

Original Article

The Patient Dignity Inventory: A Novel Way of Measuring Dignity-Related Distress in Palliative Care

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Abstract

Quality palliative care depends on a deep understanding of distress facing patients nearing death. Yet, many aspects of psychosocial, existential and spiritual distress are often overlooked. The aim of this study was to test a novel psychometric—the Patient Dignity Inventory (PDI)—designed to measure various sources of dignity-related distress among patients nearing the end of life. Using standard instrument development techniques, this study examined the face validity, internal consistency, test–retest reliability, factor structure and concurrent validity of the PDI. The 25-items of the PDI derive from a model of dignity in the terminally ill. To establish its basic psychometric properties, the PDI was administered to 253 patients receiving palliative care, along with other measures addressing issues identified within the Dignity Model in the Terminally Ill. Cronbach’s coefficient alpha for the PDI was 0.93; the test–retest reliability was $r = 0.85$. Factor analysis resulted in a five-factor solution; factor labels include Symptom Distress, Existential Distress, Dependency, Peace of Mind, and Social Support, accounting for 58% of the overall variance. Evidence for concurrent validity was reported by way of significant associations between PDI factors and concurrent measures of distress. The PDI is a valid and reliable new instrument, which could assist clinicians to routinely detect end-of-life dignity-related distress. Identifying these sources

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Key Words

Dignity, psychometrics, measurement, distress, palliative care

Introduction

Palliative care faces many pressing challenges, not the least of which is finding efficient and reliable ways to identify various types of distress encountered among dying patients. Providing quality palliative care is predicated on a deep understanding of patient experience and potential causes of suffering. Furthermore, distress at this time of life may be physical, psychosocial, spiritual, or existential in nature, or as is often the case, some combination thereof.^{1–4}

Various strategies have been used to identify end-of-life distress, each with their own inherent strengths and weaknesses. The clinical interview is, of course, a critical element of any comprehensive assessment. The information it yields, however, depends on the skill of the individual clinician and the degree of reticence patients may feel in sharing the extent or nature of their distress. Self-report screening instruments are sometimes used to elicit the characteristics of patient distress. Unidimensional scales, such as some measures of quality of life⁵ or the generic distress thermometer,⁶ are able to quantify distress without necessarily eliciting its exact nature or description. Some of the multidimensional scales are either encumbered by their length or may be limited because they tend to narrowly focus on traditional dimensions of patient distress.^{7,8}

In spite of an assortment of newer scales that tap into various aspects of the end-of-life experience, few have been broadly applied to the clinical practice of palliative care. So, for example, although there are measures for desire for death,^{9,10} will to live,¹¹ and demoralization,¹² these tend to be used almost exclusively for research purposes, with limited application to most patients nearing death. Some instruments, such as the Structured Interview Assessment of Symptoms and Concerns in Palliative

Care (SISC), address various dimensions of end-of-life distress, but must be administered by a trained interviewer and thus limit their routine application. On the other hand, self-report instruments, such as the Edmonton Symptom Assessment Scale (ESAS), seem to have achieved a higher degree of uptake within palliative care. The ESAS consists of a series of visual analog scales, covering primarily physical, along with a few common psychological, symptoms that are common toward the end of life. Aside from depression and anxiety, however, the ESAS does not address other psychosocial, existential, or spiritual sources of discomfort or distress.

Clearly, the field of palliative medicine would be well served by a clinically relevant self-report instrument, which has sufficient breadth and depth to tap into a variety of sources of distress facing patients nearing death. To define the scope of such an instrument, we turned to our empirical work on dying with dignity, particularly the Model of Dignity in the Terminally Ill.^{13–16} This model, with each of its major themes and subthemes (previously reported),¹³ encapsulates a broad range of issues—physical, psychosocial, spiritual, and existential—that may influence a dying patient's sense of dignity. This broad and eclectic range of issues can be subsumed under the rubric of dignity-related distress. To measure this, we produced a prototype of a Patient Dignity Inventory (PDI), with individual questions being written to correspond to specific Dignity Model themes and subthemes (see Table 1). For example, the subtheme entitled “role preservation” resulted in a question about being able to carry out important roles, while the theme “burden to others” informed a question about “feeling a burden to others.”

