

Original Article

The Landscape of Distress in the Terminally Ill

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Abstract

Understanding the complexities of distress and knowing who is most vulnerable is foundational to the provision of quality, palliative end-of-life care. Although prior studies have examined the prevalence of symptom distress among patients nearing death, these studies have tended to largely focus on physical and, to a lesser extent, psychological challenges. The aim of this study was to use the Patient Dignity Inventory (PDI), a novel, reliable, and validated measure of end-of-life distress, to describe a broad landscape of distress in patients who are terminally ill. The PDI, a 25-item self-report, was administered to 253 patients receiving palliative care. Each PDI item is rated by patients to indicate the degree to which they experience various kinds of end-of-life distress. Palliative care patients reported an average of 5.74 problems (standard deviation, 5.49; range, 0–24), including physical, psychological, existential, and spiritual challenges. Being an inpatient, being educated, and having a partner were associated with certain kinds of end-of-life problems, particularly existential distress. Spirituality, especially its existential or “sense of meaning and purpose” dimension, was associated with less distress for terminally ill patients. A better appreciation for the nature of distress is a critical step toward a fuller understanding of the challenges facing the terminally ill. A clear articulation of the landscape of distress, including insight regarding those who are most at risk, should pave the way toward more effective, dignity-conserving end-of-life care. J Pain Symptom Manage 2009;38:641–649. © 2009 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

The work was supported by a grant from the National Cancer Institute of Canada, with funding from the Canadian Cancer Society. Dr. Chochinov is a Canada Research Chair in Palliative Care, funded by the Canadian Institutes for Health Research. The authors declare no conflicts of interest.

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Accepted for publication: April 1, 2009.

Key Words

Distress, Patient Dignity Inventory, palliative care

Introduction

Providing quality palliative care is predicated on a deep understanding of patient experience and potential causes of end-of-life distress.¹ Although some research has been undertaken to better understand this distress, for the most part, the focus has been relatively narrow, dominated by physical and, to a lesser extent, psychological sources of the distress.²⁻⁴ Less work has been undertaken to identify the existential and spiritual challenges people face near the end of life.⁵ Albeit not as readily quantified, nor as easily addressed, the latter are ubiquitous among the terminally ill.⁶ Furthermore, these are issues that the patients want to have addressed within the context of palliative end-of-life care.^{7,8}

To measure and track a broad spectrum of end-of-life distress, our research group developed a novel psychometric tool, coined the Patient Dignity Inventory (PDI, available online at www.jpsmjournal.com).⁹ The PDI contains 25 items covering various physical, psychological, existential, and spiritual sources of end-of-life distress. Patients rate each item, indicating the extent to which they experience it as problematic. The construct and face validity, test-retest reliability, and factor structure of the PDI have been established and previously reported.⁹ Hence, the PDI provides clinicians an easy way to identify various issues that can cause distress among patients nearing death. The aim of this study was to use the PDI to explore the broad spectrum of end-of-life distress and examine its various possible influences.

Methods

Participants

Between March 2004 and July 2007, the patients receiving palliative care from the Winnipeg Regional Health Authority Palliative Care Program and meeting eligibility criteria were approached to participate in this study. This program provides comprehensive inpatient care and coordinated, community-based, end-of-life care services. Then in February 2006

and in July 2006, the Palliative Care Program in Perth, Australia and the Calgary Health Region Palliative Care program in Calgary, Canada, respectively, were invited to partner in participant recruitment. These programs were chosen because of our long-standing research affiliations with those centers. These centers also are affiliated with palliative care programs that provide end-of-life care services comparable to the primary recruitment site.

Eligibility for the study was independently determined for each patient by the treatment staff, on the basis of clinical consensus. Eligibility criteria included being age 18 years or older; being enrolled in the palliative care program in their respective recruitment site; having a life expectancy of less than six months; an ability to read and speak English; demonstrating no evidence of dementia or delirium; and being able to provide informed consent. The patients were not referred to the study if they were cognitively impaired, unable to give informed consent, or too ill to take part in the protocol. Across the three recruitment sites, 806 patients were identified by the clinical staff as appropriate for referral to the study. Of these patients, the research staff found that 261 did not meet eligibility criteria, 205 were not interested in hearing about the study, and 28 were too ill. Of the remaining 312, 35 patients refused to take part. Of the remaining 277 patients, all of whom gave verbal and written consent, 24 dropped out for various reasons, primarily because they became too ill to complete the protocol. The final sample of 253 patients consisted of 190 patients from Winnipeg, Canada; 42 from Calgary; and 21 from Perth.

