Trajectories of caregiver depressive symptoms while providing end-of-life care

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Abstract

Objective: The course of caregivers' depressive symptoms may not be homogenous. This study identified trajectories of depressive symptoms among caregivers providing end-of-life care to cancer patients and profiled the unique characteristics of caregivers within each trajectory.

Methods: Trajectories of depressive symptoms were explored in 447 caregivers who completed the Center for Epidemiological Studies Depression Scale over four periods close to the patient's death (1–30, 31–90, 91–180, and >180 days). Distinct trajectories were identified by latent class analysis.

Results: Four trajectories were identified as endurance, resilience, moderately symptomatic, and chronically distressed and contained 32.0%, 11.4%, 36.9%, and 19.7% of the sample, respectively. Caregivers in the endurance trajectory were relatively well-adjusted individuals with less education, adequate financial support, and ample psychological resources but provided care to older patients with greater symptom distress. They perceived less subjective caregiving burden than caregivers with moderate or chronic depressive symptoms. Caregivers in the resilience trajectory were in a more vulnerable position than those in other trajectories when they first transitioned into the caregiving role because they were more likely to be the patient's spouse, have greater educational attainment and insufficient finances, provide higher intensity assistance to a younger relative, and have weaker psychological resources. However, they were older, reported greater confidence in caregiving, and perceived less caregiving burden than caregivers in other trajectories. The moderately symptomatic and chronically distressed trajectories were differentiated only by the strength of psychological resources.

Received: 30 September 2012 Revised: 12 May 2013 Accepted: 13 May 2013 Conclusions: Caregivers of terminally ill cancer patients follow distinct depressive-symptom trajectories while providing end-of-life care. Copyright © 2013 John Wiley & Sons, Ltd.

Introduction

Family caregiving at end-of-life (EOL) is essential for patients [1] and society [2] but is a stressful role, especially when death approaches, with deleterious caregiver consequences such as increasing depressive symptoms [3,4] and deteriorating quality of life [5,6]. Such effects extend into bereavement, with adjustment difficulties and increased morbidity and mortality [7,8].

Caregivers respond differently to similar events in caregiving. Individual reactions to the possible stressors of caregiving are explained in a widely used framework, the stress-appraisal/coping model [9–11]. A potentially threatening caregiving event cannot be assumed to be stressful *per se* but is mediated by a complex web of (i) contextual factors, (ii) objective caregiving demands, (iii) appraisal of the caregiving situation, and (iv) available psychological resources. Contextual factors refer to caregivers' and care recipients' characteristics, which they bring into the caregiving experience. Caregiving demands

stem from the nature and magnitude of care provided to meet the dying relative's needs. Appraisal of the caregiving situation focuses on how caregivers judge the adequacy of their caregiving performance and the extent of perceived caregiving burden. Psychological resources refer to caregivers' inner strength (i.e., personal coping capacity).

To better understand caregivers' different responses over the course of EOL caregiving, the trajectories of those responses must be examined. Differentiating the caregiver population into such trajectories will identify more precisely care situations most likely to predispose caregiver subgroups to adverse health consequences and resilience factors that may attenuate negative impacts of caregiving [9–11]. Only three studies investigated distinct depressive-symptom trajectories of family caregivers of adults with chronic diseases [12–14], despite longitudinal changes in caregivers' depressive symptoms having been well characterized [15]. Four depressive-symptom trajectories were identified for women caring for husbands

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with dementia [12] and caregivers of cancer survivors [13], and two trajectories for caregivers of patients with malignant brain tumors [14]. In these studies, some caregivers had adjusted to the caregiving role, whereas others were characterized by a high-distress trajectory. However, depressive-symptom trajectories have never been explored among caregivers of cancer patients at EOL. Therefore, this study aimed to identify trajectories of caregiver depressive symptoms by levels and patterns of change throughout the patient's dying process and to characterize individuals within each trajectory.

Methods

Design and sample

A convenience sample of caregivers was recruited from March 2005 to October 2009 and followed up through February 2010. Caregivers were included if they met these criteria: (i) identified by patients as the family member most involved with their care; (ii) care recipients had terminal, advanced cancer as judged by their physician; (iii) >21 years; and (iv) willing to participate and able to communicate with data collectors.

