Original Article

Courses of Change in Good Emotional Preparedness for Death and Accurate Prognostic Awareness and Their Associations With Psychological Distress and Quality of Life in Terminally Ill Cancer Patients' Last Year of Life

Siew Tzuh Tang, DNSc, Wen-Chi Chou, MD, Wen-Cheng Chang, MD, Jen-Shi Chen, MD, Chia-Hsun Hsieh, MD, Fur-Hsing Wen, PhD, and Shih-Chi Chung, PhD

School of Nursing (S.T.T., S.-C.C.), Medical College, Chang Gung University, Tao-Yuan; Department of Nursing (S.T.T.), Chang Gung Memorial Hospital at Kaohsiung, Kaohsiung; Division of Hematology-Oncology (S.T.T., W.-C. Chou, W.-C. Chang, J.-S.C., C.-H.H.), Chang Gung Memorial Hospital at Linkou; Chang Gung University College of Medicine (W.-C. Chou, W.-C. Chang, J.-S.C., C.-H.H.), Tao-Yuan; and Department of International Business (F.-H.W.), Soochow University, Taipei, Taiwan, R.O.C.

Abstract

Context. Emotional preparedness for death is a distinct but related concept to prognostic awareness (PA). Both allow patients to prepare psychologically and interpersonally for death, but they have primarily been examined in cross-sectional studies.

Objectives. To 1) explore the courses of change in good emotional preparedness for death and accurate PA and 2) evaluate their associations with severe anxiety symptoms, severe depressive symptoms, and quality of life in cancer patients' last year.

Methods. For this prospective, longitudinal study, we consecutively recruited 277 terminally ill cancer patients. Aims 1 and 2 were examined by univariate and multivariate generalized estimating equation analyses, respectively.

Results. The prevalence of good emotional preparedness for death was 54.43%−65.85% in the last year, with a significant decrease only 91−180 vs. 181−365 days before death (odds ratio [95% CI] = 0.67 [0.47, 0.97]). Good emotional preparedness for death was associated with a lower likelihood of severe anxiety symptoms (adjusted odds ratio [95% CI] = 0.47 [0.27, 0.79]) and severe depressive symptoms (0.61 [0.39, 0.95]), but not with quality of life (β [95% CI] = 0.49 [−2.13, 3.11]). However, accurate PA improved substantially (55.12%−70.73%) as death approached and accurate PA was positively associated with severe depressive symptoms (2.63 [1.63, 4.25]).

Conclusion. Good emotional preparedness for death and accurate PA remained largely stable and improved substantially, respectively, in cancer patients' last year. Both measures were significantly associated with psychological distress. Health care professionals should not only cultivate accurate PA but also promote cancer patients' emotional preparedness for death, which may improve their psychological well-being. J Pain Symptom Manage 2019;58:623−631. © *2019 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.*

Key Words

Death preparedness, anxiety, depression, quality of life, oncology, cancer, end-of-life

Introduction

Improving the quality of dying, death, and end-of-life (EOL) care is a priority in health care systems.[1] To achieve a good death, patients must not only receive adequate symptom relief, realize psychological well-being, and have good quality of life (QOL),[1] but also prepare for EOL and their forthcoming death, an important dimension of the quality of dying and death identified by terminally ill patients.[2]

Address correspondence to: Siew Tzuh Tang, DNSc, School of Nursing, Medical College, Chang Gung University, 259, Wen-Hwa 1st Road, Kwei-Shan, Tao-Yuan, 333, Taiwan, R.O.C. E-mail: sttang@mail.cgu.edu.tw

Accepted for publication: June 25, 2019.

© 2019 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

0885-3924/$ - see front matter
https://doi.org/10.1016/j.jpainsymman.2019.06.022

Death preparedness involves transitioning to an awareness and acceptance of one's forthcoming death.[3,4] Death preparedness, a multidimensional construct including cognitive, emotional, social, and behavioral components,[2–5] allows patients to prepare, psychologically, interpersonally, and practically, for death.[2–5] Cognitively accurate prognostic awareness (PA) is a prerequisite for informed EOL care to improve EOL-care quality by limiting potentially futile anticancer and life-sustaining treatments[6,7] and promoting care concordant with one's values and wishes.[6,8]

However, accurate PA does not guarantee emotional preparedness for death.[9–11] Cognitive PA and emotional preparedness for death are distinct but related concepts,[5] although the distinction between these two concepts has never been empirically investigated. Emotional preparedness for death reflects emotional acceptance of the dying role[12] and the situation imposed by the dying process, including becoming realistic within the constraints of present circumstances, relinquishing one's unattainable future, and preparing one's loved ones for life without oneself.[12] Indeed, peacefully accepting one's terminal illness, compared with cognitively accurate PA, is associated with lower levels of anxiety and depressive symptoms, post-traumatic distress, and psychiatric disorders, as well as greater spiritual well-being at EOL,[10,11,13,14] and better quality of death and dying.[10]

