary language, 21.3% spoke Spanish, and 9.6% spoke another language. Although more than one-half of the sample was not married (64.8%), 74.5% did not live alone. Most patients (80.3%) lived in a ZIP code in which 10.0–39.9% lived below the federal poverty line; only 10.3% lived in a ZIP code where <10.0% lived below the poverty level, and only 9.4% lived in a ZIP code with a rate of poverty >40.0%. Most patients had commercial insurance (67.8%) or Medicare (28.7%); 3.6% had Medicaid.

The most common primary diagnoses were cancer (40.6%), neurodegenerative diseases (26.2%), chronic obstructive pulmonary disorder (8.3%), or congestive heart failure and related diseases (6.1%). A total of 84.4% had a KPS score of 50–70, indicating an inability to work but being capable of caring for most personal needs with varying amount of assistance. About 14.6% of patients were more severely disabled (KPS 10–40) and were unable to care for self. Few patients (1.0%) had a KPS of 80–100.

Pain and pain-related distress

Of the 506 patients completing the pain item, 503 (99.4%) experienced some degree of pain-related distress: "a little bit," 18.2%,

https://doi.org/10.1017/S1478951518000251 Published online by Cambridge University Press

Table 3. Multivariate analysis of pain-related distress using linear regression

Demographic characteristics	Estimate	p
Age	−0.006	0.045
Sex		
Men		
Women	0.100	0.204
Race/ethnicity		
Asian	−0.078	0.728
Black	−0.058	0.564
White		
Hispanic	−0.176	0.076
Other	−0.405	0.041
Disease diagnosis		
Cancer		
CHF/cardiac	0.064	0.705
COPD	−0.178	0.234
Neurodegenerative	−0.345	0.001
Chronic renal failure	−0.080	0.690
Cirrhosis	0.425	0.244
Others	−0.076	0.527
KPS		
10–40 Unable to care for self	0.151	0.172
50–100 Unable to work, able to carry on normal activities		

CHF, congestive heart failure; COPD, chronic obstructive pulmonary disease.

"somewhat," 37.5%, "quite a bit," 34.6%, and "very much," 9.1% (Table 1).

Mean pain-related distress was 2.67 ± .72 and bivariate analyses revealed significant differences in distress by age, race/ethnicity, primary language spoken, neighborhood poverty level, disease diagnosis, and KPS score (Table 2). Patients aged ≤70 years had higher pain-related distress compared with those who were >70 years ($p < 0.05$). Whites had the highest mean distress score compared with other race/ethnicities ($p < 0.05$) and those who spoke English had higher pain-related distress than those who spoke Spanish ($p < 0.05$). Those living in neighborhoods with the least amounts of poverty also had the highest pain-related distress ($p < 0.01$). Those with a diagnosis of cirrhosis, congestive heart failure/cardiac diseases and cancer had mean pain-related distress scores of 3.2, 2.9, and 2.8, respectively ($p < 0.001$). Those with lower KPS scores (unable to care for self) had a higher average distress score than those with higher KPS scores (2.86 and 2.63, respectively; $p < 0.05$).

In a multivariate analysis that modeled pain-related distress as a continuous variable, higher distress was predicted by age, race/ethnicity, and primary diagnosis (Table 3). Patients aged ≤70 years were more likely to report higher distress ($p < 0.05$). Patients who were white were more likely to report higher distress than those who identified as other race/ethnicities ($p < 0.05$). Patients with cancer were more likely to report higher distress than those with neurodegenerative diseases ($p < 0.05$). Although KPS score was associated with pain distress in the bivariate analyses, it was not significant in the multivariable analysis.

To further explore the associations with high pain-related distress, distress scores were dichotomized into low versus high. In bivariate analysis, higher odds of pain-related distress were associated with disease diagnosis, KPS score, language spoken, and age

Table 4. Bivariate and multivariate analysis of characteristics associated with low versus high pain-related distress, using logistic regression

	Bivariate			Multivariate	
Demographic characteristics	Low pain distress *n* (%) *n* = 285 (56.30)	High pain distress *n* (%) *n* = 221 (43.70)	p	OR ($CI_{95\%}$)	p
Disease diagnosis					
Cancer	89 (49.17)	92 (50.83)			
CHF/cardiac	12 (44.44)	15 (55.56)		0.98 (0.42–2.27)	0.954
COPD	24 (64.86)	13 (35.14)		0.53 (0.25–1.10)	0.089
Neurodegenerative	86 (73.50)	31 (26.50)	<0.001	0.38 (0.23–0.64)	<0.001
Chronic renal failure	9 (50.00)	9 (50.00)		0.98 (0.37–2.59)	0.960
Cirrhosis	1 (20.00)	4 (80.00)		4.31 (0.47–39.45)	0.196
Others	32 (52.46)	29 (47.54)		0.91 (0.51–1.64)	0.757
KPS					
10–40 Unable to care for self	37 (41.67)	42 (58.33)		1.84 (1.05–3.23)	0.034
50–70 Unable to work	247 (59.23)	170 (40.77)	0.012		
80–100 Able to carry on normal activities	4 (80.00)	1 (20.00)			
Sex					
Men	102 (56.35)	79 (43.65)	0.522		
Women	182 (56.17)	142 (43.83)			