Procedures

Patients recognized by their primary physicians as terminally ill were referred to data collectors who were bachelor-prepared experienced oncology nurses. These data collectors approached patients to explain the study and ask permission to invite their identified family caregiver to participate in the study. Identified caregivers who agreed to participate were interviewed in person when they next visited their hospitalized relative (baseline) and approximately every 2 weeks thereafter (when the patient returned for outpatient visits) until they declined to participate or patient death. Information on patients' death was obtained by reviewing medical records or telephoning caregivers. The study sites' human research ethics review committees approved the research protocol. All subjects provided written informed consent.

Measures

All instruments were well established [16–22] and had been used in previous studies [23,24] to investigate caregiving effects on Taiwanese caregivers of terminally ill cancer patients.

Outcome variable

Caregiver depressive symptoms were assessed by the 20-item Center for Epidemiological Studies Depression Scale (CES-D) [16]. CES-D scores range from 0 to 60, with scores >16 indicating clinical depression (Cronbach's alpha = 0.92 in this study).

Independent variables

Contextual factors included caregivers' demographic characteristics (gender, age, education [years], financial status [sufficient income to make ends meet: yes/no], and relationship with the patient) and patients' age and symptom distress. Caregivers' perceived patient symptom distress was measured by the 13-item Symptom Distress Scale [18]. Scores range from 13 to 65; higher scores indicate greater distress (Cronbach's alpha = 0.84 in this study).

Objective caregiving demands included caregiving intensity and time providing care each day (hours). Caregiving intensity was measured by the amount of assistance provided in personal care, homemaking, transportation, and health care on a 4-point scale (1 = none at all to 4 = a lot) [19]. Scores for caregiving intensity range from 4 to 16 (Cronbach's alpha = 0.88 in this study).

Appraisal of caregiving situation: Caregiving was appraised by caregivers' perceived confidence in caregiving and perceived caregiving burden. Caregiving confidence was measured by three items: caregivers' perceived confidence in what to expect while the patient is dying, what to do at time of death, and how to care for the patient at home [20] on a 3-point scale (1 = very confident, 2 = fairly confident, 3 = not at all confident). Total scores range from 1 to 9; higher scores indicate greater lack of caregiving confidence (Cronbach's alpha = 0.69 in this study).

Subjective caregiving burden was measured by the Caregiver Reaction Assessment [21], with five subscales: impact on schedule, caregiver esteem (whether providing care is meaningful and rewarding), lack of family support, impact on health, and impact on finances. Total scores range from 24 to 120. Higher scores represent stronger negative caregiving impact (Cronbach's alpha=0.87 in this study).

Psychological resources of caregivers were measured by Antonovsky's 13-item Sense of Coherence (SOC) scale [22], representing three SOC attributes: meaningfulness, comprehensibility, and manageability. Total scores range from 13 to 91; higher scores indicate stronger SOC (Cronbach's alpha=0.83 in this study).

We hypothesized that SOC and caregiver confidence protect caregivers from the stress of caregiving and that patient symptom distress, objective caregiving demands, and subjective caregiving burden are risk factors predisposing caregivers to experiencing more depressive symptoms.

Data analysis

Data were first analyzed for variable distributions. To explore trajectories of caregivers' depressive symptoms, time proximity to the patient's death was defined as the period between death and day of interview and was further categorized as 1–30, 31–90, 91–180, and >181 days before patient's death.

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To identify latent depressive-symptom trajectories throughout the patient's dying process, we computed latent class analysis with continuous latent class indicators by using the software Mplus (Version 4.2, Muthén & Muthén, Los Angeles, CA). This latent class model performed two analyses simultaneously. The goal of the first analysis was to identify discrete trajectories of family caregiver depressive symptoms. Each estimated trajectory is viewed as comprising a homogenous group of individuals sharing a distinct pattern of depressive symptoms over four-time proximities to the patient's death. As caregivers' CES-D scores might be influenced by gender, age, and education, and patients' symptom distress, these factors were adjusted in the analysis to obtain groupings that reflected more accurately the underlying trajectories of depressive symptoms.

The second analysis of the latent class model involved a multinomial logistic regression to test predictors of caregivers' membership within distinct depressive-symptom trajectories. We modeled the latent trajectories of depressive symptoms with contextual factors, objective caregiving demands, appraisals of the caregiving situation, and psychological resources. Except for the time-invariant independent variables of demographics and patient disease-related characteristics, factors used to predict group membership were calculated by averaging all measurements collected during each time interval.