Among the studies on cancer patients' emotional acceptance/preparedness for death,[9–11,13–19] only one[18] is from an Asian country (Taiwan) where people avoid discussing death and dying, two taboo topics.[20] Death preparedness for Asian patients may not be the same as for those in Western countries. Furthermore, perceptions of death preparedness are dynamic,[3] but all existing studies except one[18] are cross-sectional, and two studies[11,17] used panel data organized by the interval between data collection and death. Death acceptance was shown to increase,[17] decrease,[18] or not change[11] as death approached. Therefore, how emotional preparedness for death changes over cancer patients' dying process remains unclear. Finally, associations of death preparedness with psychological distress and QOL were commonly evaluated[10,11,14–16,19] without adjusting for well-recognized covariates, including time-invariant (e.g., gender[21,22] and age)[22,23] and time-varying (e.g., symptom distress,[21] functional dependency,[21] and social support).[24] To address these shortcomings, we designed this study to preliminarily evaluate the distinction between emotional preparedness for death and accurate PA by 1) longitudinally investigating their courses of change and 2) evaluating their associations with psychological distress and QOL while adjusting for well-recognized covariates over terminal cancer patients' last year.

Methods

Study Design and Sample

For this prospective, longitudinal study, consecutive eligible adult (≥20 years old) cancer patients were recruited from August 2015 through July 2018 from a medical center in northwest Taiwan and followed through December 2018. Patients were referred by their oncologists when they first recognized the patients' cancer as terminal and the patients as cognitively competent to communicate with data collectors.

Procedures

Eligible patients were referred to experienced, trained oncology nurses who explained the study, invited patients to participate, and collected participants' data. Participants were interviewed in person while they were hospitalized and approximately every four weeks thereafter (when they returned for outpatient visits or were re-hospitalized) until they declined to participate or died. The research ethics committee of the study site approved the research protocol (103-7015B). All subjects provided written informed consent.

Measures

Primary Independent Variables. *Emotional preparedness for death* was measured by the five-item Preparation for End-of-Life subscale of the Quality of Life at the End-of-Life (QUAL-E) scale (QUAL-E Preparation for EOL subscale),[15,25] whose development was based on qualitative research on perceptions of a good death.[2] The QUAL-E Preparation for EOL subscale assesses the extent of concerns about impending issues related to one's forthcoming death, for example, financial strain, being a burden to family, family preparation for and ability to cope with one's death/dying, reflection on life regrets, and fear of dying, which are concerns for terminal Asian cancer patients.[26,27] Furthermore, when we launched this study, death preparedness/emotional acceptance of illness was measured in most studies[9,10,14,17,18] by a single question, raising concerns about measurement validity because death preparedness is a multidimensional construct.[2,5] Among other studies on this topic, four[13,15,16,19] assessed death preparedness using the same instrument as this study, whereas one used the Peace, Equanimity, and Acceptance in the Cancer Experience scale.[11] This scale assesses patients' sense of acceptance, calmness, and peace as well as their struggle or desperation concerning their illness. These concerns are reflected in two items of the QUAL-E Preparation for EOL subscale, that is, "reflection on life regrets" and "fear of dying," but the Peace, Equanimity, and Acceptance in the Cancer Experience scale lacks items for concerns about being a

burden to family and family preparation for and ability to cope with the patient's death/dying. The last two issues are especially important in a family-oriented Confucian society[26,28] like Taiwan's. Therefore, we used the QUAL-E Preparation for EOL subscale to measure emotional preparedness for death.

Example items of the QUAL-E Preparation for EOL subscale are "At times, I worry that I will be a burden to my family" and "I have regrets about the way I have lived my life." Each item is measured on a five-point Likert scale, with the total score ranging from 5 (poor preparation) to 25 (excellent preparation). To derive a binary measure of emotional preparedness for death, the total score is dichotomized into "with" (≥19, the median score in this study) and "without" (<19) good emotional preparedness for death."[13] Internal consistency of this subscale was 0.68−0.73[15,16] and 0.72 in this study. Test-retest reliability and divergent and convergent construct validity were well established.[15]

PA was measured by asking patients whether they knew their prognosis, and if so, whether their disease 1) was curable; 2) might recur in the future, but their life was not currently in danger; and 3) could not be cured, or they would probably die soon.[18] Patients were recognized as having accurate PA only if they chose option 3; inaccurate PA reflected not knowing their prognosis or choosing option 1 or 2. This measure of PA was developed based on a literature review and Taiwanese physicians' cultural practice of prognostic disclosure. The validity of this measure is supported by its reflecting PA conceptualizations and measures used in a 34-study review of PA,[29] and its use showing that accurate PA was significantly associated with life-sustaining treatment preferences[30] as well as QOL, anxiety and depressive symptoms[18] over terminally ill Taiwanese cancer patients' last year.