The Faculty of Medicine Ethics Committees at the University of Manitoba and Curtin University of Technology in Perth, and the University of Calgary Conjoint Health Research Ethics Board, approved the study, with the various Hospital Research Review Boards at participating institutions granting formal patient access. Prior to the onset of data collection, all the patients provided written informed consent.

Procedures

For this study, the patients were asked to complete the 25-item PDI (1 = no problem; 2 = somewhat of a problem; 3 = a problem; 4 = a big problem; 5 = an overwhelming problem).⁹ The patients also completed the Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being (FACIT-Sp).¹⁰ This is a psychometrically sound measure of spiritual well-being for people with cancer and other chronic illnesses. It consists of two subscales: Meaning and Peace, measuring existential well-being; and Faith, reflecting religious or faith-based dimensions of spirituality. Quality of life was measured using the brief Quality-of-Life Scale.¹¹ This two-item scale rates patients' self-assessed quality of life and satisfaction with their current quality of life (ranging from 1 [poor] to 10 [excellent]). Basic demographic information—including age, gender, marital status, living arrangements, religion, inpatient vs. outpatient status and education—also was collected from every patient.

Statistical Analysis

Descriptive statistics (mean, standard deviation [SD], and percentages, as appropriate) were calculated. The proportion of individuals experiencing a particular problem, defined as a PDI item rating of ≥ 3 , was compared between groups using the Chi-squared test (when expected values fell below five, the Fisher's exact test was used). The total number of problems was compared between groups using the Student's *t*-test. Associations between FACIT scales and subscales and the individual PDI items were tested, using Spearman's Rank Correlation Coefficient. All tests were carried out on a two-tailed basis. Because of the number of tests of significance being carried out, the level of probability for significance was raised to 0.01. All statistical analyses were carried out using SPSS 15.0 (Chicago, IL).

Findings

The mean age of the 253 participants was 69 years (SD 13.5), and 136 (58%) were female. Thirty-six percent had less than a high school education, 19% had completed only high school, and 45% had some college or post-graduate training. Fifty-four percent of patients were

married or cohabiting, 27% were widowed, 10% divorced, 8% were never married, and 2% were separated. Fifty-four percent of patients were living with a spouse or a partner. Thirty-two percent were living alone, 19% were living with children, 3% with parents, 1% with children, and 7% with others. In terms of religious affiliation, 37% were Protestant, 23% Catholic, 20% other, 17% no religious affiliation, and 3% Jewish. Primary tumor sites included lung (25%), gastrointestinal (18%), genitourinary (11%), breast (7%), hematologic (6%), and other solid tumors (23%); 8% had noncancer diseases, such as chronic obstructive pulmonary disease, amyotrophic lateral sclerosis, and various other life-limiting ailments. Across the total sample, 149 (59%) were inpatients, with the remainder receiving treatment outside of the hospital setting. The mean duration of survival from the time of interview to the time of death was 78 (standard error [SE] 6.5) days.

Patients reported an average of 5.74 problems each (SD 5.49; range 0–24). The five most prevalent problems reported (all greater than 30%) were not being able to continue usual routines (51.4%); experiencing physically distressing symptoms (47.8%); not being able to carry out important roles (37.5%); no longer feeling like who I once was (36.4%); and not being able to perform tasks of daily living (30.4%) (Table 1). Sixteen PDI items were rated as problematic by 10%–30% of the patients. These latter items fell within the domains of the physical (e.g., not being able to attend to bodily functions); the psychological (e.g., feeling depressed, feeling anxious); and the existential (e.g., feeling of not having control, feeling a burden to others, feeling life no longer has meaning). Only four PDI items were ranked by less than 10% of the sample as being problematic, including concerns regarding spiritual life (6.3%); not being treated with respect (2.8%); not feeling supported by health care providers (2%); and not feeling supported by friends or family (1.6%).