Decisions about the optimal number of trajectories were based on the lowest value of Akaike's information criterion [25] and Bayesian information criterion [26]. The appropriate shape of each trajectory group (i.e., linear and quadratic) was further determined by fitting polynomial regressions of CES-D scores on linear and quadratic terms of time to the patient's death, on the basis of the individuals within the given trajectory group. Decision on trajectory shape was based on statistical significance (p < 0.05) of linear and/or quadratic terms of time: the quadratic shape if the quadratic term is significant and the linear shape if the quadratic term is not significant, but the linear term is significant. Overall fit of the final model was judged by the entropy measure, which summarizes the distinguishability of identified trajectories. Entropy ranges from 0 to 1, with values close to 1 indicating good overall fit.

Results

From 743 potential participants, 659 family caregivers were recruited. Of 659 caregivers recruited, 144 (21.9%) withdrew from follow-ups for various reasons. Among the remaining 515 caregivers, 472 lost their relative to death during the study. Another 25 caregivers were excluded because of missing information on covariates identified as potential predictors of membership within distinct depressive-symptom trajectories. Therefore, the final sample comprised 447 caregivers (Figure 1). These

caregivers and those who did not complete follow-ups did not differ significantly at baseline on independent variables. However, participating caregivers perceived that their ill relative suffered from greater symptom distress (mean \pm SD = 32.4 \pm 8.5 vs. 26.6 \pm 7.8, p < 0.001), provided more intense patient assistance (12.7 \pm 3.4 vs. 10.5 \pm 3.8, p < 0.001), and had more depressive symptoms (20.5 \pm 11.2 vs. 15.0 \pm 10.5, p < 0.001) than those who did not complete follow-ups.

A majority of caregivers were women (67.57%), with a mean age of 48.89 years (range = 21–85) (Table 1). Most caregivers were married (82.2%), the patient's spouse (45.41%) or an adult child (35.57%), and reported making ends meet (76.29%). Caregivers participated in this study on average for 83.7 ± 88.5 days (range = 1–368; median = 50) and were interviewed 6.8 ± 6.1 times (range = 1–30; median = 5.0).

Among patients, over half (57.8%) were men, with a mean age of 62.58 years (range = 21–94). Their most common cancer sites were lung (21.2%), stomach (13.8%), colon–rectum (12.9%), liver (10.6%), pancreas (8.3%), and breast (5.1%). On average, patients had been diagnosed with cancer for 23.0 ± 29.1 months (range = 1–248, median = 13.1) at caregivers' first interview.

Latent trajectories of caregiver depressive symptoms

To identify the optimal number of discrete trajectories of depressive symptoms, two to eight trajectories were fitted in latent class modeling. When the number of trajectories was less than five, the latent class model became unstable and was difficult to converge because of the model identifiability problem [27]. The Akaike's information criterion value decreased from two to eight trajectories, but the Bayesian information criterion value was lowest at three trajectories (Table 2). Four distinct trajectories of caregiver depressive symptoms were identified on the basis of the fit statistics, interpretation of class composition, and model identifiability. The entropy value for four trajectories was 0.852, indicating good overall model fit. Box plots in Figure 2 show CES-D scores across the four trajectories of caregiver depressive symptoms at four times.

The trajectory characterized by the lowest CES-D scores over the dying process was labeled "endurance" and contained 32.0% of the sample. Polynomial regression results indicated that the most appropriate shape for the endurance trajectory was quadratic. Depressive symptoms experienced by "endurance" caregivers accelerated rapidly as the patient's death approached, with mean CES-D scores of 6.95, 8.04, 9.45, and 13.34 for >181, 91–180, 31–90, and 1–30 days from the patient's death, respectively (Table 1).