Outcome Measures. *Anxiety and depressive symptoms* were measured by the Hospital Anxiety and Depression Scale (HADS).[31] The 14-item HADS, the most widely used tool for assessing psychological distress in cancer patients under palliative care,[32] has seven items measuring anxiety (HADS-A) and seven measuring depression (HADS-D). The HADS assesses psychological symptoms rather than physiological symptoms, thus avoiding confounding measures that may overestimate anxiety or depression severity for cancer patients who commonly suffer from multiple physical symptoms. The HADS-A and HADS-D subscales each has a total score ranging from 0 to 21; higher scores indicate more anxiety or depressive symptoms. Severe anxiety and depressive symptoms were identified as HADS-A and HADS-D scores ≥11, respectively.[31]

QOL was measured by a modified 13-item McGill Quality of Life Questionnaire (MQOL).[33] The original MQOL stresses psychological, social, and existential well-being. The MQOL was modified by omitting three items for the most distressing symptoms to avoid overlap with the known effect of symptom distress on QOL but retaining the item for evaluating overall physical well-being. Total scores for this modified MQOL range from 0 to 130; higher scores indicate better QOL.

Time-Varying Covariates. To reflect our longitudinal data, that is, each participant had subject-specific responses at different data-collection times, we adjusted for time-varying covariates shown to influence the three outcome variables. Each covariate was measured with a well-established instrument with detailed, published psychometric information.

Physical symptom distress from cancer patients' common symptoms (e.g., pain, dyspnea, anorexia, and insomnia) was measured using the 13-item Symptom Distress Scale.[34] Scores range from 13 to 65; higher scores indicate greater symptom distress.

Functional impairment was measured by the 10-item Enforced Social Dependency Scale.[35] Scores range from 10 to 51; higher Enforced Social Dependency Scale scores reflect greater impairment in personal and social functioning.

Social support was measured by the 19-item Medical Outcomes Study Social Support Survey.[36] The Medical Outcomes Study Social Support Survey assesses emotional, informational, tangible, and affectionate support, as well as positive social interaction.[36] For each subscale, total sums are computed, and the raw subscale scores are transformed to a 0−100 scale. Higher scores indicate better perceived social support.

Time-Invariant Covariates. We controlled for time-invariant variables, that is, demographics (age, gender, marital status [married/unmarried], educational attainment [≤ or >junior high school], financial sufficiency [financial sufficiency (making ends meet) and financial strain], and religious affiliation [none, Buddhism/Taoism, and Christianity/Catholicism]) and disease characteristics (time since diagnosis at enrollment, whether the disease is metastatic, and comorbidity) associated with the three outcome variables. Comorbidity was calculated by the Deyo-Charlson comorbidity index, categorized as 0, 1, 2, or ≥3 comorbid conditions.[37]

Statistical Analysis

To explore longitudinal changes in emotional preparedness for death and accurate PA during the dying

process, time proximity to patient death, that is, the period between death and day of data collection, was categorized as one to 30, 31−90, 91−180, and 181−365 days as conventionally used in estimating terminal cancer patients' survival. Univariate logistic and multiple regression models with the generalized estimating equation (GEE)[38] were conducted to examine the courses of change in good emotional preparedness for death and accurate PA as well as severe anxiety symptoms, severe depressive symptoms, and QOL over participants' last year, respectively. Multivariate logistic and linear regression models with the GEE were used to examine the associations of good emotional preparedness for death and accurate PA with severe anxiety symptoms and severe depressive symptoms as well as QOL over the last year, respectively, while controlling for time-varying and time-invariant covariates. The GEE uses robust standard error estimates to account for within-subject correlations[38] of emotional preparedness for death, HADS-A, HADS-D, and MQOL scores during follow-ups and to accommodate variable numbers of follow-ups, inconsistent intervals between subsequent data collections, and missing data for the outcome variables. GEE uses all outcome variables available in each specific period to construct the model, eliminating the need to delete observations in analyses or to impute missing data. The regression estimate for each independent variable in the logistic regression models was exponentiated to transform into adjusted odds ratio (AOR) with 95% CI.

Results

Participant Characteristics

Of 572 eligible patients, 344 were enrolled (60.1% participation), with participation declined primarily because of physical weakness ($n = 213$). Characteristics of patients who did and did not participate cannot be compared because of restricted access to information about those who refused participation. At the end of follow-ups, 53 participants were still alive, and 14 had participated on average 115.29 days (SD = 187.69, range 19−748, median = 54.5) before they withdrew primarily because of physical weakness. Participants who died during the study ($N = 277$) comprised the final sample. The three groups (sample, withdrew, and alive) were not different in demographics or disease characteristics, except more participants in the sample had accurate PA and severe depressive symptoms than those who withdrew and were still alive, respectively (data not shown).