Patients with partners (either spouse or common law) reported more problems on average (6.67; SD 5.78) compared with patients without partners (widowed, divorced, separated) (4.68; SD 4.95) ($t = -2.811$; $P = 0.005$). Disease site, age, gender, living arrangements, religion, inpatient vs. outpatient status, and education were

Table 1
Prevalence of Distress in Palliative Care

PDI Item	Percentage with Problem
Not able to continue usual routines	51.4
Physically distressing symptoms	47.8
Not able to carry out important roles	37.5
Feeling no longer who I was	36.4
Not able to perform tasks of daily living	30.4
Feeling of not having control	29.2
Feeling uncertain	26.9
Not able to attend to bodily functions	26.5
Feeling anxious	24.5
Feeling of reduced privacy	24.5
Feeling a burden to others	24.1
Feeling how you look has changed	22.5
Feeling depressed	22.5
Worried about future	20.9
Not being able to think clearly	20.2
Feeling of unfinished business	19.4
Feeling life no longer has meaning or purpose	17.4
Not feeling worthwhile or valued	17.0
Feeling have not made meaningful contribution	11.9
Not feeling able to mentally fight illness	11.9
Not being able to accept things as they are	11.5
Concerns regarding spiritual life	6.3
Not being treated with respect	2.8
Not feeling supported by health care providers	2.0
Not feeling supported by friends or family	1.6

not significantly associated with the number of PDI items patients identified as problematic (Table 2). To further clarify the nature of distress in this patient population, the proportion of

individuals experiencing specific problems, as indicated by the PDI, were calculated across each of the major demographic variables (Table 3). Within the bivariate comparisons, some significant relationships between patient characteristics and PDI-related distress emerged. For instance, younger patients reported more difficulty with feelings of not having control compared with older patients ($\chi^2 = 8.109$; $P = 0.004$). Although there were no significant gender differences for the average number of problems, men were more likely to report feeling a burden to others ($\chi^2 = 6.715$; $P = 0.010$). When compared with those without partners, the patients with partners were much more likely to report that not feeling in control was a problem ($\chi^2 = 15.855$; $P < 0.001$). The patients living with someone were more likely to report feeling worried about the future ($\chi^2 = 7.074$; $P = 0.005$), feelings of not having control ($\chi^2 = 7.955$; $P = 0.005$), and not being able to attend to bodily functions ($\chi^2 = 6.661$; $P = 0.010$). Inpatients were far more likely than outpatients to report “not being able to attend to bodily functions” as problematic ($\chi^2 = 20.89$, $P < 0.001$). Patients who were more educated were significantly more likely to report problems with feelings of having lost control ($\chi^2 = 10.256$; $P = 0.001$); this pattern held true for feelings of unfinished business ($\chi^2 = 10.063$; $P < 0.002$) and not being able to perform tasks of daily living ($\chi^2 = 9.637$; $P = 0.002$).

Table 2
Demographic Variables and Their Association with Distress and Quality of Life

Variable	Number of Problems	SD	t-Test	P-value	Quality of Life	SD	t-Test	P-value
Age (years)								
<70	6.34	5.69	1.672	NS	5.98	2.63	$t = 0.687$	NS
≥ 70	5.15	5.24			5.74	2.87		
Gender								
Male	5.94	5.63	0.521	NS	5.79	2.71	$t = -0.416$	NS
Female	5.57	5.38			5.93	2.79		
Inpatient vs. outpatient								
In	6.23	5.60	1.714	NS	5.53	2.85	$t = -2.312$	NS
Out	4.98	5.26			6.34	2.55		
Partner								
Yes	6.67	5.78	—	0.005	6.06	2.77	$t = 1.042$	NS
No	4.68	4.95	2.811		5.70	2.73		
Living alone vs. living with someone								
Yes	4.73	5.50	—	NS	5.80	2.85	$t = -0.257$	NS
No	6.20	5.44	1.924		5.89	2.71		
Education								
\leq High school	5.38	5.51	—	NS	5.91	2.72	$t = 0.317$	NS
>High school	6.18	5.47	1.106		5.80	2.80		
Declared religion								
Yes	5.85	5.63	0.684	NS	5.78	2.76	$t = -1.209$	NS
No	5.20	4.76			6.26	2.71		

Table 3
Association Between Demographic Variables and Individual Sources of Distress