Approximately one-tenth (11.4%) of caregivers' depressive symptoms followed a trajectory described as "resilience"

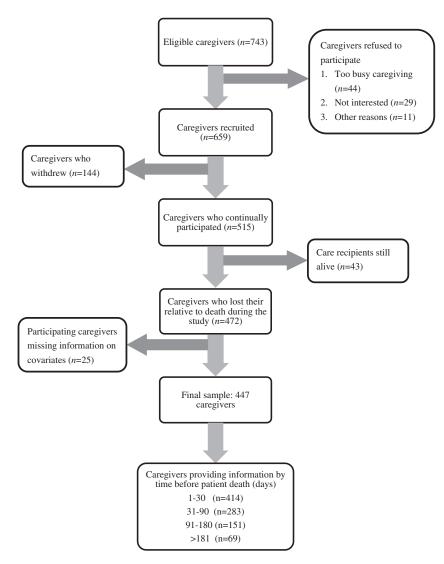


Figure 1. Participant flow chart

(Figure 2) and exhibited a curvilinear shape. Caregivers in this trajectory experienced a high level of depressive symptoms (mean CES-D score = 20.90) when the patient's death was >180 days away (Table 1). Depressive symptoms dropped sharply to around the clinical threshold within 91–180 and 31–90 days before the patient's death (mean CES-D scores = 16.45 and 16.25, respectively), then increased to 18.38 in the patient's last month of life.

The final two trajectories were categorized by high depressive-symptom levels (Table 1). These two trajectories were named "moderately symptomatic" and "chronically distressed" and contained 36.9% and 19.7% of the sample, respectively (Figure 2). Polynomial regression results indicated that the most appropriate shape for these trajectories was linear. The mean CES-D scores increased steadily from 17.32 and 26.86 at >181 days from the patient's death to 21.45 and 32.18 within the patient's last month of life for the "moderately symptomatic" and "chronically distressed" trajectories, respectively (Table 1).

Predictors of membership in distinct depressive-symptom trajectories

The results of latent class analysis indicated that caregivers in the "endurance" trajectory were significantly more likely than those in other depressive-symptom groups to report less education, indicate making ends meet financially, provide EOL care to older patients with greater symptom distress, and have stronger psychological resources (Table 3). Caregivers in the "endurance" trajectory were also significantly less likely than those in the "moderately symptomatic" and "chronically distressed" trajectories to perceive a higher degree of caregiving burden.

Caregivers in the "resilience" trajectory were significantly more likely than those in the "moderately symptomatic" and "chronically distressed" trajectories to be older, to be the patient's spouse, and to provide greater intensity assistance to their terminally ill relative, but were significantly less likely to appraise themselves as lacking confidence in providing EOL care and perceived less subjective

Table 1. Sample characteristics, independent variable measures, and CES-D scores across depressive-symptom trajectories for family caregivers

	Unit	Total (n = 447)	Depressive-symptom trajectory					
Variable			Endurance (n = 143)	Resilience (n = 51)	Moderately symptomatic (n = 165)	Chronically distressed (n = 88)		
Caregiver characteristics								
Gender: male	%	32.43	37.06	41.18	36.36	12.50		
Age	M(SD)	48.89(12.64)	52.29(11.95)	56.10(12.08)	44.29(11.84)	47.80(12.13)		
Education (years)	M(SD)	11.81(3.94)	11.66(4.24)	10.98(4.00)	12.68(3.66)	10.91(3.62)		
Relationship to patient								
Spouse	%	45.41	41.26	82.35	30.91	57.95		
Adult child	%	35.57	35.66	11.76	47.27	27.27		
Other	%	19.02	23.08	5.89	21.82	14.78		
Financial status: not	%	23.71	4.90	52.94	20.00	44.32		
making ends meet								
Patient demographics and disease-	related variab	es						
Symptom distress (SDS score)	M(SD)	32.35(7.30)	33.46(6.76)	29.45(6.37)	32.09(6.79)	32.74(7.80)		
Age (years)	M(SD)	62.58(14.17)	68.10(12.46)	58.78(12.41)	60.49(14.80)	59.71(14.13)		
Objective caregiving demands								
Intensity of assistance	M(SD)	12.92(2.83)	12.98(3.30)	13.97(1.71)	12.52(2.78)	12.96(2.45)		
Time providing care (hours)	M(SD)	4.33(1.42)	4.07(1.64)	5.11(1.01)	4.17(1.28)	4.59(1.29)		
Appraisal of caregiving situation								
Lack of confidence in	M(SD)	6.08(1.36)	5.69(1.27)	5.54(1.56)	6.21(1.16)	6.76(1.40)		
EOL caregiving Subjective caregiving	M(SD)	61.29(10.09)	55.80(9.16)	57.83(6.90)	63.13(8.68)	68.76(9.79)		
burden (CRA score)	1 1(32)	01.27(10.07)	33.00(7.10)	37.03(0.70)	03.13(0.00)	00.70(7.77)		
Psychological resources	M(SD)	63.90(15.23)	76.76(8.63)	57.76(14.69)	63.66(11.07)	47.01(11.36)		
(SOC score)								
CES-D score before patient's deat	th (days)							
I-30	M(SD)	20.49(9.83)	13.34(7.13)	18.38(7.17)	21.45(6.93)	32.18(8.49)		
31–90	M(SD)	19.04(9.95)	9.45(5.65)	16.25(6.75)	20.25(6.12)	31.00(8.14)		
91-180	M(SD)	18.89(8.93)	8.04(4.90)	16.45(5.39)	18.84(5.20)	29.36(4.52)		
>180	M(SD)	18.14(9.01)	6.95(5.57)	20.90(6.66)	17.32(7.67)	26.86(4.92)		