For details of participants' baseline demographics, disease characteristics, prevalence of good emotional preparedness for death, prevalence of accurate PA, and the three outcome variables, see Table 1. After enrollment, participants survived 119.04 days (SD = 143.82, range one to 964, median = 67.0), with 59 (21.3%), 110 (39.7%), 54 (19.5%), and 54 (19.5%) patients surviving one to 30, 31−90, 91−180, and 181−365 days after enrollment, respectively. At enrollment, less than one-tenth of participants were under hospice care (9.0%), with 84.5% under hospice care in the last month. Participants completed on average 3.81 follow-up assessments (SD = 2.96, median = 3, range one to 13) in their last year, and 45 participants (16.3%) were assessed only once. The following results are based on 1054 assessments with a mean interval between interviews of 28.52 days (SD = 12.89, range one to 123, median = 28). At one to 30, 31−90, 91−180, and 181−365 days before death, 212, 204, 104, and 54 participants received 246, 366, 237, and 205 assessments, respectively.

Courses of Change in Good Emotional Preparedness for Death, Accurate PA, Psychological Distress, and QOL in Participants' Last Year

The prevalence of good emotional preparedness for death was 65.85%, 54.43%, 58.20%, and 57.72% at 181−365, 91−180, 31−90, and one to 30 days before death, respectively. Good emotional preparedness for death changed significantly only 91−180 days relative to 181−365 days before death by univariate GEE analysis (OR [95% CI] = 0.67 [0.47, 0.97]; Table 2). In contrast, accurate PA increased significantly as death approached (prevalence increased from 55.12% to 70.73% at 181−365 vs. one to 30 days before death, and OR [95% CI] ranged from 1.51 [1.07, 2.15] to 3.21 [1.98, 5.18] relative to 181−365 days before death; Table 2).

Severe anxiety-symptom prevalence (HADS-A score ≥11) 181−365, 91−180, 31−90, and one to 30 days before death was 6.83%, 9.70%, 8.47%, and 22.76%, respectively. Unadjusted GEE analysis showed that the closer the time to patient death, the higher the likelihood of severe anxiety symptoms, but this likelihood was only significant in the last month relative to 181−365 days before death (OR [95% CI] = 2.99 [1.63, 5.49]; Table 2). However, after controlling for covariates in multivariate GEE analysis, severe anxiety-symptom prevalence did not change significantly as death approached (Table 3). Similarly, the likelihood of severe depressive symptoms increased as death approached. In unadjusted GEE, this likelihood increased significantly in the last three months relative to 181−365 days before death (Table 2), whereas multivariate analysis showed no significant changes in severe depressive-symptom prevalence as death approached (Table 3). Despite the raw data showing that QOL decreased as death approached (Table 2), this downward trend was significant only

for one to 30 days (β [95% CI] = -3.76 [−6.94, −0.58]) before death in adjusted analyses (Table 3).

Associations of Good Emotional Preparedness for Death and Accurate PA with Psychological Distress and QOL in Participants' Last Year

Scores on the QUAL-E Preparation for EOL subscale were significantly correlated with HADS-D, HADS-A, and MQOL scores in each period before death (Appendix). Good emotional preparedness for death significantly reduced the likelihood of both severe anxiety symptoms (AOR [95% CI] = 0.47 [0.27, 0.79]) and severe depressive symptoms (AOR [95% CI] = 0.61 [0.39, 0.95]) after controlling for covariates (Table 3). However, QOL did not differ for participants with or without good emotional preparedness for death (β [95% CI] = 0.49 [−2.13, 3.11]). In addition, participants with accurate PA were more likely to experience severe depressive symptoms (AOR [95% CI] = 2.63 [1.63, 4.25]), whereas accurate PA was not associated with either the likelihood of severe anxiety symptoms or QOL.

Discussion

We found that good emotional preparedness for death decreased slightly as death become imminent (from 65.85% to 57.72%), with a significant change only 91−180 vs. 181−365 days before death, contrary to the substantial improvement in accurate PA (from 55.12% to 70.73%) as death approached. Furthermore, severe anxiety symptoms and severe depressive symptoms may not be inevitable as death approaches and were significantly associated with good emotional preparedness for death and accurate PA. QOL at EOL became significantly worse in the last month but was not associated with good emotional preparedness for death or accurate PA.

PA and emotional preparedness for death are distinct but related cognitive and affective concepts, respectively,[5] despite cognitively acknowledging one's forthcoming death being a prerequisite for initiating the process of emotionally preparing for death.[39] The assertion that PA and emotional preparedness for death are distinct concepts is supported by our finding of different courses of change for these variables as death approached. Our participants' good emotional preparedness for death decreased slightly over their last year, whereas they gradually developed accurate PA near EOL, as reported.[17,18,40] Our participants' predominantly stable prevalence of good emotional preparedness for death over their last year is consistent with reports of no change[11] or a downward trend[18] in peaceful acceptance, but contrary to a report that peaceful awareness increased as death approached.[17] Preparedness for death are broader and more highly emotionally laden than cognitive awareness of one's poor prognosis because they involve gaining psychological insights into one's inevitable and imminent death (in contrast to intellectually

