

Symptom burden, loss of dignity, and demoralization in patients with cancer: a mediation model

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Abstract

Background: Demoralization is a syndrome of existential distress that occurs in a substantial minority of cancer patients and is associated with a higher number of physical problems. Loss of dignity refers to a range of specific existential concerns. This study examines whether the association between number of physical problems and demoralization is mediated by loss of dignity.

Methods: This cross-sectional study examined $N = 112$ inpatients with mixed tumor sites at early and advanced disease stages using the following standardized self-report questionnaires: Physical problems list of the National Comprehensive Cancer Network (NCCN) Distress Thermometer (DT), Patient Dignity Inventory (PDI), Demoralization Scale (DS), Patient Health Questionnaire-9 (PHQ-9) and Illness-Specific Social Support Scale Short Version-8 (ISSS-8). The mediation hypothesis was tested by multiple regression analyses controlling for age, gender, curative versus palliative treatment phase, and social support.

Results: Patients reported $M = 4.7$ ($SD = 6.0$) dignity-related problems; 20% showed moderate to severe demoralization. Loss of dignity significantly mediated 81% of the effect of the number of physical problems on demoralization (Sobel $z_s = 4.4$, $p < .001$). Testing the reverse direction, we found that demoralization mediated only 53% of the association between physical problems and loss of dignity ($z_s = 3.7$, $p < .001$).

Conclusions: By supporting the mediation hypothesis, our results indicate that loss of dignity partially explains the association between physical problems and demoralization. Early recognition of dignity-related existential concerns and interventions to enhance the sense of dignity may prevent demoralization in patients with cancer. Results provide a conceptual link between existential concerns (loss of dignity) and existential distress (demoralization) as two approaches to existential suffering in patients with cancer.

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Introduction

The last decade has witnessed increasing efforts to understand the psychological well-being of patients with cancer within an existential framework. Researchers have emphasized the threat that having cancer may pose to fundamental existential human needs, whether resulting from the diagnosis itself, its treatment, survivorship, recurrence, or advanced and terminal illness [1–3]. Accordingly, a broad spectrum of cancer-related *existential concerns* has been described, frequently including the confrontation with death, uncertainty, loss of control, feeling a burden to others, and loss of meaning given often profound changes in personal goal orientations and roles [4–7].

A variety of these *existential concerns* enters into the empirical dignity model by Chochinov *et al.* [8]. On the basis of an interview study with 50 terminally ill patients, the model defines a set of concerns that were found to influence the sense of personal dignity. These concerns are categorized into three major domains: Illness-related concerns refer to physical and psychological stressors associated with the illness, such as restricted functional

capacity, symptom distress, and medical uncertainty. The dignity conserving repertoire comprises personal attitudes that may facilitate or, if missing, impair the sense of personal dignity, such as a sense of control and preservation of important roles. The social dignity inventory refers to concerns emerging from social interactions, such as feeling a burden to others and reduced privacy. The specification of concerns within the model was based on their significance for the maintenance or loss of sense of dignity. Loss of dignity was closely related to concerns that challenge the existential need for a coherent view of the self, indicating that the dignity model specifically contributes to the understanding of existential concerns [1,8].

A different perspective on existential suffering emerges from the focus on maladaptive *responses* to existential challenges that may evolve into clinically relevant *states of severe existential distress*, such as the demoralization syndrome. The core phenomena of demoralization are affective states of hopelessness and loss of meaning and purpose, along with cognitions of helplessness and personal failure [9]. In the literature, the occurrence of demoralization has been repeatedly linked to the setting

of medical illness, emphasizing that it is essentially characterized by an entrapped feeling that ‘nothing can be done’ and a subsequent loss of hope and meaning, whereas the core symptoms of major depression, anhedonia and loss of interest, are typically not present [10–13]. Demoralization has been shown to be empirically distinguishable from depression in factor analytic studies [11,14,15]. Further, validated measures have shown good psychometric properties and capacity to differentiate demoralized from depressed patients, despite considerable overlap [16,17].