The prototype PDI was vetted by 18 patients receiving end-of-life care from the Winnipeg Regional Health Authority Palliative Care

Table 1
Dignity Model and the Basis of the Patient Dignity Inventory

Major Dignity Categories, Themes, and Subthemes		
ILLNESS-RELATED CONCERNS	DIGNITY CONSERVING REPERTOIRE	SOCIAL DIGNITY INVENTORY
Level of independence (1, 2)	Dignity conserving perspectives	Privacy boundaries (20)
Cognitive acuity (9)	Continuity of self (4, 11)	Social support (21, 22)
Functional capacity (8)	Role preservation (13)	Care tenor (25)
Symptom distress	Generativity/legacy (15, 16)	Burden to others (18)
Physical distress (3)	Maintenance of pride (12)	Aftermath concerns
Psychological distress (5, 6)	Hopefulness (14)	
Medical uncertainty (7)	Autonomy/control (19)	
Death anxiety (8)	Acceptance (24)	
	Resilience/fighting spirit (23)	
	Dignity conserving practices	
	Living in the moment (10)	
	Maintaining normalcy (10)	
	Seeking spiritual comfort (17)	

Numbers in parentheses correspond to the PDI item number that derives from each individual theme and subtheme.

Sub-Program. To arrive at this sample, 33 patients were identified as potential participants (see selection criteria described below), two of whom refused, one of whom did not speak English, and 12 of whom were either too tired or felt too ill to take part. Of the remaining 18, nearly all had end-stage solid tumors; the median age was 73 (range 47–89), the median survival was 32 days (range 2–274), and eight (44%) were female. These patients were asked to provide their feedback regarding the prototype PDI. This provided an opportunity to clarify the exact wording for every item, along with reaffirming the content validity of this emerging instrument. This prototype, consisting of 22 items, was then administered to 211 patients within the Winnipeg Regional Health Authority Palliative Care Program (the specific demographics and recruitment details pertaining to this sample have been previously reported).¹⁷ This phase of recruitment asked patients to indicate the degree that each item related to their sense of dignity (from “not at all” to “very much so”).

Based on this initial experience, several revisions to the PDI prototype were made. First and most important, patients and clinicians pointed out the limitation of the instrument, given that each item was rated according to its association with sense of dignity, rather than the extent to which the issue was felt to be a problem. As such, each item was reframed accordingly. This is a critical distinction, given that patients and care providers are far more concerned if an issue is problematic as opposed to its putative association with the construct of dignity. Other revisions included dividing a question on social

support into two questions, one addressing friend and family support and the other health care provider support, given that patients felt these were separate issues requiring individual items. For similar reasons, the item on psychological distress was divided into an item on depression and a separate item on anxiety; a question on unfinished business was added to supplement an item about “having made a meaningful contribution.” In response to patient feedback, a question about “worrying how life might end” was revised to be somewhat more general and less jarring, that is, “worrying about the future.”

This 25-item PDI serves as the basis for the current study (Fig. 1), whose aim was to test and establish the psychometric properties of this instrument. The PDI is meant to provide a measure of dignity-related distress and serve as a screening tool to assess a broad range of issues that have been reported to influence sense of dignity.^{13,15} It thus offers a relatively easy way to help clinicians identify a broad range of issues that can cause distress among patients nearing death.

Method

Participants

Between March 2004 and July 2007, patients receiving palliative care from the Winnipeg Regional Health Authority Palliative Care Program, 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. In February 2006 and in

July 2006, the Palliative Care Program in Perth, Australia and the Calgary Health Region Palliative Care program, respectively, were invited to partner in participant recruitment. These programs were chosen because of our longstanding 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.

The medical status of every patient was reviewed by the treatment staff, who independently ascertained their eligibility for the study on the basis of clinical consensus. Eligibility criteria included being age 18 years or older; being enrolled in the palliative care program within the respective recruitment site; having a life expectancy of less than six months; having an ability to read and speak English; demonstrating no evidence of dementia or delirium that might make completion of the study protocol difficult; and having the ability to provide informed consent. Patients were not referred to the study if they were cognitively impaired, unable to give informed consent, or too gravely 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. This left a final sample of 253 patients, consisting of 190 patients from Winnipeg, Canada; 42 from Calgary, Canada; and 21 from Perth, Australia.

The Faculty of Medicine Ethics Committees at the University of Manitoba, 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 patients provided written informed consent.

Procedures

Patients were asked to complete the 25-item PDI. Each item was rated on a five-point scale

(1=not a problem; 2= a slight problem; 3=a problem; 4=a major problem; 5=an overwhelming problem) (see [Appendix](#)). Five-point scales of this nature have been reported most reliable on measurements of attitude-judgment, with response categories above five not yielding significant additional discrimination.^{18,19} Patients completed the PDI as a self-report, or were assisted by a highly experienced research nurse, who when required, read the questions aloud and recorded their responses. Patients who were willing and able to do so were asked to complete the PDI 24 hours later, to allow researchers to examine the inventory's stability over time.