Table 1
Participants' Baseline Demographic and Disease-Related Characteristics ($N = 277$)

Parameter	*n* (%)
Gender	
Male	216 (78.0)
Female	61 (22.0)
Age, yrs	
≤45	23 (8.3)
46−55	70 (25.3)
56−65	117 (42.2)
>65	67 (24.2)
Marital status ($n = 276$)	
Married	242 (87.7)
Unmarried	34 (12.3)
Religious affiliation ($n = 276$)	
Taoism/Buddhism	218 (79.0)
Christianity/Catholicism	22 (8.0)
None	36 (13.0)
Educational attainment ($n = 276$)	
≤Junior high school	158 (57.2)
>Junior high school	118 (42.8)
Better emotional preparedness for death[a]	
Yes	190 (68.6)
No	87 (31.4)
Accurate prognostic awareness	
Yes	162 (58.8)
No	115 (41.5)
Cancer site	
Liver	67 (24.2)
Pancreas	48 (17.3)
Stomach	42 (15.2)
Esophagus	39 (14.1)
Lung	18 (6.5)
Breast	8 (2.9)
Head and neck	8 (2.9)
Colon-rectum	6 (2.2)
Others	41 (14.8)
Metastasis	
Yes	265 (95.7)
No	12 (4.3)
Comorbidities[b]	
0	75 (27.1)
1	98 (35.4)
2	62 (22.4)
≥3	42 (15.2)
Severe anxiety symptoms	
Yes	138 (49.8)
No	139 (50.2)
Severe depressive symptoms	
Yes	35 (12.6)
No	242 (87.4)
	Mean (SD)
Emotional preparedness for death	19.12 (3.63)
Anxiety symptoms	6.09 (3.95)
Depressive symptoms	10.49 (4.60)
Quality of life	83.71 (19.16)
Symptom distress	26.25 (6.29)
Functional dependence	27.52 (7.52)
Social support	64.93 (9.41)
Time since diagnosis	11.78 (20.68)

[a]Preparation for End-of-Life subscale of the QUAL-E scale score ≥19.
[b]Measured by the Deyo-Charlson comorbidity index.

Table 2
Changes in Better Emotional Preparedness for Death, Accurate Prognostic Awareness, Severe Anxiety Symptoms, Severe Depressive Symptoms, and Quality of Life Over Participants' Last Year of Life

Time proximity to death											
Parameter	Better Emotional Preparedness for Death		Accurate Prognostic Awareness		Severe Anxiety Symptoms		Severe Depressive Symptoms		Quality of Life		
Days	%	OR (95% CI)	%	OR (95% CI)	%	OR (95% CI)	%	OR (95% CI)	M (SD)	β	95% CI
1–30	57.72	0.72 (0.47–1.11)	70.73	3.21[a] (1.98–5.18)	22.76	2.99[a] (1.63–5.49)	78.46	4.53[a] (2.60–7.91)	71.22 (17.74)	−16.50[a]	−20.26 to −12.74
31–90	58.20	0.70 (0.47–1.04)	68.31	2.09[b] (1.37–3.17)	8.47	1.12 (0.61–2.07)	62.57	2.10[b] (1.32–3.35)	80.10 (17.90)	−8.10[a]	−11.59 to −4.61
91–180	54.43	0.67[c] (0.47–0.97)	64.14	1.51[c] (1.07–2.15)	9.70	1.22 (0.72–2.07)	54.43	1.23 (0.84–1.79)	85.14 (17.09)	−2.38	−5.44 to 0.68
181–365	65.85	Ref	55.12		6.83	Ref	44.88	Ref	88.68 (18.69)	Ref	

At one to 30, 31–90, 91–180, and 181–365 days before death, 212, 204, 104, and 54 participants received 246, 366, 237, and 205 assessments, respectively.
[a] $P < 0.001$.
[b] $P < 0.005$.
[c] $P < 0.05$.

acknowledging one's demise) and closing, reconciling, and renewing bonds with one's family members.[2,4,5,12] Without active interventions to counteract Taiwan's current clinical practice of not discussing or family-consent discussions of EOL-care issues,[41] the goal of facilitating good emotional preparedness for death as death approaches may not be easily achieved. However, the significant decrease in good emotional preparedness for death between 91–180 and 181–365 days before death warrants further in-depth investigation, preferably by qualitative research, despite this finding being based on univariate analysis without adjusting for potential confounders.

