

Original Article

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Is there a relationship between end-of-life cancer patients' dignity-related distress and caregivers' distress? An exploratory study

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Abstract

Objectives. The mutual influence between end-of-life cancer patients and their family caregivers is widely endorsed. The present study aimed to explore the relationship between end-of-life cancer patients' dignity-related distress and the distress of their caregivers.

Method. A cross-sectional approach was used. The sample consisted of 128 patients with a Karnofsky Performance Status (KPS) below 50 and a life expectancy of a few weeks, and their family caregivers. Personal and clinical data were collected and validated rating scales were administered: *Patient Dignity Inventory* (PDI) to terminal cancer patients; *Hospital Anxiety and Depression Scale* (HADS), *Demoralization Scale* (DS), *Herth Hope Index* (HHI), *Caregiver Reaction Assessment* (CRA), *Short Form Health Survey 36* (SF-36), and *Distress Thermometer* (DT) to caregivers.

Results. Findings highlighted significant correlations between patients' scores on the Psychological Distress PDI subscale and the PDI Total Score and caregivers' Emotional Role. Patients' Psychological Distress, PDI Total Score, and Loss of Purpose and Meaning were associated with caregivers' Disrupted Schedule. Finally, patients' Physical Symptoms and Dependency, Loss of Purpose and Meaning, and PDI Total Score were correlated with caregivers' Disheartenment.

Significance of results. The results highlighted the key role of dignity as a relational dimension during the end-of-life phase. Therefore, because of caregivers' distress could affect patients' dignity-related distress by influencing the interpersonal aspects of patients' autonomy, it would be important to relieve caregivers' distress in order to promote patients' autonomy and minimize their fear of being a burden.

Introduction

Providing end-of-life care to both patients and their families represents a core principle in person-centered palliative care. This holistic care approach has increasingly recognized caregivers as a key component for improving patients' quality of life (McGuire et al., 2012; Gillan et al., 2014; Choi and Seo, 2019). Since patients and caregivers together constitute the “unit of care”, the debilitating nature of advanced cancer statuses concerns not only patients, which require constant assistance to treat their physical health and quality of life, but also their caregivers through distress, depression, and impaired quality of life (O'Hara et al., 2010; Hack et al., 2018). The association between patients' functional status and caregivers' burden is bidirectional: the continuous care demands from their dying relatives distresses caregivers, which in turn may decrease the patients' quality of life, further exacerbating caregiving (Given et al., 2004; Tang et al., 2008; O'Hara et al., 2010; Milbury et al., 2013; Rha et al., 2015). Considering this reciprocity, promoting global patient care also requires taking care of caregivers (Braun et al., 2007). In fact, caregivers could experience significant distress referred to as the “burden of care.” The burden of care is characterized by isolation, depressive and anxious symptoms, feelings of helplessness, fatigue, somatic health and financial problems, restrictions of roles and activities, and stress in close relationships (Rha et al., 2015; Bovero et al., 2021). Caregivers' efforts often lead to stressful situations analogue to those affecting patients; hence, they could be identified as “hidden patients,” additional victims of the disease (Hoerger and Cullen, 2017; Choi and Seo, 2019). Being overburdened with responsibility could have negative effects on the quality of life of both cancer patients and their caregivers, unbalancing close relationships and the family structure itself, especially during the final stage of terminal cancer (Given et al., 2004; Waldrop et al., 2005; Cooper et al., 2006; Saria et al., 2017; Choi and Seo, 2019).

This concept of mutual influence between patients and caregivers is also supported by Chochinov's et al. *Dignity Model* that recognizes the “Social Dignity Inventory” as an essential

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area contributing to defining social concerns that influence a patient's dignity (Chochinov, 2002, 2006; Chochinov et al., 2002, 2008; Thompson and Chochinov, 2008; Östlund et al., 2012; Best, 2019). Loss of dignity has been reported as one of the primary causes of patient suffering during the end-of-life phase (Chochinov et al., 2002, 2009; Hosseini et al., 2017). According to Chochinov's Dignity Model, helping patients achieve a strong sense of dignity and facilitating passing with dignity is an intrinsic and primary goal in providing end-of-life palliative care (Oechsle et al., 2014; Hosseini et al., 2017; Best, 2019). To achieve this purpose of dying with dignity, it is essential that patients have significant relationships in which they feel recognized by others as a "complete individual," regardless of his or her fragility (Best, 2019).