To examine the instrument's concurrent validity, patients were also asked to complete a number of self-report measures, tapping into areas of distress identified within the Model of Dignity in the Terminally Ill.¹³ This included the Revised ESAS (which included a "will to live" visual analog scale),⁸ the Beck Depression Inventory (BDI);²⁰ and the suffering and dignity items from the SISC.²¹ Quality of life was measured using the brief Quality-of-Life Scale.⁵ This two-item scale rates the patient's self-assessed quality of life and his or her satisfaction with the current quality of life (ranging from 1 [poor] to 10 [excellent]). Likert-type scales, ranging from one to 10, were used to measure two conceptual dimensions of social support: the structural aspects of support network (i.e., the availability of social support) and satisfaction with the degree of support provided.^{22,23} Using this approach, patients' perceptions of support from their families and friends, and health care providers were measured. The Functional Assessment of Chronic Illness Therapy—Spiritual Well-Being (FACIT-Sp), a measure of spiritual well-being for people with cancer and other chronic illnesses, was also administered to all participants.²⁴ As well, all participants completed the National Center for Health Statistics General Well-Being Schedule, which is a brief, reliable, and valid measure of subjective well-being that is widely used as an indicator of psychological health and dysfunction.²⁵ Basic demographic information was also collected from every patient.

Experienced palliative care research nurses administered the study psychometrics, with regular monitoring by the principal

investigator (HMC) to ensure data integrity and standardized application of the protocol. The protocol was generally well tolerated by patients, taking between 30 and 45 minutes to administer.

Statistical Analysis

To assess the instrument's internal structure, a factor analysis using the conventional approach of an initial principal components solution followed by varimax rotation was undertaken. The selection of factors for rotation was based on the dual criteria of eigenvalues greater than 1 and the assessment of a scree plot. To examine whether the orthogonal factor structure inherent to varimax rotation was appropriate, the data also were subjected to an oblique factor rotation in order to explore factor independence.

The internal consistency of the PDI was examined by determining Cronbach's coefficient alpha. Its test-retest reliability was assessed by correlating the initial PDI self-report with the PDI self-report obtained 24 hours later. To examine the concurrent validity, individual factors were analyzed by determining their correlation with other measures thought to be conceptually overlapping. Unless otherwise specified, all tests were carried out and reported on a two-tailed basis.

Results

The mean age of the 253 participants was 69 years (SD 13.5); 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% were divorced, 8% were never married, and 2% were separated. Fifty-four percent of patients were living with a spouse or partner. Thirty-two percent were living alone, 19% were living with children, 3% with parents, 1% with children, and 7% with other. 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 tumor 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 (41%) receiving treatment outside of the hospital setting. The mean duration of survival from the time of interview to the time of death was 78 (SE 6.5) days.

Cronbach's coefficient alpha for the PDI was calculated to be 0.93. The test-retest reliability for the full PDI was $r = 0.85$, with individual variables' test-retest reliabilities ranging from $r = 0.37$ to $r = 0.76$ (see Table 2).

As a result of the factor analysis, five factors, accounting for 58% of the overall variation, were selected for rotation. This was based on an examination of the factor scree plot; all selected factors had eigenvalues greater than 1, with a discontinuity in eigenvalue size judged to have occurred between factors five and six.

Table 2
Test-Retest Reliability
(mean time interval = one day)

Variable	Pearson r ($n = 133$)	P -value
Not being able to think clearly	0.76	0.001
Not able to perform tasks of daily living	0.71	0.001
Feeling have not made meaningful contribution	0.71	0.001
Not feeling worthwhile or valued	0.70	0.001
Not able to attend to bodily functions	0.69	0.001
Physically distressing symptoms	0.69	0.001
Concerns regarding spiritual life	0.69	0.001
Feeling of reduced privacy	0.67	0.001
Feeling depressed	0.65	0.001
Feeling anxious	0.65	0.001
Feeling no longer who I was	0.64	0.001
Feeling of not having control	0.62	0.001
Feeling of unfinished business	0.61	0.001
Not being able to accept things as they are	0.61	0.001
Feeling how you look has changed	0.59	0.001
Feeling uncertain	0.58	0.001
Not feeling supported by friends or family	0.58	0.001
Feeling a burden to others	0.57	0.001
Feeling life no longer has meaning or purpose	0.56	0.001
Not feeling able to mentally fight illness	0.52	0.001
Not able to continue usual routines	0.49	0.001
Worried about the future	0.48	0.001
Not able to carry out important roles	0.44	0.001
Not feeling supported by health care providers	0.43	0.001
Not being treated with respect	0.37	0.001
Total correlation PDI	0.85	0.001

The 10 largest initial eigenvalues, together with the percentage variance explained, are summarized in Table 3. The five rotated factors (variable loadings less than 0.55 are not shown) are presented in Table 4. These factors are labeled as follows: *Symptom Distress*, *Existential Distress*, *Dependency*, *Peace of Mind*, and *Social Support*. An oblique factor analysis demonstrated that the factors labeled *Symptom Distress* and *Existential Distress* were modestly positively correlated, while other factors were weakly correlated with one another. These correlations were insufficient to require treatment as a single scale (see Table 5).