Evidence suggests that existential distress in terms of demoralization is associated with a higher physical symptom burden in patients with cancer [15,18–20]. Studies that have examined the constructs of hopelessness and desire for hastened death as indicators of existential distress have also found positive associations with physical symptoms [21–24]. A longitudinal study has further shown a high prospective effect of the number of physical problems on demoralization, controlling for demographic factors and tumor stage [25]. However, in the context of generally limited knowledge concerning risk factors of existential distress, the mechanisms behind the longitudinal association of physical symptom burden and demoralization are poorly understood [1,26].

We hypothesize that one mechanism explaining the relationship between the number of physical problems and demoralization is loss of sense of dignity (Figure 1). Central to this mediation hypothesis is the idea that existential concerns, such as loss of control and feeling a burden to others, are highly prominent within the dignity model: We assume that patients reporting a higher number of physical symptoms may experience more numerous, frequent, or intense existential concerns defined in the dignity model and, hence, a higher loss of dignity (*path A*, Figure 1). At first, a higher number of physical symptoms may likely increase concerns of symptom distress

and loss of independence. Previous findings, however, suggest that physical symptom burden is also related to a number of other existential concerns, for example, feeling a burden to others [8,27], loss of control, loss of important roles, and an incoherent view of the self [6,28]. The relationship between loss of dignity and physical symptoms, especially those that often provoke shame and threaten the sense of self-worth, has been emphasized by Kissane [29]. Quantitative studies that have examined this relationship in patients with cancer are limited; however, results point toward a positive association [30,31].

We assume that existential concerns related to loss of dignity can emerge from the difficulty to integrate especially a high physical symptom burden into a coherent view of the self, which may increase the risk for loss of meaning and hope. We thus assume a positive association between loss of dignity and demoralization (*path B*, Figure 1). This is consistent with the proposed process of demoralization. According to Clarke [32], demoralization may develop from the perceived inability to cope with existential concerns: If existential concerns become overwhelming, helplessness and a sense of incompetence or failure may emerge, until hopelessness and ultimately loss of meaning and purpose can evolve [9]. Moreover, Chochinov *et al.* [8] have suggested that loss of dignity may be a precursor of severe existential distress in terms of desire for hastened death. Accordingly, a recent meta-ethnography suggests that loss of dignity increases the desire for hastened death through its negative impact on the sense of meaning and purpose [33].

In summary, the purpose of this paper is to test the hypothesis that loss of dignity mediates the association between the number of physical problems and demoralization in a sample of cancer patients. This study suggests a mediation model that provides (1) a possible explanation to the relationship between number of physical problems and demoralization and (2) a conceptual link between loss of dignity and demoralization as two distinct approaches to existential suffering.

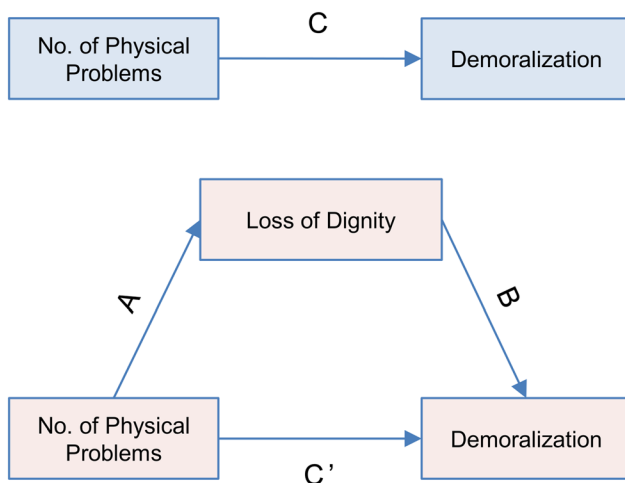


Figure 1. Mediation model linking number of physical problems, loss of dignity, and demoralization