Although the mutual influence in the patient-caregiver unit is widely endorsed (Given et al., 2004; Thekkumpurath et al., 2008; Götze et al., 2014), to our knowledge there is a lack of research specifically on the relationship between patients' dignity-related distress and the caregivers' distress. Thus, the present study aimed to explore this relationship.

Methods

Study design and participants

Sample data was gathered from October 2018 to December 2019, at "Città della Salute e della Scienza" Hospital and at the "Vittorio Valletta" Hospice, in Turin. To be included, patients had to be at least 18 years old, have received a diagnosis of cancer, be capable of providing informed consent, and meet the criteria for accessing Palliative Care (National Law on Palliative Care and Pain Treatment, No. 38/2010). These criteria, specifically, include the presence of an advanced disease in its terminal phase, for which there are no feasible or appropriate curative treatments and with an adverse/poor prognosis; an estimated life expectancy of less than 4 months; a Karnofsky Performance Status (Schag et al., 1984) (KPS) of 50 or lower. To be invited to participate, caregivers also had to be at least 18 years old and capable of providing informed consent. Furthermore, they had to be a family caregiver of a patient with a diagnosis of cancer at the end of life. A family caregiver is any family member who, regularly and without pay, provide support or care to a person who has a significant or persistent health problem or loss of autonomy. This may include biological family, acquired family (related by marriage/contract), family of choice, and friends. Finally, exclusion criteria for both patients and caregivers were being diagnosed with any severe psychiatric disorder or showing cognitive impairment that could have influenced the ability to provide informed consent or complete the protocol. The psychologists involved in data collection administered the *Hospital Anxiety and Depression Scale* (HADS), *Demoralization Scale* (DS), *Herth Hope Index* (HHI), *Caregiver Reaction Assessment* (CRA), *Short Form Health Survey 36* (SF-36), and *Distress Thermometer* (DT) to caregivers, in order to explore many distress dimensions related to their relatives' terminal illness. At the same time, another psychologist administered the *Patient Dignity Inventory* to the terminal cancer patients. A total of 170 participants were identified. Of these, 12 patients declined participation, 8 patients could not be assessed due to their severe clinical conditions, 10 patients did not provide permission for contacting their caregivers, and 12 caregivers declined participation. The total sample consisted of 128 of end-of-life cancer patients and their respective caregivers.

All participants provided informed consent and the study was approved by "Comitato Etico Interaziendale A.O.U. San Giovanni Battista di Torino A.O. C.T.O./Maria Adelaide di Torino" protocol number 0073054, procedure number 255, date of approval: 04/14/15.

Measures

The Italian versions of the following validated rating scales were used.

The *Patient Dignity Inventory* (PDI) (Chochinov et al., 2008; Ripamonti et al., 2012a) is a 25-item scale, based on Chochinov's Dignity Model, measuring various sources of patients' dignity-related distress. The items are scored using a 5-point Likert scale, from one, "not a problem," to five, "an overwhelming problem." The version used in this study, whose factor structure was analyzed with end-of-life cancer patients, is composed of five subscales: *Psychological Distress*, *Social Support*, *Physical Symptoms and Dependency*, *Existential Distress*, and *Loss of Purpose and Meaning* (Bovero et al., 2018a). The total score ranges from 25 to 125, and higher scores indicate higher dignity-related distress.

The *Hospital Anxiety and Depression Scale* (HADS) is a 14-item self-report scale, which measures depression and anxious symptoms (Zigmond and Snaith, 1983; Costantini et al., 1999). Both the *Depression* and *Anxiety* subscales are composed of seven items scored using a four-point Likert scale. Scores of eight or higher indicate significant clinical symptomatology (Castelli et al., 2011).

The *Demoralization Scale* (DS) (Kissane et al., 2004; Costantini et al., 2013) is a self-report scale aimed at assessing existential distress related to demoralization syndrome. The 24 items are scored using a 5-point Likert scale (from zero "never," to four "always") and they explore five demoralization dimensions: *Loss of Meaning and Purpose*, *Dysphoria*, *Disheartenment*, *Helplessness*, and *Sense of Failure*. Total scores range from 0 to 96.

The *Herth Hope Index* (HHI) (Herth, 1992; Ripamonti et al., 2012b) is a 12-item self-report scale evaluating hope in adults in clinical settings. Caregivers are asked to indicate how much they agree with the statement right now (from one "strongly disagree," to four "strongly agree"). The items refer to three subscales: *Temporality and Future*, *Positive Readiness and Expectancy*, and *Interconnected*. Summative scores can range from 12 to 48, with a higher score denoting greater level of hope (Herth, 1993).