Factor Details: Internal Consistency and Reliability

Further analysis was undertaken to establish the psychometric characteristics of each individual factor. Cronbach's coefficient alpha was calculated for the five factors using the items that loaded greater than 0.55 on each respective factor (Table 4). Thus, Cronbach's coefficient alpha was used to measure the reliability of the subscales created from the individual items loading heavily on each factor. The concurrent validity of each factor was examined by generating a list of hypothesized concurrent measures against which it might be correlated (Table 6 lists all measures tested and associated findings).

Symptom Distress. This factor comprised the PDI items that essentially covered physical as well as psychological sources of distress. Items contained within this factor had factor loadings that ranged from 0.57 to 0.71. This factor's internal consistency, as measured by Cronbach's coefficient alpha, was 0.80. To establish concurrent validity, this factor was

Table 3
Initial Factor Loading for the PDI

Initial Factor	Initial Eigenvalues		
	Total	% of Variance	Cumulative %
1	8.937	35.747	35.747
2	1.695	6.781	42.529
3	1.515	6.061	48.590
4	1.304	5.215	53.805
5	1.267	5.069	58.874
6	1.039	4.155	63.029
7	0.992	3.970	66.998
8	0.838	3.353	70.351
9	0.736	2.944	73.295
10	0.700	2.799	76.094

Table 4
Factor Analysis (Five-Factor Solution)

Factor 1. Symptom Distress		Cronbach's Coefficient Alpha=0.80
Item	Factor Loading	
Physically distressing symptoms	0.57	
Feeling depressed	0.71	
Feeling anxious	0.71	
Feeling uncertain	0.68	
Worried about future	0.64	
Not being able to think clearly	0.58	
Factor 2. Existential Distress		Cronbach's Coefficient Alpha=0.83
Item	Factor Loading	
Feeling how you look has changed	0.57	
Feeling no longer who I was	0.63	
Not feeling worthwhile or valued	0.74	
Not able to carry out important roles	0.65	
Feeling life no longer has meaning or purpose	0.68	
Feeling a burden to others	0.58	
Factor 3. Dependency		Cronbach's Coefficient Alpha=0.77
Item	Factor Loading	
Not able to perform tasks of daily living	0.77	
Not able to attend to bodily functions	0.80	
Reduced privacy	0.55	
Factor 4. Peace of Mind		Cronbach's Coefficient Alpha=0.63
Item	Factor Loading	
Feeling have not made meaningful contribution	0.61	
Feeling of unfinished business	0.56	
Concerns regarding spiritual life	0.82	
Factor 5. Social Support		Cronbach's Coefficient Alpha=0.70
Item	Factor Loading	
Not feeling supported by friends or family	0.81	
Not feeling supported by health care providers	0.70	
Not being treated with respect	0.76	

examined in terms of how it correlated with other conceptually overlapping protocol measures (see Table 6). The *Symptom Distress* factor was significantly correlated ($r=0.26-0.56$;

Table 5
Oblique Factor Analysis Exploring the Extent of Correlation Between Factors in the Five-Factor Solution

Correlation Matrix					
Factors	1	2	3	4	5
1	1.00	0.45	0.34	0.28	0.21
2	0.45	1.00	0.27	0.26	0.24
3	0.34	0.27	1.00	0.16	0.16
4	0.28	0.26	0.16	1.00	0.18
5	0.21	0.25	0.16	0.18	1.00

$P < 0.001$) with most of the ESAS symptom distress items (pain, anxiety, nausea, depression, drowsiness, and shortness of breath). While *Symptom Distress* did not significantly correlate with level of activity, it did correlate with will to live ($r = -0.17$; $P = 0.012$), along with the General Well-Being Scale ($r = 0.68$; $P < 0.001$), the BDI ($r = 0.37$; $P < 0.001$), and the single item measure of suffering ($r = 0.43$; $P < 0.001$).

Existential Distress. The factor labeled *Existential Distress* consists of the following items: feeling how I look has changed (factor loading=0.57); no longer feeling like who I was (factor loading=0.63); not feeling worthwhile or valued (factor loading=0.74); not being able to carry out important roles (factor loading=0.65); feeling life no longer has meaning or purpose (factor loading=0.68); and feeling a burden to others (factor loading=0.58). Cronbach's coefficient alpha for this factor was 0.83. *Existential Distress* was significantly correlated with measures of suffering ($r = 0.16$, $P < 0.012$), well-being ($r = -0.18$, $P < 0.005$ [ESAS]; $r = 0.24$, $P < 0.005$ [General Well-Being]); depression ($r = 0.30$, $P < 0.001$ [ESAS]; $r = 0.38$, $P < 0.001$ [BDI]); anxiety ($r = 0.17$; $P < 0.001$); and rating and satisfaction with quality of life ($r = -0.20$, $P < 0.003$ and $r = -0.21$, $P < 0.002$, respectively). It did not, however, correlate significantly with either sense of dignity or will to live.