The assertion that cognitive PA and emotional preparedness for death are distinct but related concepts[5] is further supported by our finding that they had inverse associations with severe depressive symptoms in participants' last year. As reported, good emotional preparedness for death decreased,[10,11,14] whereas accurate PA increased[7,41] our participants' likelihood of severe depressive symptoms. Furthermore, good emotional preparedness for death buffered our participants' severe anxiety symptoms, whereas no association was found with accurate PA. Our results confirm reports that accurate PA without emotionally preparing for one's imminent death precipitates

Table 3
Associations of Participants' Good Emotional Preparedness for Death and Accurate Prognostic Awareness With Severe Anxiety Symptoms, Severe Depressive Symptoms, and Quality of Life

	Severe Anxiety Symptoms		Severe Depressive Symptoms		Quality of Life		
Variable	AOR (95% CI)	*P*-value	AOR (95% CI)	*P*-value	β	95% CI	*P*-value
Time proximity to patient death, d							
1–30	0.89 (0.37–2.17)	0.798	1.00 (0.46–2.17)	0.999	−3.76	−6.94 to −0.58	0.020
31–90	0.61 (0.28–1.35)	0.226	0.85 (0.46–1.57)	0.596	−2.41	−4.91 to 0.10	0.060
91–180	1.00 (0.51–1.97)	0.995	0.87 (0.50–1.49)	0.604	0.08	−2.22 to 2.39	0.944
181–365	Ref		Ref		Ref		
Good emotional preparedness for death							
Yes	0.47 (0.27–0.79)	0.005	0.61 (0.39–0.95)	0.028	0.49	−2.13 to 3.11	0.714
No	Ref		Ref		Ref		
Accurate prognostic awareness							
Yes	1.25 (0.66–2.37)	0.488	2.63 (1.63–4.25)	<0.001	−1.51	−4.22 to 1.20	0.274
No	Ref		Ref		Ref		
Social support	0.92 (0.88–0.95)	<0.001	0.86 (0.83–0.89)	<0.001	0.44	0.31 to 0.58	<0.001
Symptom distress	1.06 (1.03–1.09)	<0.001	1.23 (1.18–1.28)	<0.001	−0.68	−0.81 to −0.54	<0.001
Functional dependence	1.04 (1.00–1.08)	0.044	1.07 (1.04–1.10)	<0.001	−0.45	−0.59 to −0.31	<0.001

AOR = adjusted odds ratio.
We controlled for time-invariant covariates: age, gender, marital status, educational attainment, financial sufficiency, religious affiliation, time since diagnosis at enrollment, metastatic status, and comorbidities.

psychological distress for terminally ill cancer patients at EOL,[10,18] probably because of insights about one's inevitable demise.

Preparation for death has been positively associated with emotional, social, and spiritual well-being,[15,16] thereby improving QOL. However, after controlling for covariates, we did not find an association between good emotional preparedness for death and QOL in our participants' last year, as found with univariate analysis only.[19] We did find positive associations with QOL for good emotional preparedness for death before controlling for well-established time-varying covariates (social support, symptom distress, and functional dependence). Each time-varying covariate was significantly associated with QOL in the expected direction (data not shown). Therefore, terminal cancer patients' QOL may have been more compromised and enhanced by their symptom distress/functional impairment and perceived social support, respectively, than by the extent of emotional preparedness for their forthcoming death.

Study Strengths and Limitations

Strengths of our study include its prospective, longitudinal design to illustrate the courses of change in good emotional preparedness for death and accurate PA as well as their associations with psychological distress and QOL, appropriately adjusting for well-known covariates for terminal cancer patients, and its Asian perspective where these topics are seldom explored. However, our findings should be interpreted with some caveats. Participants were recruited consecutively from a single medical center in Taiwan, limiting representativeness of the national and international target populations and generalizability of our results. Indeed, patients with lung cancer and ≥65 years old were substantially underrepresented in our sample. Our sample comprised a younger cohort than that of many palliative care samples, which may partially explain our moderate and stable prevalence of good emotional preparedness and high prevalence of severe anxiety and depressive symptoms. Indeed, elderly cohorts typically show a greater acceptance of dying[11,13,14] as they are more likely to develop a deep sense of fulfillment and become more prepared for death over their life trajectory. A substantial proportion of patients (19.5%) withdrew from the study or were still alive at the end of the study, preventing generalization of our findings to those patients. Despite the QUAL-E Preparation for EOL subscale being recognized as culturally and conceptually appropriate to measure emotional preparedness for death in terminal Taiwanese cancer patients and its face validity being supported by the high prevalence of good emotional preparedness for death in our participants' last year, further investigation is warranted on the comprehensiveness of its items to capture the concept of emotional preparedness for death. Our measure of PA was developed based on Taiwanese physicians' cultural practice of prognostic disclosure and reflects PA conceptualizations and measures in a 34-study review of PA,[29] but its psychometric properties need to be validated, especially for international populations. Anxiety and depression were screened using the HADS rather than psychiatrists' diagnostic interviews, possibly overestimating the prevalence of severe anxiety symptoms and severe depressive symptoms but avoiding the failure to recognize terminal cancer patients' need for psychological support. Associations of psychological distress and QOL with good emotional preparedness for death and accurate PA do not imply causal relationships in this observational study and may be related to unmeasured factors, for example, physician-patient EOL-care discussions, health care professional support,[15,42] personal coping capacities or strategies,[43] and family caregivers' preparedness for death.[3]

Conclusions

Good emotional preparedness for death among terminal cancer patients remained largely stable as death approached, with a significant decrease only 91−180 vs. 181−365 days before death. Good emotional preparedness for death was significantly associated with a lower likelihood of severe anxiety symptoms and severe depressive symptoms, but was not associated with QOL in participants' last year. In contrast, participants' accurate PA improved substantially as death approached and was associated with an increased likelihood of severe depressive symptoms. Health care professionals should not only cultivate cancer patients' accurate PA to facilitate high-quality[6,7] and value-concordant EOL care,[6,8] but also promote their emotional preparedness for death to improve their psychological well-being at EOL.