Method

Participants and procedures

This study investigates a subsample of a cross-sectional, representative multicenter study primarily focusing on the prevalence of comorbid psychiatric disorders [34]. The present sample includes inpatients recruited from two oncological wards at the University Medical Clinic and two community care hospitals in the major study center in Hamburg, Germany. Cancer patients admitted for treatment were consecutively approached within 3 days by trained research assistants and invited to participate in the study. After written informed consent had been obtained, participants were asked to complete a set of

questionnaires, which could be returned to the staff or via stamped envelopes. Exclusion criteria were age younger than 18 years, severe physical and cognitive impairment as evaluated by the treating physician and documented in medical treatment reports, and insufficient proficiency in German to provide informed consent and complete questionnaires. The study was approved by the local medical association research ethics committee.

The subsample included a total of 202 eligible patients. Of these, $N = 115$ (57%) patients participated in the study; $n = 87$ (43%) patients did not wish to participate and $n = 3$ patients were excluded because of incomplete data. Reasons for non-participation were lack of interest (51%), high symptom burden (21%), and others (29%). Basic demographic data were recorded from non-participants. Non-participants did not significantly differ from participants regarding to age ($p = .13$) and gender ($p = .95$).

Measures

Loss of dignity was assessed by the total score of the German version of the Patient Dignity Inventory (PDI) [35,36]. This instrument is based on the empirical dignity model [8] and covers a broad range of existential concerns relevant to the perception and loss of dignity in patients with terminal illness. Patients are asked to what extent each of 25 concerns has been a problem to them within the last few days on a scale from 1 (not a problem) to 5 (an overwhelming problem). Examples for concerns assessed are 'feeling that how I look to others has changed significantly', 'feeling that I don't have control over my life', and 'not being able to carry out important roles (e.g., spouse, parent)'. Item scores ≥ 3 indicate that a relevant problem is experienced. The German version showed excellent internal consistency ($\alpha = .96$).

Demoralization was assessed by the German version of the Demoralization Scale (DS) [16,20]. The scale was developed according to the definition of demoralization by Clarke and Kissane [11,37]. The scale comprises 24 items, pertaining to the five subscales (1) loss of meaning and purpose, (2) dysphoria, (3) disheartenment, (4) helplessness, and (5) sense of failure. Items are rated on a five-point Likert scale from 0 (never) to 4 (all the time). Total scale scores may range from 0 to 96 ($\alpha = .84$). The cutoff scores ≥ 30 and ≥ 36 were used to indicate moderate and high demoralization, respectively [16,25].

The *number of physical problems* was measured by the physical problems list of the NCCN Distress Thermometer, German version (DT) [38], assessing the presence of 21 physical symptoms common in patients with cancer. *Social support* was assessed as a control variable and measured by the positive support subscale of the Illness-Specific Social Support Scale Short Version-8 (ISSS-8) [39,40]. Total scores may range from 0 to 16. *Depression* within the past 2 weeks was assessed using the DSM-IV-based depression

module of the Patient Health Questionnaire (PHQ-9) [41]. Scores may range from 0 to 27. The cutoff scores ≥ 10 and ≥ 15 indicate moderate and severe depression, respectively.

Medical data including tumor entity, date of first diagnosis, Union Internationale Contre le Cancer (UICC) stage, and curative versus palliative treatment phase were obtained from medical charts and professional treatment reports. *Sociodemographic data* including age, gender, marital status, and education were assessed by a standardized self-report questionnaire.

Statistical analysis

Descriptive statistics including means, standard deviations, and frequencies were calculated. Bivariate associations were calculated using Pearson correlation coefficients. Group differences were determined by dummy variable regression analyses in metric variables and χ^2 -tests in nominal data, respectively.