Dependency. The items loading on this factor include not being able to perform task of daily living (factor loading=0.77), not being able to attend to bodily functions (factor loading=0.08) and reduced privacy (factor loading=0.55). Cronbach's coefficient alpha for the *Dependency* factor was 0.77. *Dependency* correlated with concurrent measures of activity ($r = -0.35$, $P < 0.001$), ability to work ($r = 0.22$, $P < 0.001$), current rating and satisfaction with quality of life ($r = -0.36$, $P < 0.001$ and $r = -0.28$, $P < 0.001$,

Table 6
Concurrent Validity

Factor 1. Symptom Distress		
Instrument	Correlation with Factor 1	Significance
Current level of pain (ESAS)	0.283	0.001
Current level of anxiety (ESAS)	0.453	0.001
Current level of nausea (ESAS)	0.274	0.001
Current level of drowsiness (ESAS)	0.346	0.001
Current level of shortness of breath (ESAS)	0.260	0.001
Current level of satisfaction with pain relief (ESAS)	-0.256	0.001
Current will to live	-0.165	0.012
Current appetite	-0.153	0.019
Current level of activity	-0.076	0.247
Current level of well-being	-0.249	0.001
Beck Depression Inventory	0.374	0.001
General Well-Being total score	0.678	0.001
Suffering	0.434	0.001
Factor 2. Existential Distress		
Instrument	Correlation with Factor 2	Significance
Current level of depression (ESAS)	0.301	0.001
Current level of anxiety (ESAS)	0.169	0.011
Current will to live (ESAS)	-0.045	0.497
Current level of well-being (ESAS)	-0.185	0.005
Current quality of life	-0.196	0.003
Current satisfaction with quality of life	-0.206	0.002
Beck Depression Inventory	0.381	0.001
Suffering (SISC)	0.163	0.012
Loss of dignity (SISC)	0.095	0.148
General Well-Being total score	0.246	0.005
Factor 3. Dependency		
Instrument	Correlation with Factor 3	Significance
Current level of activity (ESAS)	-0.349	0.001
Ability to work (Beck)	0.224	0.001
Current quality of life	-0.367	0.001
Current satisfaction with quality of life	-0.284	0.001
Loss of dignity (SISC)	0.397	0.001
Factor 4. Peace of Mind		
Instrument	Correlation with Factor 4	Significance
Current level of anxiety (ESAS)	0.152	0.021
Current will to live (ESAS)	0.009	0.894
Current level of well-being (ESAS)	0.007	0.918

(Continued)

Table 6
Continued

Factor 4. Peace of Mind		
Instrument	Correlation with	
	Factor 4	Significance
Current quality of life	-0.041	0.538
Satisfaction with quality of life	-0.101	0.128
Beck Depression Inventory	0.173	0.010
FACIT total	-0.062	0.368
FACIT inner peace	-0.213	0.002
FACIT faith/spirituality	0.035	0.618
FACIT meaning and spirituality	0.098	0.155
General Well-Being Scale	0.070	0.431
Suffering	0.010	0.881

Factor 5. Social Support		
Instrument	Correlation with	
	Factor 5	Significance
Availability of Support	-0.256	0.006
Satisfaction with Support	-0.362	0.001

respectively), and sense of dignity ($r=0.40$, $P<0.001$).

Peace of Mind. The items loading on this factor included concerns about one's spiritual life (factor loading=0.61), feelings of unfinished business (factor loading=0.56) and feelings of not having made a meaningful contribution (factor loading=0.82). Cronbach's coefficient alpha was 0.63. This factor was perhaps the most intriguing in terms of its correlational patterns. An initial examination of the correlations between this factor and various measures of current psychosocial well-being failed to show significant relationships, aside from a small but significant relationship with anxiety ($r=0.15$, $P<0.021$). Given that concerns regarding spiritual life loaded on this factor, correlations between *Peace of Mind* and the FACIT (Secular Subscale, Nonsecular Subscale, and Total Score) were examined. Surprisingly, this revealed no significant correlations. This finding was puzzling and thus led to a factor analysis on the FACIT data. This initial principal component factor analysis revealed three clear and distinctive factors—Inner Peace, Faith/Spirituality, and Meaning and Purpose (see Tables 7 and 8). There was a significant correlation between the FACIT Inner Peace factor and the PDI *Peace of Mind* Factor ($r=-0.21$, $P<0.002$). Each of the three individual items loading on the PDI *Peace of Mind*

Table 7
Initial Factor Loading for FACIT

Initial Factor	Initial Eigenvalues		
	Total	% of Variance	Cumulative %
1	5.188	43.23%	43.23%
2	1.547	12.89%	56.12%
3	1.138	9.49%	65.61%
4	0.885	7.38%	72.99%
5	0.624	5.20%	78.19%

factor—feelings of not having made a meaningful contribution, feelings of unfinished business, and concerns regarding spiritual life—correlated significantly with the Inner Peace factor of the FACIT ($r=-0.26$ to -0.28 , $P<0.001$).