Variable	% With Problem	χ^2	Pvalue	χ^2^a	Pvalue ^a
Age (younger [<70 years] vs. older [≥ 70 years])					
Feeling of not having control	Y 37.6, O 21.3	8.109	0.004	4.492	0.034
Feeling anxious	Y 31.2, O 18.0	5.984	0.014	5.844	0.016
Worried about future	Y 27.4, O 14.8	5.997	0.014	2.461	0.117
Gender (male vs. female)					
Feeling a burden to others	M 31.6, F 17.6	6.715	0.010	4.09	0.043
Not feeling worthwhile or valued	M 22.6, F 12.5	4.485	0.034	3.629	0.057
Partner vs. no partner					
Feeling of not having control	P 40.0, NP 17.1	15.855	<0.001	11.108	<0.001
Feeling no longer who I was	P 43.4, NP 28.2	6.261	0.012	6.111	0.013
Not able to attend to bodily functions	P 32.4, NP 19.7	5.206	0.023	1.601	0.206
Not feeling worthwhile or valued	P 22.1, NP 11.3	5.076	0.024	3.735	0.053
Feeling a burden to others	P 29.4, NP 17.9	4.517	0.034	3.276	0.070
Feeling life no longer has meaning or purpose	P 22.1, NP 12.0	4.460	0.035	0.006	0.939
Living with someone vs. living alone					
Worried about the future	LS 25.7, LA 11.1	7.074	0.005	4.704	0.030
Feeling of not having control	LS 34.9, LA 17.5	7.955	0.005	0.780	0.377
Not able to attend to bodily functions	LS 31.4, LA 16.0	6.661	0.010	1.038	0.308
Inpatient vs. outpatient					
Not able to attend to bodily functions	I 37.2, OP 11.4	20.892	<0.001	21.435	<0.001
Feeling of not having control	I 35.1, OP 21.2	5.756	0.016	9.853	0.002
Declared religion (yes vs. no)					
Feeling a burden to others	Y 21.4, N 37.2	4.858	0.028	4.409	0.036
Education \leq high school vs. $>$ high school					
Feeling of not having control	\leq H 21.0, $>$ H 39.5	10.256	<0.001	12.090	<0.001
Feeling of unfinished business	\leq H 12.2, $>$ H 28.1	10.063	0.002	7.796	<0.005
Not able to perform tasks of daily living	\leq H 22.3, $>$ H 40.4	9.637	0.002	11.243	<0.001

Y = younger; O = older; M = male; F = female; P = partner; NP = no partner; LS = live with someone; LA = live alone; I = inpatient; OP = outpatient; C = cancer; NC = not cancer; H = high school.

Correlations that are significant at <0.01 are set off in bold.

^aAfter controlling for all other demographic variables (i.e., age, gender, partner, living arrangements, inpatient vs. outpatient status, religion, and education).

To further examine the relationship between patient characteristics and PDI distress, logistic regression analyses were conducted. This allowed us to examine the strength of associations between individual sources of end-of-life distress and demographic variables, after controlling for the latter. Although initial bivariate associations reported for age, gender and living arrangement did not hold their significance, those for partner status, inpatient vs. outpatient status and education all remained highly significant (Table 3).

Besides simply a declaration of religious affiliation, the association between spirituality and symptom distress was explored on the basis of evaluating the connections between patient responses to the PDI and the FACIT-Sp and its two subscales, Meaning and Peace, and Faith (Table 4). A higher score on the FACIT-Sp and its subscales indicates a stronger sense of spirituality; higher scores on the PDI indicate more

distress. Overall, there were significant negative associations between the total score on the FACIT-Sp and the number of PDI items rated as problematic ($r = -0.349$; $P < 0.001$) (i.e., higher spirituality scores corresponded to the fewer PDI-specific problems); the same held true for the FACIT Meaning and Peace subscale ($r = -0.411$; $P < 0.001$), but not for the Faith subscale. Eighteen of the 25 PDI items correlated significantly with the total FACIT-Sp score; 20 PDI items correlated significantly with the FACIT Meaning and Peace subscale. In contrast, only two of the PDI items (feeling depressed [$r = -0.190$, $P = 0.003$] and concerns regarding spiritual life [$r = -0.213$, $P = 0.001$]) were significantly correlated with the FACIT-Faith subscale.