(*Continued*)

https://doi.org/10.1017/S1478951518000251 Published online by Cambridge University Press

Table 4. (*Continued.*)

Demographic characteristics	Bivariate			Multivariate	
	Low pain distress *n* (%) *n* = 285 (56.30)	High pain distress *n* (%) *n* = 221 (43.70)	*p*	OR ($CI_{95\%}$)	*p*
Race/ethnicity					
Asian	6 (50.00)	6 (50.00)			
Black	57 (53.27)	50 (46.73)			
White	65 (51.59)	61 (48.41)	0.215		
Hispanic	76 (61.29)	48 (38.71)			
Other	13 (76.47)	4 (23.53)			
Language					
English	154 (50.99)	148 (49.01)			
Spanish	61 (65.59)	32 (34.41)	0.038		
Other	25 (59.52)	17 (40.48)			
Marital status					
Not married	101 (50.25)	100 (49.75)	0.472		
Married	56 (51.38)	53 (48.62)			
Living status					
Lives alone	51 (60.71)	33 (39.29)	0.310		
Doesn't live alone	132 (53.88)	113 (46.12)			
Poverty status below poverty					
1 (<10%)	27 (54.00)	23 (46.00)			
2 (10–19.9%)	63 (49.22)	65 (50.78)			
3 (20–29.9%)	98 (64.47)	54 (35.53)	0.089		
4 (30–39.9%)	63 (56.25)	49 (43.75)			
5 (≥40%)	30 (65.22)	16 (34.78)			
Primary payer					
Medicaid	9 (50.00)	9 (50.00)			
Medicare	76 (52.41)	69 (47.59)	0.418		
Commercial	200 (58.31)	143 (41.69)			
	Mean (*SD*)	Mean (*SD*)			
Age	71.78 (13.34)	69.33 (14.24)	0.047		

CHF, congestive heart failure; $CI_{95\%}$, 95% confidence interval; COPD, chronic obstructive pulmonary disease.

(Table 4). In multivariate analysis, higher odds of pain-related distress were predicted by disease and KPS score. Compared with patients with cancer diagnoses, those with neurodegenerative disease ($p < 0.001$) were less likely to have pain-related distress; patients with lower KPS (10–40) scores were more likely to have pain-related distress than those with higher KPS scores ($p < 0.05$).

Discussion

In a sample of 506 community-dwelling chronically ill patients who could provide scores on a validated symptom measure and experienced pain during the past week, pain-related distress was high: 99.4% reported pain-related distress of any level and 43.7% described distress as "quite a bit" or "very much." Cancer patients and patients with poor performance status were more likely to report high pain-related distress.

The present study confirms an earlier one that used the same symptom scale to evaluate a group of patients with advanced illness and described the average pain-related distress as between "somewhat" and "quite a bit" (Kutner et al., 2007). The latter study included patients receiving hospice care or specialist-level palliative care; the sample was less diverse than our sample and included only 21% of patients who resided at home. Our study confirms that high pain-related distress is a common phenomenon among those with advanced illness and underscores the need for additional studies to explore the extent to which distress is experienced by the heterogeneous population referred to specialist palliative care in community settings.

https://doi.org/10.1017/S1478951518000251 Published online by Cambridge University Press

Our multivariate analyses suggest that higher pain-related distress is more likely among those with cancer and those with lower performance status. The latter finding confirms earlier work showing that pain in medical illness tends to be worse when the disease is more advanced and function is more compromised (Portenoy & Lesage, 1999; Van den Beukrn-van Everdingen et al., 2007).

The interpretation of these findings should consider important study limitations. Data were collected by treating clinicians as part of routine care, potentially risking bias, and there was no ability to evaluate interrater reliability. Many variables of potential interest, such as pain intensity and pain treatments, could not be evaluated because they were not available in the electronic health record. Moreover, all data were obtained from one organization, which may also limit the generalizability of the results.

Notwithstanding these limitations, our data evaluate a characteristic of chronic pain, pain-related distress, that has received little attention in large literature describing the epidemiology and phenomenology of pain in the medically ill. Pain-related distress is likely to be high among those referred to palliative care programs. The level of pain-related distress may inform assessment, urgency of treatment, and treatment selection. Studies are needed to further describe the phenomenon and determine the extent to which it could guide an approach to the management of symptom burden.

Disclosures and acknowledgments. The authors thank Bill Luecken, Stuart Geller, and MJHS Corporate Information Systems staff for their assistance with data analysis and management. None of the authors are affiliated with industry in a manner that we believe represents a conflict of interest with the current manuscript.

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