The *Caregiver Reaction Assessment* (CRA) (Given et al., 1992; Lucchiari et al., 2010) consists of 24 items divided into five subscales including dimensions of caregiving reactions: *Disrupted Schedule* (changes in the individual's daily activities); *Financial Problems*; *Lack of Family Support*; *Health Problems*, and *Impact of Caregiving on Caregiver's Self-Esteem*.

The *Short Form Health Survey 36* (SF-36) (Ware and Sherbourne, 1992; Apolone, 1997) is a generic health quality-of-life questionnaire used with both generic populations and populations affected by chronic diseases. It is composed of 36 questions organized into eight scales: *Physical Functioning*, *Role-Physical* (limitations in performing one's daily role due to physical health), *Role-Emotional* (limitations in performing one's daily role due to mental health), *Bodily Pain*, *General Health*, *Vitality*, *Social Functioning*, and *Mental Health*. The raw scale scores of the SF-36 are linearly transformed into a range between 0 and 100. Higher scores represent better levels of functioning (Albertsen et al., 1997).

The *Distress Thermometer* (DT) (Grassi et al., 2013) is a visual analogue tool that asks patients to rate their level of distress in the

Table 1. Socio-demographic and clinical data of the patients (N=128) and their caregivers (N=128)

Characteristics	Patients			Caregivers		
	n ^a (%)	Mean	SD	n ^a (%)	Mean	SD
Sex						
Male	75 (58.6)			37 (28.9)		
Female	53 (41.4)			91 (71.1)		
Age		68.30	13.33		58.10	14.6
Site						
Hospice	47 (36.7)					
Hospital	81 (63.3)					
Education						
Primary school	33 (26.0)			16 (12.5)		
Middle school	48 (37.4)			42 (32.8)		
High school	34 (26.8)			56 (43.8)		
Graduate	13 (9.8)			12 (9.4)		
Master				1 (0.8)		
Marital status						
Married	79 (61.7)			93 (72.7)		
Cohabitant	2 (1.6)			11 (8.6)		
No cohabitant partners	–			1 (0.8)		
Single	15 (11.7)			13 (1.2)		
Divorced	15 (11.7)			6 (4.7)		
Widow(er)	17 (13.3)			4 (3.1)		
Degree of relationship						
Spouse/Partner				60 (46.87)		
Parent				13 (10.15)		
Other family member				55 (42.97)		
Cancer site						
Respiratory	31 (24.22)					
Gastrointestinal	10 (7.81)					
Genitourinary	37 (28.90)					
Hepatic-Pancreatic	12 (9.38)					
Breast	13 (1.16)					
Other	25 (19.53)					
Cancer stage						
Local	9 (7.3)					
Loco-regional	26 (20.3)					
Metastatic	93 (72.4)					
Religious practice						
Catholic	119 (62.8)			107 (83.6)		
Ortodox	–			2 (1.6)		
Atheist	9 (7.3)			17 (13.3)		
Other	–			2 (1.6)		
Awareness						

(Continued)

Table 1. (Continued.)

Characteristics	Patients			Caregivers		
	n ^a (%)	Mean	SD	n ^a (%)	Mean	SD
No Diagnosis, no prognosis	16 (12.5)			1 (.6)		
Diagnosis	24 (18.8)			19 (15)		
Diagnosis, prognosis overestimation	51 (39.8)			12 (9.4)		
Prognosis, no diagnosis	2 (1.6)			2 (1.6)		
Total	35 (27.3)			94 (73.4)		
KPS		38.71	9.8			

^an: absolute frequencies, %: percent frequencies.
SD, standard deviation; KPS, Karnofsky Performance Status.

past week on a scale ranging from 0 (no distress) to 10 (extreme distress).

Statistical analysis

Data analysis was performed by first considering the descriptive statistics of socio-demographic and clinical characteristics of both patients and caregivers. Later, the *Braivais-Pearson* correlation index was determined to identify associations between terminal cancer patients' dignity-related distress and their family caregivers' distress, demoralization, hope, care burden, and quality of life. All statistical analyses were conducted using the Statistical Package for Social Sciences (SPSS) software (Statistics Version 25.0.0, IBM).

Results

Socio-demographic and clinical characteristics of the sample

The socio-demographic characteristics of the patients and caregivers are presented in Table 1.