Social Support. The PDI items loading of the *Social Support* factor included not feeling supported by friends and family (factor loading=0.81), not feeling supported by health care providers (factor loading=0.70), and not being treated with respect (factor loading=0.76). The Cronbach's coefficient alpha for this factor was 0.70. It correlated significantly with composite measures of friend, family, and health care provider support, that is, availability of support and satisfaction with

Table 8
FACIT Factor Analysis

Factor 1. Inner Peace	
Item	Factor Loading
I feel peaceful	0.742
I have trouble feeling peace of mind	-0.696
I am able to reach down into myself for comfort	0.630
I feel a sense of harmony within myself	0.751
I know whatever happens with my illness, things will be ok	0.659

Factor 2. Faith/Spirituality	
Item	Factor Loading
I find comfort in my faith or spiritual beliefs	0.889
I find strength in my faith or spiritual beliefs	0.910
My illness has strengthened my faith or spiritual beliefs	0.780

Factor 3. Meaning and Purpose	
Item	Factor Loading
I have a reason for living	0.842
My life has been productive	0.589
I feel a sense of purpose in my life	0.669
My life lacks meaning or purpose	-0.712

support across these three sources ($r=-0.26$, $P<0.006$ and $r=-0.36$, $P<0.001$, respectively).

No PDI item loaded significantly on more than one factor, and each item loaded on its theoretically appropriate factor. There were, however, four items that did not obviously load on any of the five factors: not being able to continue usual routines, not feeling in control, not being able to fight the challenges of illness, and not being able to accept the way things are. Had we adjusted the critical threshold for variable loading to 0.4, not being able to carry out usual routines would have loaded on Factors 2 and 3 (*Existential Distress* and *Dependency* [factor loading=0.43]); not feeling in control also would have loaded on Factors 2 and 3 (factor loadings=0.42 and 0.46, respectively); not being able to fight the challenges of illness would have loaded on Factor 1 (*Symptom Distress* [factor loading=0.53]) and not being able to accept the way things are would have loaded on Factors 1 and 3 (*Symptom Distress* and *Dependency* [factor loadings=0.53 and 0.42, respectively]).

Discussion

The need to identify distress among patients nearing death is paramount in the field of palliative care. Any attempt to attenuate or ameliorate distress in this patient population must be predicated on an awareness of its presence.⁴ Although the field has benefited from various screening approaches, symptom distress instruments and quality-of-life tools, few have become a routine part of clinical practice.

The development of the PDI is an attempt to provide the field with a feasible and reliable way of identifying dignity-related distress—distress that all too often contributes to suffering toward the end of life. Because this instrument is based on the empirical Model of Dignity in the Terminally Ill, it contains a wide range of items covering the physical, psychosocial, existential, and spiritual facets of patient experience. Even though many sources of disquietude may not be readily visible or easily articulated by sick patients, the degree to which these can shape end-of-life experience is profound. Yet, without a means of making their presence known, many sources of distress remain ubiquitous and intractable.

The basic standard psychometric properties of the PDI have been examined, following standard approaches that are required for the introduction of any new measure. A Cronbach's coefficient alpha of 0.93 provides evidence that this 25-item inventory shows excellent internal consistency, as do each of its component factors. The test-retest reliability, $r=0.85$, demonstrates that the ratings obtained using the instrument over a 24-hour time frame are highly consistent. This assumes that the items being measured are themselves relatively steady. Some lower individual item test-retest reliability may be based on expected distress fluctuations that are not uncommon in palliative care. Future studies may want to consider slightly longer time intervals to fully explore the temporal stability of dignity-related distress in the context of palliative end-of-life care.

The PDI factor analysis was particularly enlightening and revealed a five-factor solution, consisting of *Symptom Distress*, *Existential Distress*, *Dependency*, *Peace of Mind*, and *Social Support*. To establish the concurrent validity of the PDI, correlations between each individual factor and concurrent measures with putative theoretical overlap were examined. The correlational patterns involving *Symptom Distress*, *Dependency*, and *Social Support* were straightforward and predictable. In each of these instances, these factors correlated significantly with other protocol measures that were theoretically synchronous.