The mediation hypothesis was tested by regression analyses according to the Baron and Kenny causal steps method [42]. Three subsequent regression models were calculated in order to test the conditions necessary to establish a mediator effect. First, the effect b_c of the independent variable number of physical problems on the outcome demoralization was tested for significance (Figure 1, path C). Second, the effect b_a of the number of physical problems on the mediator variable loss of dignity was tested for significance (path A). Third, the effect b_c' of the number of physical problems on demoralization was tested again after including the mediator loss of dignity into the regression model (path C'); the effect of loss of dignity on demoralization in this step defines path B. A significant reduction of the effect of physical problems on demoralization from step 1 to step 3, that is, a significant difference $b_c - b_c'$ between the unstandardized regression coefficients of paths C and C', indicates partial mediation. This difference (i.e., the size of the mediated or indirect effect) was tested for significance using the Sobel test [43,44]. Finally, the proportion of the total effect of physical problems on demoralization that was mediated by loss of dignity was calculated by the ratio $\frac{b_c - b_c'}{b_c}$ of mediated to total effect.

Control variables age, gender, treatment phase, and social support were included in all regression models. All significance tests were two-sided using a significance level of $\alpha < .05$. The PASW Statistics software version 18.0 (IBM, New York) was used.

Results

Sample characteristics and descriptive statistics

Demographic and medical sample characteristics are shown in Table 1. The mean score on the PDI was $M = 42.1$ ($SD = 17.2$). The total loss of dignity score was higher in women ($r = -.23$, $p = .014$) but not related to

Table 1. Demographic and medical sample characteristics

	Sample (N = 112)	
	N	(%)
Age, mean (SD)	56.0 (14.1)	
Gender		
Female	48	43
Male	64	57
Marital status		
Married/partnership	84	77
Single	12	11
Separated/divorced	6	6
Widowed	7	6
Education		
Elementary school (8–9 years)	31	28
Junior high school (10 years)	42	38
High school (13 years)	14	13
University	25	22
Tumor site		
Hematologic	40	36
Digestive organs	18	16
Prostate	12	11
Lung	11	10
Gynecologic	11	10
Breast	7	6
Other	13	12
Treatment phase		
Curative	69	67
Palliative	34	33
UICC tumor stage		
0–II	42	48
III–IV	46	52
Type of disease		
Initial diagnosis	82	76
Recurrence	12	11
Second tumor	14	13
Months since initial diagnosis, mean (SD)	13.9 (25.6)	

any of the other demographic and medical characteristics, including tumor stage and treatment phase. On average, patients experienced $M = 4.7$ dignity-related problems ($SD = 6.0$). Most frequent dignity-related problems (defined as item scores ≥ 3) were ‘experiencing physically distressing symptoms’ (18%), ‘feeling uncertain about illness and treatment’ (13%), ‘feeling like I am no longer

who I was’ (12%), ‘worrying about the future’ (12%), and ‘feeling a burden to others’ (7%). The average number of physical problems was $M = 5.6$ ($SD = 3.7$). Most frequent physical problems were mobility constraints (59%), sleeping problems (56%), and loss of energy (55%). Moderate demoralization was found in 11% of the patients; 9% showed high demoralization. The demoralization mean score was $M = 19.1$ ($SD = 11.7$). Moderate to high depression according to the Patient Health Questionnaire-9 was found in 24.5% of the sample ($M = 6.3$, $SD = 4.5$). Depression was positively associated with both loss of dignity ($r = .59$, $p < .001$) and demoralization ($r = .59$, $p < .001$). The mean score for positive social support was $M = 14.4$ ($SD = 2.3$); 23% indicated utilization of psychosocial support services including psychologists, psychiatrists, or social workers.

Test of mediation hypothesis

Bivariate associations between loss of dignity, demoralization, number of physical problems, and control variables are reported in Table 2. Variance inflation factors of all predictor variables included into the regression model varied between 1.0 and 1.2, indicating that multicollinearity between predictor variables did not bias our results. The correlation between loss of dignity and demoralization was $r = .67$ ($p < .001$).