Patients' dignity-related distress and caregivers' distress

The descriptive analysis shows that *Existential* and *Psychological Distress* PDI subscale scores and PDI Total Scores were on average higher than the scores of the other PDI subscales. The caregivers in the sample, on average, scored high on the *Impact of Caregiving*, *Caregiver's Self-Esteem*, and *Disrupted Schedule* CRA subscales. Moreover, caregivers' quality of life, explored using the Short Form Health Survey 36 (SF-36), got moderate-high mean scores on most of subscales. Caregivers' anxious symptomatology (HADS) was higher than depressive symptomatology. The caregivers scored low on DS and moderate on HHI.

The descriptive statistics for both patients and caregivers are reported in Table 2.

Association between patients' dignity-related distress and caregivers' distress

Findings highlighted that caregiver's *Emotional Role* SF-36 scores correlated negatively with both the patients' *Psychological Distress* PDI scores ($r = 0.202$; $p \leq 0.05$) and the *PDI Total Scores* ($r = -0.183$; $p \leq 0.05$). The caregivers' *Disrupted Schedule* CRA scores were positively associated with patients' *Psychological Distress* PDI

scores ($r = 0.218$; $p \leq 0.01$), *PDI Total Scores* ($r = 0.183$; $p \leq 0.05$), and *Loss of Purpose and Meaning* PDI scores ($r = 0.176$; $p \leq 0.05$). Finally, the caregiver *Disheartenment* DS scores were positively correlated to patients' *Physical Symptoms and Dependency* PDI scores ($r = 0.180$), *Loss of Purpose and Meaning* PDI scores ($r = 0.196$), and *PDI Total Scores* ($r = 0.216$; $p \leq 0.05$).

No significant correlation between caregivers' anxiety and depression (HADS), hope (HHI), and distress (DT), and patients' dignity-related distress (PDI Total Score) emerged.

All significant correlations between caregivers' distress and patients' dignity-related distress can be found in Table 3.

Discussion

The present study aimed to investigate the relation between end-of-life cancer patients' dignity-related distress and caregivers' distress.

Emotional Role, which refers to role limitations and difficulties while working or during other daily activities due to emotional problems (Ware and Sherbourne, 1992), was correlated with psychological distress and global distress related to patients' sense of dignity. The limitations in caregiver daily activities due to emotional problems (anxious and depressive symptoms) could contribute to a patient's sense of guilt which may in turn decrease his/her sense of dignity. Specifically, a patient's anxiety, feelings of depression, uncertainty and worry regarding illness and the future, no longer being able to mentally fight and accept the situation could also arise in their caregiver, as a consequence of emotional attunement.

The association between changes in caregivers' daily activities and both dignity-related psychological distress and general sense of dignity patients' dimensions could be explained as a vicious cycle. Daily management concerns of caring activities could compromise patients' sense of dignity due to perception of oneself as a burden to their caregivers; which, in turn, might further overwhelm caregivers. Thus, patients perception of how they are perceived by caregivers and healthcare providers might be a powerful mediator of dignity (Chochinov, 2007). We focused on this relational dimension in our previous study on patients' dignity-related existential distress (Bovero et al., 2018b). In that study, it was emerged that one of the clinical subdimensions of patients' dignity-related distress was loss of autonomy intended as interpersonal: being treated as a whole person, with respect and with mutual trust in others. Thus, this

Table 2. Descriptive statistics of the sample's scores on the scales

	Mean	SD
Patients		
Patient Dignity Inventory (PDI)		
Psychological Distress	17.27	5.32
Social Support	4.23	1.89
Physical Symptoms and Dependency	12.09	3.94
Existential Distress	19.91	6.03
Loss of Purpose and Meaning	8.00	4.61
PDI Total Score	61.27	16.3
Caregivers		
Hospital Anxiety and Depression Scale (HADS)		
Anxiety	10.49	4.67
Depression	8.96	4.96
Demoralization Scale		
Loss of Meaning and Purpose	2.71	3.41
Dysphoria	6.42	4.3
Disheartenment	12.66	5.73
Helplessness	5.30	3.72
Sense of Failure	2.44	2.39
DS Total Score	29.43	14.82
Herth Hope Index (HHI)		
Temporality and Future	11.64	2.37
Positive Readiness and Expectancy	13.39	1.78
Interconnected	12.80	1.87
HHI Total Score	37.79	5.08
Caregiver Reaction Assessment (CRA)		
Impact of Caregiving on Caregiver's Self-Esteem	31.38	2.77
Financial Problems	6.36	3.17
Lack of Family Support	9.08	4.68
Health Problems	9.55	3.56
Disrupted Schedule	16.38	4.27
Short Form Health Survey 36 (SF-36)		
Physical Functioning	86.25	25.41
Role-Physical	68.95	40.75
Bodily Pain	75.61	28.59
General Health	64.22	21.48
Vitality	41.05	23.23
Social Functioning	66.00	28.52
Role-Emotional	42.45	39.84
Mental Health	43.97	23.78