The factor labeled *Existential Distress*, as distinct from *Peace of Mind*, denotes issues or sources of distress that would be expected to resolve upon death (i.e., not feeling like who I once was, not feeling worthwhile or valued, a change in appearance, not being able to carry our important roles, feeling life no longer has meaning, and feeling a burden). *Existential Distress* correlated significantly with various measures of psychological distress, quality of life, and suffering. It did not, however, correlate significantly with will to live or sense of dignity. Our own research has shown that will to live fluctuates in response to various influences, depending on proximity to death.¹¹ For patients nearing death, symptom distress is one of the most ardent predictors of will to live; it is noteworthy that the *Symptom Distress* factor was significantly correlated with

the variable will to live. Although a correlation between *Existential Distress* and sense of dignity might have been anticipated, its absence should come as no surprise. The construct of dignity, after all, is multifaceted and dependent on physical, psychological, social, and spiritual sources of distress. We have previously reported how dignity is often externally mediated, especially in terms of how one perceives himself/herself by others.¹⁵ This latter observation is underscored by the finding that dignity correlates significantly with the PDI factor labeled *Dependency*.

The *Peace of Mind* factor proved to be the most challenging, and in some respects, most interesting. Unlike *Existential Distress*, *Peace of Mind*—consisting of the PDI items “not have made a meaningful contribution,” “feelings of unfinished business,” and “concerns about spiritual life”—address concerns that may transcend death itself. That is, dying patients might anticipate that spiritual matters, concerns about things they have left undone or the lack of having made difference in this life, could have ramifications beyond death. As such, none of the measures of current distress (such as depression, will to live, well-being, or quality of life) correlated significantly with *Peace of Mind*. It was this unexpected finding that led to our performing a factor analysis on the FACIT itself (see Table 7 for FACIT factor loading). When the relationship between the three FACIT factors and *Peace of Mind* was examined, the only significant correlation was with the Inner Peace factor (FACIT) [$r = -0.21$, $P < 0.002$]. Unlike the FACIT Faith and Spirituality factor, or the Meaning and Purpose factor, which largely speak to issues based on current patient experience, the FACIT Inner Peace factor addresses issues that could easily apply to any of the *Peace of Mind* items and their relationship to the transcendent. It is worth noting that the *Peace of Mind* factor, which included an item regarding spiritual concerns, had the lowest Cronbach's coefficient alpha. It is important to acknowledge that the term spirituality lacks definitional specificity.^{26,27} Hence, idiosyncratic respondent interpretation may account for the lower internal consistency of this particular factor. Although future versions of the PDI may amend and revise the current spirituality item, clinicians are well advised to seek

clarification from those patients using the PDI as a way of disclosing spiritual distress.

The PDI has excellent face validity and is easily completed by patients in various circumstances of deteriorating health (i.e., in hospital settings, palliative care units, and within community based settings). Depending on the patient's health and energy, it can take little more than a minute or two to complete; in other instances, particularly if the patient requires assistance, it can take longer (about 10–15 minutes).

Like any study, this one has its limitations. The participants were predominantly older patients with cancer. Although one might anticipate that the landscape of distress revealed by the PDI could be skewed by this select patient population, it should have little bearing on establishing the psychometrics of this new instrument. However, research examining how the PDI applies and performs among other populations, be they younger patients or those facing noncancer-related terminal conditions, would be well advised. There was also a large difference in the number of subjects recruited from 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.

Of the 25 PDI items, four did not load on any of the five factors. These included not being able to continue usual routines, not feeling in control, not being able to fight the challenges of illness and not being able to accept the way things are. Although this might be used to justify eliminating these items from the PDI, there is good reason to retain them within this first iteration of the PDI. Although reporting the prevalence of distress as reflected by the PDI goes beyond the scope of this manuscript, each of the four items in question identified substantial distress; 51.8% of the cohort identified not being able to continue usual routines as a problem; not feeling in control, 29.4%; not being able to fight the challenges of illness, 12%; and not being able to accept the way things are, 11.5%. Although future versions of the PDI may see revisions consisting of somewhat fewer items, further field testing and broad experience with the current version would seem prudent.

The development of a new screening tool for palliative care offers some exciting and important opportunities. Like any novel instrument designed to disclose things that are otherwise difficult to see, the PDI will allow for a more precise and accessible view of dying patients' experiences. The data contained within this report provide initial evidence that the PDI is internally consistent, reliable, and valid. Its factor structure spans various domains, covering the spectrum of end-of-life distress. Because it takes little time or effort to complete, the PDI provides a feasible way of having patients disclose and discuss what specific issues are causing them distress.