Disclosures and Acknowledgments

This study was funded by the Ministry of Science and Technology (MOST 104-2314-B-182-027-MY), National Health Research Institutes (NHRI-EX108-10704PI), and Chang Gung Memorial Hospital (BMRP888).

The authors declare no financial or other conflict of interest.

No funding sources had any role in designing and conducting the study; collecting, managing, analyzing,

and interpreting the data; or preparing, reviewing, or approving the article.

References

1. Institute of Medicine. Dying in America: Improving quality and honoring Individual preferences near the end of life. Washington, DC: The National Academies Press, 2014.

2. Steinhauser KE, Christakis NA, Clipp EC, et al. Factors considered important at the end of life by patients, family, physicians, and other care providers. JAMA 2000;284:2476–2482.

3. Hebert RS, Prigerson HG, Schulz R, Arnold RM. Preparing caregivers for the death of a loved one: a theoretical framework and suggestions for future research. J Palliat Med 2006;9:1164–1171.

4. McLeod-Sordjan R. Death preparedness: a concept analysis. J Adv Nurs 2013;70:1008–1019.

5. Prigerson HG, Maciejewski PK. Grief and acceptance as opposite sides of the same coin: setting a research agenda to study peaceful acceptance of loss. Br J Psychiatry 2008;193:435–437.

6. Mack JW, Weeks JC, Wright AA, et al. End-of-life discussions, goal attainment, and distress at the end of life: predictors and outcomes of receipt of care consistent with preferences. J Clin Oncol 2010;28:1203–1208.

7. El-Jawahri A, Traeger L, Park ER, et al. Associations among prognostic understanding, quality of life, and mood in patients with advanced cancer. Cancer 2014;120:278–285.

8. Lundquist G, Rasmussen BH, Axelsson B. Information of imminent death or not: does it make a difference? J Clin Oncol 2011;29:3927–3931.

9. Lokker ME, van Zuylen L, Veerbeek L, van der Rijt CC, van der Heide A. Awareness of dying: it needs words. Support Care Cancer 2012;20:1227–1233.

10. Ray A, Block SD, Friedlander RJ, et al. Peaceful awareness in patients with advanced cancer. J Palliat Med 2006;9:1359–1368.

11. Mack JW, Nilsson M, Balboni T, et al. Peace, Equanimity, and Acceptance in the Cancer Experience (PEACE): validation of a scale to assess acceptance and struggle with terminal illness. Cancer 2008;112:2509–2517.

12. Emanuel L, Bennett K, Richardson VE. The dying role. J Palliat Med 2007;10:159–168.

13. Wentlandt K, Burman D, Swami N, et al. Preparation for the end of life in patients with advanced cancer and association with communication with professional caregivers. Pscyho-Oncol 2012;21:868–876.

14. Thompson GN, Chochinov HM, Wilson KG, et al. Prognostic acceptance and the well-being of patients receiving palliative care for cancer. J Clin Oncol 2009;27:5757–5762.

15. Steinhauser KE, Clipp EC, Bosworth HB, et al. Measuring quality of life at the end of life: validation of the QUAL-E. Palliat Support Care 2004;2:3–14.

16. Lo C, Burman D, Swami N, et al. Validation of the QUAL-EC for assessing quality of life in patients with advanced cancer. Eur J Cancer 2011;47:554–560.

17. Lichtenthal WG, Nilsson M, Zhang B, et al. Do rates of mental disorders and existential distress among advanced stage cancer patients increase as death approaches? Psycho-Oncol 2009;18:50–61.

18. Tang ST, Chang WC, Chen JS, et al. Associations of prognostic awareness/acceptance with psychological distress, existential suffering, and quality of life in terminally ill cancer patients' last year of life. Psycho-Oncol 2016;25:455–462.

19. Adorno G, Wallace C. Preparation for the end of life and life completion during late-stage lung cancer: an exploratory analysis. Palliat Support Care 2017;15:554–564.

20. McDermott E, Selman LE. Cultural factors influencing advance care planning in progressive, incurable disease: a systematic review with narrative synthesis. J Pain Symptom Manage 2018;56:613–636.

21. Spencer R, Nilsson M, Wright A, Pirl W, Prigerson H. Anxiety disorders in advanced cancer patients: correlates and predictors of end-of-life outcomes. Cancer 2010;116:1810–1819.