Table 3 shows the results of the three separate regression analyses testing the mediation hypothesis. In step 1, a significant effect of the number of physical problems on demoralization resulted ($b_c = 1.4$, $p < .001$). In step 2, the effect of physical problems on loss of dignity was also significant. In step 3, after including the mediator variable loss of dignity as a predictor into the regression model, the effect of physical problems on demoralization decreased to $b_c = .25$ ($p = .40$). The difference $b_c - b_c' = 1.15$ was highly significant (Sobel test: $z_s = 4.40$, $p < .001$). Loss of dignity was thus a significant partial mediator of the association between physical problems and demoralization. The original regression coefficient of the effect of physical problems on demoralization decreased by 81% when loss of dignity was included as a predictor; hence,

Table 2. Bivariate associations between loss of dignity, demoralization, control variables, and number of physical problems

	Loss of dignity		Demoralization		Age		Gender ^a		Treatment phase ^b		Social support	
	r	p	r	p	r	p	r	p	r	p	r	p
Demoralization	.67	<.001	—	—								
Age	-.08	.39	-.04	.69	—	—						
Gender ^a	-.23	.014	-.18	.054	.19	.049	—	—				
Treatment phase ^b	.01	.95	.00	.99	.22	.027	.09	.36	—	—		
Social support	.00	.99	-.13	.16	.06	.55	-.03	.72	-.09	.36	—	—
No. of physical problems	.49	<.001	.42	<.001	-.28	.005	-.11	.26	.21	.042	-.17	.087

^a0 = female, 1 = male.

^b0 = curative, 1 = palliative.

Table 3. Regression analyses testing the mediation hypothesis in three subsequent steps

	PATH C (step 1) Demoralization				PATH A (step 2) Loss of dignity			
	b	SE	β	p	b	SE	β	p
Control variables								
Age	.12	.09	.15	.16	.12	.12	.10	.33
Gender ^a	-3.41	2.33	-.14	.15	-4.71	3.24	-.14	.15
Treatment phase ^b	-3.78	2.54	-.15	.14	-5.13	3.54	-.14	.15
Social support	-.49	.49	-.10	.33	.53	.69	.07	.45
Independent variable								
No. of physical problems	1.40	.33	.45	<.001	2.44	.46	.54	<.001
PATHS C' and B (step 3) Demoralization								
	b	SE	β	p				
Control variables								
Age	.07	.07	.08	.31				
Gender ^a	-1.18	1.79	-.05	.51				
Treatment phase ^b	-1.35	1.95	-.05	.49				
Social support	-.74	.38	-.15	.05				
Independent variable								
No. of physical problems	.25	.29	.08	.40				
Mediator variable								
Loss of dignity	.47	.06	.68	<.001				

Explained variance: step 1, $R^2 = .22$, adj. $R^2 = .17$; step 2, $R^2 = .28$, adj. $R^2 = .23$; step 3, $R^2 = .56$, adj. $R^2 = .53$.

b, unstandardized regression coefficient; SE, standard error of b; β , standardized regression coefficient.

^a0 = female, 1 = male.

^b0 = curative, 1 = palliative.

81% of the effect of physical problems on demoralization was mediated by loss of dignity. Figure 2 illustrates the significant mediator effect.

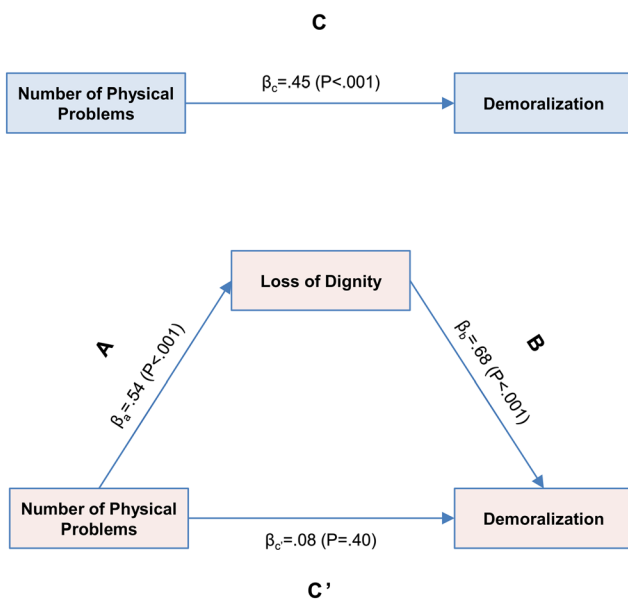


Figure 2. Standardized regression coefficients for paths within the mediation model. Analyses were controlled for age, gender, curative versus palliative treatment phase, and social support. Sobel test of indirect or mediated effect: $z_s = 4.40$, $p < .001$