SDS, Symptom Distress Scale; CRA, Caregiving Reaction Assessment; SOC, Sense of Coherence scale; CES-D, Center for Epidemiological Studies Depression Scale.

caregiving burden (Table 3). Furthermore, caregivers in the "resilience" trajectory were significantly more likely than those in the "moderately symptomatic" trajectories to have more education, report their financial status as not making ends meet, provide care to younger patients, and have weaker psychological resources.

The two trajectories categorized by more depressive symptoms ("moderately symptomatic" and "chronically distressed") were similar in nearly every aspect of the caregiving-risk and caregiving-protective factors identified in this study (Table 3), except for psychological resources

(SOC score). With each unit increase in SOC score, the likelihood of being in the "moderately symptomatic" rather than in the "chronically distressed" trajectory increased by 1.19 (95% confidence interval: 1.06, 1.35).

Discussion

This study contributes to family caregiving research by adding to the few studies identifying latent classes of depressive symptoms in caregivers of adult patients with chronic diseases. We identified four distinct depressive-

Table 2. Fit statistics for model selection

No. of groups	2	3	4	5	6	7	8
Akaike's information criterion	6356.869	6257.233	6241.34	6191.377	6171.443	6149.649	6116.278
Bayesian information criterion	6538.176	6503.387	6561.34	6585.222	6639.134	6691.187	6731.662

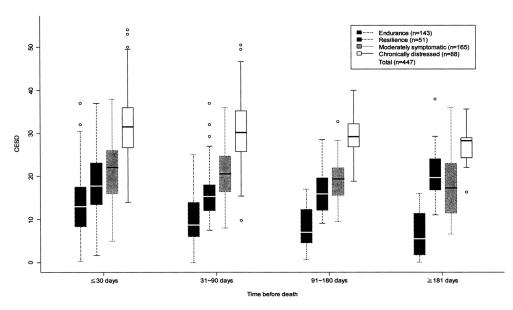


Figure 2. Box plot of family caregiver depressive-symptom trajectories

symptom trajectories for family caregivers providing EOL care to terminally ill cancer patients. These distinct trajectories varied significantly in magnitude and patterns of change, consistent with the heterogeneity of depressive-symptom trajectories reported for caregivers of patients with chronic diseases [12–14].

Approximately one-third of our caregiver subjects were categorized in the "endurance" trajectory. These caregivers thrived in the caregiving experience, considering that their depressive symptoms never reached the clinical CES-D cutoff score throughout the patient's dying process. This proportion (32.0%) of caregivers who never acknowledged depressive symptoms above the clinical threshold was substantially lower than for caregivers of cancer survivors (70.4%) [13], dementia patients (69.8%) [12], and patients with malignant brain tumors (48.9%) [14], indicating the extraordinarily high stress of EOL caregiving.

Consistent with the literature on caregivers in general, caregivers of Taiwanese terminally ill cancer patients in the "endurance" trajectory comprised relatively welladjusted individuals with adequate resources for their caregiving demands, as indicated by adequate financial support [10,14,28] and ample personal psychological resources [29,30]. Family caregivers in this trajectory perceived less caregiving burden [15,31,32] than those in both the "moderately symptomatic" and "chronically distressed" trajectories. They were also more likely to provide EOL care to older terminally ill cancer patients [3,28]. Aging is recognized in Chinese culture as a natural process [33], and advanced age may be associated with greater acceptance of the evolution of illness and impending mortality [34]. Therefore, Taiwanese caregivers may experience low-level anticipatory grief over the forthcoming loss of their older relative.