22. Linden W, Vodermaier A, Mackenzie R, Greig D. Anxiety and depression after cancer diagnosis: prevalence rates by cancer type, gender, and age. J Affect Disord 2012;141:343–351.

23. Quinten C, Coens C, Ghislain I, et al. The effects of age on health-related quality of life in cancer populations: a pooled analysis of randomized controlled trials using the European Organisation for Research and Treatment of Cancer (EORTC) QLQ-C30 involving 6024 cancer patients. Eur J Cancer 2015;51:2808–2819.

24. Kroenke CH. A conceptual model of social networks and mechanisms of cancer mortality, and potential strategies to improve survival. Transl Behav Med 2018;8:629–642.

25. Steinhauser KE, Bosworth HB, Clipp EC, et al. Initial assessment of a new measure of quality of life at the end of life (QUAL-E). J Palliat Med 2002;5:829–842.

26. Tang ST, Hsieh CH, Chiang MC, et al. Impact of high self-perceived burden to others with preferences for end-of-life care and its determinants for terminally ill cancer patients: a prospective cohort study. Psycho-Oncol 2017;26:102–108.

27. Lee JE, Shin DW, Cho J, et al. Caregiver burden, patients' self-perceived burden, and preference for palliative care among cancer patients and caregivers. Psycho-Oncol 2015;24:1545–1551.

28. Lai KL. Confucian moral thinking. Philos East West 1995;45:249–272.

29. Chen CH, Kuo SC, Tang ST. Current status of accurate prognostic awareness in advanced/terminally ill cancer patients: systematic review and meta-regression analysis. Palliat Med 2017;31:406–418.

30. Tang ST, Wen FH, Hsieh CH, et al. Preferences for life-sustaining treatments and associations with accurate prognostic awareness and depressive symptoms in terminally ill cancer patients' last year of life. J Pain Symptom Manage 2016;51:41–51.

31. Zigmond AS, Snaith RP. The hospital anxiety and depression scale. Acta Psychiatr Scan 1983;67:361–370.

32. Wasteson E, Brenne E, Higginson IJ, et al. Depression assessment and classification in palliative cancer patients: a systematic literature review. Palliat Med 2009;23:739–753.

33. Cohen SR, Mount BM, Tomas JJN, et al. Existential well-being is an important determinant of quality of life. Evidence from the McGill Quality of Life Questionnaire. Cancer 1996;77:576–586.

34. McCorkle R, Young K. Development of a symptom distress scale. Cancer Nurs 1978;1:373–378.

35. Benoliel JQ, McCorkle R, Young K. Development of a social dependency scale. Res Nurs Health 1980;3:3–10.

36. Sherbourne CD, Stewart AL. The MOS social support survey. Soc Sci Med 1991;32:705–714.

37. Deyo RA, Cherkin DC, Ciol MA. Adapting a clinical comorbidity index for use with ICD-9-CM administrative databases. Clin Epidemiol 1992;45:613–619.

38. Diggle P, Liang KY, Zeger SL. Analysis of longitudinal data. New York: Oxford University Press, 2002.

39. Jennings J, Galupo M, Cartwright K. The role of postformal cognitive development in death acceptance. J Adult Devel 2009;16:166–172.

40. Burridge LH, Barnett AG, Clavarino AM. The impact of perceived stage of cancer on carers' anxiety and depression during the patients' final year of life. Psycho-Oncol 2009;18:615–623.

41. Tang ST, Chen CH, Wen FH, et al. Accurate prognostic awareness facilitates, whereas better quality of life and more anxiety symptoms hinder end-of-life care discussions: a longitudinal survey study in terminally ill cancer patients' last six months of life. J Pain Symptom Manage 2018;55:1068–1076.

42. Cripe LD, Rawl SM, Schmidt KK, et al. Discussions of life expectancy moderate relationships between prognosis and anxiety or depression in men with advanced cancer. J Palliat Med 2012;15:99–105.

43. Nipp RD, Greer JA, El-Jawahri A, et al. Coping and prognostic awareness in patients with advanced cancer. J Clin Oncol 2017;35:2551–2557.

Appendix

Appendix

Correlations Between Scores of the Preparation for End-of-Life Subscale of the QUAL-E Scale and HADS-D, HADS-A, and MQOL by Time Proximity to Death

Time Proximity to Death, d	HADS-D	HADS-A	MQOL
1−30	−0.371	−0.402	0.288
31−90	−0.409	−0.341	0.192
91−180	−0.424	−0.416	0.200
181−365	−0.545	−0.524	0.461

QUAL-E scale = Quality of Life at the End-of-Life scale; HADS-D = Depression subscale of the Hospital Anxiety and Depression Scale; HADS-A = Anxiety subscale of the Hospital Anxiety and Depression Scale; MQOL = McGill Quality of Life Questionnaire.
All correlation coefficients are significant ($P < 0.001$).