Two further analyses were performed in order to exclude possible alternative explanations to this result. First, the same analyses were performed after removing the item ‘having physically distressing symptoms’ from the PDI in order to test if a possible overlap between the PDI and physical problems might have altered our results. This test, however, yielded a nearly identical result ($z_s = 4.47$, $p < .001$). Second, because this is a cross-sectional study, we repeated the mediator analyses in the reverse direction (i.e., testing demoralization as the mediator and loss of dignity as the outcome variable). After interchanging mediator and outcome, a significant but smaller mediator effect was obtained: Only 53% of the original effect of physical problems on loss of dignity was mediated by demoralization ($z_s = 3.74$, $p < .001$).

Discussion

We found that loss of dignity significantly mediated the relationship between number of physical problems and demoralization in a mixed cross-sectional sample of 112 cancer inpatients at early and advanced disease stages. Mediation analyses showed that 81% of the effect of number of physical problems on demoralization was mediated by loss of dignity. In a control test of the reverse direction, demoralization mediated only 53% of the effect of physical problems on loss of dignity.

As proposed by the mediation model, significant positive associations were found between loss of dignity and number of physical problems and demoralization, respectively. This is consistent with previous studies indicating positive associations between physical impairment and loss of dignity in cancer patients [30,31], as well as healthy samples [45]. As a frequent dignity-related concern, feeling a burden to others has been associated with the presence of certain physical symptoms [27,46,47]. Although, to our knowledge, the association between loss of dignity and demoralization has not been examined so far, studies have shown significant associations between loss of dignity and related phenomena including hopelessness and the desire for hastened death [30,48]. Loss of dignity further showed negative associations to existential well-being [31,49]; similar results were found for feeling a burden to others [27,46,47]. A longitudinal study further showed that perceived burdensomeness predicted lower meaning in life among older adults [50].

The fit of our data to the mediation hypothesis supports the conceptual assumption that a higher number of physical symptoms may heighten the risk for a loss of the sense of dignity, which may then raise the risk for demoralization. Our results thus suggest a mechanism by which two different approaches to existential suffering, focusing on existential concerns (loss of dignity) and existential distress (demoralization), respectively, may be linked. Existential concerns, such as loss of control and feeling a burden to others, may reflect problems integrating physical changes into the self that occur in a number of patients. Existential concerns, then, may, but need not necessarily lead to states of existential distress such as demoralization [6]. The conceptual distinction we have drawn between loss of dignity and demoralization might, however, have been blurred by our operationalization of loss of dignity. Originating from its primary practical intention to assess a *comprehensive range* of dignity-related concerns, the PDI might (a) in some instances overlap with the Demoralization Scale (e.g., the PDI also includes an item regarding loss of meaning and purpose) and (b) include concerns exceeding the existential category. Future research thus needs to further clarify distinctive features of existential concerns and consolidate the distinction between loss of dignity (existential concerns) and demoralization (existential distress) on which this study is based. For research purposes, a more focused assessment of existential concerns may facilitate profound estimates of their prevalence and relationship with existential distress syndromes. A review of studies on existential suffering [26] has consistently concluded the need for conceptual advances in this field and emphasized their potential benefit for clinical practice.