SD, standard deviation.

relational dimension can influence patients' distress and it is conceivable that caregivers' distress could affect this relational wellbeing, predicting patients' dignity-related distress.

Greater impact of caregiving on daily activities was associated with self-reported loss of dignity-related purpose and meaning. The impairment of caregivers' daily routine and the decline of time dedicated to themselves and their social relationships could affect the quality of care dedicated to patients. As a consequence, patients may feel that they no longer possess active roles in their own lives, instead experiencing a greater degree of helplessness (den Hartogh, 2017).

Similarly, data showed that caregivers' feelings of demoralization-related hopelessness were associated with patients' dignity-related loss of purpose and meaning and general distress, underlining the interdependence and reciprocal influence among patients' and their caregivers' spiritual wellbeing (Mehnert et al., 2011). Furthermore, the disheartenment of caregivers was also related to physical symptoms and dependency of patients, suggesting that increases in a caregiver's hopelessness could be related to the worsening of a patient's physical condition.

Our findings highlight the importance of assessing variables that might affect patients' dignity from a relational perspective in order to help the healthcare system to be more able to implement focused and psychological brief treatments. Therefore, healthcare providers should develop a close personal relationship with dying patients according to the need of patients to ensure multidimensional assessment and psychological support to both patients and caregivers. Further research with caregivers should be performed to determine if other characteristics are associated with end-of-life cancer patients' dignity-related distress. For instance, it might be interesting to explore how the attachment relationship between patients and their relatives could mediate distress, demoralization, quality of life, and reactions at the end of life.

A limitation of this study was the impossibility to identify the causality of the association between patient and caregiver distress: it was used a cross-sectional design, whereas the development of the studied relations could be interesting. Future studies should expand on the results found using a longitudinal assessment. In this way, the association between the potential psychological aspects of caregivers' distress with patients' dignity-related distress could be further understood. In fact, it could shed light on the specific factors which influence caregiver distress, e.g., physical factors related to the patient clinical condition. This approach could be also applied to patients affected not only by cancer but also by life-limiting or life-threatening disease in general.

Finally, the study evidence is difficult to generalize because they are relative to the specific population of cancer patients in hospice or hospital with a life expectancy of less than 4 months. Further studies could involve patients in different settings, e.g., in home, since the issues which affect patients and caregivers could be different depending on the objective circumstances.

Conclusion

The results of this study stress the key role of relational dimensions on dignity during the end-of-life phase. Focusing on caregivers' distress, it could affect patients' dignity-related distress by influencing the interpersonal aspects of patients' autonomy. In light of this relational perspective, it would be important to propose supportive interventions to relieve caregivers' distress and to promote patients' autonomy, minimizing their fear of being a burden. This could help caregivers to control their distress by paying special attention to social factors and creating more conditions in which patients experience greater autonomy. Finally, attending to the caregivers might benefit the entire family,

Table 3. Correlations between patients' PDI dimensions and caregivers' distress

		Patients				
		PDI				
		Psychological distress <i>r</i>	Physical symptoms and dependency <i>r</i>	Loss of purpose and meaning <i>r</i>	PDI total score <i>r</i>	
Caregivers	SF-36	Role Limitations (Emotional)	-0.202**	0.099	-0.160	-0.183**
	CRA	Disrupted Schedule	-0.218**	0.141	0.176**	0.183**
	DS	Disheartenment	0.157	0.180**	0.196**	0.216**

r: Pearson correlation coefficient; PDI, Patient Dignity Inventory; SF-36, Short Form Health Survey 36; CRA, Caregiver Reaction Assessment; DS, Demoralization Scale. Table only contains variables significantly correlated to PDI Total Score. Significant correlations are highlighted in bold.

***p* ≤ 0.01.

improving not only the management of patient needs but also the active coping strategies in facing daily activities and relationships.

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