However, our finding regarding caregiver educational attainment as a predictor of membership in the "endurance" trajectory does not agree with the literature. Greater educational attainment is generally recognized as associated with low-stable levels of depressive symptoms [10,28,29] because better educated caregivers are more likely to have an advantaged social status and a sense of control over their lives [35]. However, caregivers in the "endurance" trajectory were less educated, consistent with a previous report that less educated caregivers experienced fewer depressive symptoms [15]. Caregiving tasks may be perceived as less rewarding by better educated caregivers familiar with more intellectual activities, whereas less educated caregivers may derive more positive reinforcement from caregiving [36]. Furthermore, devotion to caregiving may deprive better educated caregivers of the success and benefits from status achievement in their non-caregiving roles.

Caregivers in the "endurance" trajectory were also more likely to provide EOL care to a relative with greater symptom distress, in contrast to the commonly reported conclusion that caregivers of cancer patients with greater symptom distress experience more depressive symptoms [31,37]. Caregivers providing EOL care to relatives with greater symptom distress may require increased support and assistance from healthcare professionals with concrete symptom-management tasks. Such assistance may improve confidence in caregiving, reduce subjective caregiving burden, and alleviate depressive symptoms. However, further study is needed to validate this hypothesis.

Caregivers in the "resilience" trajectory experienced transient perturbations, with initially moderate depressive symptoms (at a level lower than only that for the

Table 3. Significant predictors of individual depressive-symptom trajectories

Resilience

1.75

0.82

0.41*

0.003*

(0.67, 1.00)

(0.23, 0.74)

Potential predictors

Caregiver characteristics Age (years)

Education (years)

Relationship to patient

Spouse

Endurance vs.		Resilie	Moderately	
Moderately symptomatic	Chronically distressed	Moderately symptomatic	Chronically distressed	symptomatic vs. Chronically distressed
1.05	0.99	1 28*	121*	0.94
(0.98, 1.12)	(0.92, 1.08)	20		
(0.56, 1.12)	0.52, 1.06)	(1.06, 1.55) 1.69*	(1.02, 1.45) 1.41	(0.89, 1.01) 0.84
0.07	0.50	,		
(0.51, 0.94)	(0.40, 0.83)	(1.03, 2.76)	(0.95, 2.11)	(0.67, 1.04)

21422*

0.35

Adjusted odds ratio (95% confidence interval)

612.78*

 $(0.2 \times 10^{-4}, 0.34)$ (0.07, 50.00)(0.02, 20.00) $(11.33, 33.1 \times 10^{3})$ $(3.11, 14.7 \times 10^3)$ (0.07, 1.72) 0.7×10^{-5} * 0.02* 0.006* 3238.94* 894.26 0.28 Financial status: not making ends meet $(0.2 \times 10^{-8}, 0.03)$ $(0.57, 139 \times 10^4)$ (0.0008, 0.65)(0.0002, 0.23) $(1.51, 693 \times 10^4)$ (0.06, 1.19)Patient demographics and disease-related variables Age (years) 1.35* 1.15 1.22* 0.85* 0.90 1.05 (1.00, 1.33)(0.76, 0.96)(0.82, 1.00)(0.99, 1.12)(1.12, 1.64)(1.05, 1.43)Symptom distress (SDS score) 1.96* 1.43* 1.54* 0.74 0.79 1.08 (1.14, 3.33)(1.14, 1.79)(1.21, 1.96)(0.45, 1.21)(0.84, 1.31)(0.97, 1.19) Objective caregiving demands 0.21* 0.84 0.83 3 99* 391* 0.98 Intensity of caregiving (0.08, 0.57)(0.59, 1.21)(0.55, 1.24)(1.73, 9.17)(1.65, 9.24)(0.79, 1.22)0.94 0.98 0.15 0.93 6.21 6.09 Time spent providing care (0.02, 1.56)(0.48, 1.85)(0.41, 2.08)(0.65, 59.03)(0.68, 54.18)(0.59, 1.64)Appraisal of caregiving situation Lack of confidence in EOL caregiving 227 0.59 0.37* 0.26* 0.16* 0.63 (0.79, 6.67)(0.28, 1.24)(0.15, 0.93)(0.10, 0.65)(0.07, 0.39)(0.35, 1.15)0.79* Subjective caregiving burden 1.67* 0.79* 0.48* 0.48* 1.01 (CRA score) (1.02, 2.70)(0.66, 0.94)(0.67, 0.94)(0.30, 0.76)(0.30, 0.77)(0.94, 1.08)Psychological resources 1.75* 1.35* 1.61* 0.77* 0.92 1.19* (SOC score) (1.35, 2.27) (1.12, 1.61)(1.32, 2.00)(0.65, 0.91)(0.80, 1.06)(1.06, 1.35)