Discussion

Understanding distress and its associated risk factors is vital to the field of palliative care. Even

Table 4
Spirituality and End-of-Life Distress

PDI Item	FACIT Total		FACIT Meaning and Peace		FACIT Faith	
	<i>r</i>	<i>P</i>	<i>r</i>	<i>P</i>	<i>r</i>	<i>P</i>
Not able to continue usual routines	-0.187	0.005	-0.250	< 0.001	-0.026	0.690
Physically distressing symptoms	-0.253	0.001	-0.269	< 0.001	-0.112	0.088
Not able to carry out important roles	-0.226	0.001	-0.263	< 0.001	-0.044	0.500
Feeling no longer who I was	-0.316	< 0.001	-0.366	< 0.001	-0.105	0.107
Not able to perform tasks of daily living	-0.213	0.001	-0.222	0.001	-0.084	0.197
Feeling of not having control	-0.185	0.006	-0.238	< 0.001	-0.090	0.172
Feeling uncertain	-0.308	< 0.001	-0.336	< 0.001	-0.155	0.017
Not able to attend to bodily functions	-0.0189	0.005	-0.221	0.001	-0.042	0.522
Feeling anxious	-0.295	< 0.001	-0.382	< 0.001	-0.102	0.118
Feeling of reduced privacy	-0.201	0.003	-0.236	0.001	-0.064	0.331
Feeling a burden to others	-0.200	0.003	-0.191	0.003	-0.128	0.050
Feeling how you look has changed	-0.129	0.054	-0.119	0.070	-0.032	0.623
Feeling depressed	-0.359	< 0.001	-0.397	<0.001	-0.190	0.003
Worried about future	-0.178	0.008	-0.191	0.003	-0.092	0.158
Not being able to think clearly	-0.17	0.010	-0.188	0.004	-0.061	0.357
Feeling of unfinished business	-0.164	0.014	-0.181	0.006	-0.121	0.063
Feeling life no longer has meaning or purpose	-0.287	< 0.001	-0.335	< 0.001	-0.087	0.186
Not feeling worthwhile or valued	-0.276	< 0.001	-0.290	< 0.001	-0.152	0.020
Feeling have not made meaningful contribution	-0.137	0.042	-0.150	0.022	-0.047	0.471
Not feeling able to mentally fight illness	-0.276	< 0.001	-0.323	< 0.001	-0.129	0.049
Not being able to accept things as they are	-0.227	0.001	-0.281	< 0.001	-0.050	0.447
Concerns regarding spiritual life	-0.236	< 0.001	-0.190	0.004	-0.213	0.001
Not being treated with respect	-0.103	0.129	-0.124	0.059	-0.019	0.774
Not feeling supported by health care providers	0.047	0.490	-0.075	0.254	0.011	0.866
Not feeling supported by friends or family	0.011	0.870	-0.015	0.815	0.027	0.676

Correlations that are significant at <0.01 are bolded; correlations with significance levels between 0.05 and 0.01 are italicized.

though many sources of distress may not be readily visible or easily articulated by patients, the degree to which these shape end-of-life experience is profound. This study represents a first attempt, using the PDI, to explore the landscape of distress for patients nearing death.

The patients identified nearly six problems each, as determined by their PDI scores. The most highly endorsed items included a combination of physical challenges (distressing symptoms), functional limitations (not able to continue usual routines; not able to perform tasks of daily living; not able to carry out important roles), and existential concerns (no longer feeling like who I was). Although few of these, aside from symptom distress, are routinely evaluated, their prominence suggests that within the context of end-of-life care, they should be. Items not as highly endorsed should not be misconstrued as unimportant. We previously reported that 87.5% of palliative care patients felt "not being treated with respect" would have a profound influence on their sense of dignity.¹² The fact that only 2.8% of participants reported this to be

problematic says less about the salience of this item and more perhaps about the quality of care they received.

The pattern that initially emerged in our analysis suggested that being younger, being male, being an inpatient, being more educated, and having a partner or living with someone was associated with a greater likelihood of certain kinds of distress. The fact that younger patients reported more problems than older patients is consistent with the literature.^{13,14} The particular problems that younger patients identify indicate that anticipation of death raises various existential concerns, such as feeling a loss of control, generalized psychological distress, and a sense of unfinished business. These patients have had less time to realize their life goals or ambitions and may, more than older patients, sense their death is premature or untimely.

Further analysis using logistic regression indicated that the impact of age, gender, partner status, and living arrangements on individual sources of distress was noticeably reduced, when controlled for the other demographic variables

(Table 3). This suggests that age, gender, partner status, and living arrangements are strongly conflated with one another, reflecting the fact that older individuals were more likely to be female, have lost their partners, and to be living alone. Controlling for any three of these variables, therefore, inevitably substantially reduces the impact of the remaining variable. Partner status, however, continued to be very significantly associated with feelings of not having control, even after controlling for all the other demographic variables.