As a clinical implication of the mediation effect, early recognition and adequate attention toward concerns indicating violations of dignity may prevent the emergence of existential distress in terms of demoralization in patients with cancer. This is consistent with the aim of dignity-conserving

care and Dignity Therapy to preserve each patient's integrity as a whole valued person and thereby reduce or prevent symptoms of existential distress [51,52]. The link between the two constructs is also reflected by the similarity of basic techniques underlying Dignity Therapy and interventions proposed against loss of meaning and demoralization in cancer, such as Meaning-Centered Psychotherapy. For example, valuing a patient's life story and reflecting on sources of personal meaning may counter feelings of worthlessness and shame provoked by physical constraints and help patients to maintain or rebuild a coherent view and a sense of purpose in their lives [3,11,32,52,53]. The first results from randomized intervention studies thus show increased existential well-being in patients who had received Dignity Therapy and Meaning-Centered Psychotherapy [54,55]. Also, the first results point toward a strong negative association between positive social support and demoralization [19].

Concerning the frequency of existential distress, moderate to severe demoralization was reported by 20% of the patients in the present sample, which was somewhat lower compared with that reported in previous studies [16,19,25]. Patients, however, reported an average of 4.7 dignity-related concerns, which was only slightly less compared with the average number of 5.7 problems in a terminally ill sample [49]. However, no differences were found in demoralization and loss of dignity between patients with early and advanced cancer and between patients receiving curative and palliative treatment in our sample, consistent with earlier studies [25]. Experiencing distressing symptoms was the most frequent dignity-related problem, but interestingly, concerns related to uncertainty, identity, and perceived burdensomeness were the next most frequent concerns, stressing the significance of core existential issues to the sense of dignity in our sample.

Our study is limited by its cross-sectional design. A replication of the mediation effect in a longitudinal study is necessary to consolidate the hypothesized directions of the causal relationships within the mediation model. Our results nevertheless indicate a better fit of the data to the hypothesized model than to the alternative reversed model as the ratio of mediated to total effect was considerably higher in the former compared with the latter (81%, $z_s = 4.40$ vs. 53%, $z_s = 3.74$). The reversed version of the mediation model would imply that loss of dignity rather refers to an expression or 'by-product' of existential distress. Although the current state of research does not allow to preclude this possibility, studies indicating that loss of dignity is often a *reason* for the desire for hastened death suggest that it is unlikely [33,56]. Moreover, although the majority of cancer patients seem to experience existential concerns at some point after diagnosis, prolonged or severe states of existential distress occur in a much smaller minority throughout the illness [6,22].

Another limitation to our results is the small sample size precluding structural equation modeling techniques. The

power of our mediation analyses was, however, enhanced by the high reliability of the mediator variable ($\alpha = .96$) and higher correlation between mediator and outcome than mediator and independent variable ($r = .67, p < .001$ vs. $r = .49, p < .001$) [44]. Control for possible confounding variables age, gender, treatment phase, and social support showed that the mediation effect was not explained by these third variables. Also, the mediation effect was not explained by the overlap between number of physical symptoms and loss of dignity. Our results might have yet been biased toward lower existential distress by the 43% rate of non-participants. However, there were no differences in age and gender between participants and non-participants.

In summary, our study provides preliminary evidence that loss of dignity partially explains the positive association between the number of physical problems and demoralization in cancer patients. Our findings emphasize the importance of dignity-conserving psychosocial interventions that enhance or maintain the sense of dignity by focusing on existential issues in the course of cancer. The study may further contribute to the conceptualization of existential distress by suggesting a causal link between two different approaches to existential suffering that focus

on existential concerns (loss of dignity) and existential distress (demoralization), respectively. This might provide further detail to previous studies that have linked physical symptoms to other constructs of existential distress and found a mediational pathway from physical problems over hopelessness to the desire for hastened death [21,57]. Longitudinal research is needed to examine further pathways to existential distress incorporating risk and protecting factors such as personal meaning and existential well-being [57–59]. These efforts may contribute to explain the multifaceted responses to existential challenges in the context of cancer ranging from states of severe existential distress to personal growth and a heightened sense of meaning and purpose in life.

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Conflict of interest

The authors declare no potential conflicts of interest.

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