0.61

SDS, Symptom Distress Scale; CRA, Caregiving Reaction Assessment; SOC, Sense of Coherence scale. *b < 0.05.

"chronically distressed" trajectory) followed by a sharp decrease to around the clinical threshold. We called this trajectory "resilience" to indicate "bouncing back" from stress rather than immunity from an adverse situation [38]. Consistent with the literature, caregivers in the "resilience" trajectory may be in a more vulnerable position than those in other trajectories when they first transitioned into the caregiving role because they are more likely to be the patient's spouse [32], have more education [15], be unable to make ends meet [10,28], provide more intense assistance [30,32] to a younger terminally ill relative, [3,28] and have weaker personal psychological resources [29,30]. However, these "resilience" caregivers are older [28], possibly facilitating their transition to the caregiving role. Caregiving often conflicts with the demands of other social roles, for example,

child-rearing, employment, and goal attainment, which are more relevant and stressful roles for younger caregivers. Furthermore, caregivers in the "resilience" trajectory more positively appraised the caregiving situation, as indicated by having greater confidence in providing EOL care [15,30] and perceiving less subjective caregiving burden. These findings may characterize their capacity to adapt flexibly to the challenges of EOL caregiving, allowing them to rapidly bounce back to healthy psychological functioning [39].

Caregivers in trajectories characterized by persistently severe (i.e., chronically distressed) and by moderate (i.e., moderately symptomatic) depressive symptoms were differentiated only by weaker psychological resources [29,30]. Being embedded in difficult caregiving circumstances and lacking the benefits of inner strength (i.e., SOC) to find meaning in caregiving or clearly comprehend and appropriately manage caregiving demands probably contributed to the highest depressive-symptom level.

This study's strengths include the large sample followed prospectively and frequent assessments of caregiver depressive symptoms over the entire patient dying process. Nevertheless, the generalizability of our findings may be limited by convenience sampling from a specific geographic area and by biases due to losses during follow-up. Our study was also limited by assessing depressive symptoms with a questionnaire rather than diagnostic interviews and by not including the potential impact of other factors, such as available social support, upholding cultural values, and expectations of caregiving, on depressive-symptom trajectories. Before caregivers enrolled in our study or shouldered the caregiving role, no reliable assessment of their depressive symptoms was available. This information would likely have strongly predicted depressive symptoms while providing EOL care. Therefore, we cannot rule out the possibility that our observations may be anchored in situations that preceded the decades in which these trajectories took shape.

In conclusion, our study demonstrates that caregivers of terminally ill cancer patients do not have uniform emotional responses to EOL caregiving; rather, they follow qualitatively distinct depressive-symptom trajectories. These trajectories are linked to their experiences as caregivers, particularly their objective caregiving demands, appraisals of the caregiving situation, and psychological resources. Our results on distinct depressive-symptom trajectories and factors associated with

different longitudinal patterns of depressive symptoms have strong clinical and policy implications. Because resources for mental health services are limited, interventions should be prioritized to interrupting the two unfavorable high depressive-symptom trajectories and facilitating rapid return to healthy psychological functioning for caregivers in the "resilience" trajectory. Our predictive models may serve healthcare professionals in developing trajectory-specific interventions tailored to risk and protective factors identified for each depressive-symptom trajectory. Research is urgently needed on caregiver depressive symptoms beyond patient death to understand how these four distinct trajectories extend into bereavement [40-42] and how they impact caregivers' bereavement adjustment. This information would guide clinicians in understanding and relieving the emotional toll exacted by family caregiving before patient death and throughout bereavement.

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Conflict of interest

No financial or other conflict of interest was involved in this study. None of the funding sources had any role in designing and conducting the study: collecting, managing, analyzing, and interpreting the data; or preparing, reviewing, or approving the manuscript.

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