In contrast, education and inpatient/outpatient status retained their highly significant associations with individual sources of distress, after controlling for all the other demographic variables, implying that these variables operate independently of the age/gender/partner status/living arrangements complex. The modeling process, therefore, confirmed that being more educated, having a partner, and being an inpatient each had an independent and significant predictive influence on poorer coping, as assessed by the PDI-related variables.

Patients with education exceeding high-school completion were more likely to report PDI-related problems, including feelings of not having control, not being able to perform tasks of daily living and feelings of unfinished business. Some studies have linked higher education with better coping—for example, among cancer survivors¹³ and women anticipating breast biopsy results;¹⁶ however, few have looked at its influences on end-of-life coping. One palliative care study found more educated participants who reported significantly higher levels of suffering, suggesting a “greater tendency to extrapolate from concrete, individual problems to a more generalized abstraction of global suffering.”¹¹ Another palliative care study reported higher education associated with a heightened sense of burden to others.¹⁷ Perhaps more education correlates with a cognitive style, whereby intellectual processing, in the face of overwhelming life-threatening circumstances, allows for rumination without, necessarily, resolution. More educated individuals may also experience greater contrast effects, whereby greater pre-illness resources and expectations regarding control and independence may find them more overwhelmed and burdened by loss of control within their current end-of-life circumstances.^{18,19}

Various studies have consistently shown that cancer inpatients tend to report more distress

than do outpatients.⁴ This is likely a proxy for illness severity; as such, it is not surprising that previous studies have reported inpatients demonstrate a poorer quality of life,¹³ with more physical^{20,21} and psychological²² distress, than patients being looked after in the community. The association between distress, as measured by the PDI, and having a partner or living with someone is seemingly counterintuitive. After all, many studies have shown the benefits of psychosocial support for patients with life-threatening and life-limiting conditions.^{10,15,23–25} Unlike previous studies, however, the PDI was able to expose various aspects of distress, covering a broad range of concerns. Patients with partners and those living with someone experienced the type of problems that could conceivably be magnified by another bearing witness. The experience of “feeling out of control” or “not being able to attend to bodily functions” can fundamentally be shaped by the presence and attitudes of people closest at hand. As such, individual distress, when perceived to be imposed on others, can intensify. However, it is important to note that people with partners or people living with someone did not report significant differences in their overall quality of life. Hence, relationships should be understood as one possible context within which nurturing and suffering give shape to the experience of approaching death.

The significant correlations between most of the PDI items and the total FACIT-Sp score confirm an association between general notions of spirituality and end-of-life distress. A heightened sense of spirituality and lack of symptom distress would appear to go hand in hand. PDI item endorsements were more closely aligned with the FACIT Meaning and Peace subscale than the FACIT-Faith subscale. This suggests that faith, in and of itself, may have less to do with end-of-life distress, relative to issues of existential well-being, such as feeling at peace with oneself or having a sense of meaning and purpose. Alternatively, a fuller understanding of the connection between faith and end-of-life distress may have to await future studies that target less secular, predominantly religious individuals approaching death.

Like any other study, this one also has its own limitations. The participants were predominantly older patients with cancer. The

landscape of distress will likely vary according to age group, diagnosis, cultural affiliations, socioeconomic status, and place of terminal care. Future research, addressing these various constituencies, will add considerably to our understanding of end-of-life distress. There was also a large difference in the number of subjects recruited across the three sites. The primary issue of concern, if any, is to what extent the patients recruited across the three sites differ from one another. Analysis of age, gender, and disease site distribution revealed no differences. Finally, although we reported on associations between distress and spirituality, future studies, evaluating various aspects of religiosity such as personal beliefs and practices, will shed light on this important, yet poorly understood area.

Understanding and identifying the diversity of distress in palliative care is a critical step toward acknowledging its importance within the realm of human suffering. A clear articulation of the typography of distress, including insight regarding those who are most at risk, should pave the way toward more effective, dignity-conserving end-of-life care.^{26,27}

Acknowledgments

The authors thank their research staff, including Kathy Cullihall (Winnipeg); Laureen Johnson, Amanda Stiles, Robert Van Dyke, Carla Stiles (Calgary); and Joanne Hale, Jenny Clarke, Sky Dawson, and Lynn Oldham (Perth).

Author contributions: H.M. Chochinov, L.J. Kristjanson, S. McClement, T. Hack, and M. Harlos contributed to the protocol design; T. Hassard and H.M. Chochinov to the analysis of the data. All team members contributed to the task of data collection and data interpretation. The report was written by H.M. Chochinov, with critique and approval by the full research team.

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