The PDI could provide new opportunities to examine and better understand the landscape of dignity-related distress among patients nearing death. It could, for example, allow investigators to study the differential distribution of distress across various populations, care settings, and approaches to end-of-life care. It could enable routine screening for distress in palliative populations to be applied to at risk patients, or used to monitor and track dignity-related distress over time. First and foremost, however, the PDI should help clinicians detect areas of distress that are often overlooked, and are thus inaccessible. Identifying these sources of discomfort is a critical step toward acknowledging their importance within the realm of human suffering. Such acknowledgement should help pave the way toward greater insights into responding, and to the extent possible, ameliorating end-of-life distress. Hence, the PDI should help clinicians to deliver quality, dignity-conserving end-of-life care.²⁸

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Appendix

Patient Dignity Inventory

For each item, please indicate how much of a problem or concern these have been for you within the last few days

1. **Not being able to carry out tasks associated with daily living (e.g., washing myself, getting dressed).**
1 Not a problem 2 A slight problem 3 A problem 4 A major problem 5 An overwhelming problem
2. **Not being able to attend to my bodily functions independently (e.g., needing assistance with toileting-related activities)**
1 Not a problem 2 A slight problem 3 A problem 4 A major problem 5 An overwhelming problem
3. **Experiencing physically distressing symptoms (such as pain, shortness of breath, nausea).**
1 Not a problem 2 A slight problem 3 A problem 4 A major problem 5 An overwhelming problem
4. **Feeling that how I look to others has changed significantly.**
1 Not a problem 2 A slight problem 3 A problem 4 A major problem 5 An overwhelming problem
5. **Feeling depressed.**
1 Not a problem 2 A slight problem 3 A problem 4 A major problem 5 An overwhelming problem
6. **Feeling anxious.**
1 Not a problem 2 A slight problem 3 A problem 4 A major problem 5 An overwhelming problem
7. **Feeling uncertain about my illness and treatment.**
1 Not a problem 2 A slight problem 3 A problem 4 A major problem 5 An overwhelming problem
8. **Worrying about my future.**
1 Not a problem 2 A slight problem 3 A problem 4 A major problem 5 An overwhelming problem
9. **Not being able to think clearly.**
1 Not a problem 2 A slight problem 3 A problem 4 A major problem 5 An overwhelming problem
10. **Not being able to continue with my usual routines.**
1 Not a problem 2 A slight problem 3 A problem 4 A major problem 5 An overwhelming problem
11. **Feeling like I am no longer who I was.**
1 Not a problem 2 A slight problem 3 A problem 4 A major problem 5 An overwhelming problem
12. **Not feeling worthwhile or valued.**
1 Not a problem 2 A slight problem 3 A problem 4 A major problem 5 An overwhelming problem
13. **Not being able to carry out important roles (e.g., spouse, parent).**
1 Not a problem 2 A slight problem 3 A problem 4 A major problem 5 An overwhelming problem
14. **Feeling that life no longer has meaning or purpose.**
1 Not a problem 2 A slight problem 3 A problem 4 A major problem 5 An overwhelming problem
15. **Feeling that I have not made a meaningful and lasting contribution during my lifetime.**
1 Not a problem 2 A slight problem 3 A problem 4 A major problem 5 An overwhelming problem
16. **Feeling I have 'unfinished business' (e.g., things left unsaid, or incomplete)**
1 Not a problem 2 A slight problem 3 A problem 4 A major problem 5 An overwhelming problem
17. **Concern that my spiritual life is not meaningful.**
1 Not a problem 2 A slight problem 3 A problem 4 A major problem 5 An overwhelming problem
18. **Feeling that I am a burden to others.**
1 Not a problem 2 A slight problem 3 A problem 4 A major problem 5 An overwhelming problem
19. **Feeling that I don't have control over my life.**
1 Not a problem 2 A slight problem 3 A problem 4 A major problem 5 An overwhelming problem
20. **Feeling that my illness and care needs have reduced my privacy.**
1 Not a problem 2 A slight problem 3 A problem 4 A major problem 5 An overwhelming problem
21. **Not feeling supported by my community of friends and family.**
1 Not a problem 2 A slight problem 3 A problem 4 A major problem 5 An overwhelming problem
22. **Not feeling supported by my health care providers.**
1 Not a problem 2 A slight problem 3 A problem 4 A major problem 5 An overwhelming problem
23. **Feeling like I am no longer able to mentally 'fight' the challenges of my illness.**
1 Not a problem 2 A slight problem 3 A problem 4 A major problem 5 An overwhelming problem
24. **Not being able to accept the way things are.**
1 Not a problem 2 A slight problem 3 A problem 4 A major problem 5 An overwhelming problem
25. **Not being treated with respect or understanding by others.**
1 Not a problem 2 A slight problem 3 A problem 4 A major problem 5 An overwhelming problem