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Factors of prolonged-grief-disorder symptom trajectories for ICU bereaved family surrogates

Fur-Hsing Wen¹, Holly G. Prigerson^{2,3}, Li-Pang Chuang⁴, Tsung-Hui Hu⁵, Chung-Chi Huang^{4,6}, Wen-Chi Chou^{7,8} and Siew Tzuh Tang^{7,9,10,11*} 

Abstract

Background Bereaved people experience distinct trajectories of prolonged-grief-disorder (PGD) symptoms. A few studies from outside critical care investigated limited factors of PGD-symptom trajectories without a theoretical framework. We aimed to characterize factors associated with ICU bereaved surrogates' PGD-symptom trajectories, drawing from the integrative framework of predictors for bereavement outcomes, emphasizing factors modifiable by ICU care.

Methods Prospective cohort study of 291 family surrogates. Multinomial logistic regression was used to determine associations of three previously identified PGD-symptom trajectories (resilient [n = 242, 83.2%] as reference group, recovery [n = 35, 12.0%], and chronic [n = 14, 4.8%]) with risk factors. Factors included intrapersonal (demographics, personal vulnerabilities), interpersonal (perceived social support), bereavement-related (patient demographics, clinical characteristics, and patient-surrogate relationship), and death-circumstance (surrogate-perceived quality of patient dying and death [QODD] in ICUs classified as high, moderate, poor-to-uncertain, and worst QODD classes) factors.

Results Most surrogates were female (59.1%), the patient's adult child (54.0%), and about (standard deviation) 49.63 (12.53) years old. As surrogate age increased, recovery-trajectory membership decreased (adjusted odds ratio [95% confidence interval] = 0.918 [0.849, 0.993]) and chronic-trajectory membership increased (1.230 [1.010, 1.498]). Being married decreased membership in the recovery (0.186 [0.047, 0.729]) trajectory. Higher anxiety symptoms 1 month post loss increased membership in recovery (1.520 [1.256, 1.840]) and chronic (2.022 [1.444, 2.831]) trajectories. Spouses were more likely and adult-child surrogates were less likely than other relationships to be in the two more profound PGD-symptom trajectories. Membership in the chronic trajectory decreased (0.779 [0.614, 0.988]) as patient age increased. The poor-to-uncertain QODD class was associated with a nearly significant increase (4.342 [0.980, 19.248]) in membership in the recovery trajectory compared to the high QODD class.

Conclusions Membership in the PGD-symptom trajectories was associated with factors modifiable by high-quality ICU care, including anxiety symptoms at early bereavement and surrogate-perceived QODD in the ICU. Clinicians should be sensitive to the psychological needs of at-risk family surrogates, provide high-quality end-of-life care to facilitate QODD, and promptly refer bereaved surrogates who suffer anxiety symptoms and profound and/or persistent PGD-symptoms for psychological support.

Keywords ICU care, Prolonged grief disorder, Quality of dying and death, Symptom trajectories, Family surrogates

*Correspondence:

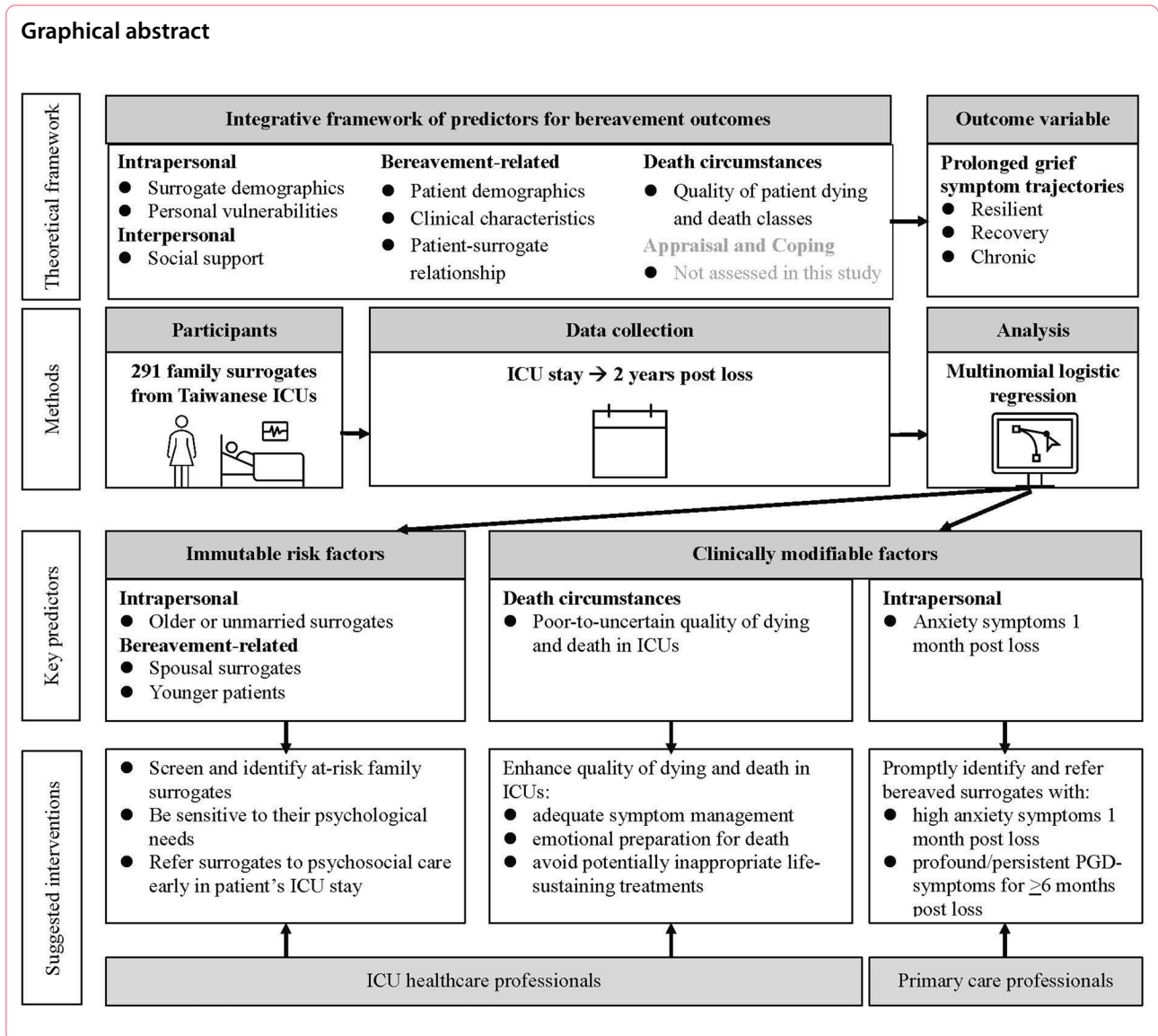
Siew Tzuh Tang

sttang@mail.cgu.edu.tw

Full list of author information is available at the end of the article



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Introduction

Death in an intensive care unit (ICU) occurs frequently [1] and increasingly [2]. Most bereaved family members of ICU decedents recover from the loss [3], whereas a significant minority remain stuck in chronic grief and suffer prolonged declines in psychological functioning without resolution, leading to prolonged grief disorder (PGD) [4]. PGD causes major functional impairment [5], low quality of life [5], substance misuse [6], and increased risk of suicidal thoughts and behaviors [5].

Research [7–20] shows that after the loss of a loved one, PGD symptoms evolve in complex ways characterized as distinct PGD-symptom trajectories. Resilient, recovery, and chronic trajectories are common across studies [7–20], except that the resilient trajectory was absent in

one [15], and the recovery trajectory was absent in two [10, 16] studies. The resilience trajectory shows low and stable PGD symptoms throughout bereavement. For the recovery trajectory, PGD symptoms peak early then gradually drop below the clinical threshold. Bereaved in the chronic trajectory suffer PGD symptoms well above threshold throughout bereavement. Bereaved in more distressed PGD-symptom trajectories (i.e., recovery and chronic trajectories) report worse mental health [7, 14], greater suicidal ideation [8], poorer quality of life [8] coupled with impaired psychological, social, and occupational functioning [14, 16, 17], greater use of preloss primary care and psychotropic medications (sedatives/antidepressants) [21], and poorer responses to postloss psychotherapy [7], highlighting the necessity to identify

bereaved vulnerable to more distressed PGD-symptom trajectories.

Abundant research explores risk factors of PGD/PGD symptoms shown by a systematic review of 120 studies on 61,580 bereaved who suffered all kinds of losses [22] and by systematic reviews specific to adult refugees exposed to traumatic losses (12 studies) [23], adult survivors of violent losses (30 studies) [24], and bereaved family of palliative care patients (17–18 studies) [25, 26] or ICU decedents (7 studies) [27]. In contrast, only a handful of studies investigated factors associated with heterogeneous PGD-symptom trajectories [7, 10, 12, 13, 15–18, 28]. Existing studies are virtually all from Western countries except one from Taiwan [28], though grief is indeed affected by culture [29]. Furthermore, according to the integrative framework of risk factors for bereavement outcomes [30], intrapersonal, interpersonal, and contextual (e.g., death circumstance and bereavement-related) risk factors interplay with the individual's appraisal and coping, thus conjointly influencing bereavement outcomes. All existing studies explored demographics in the intrapersonal domain (gender [7, 10, 12, 13, 15–18, 28], age [7, 10, 12, 13, 16, 18, 28], education) [10, 13, 16, 18, 28], followed by bereavement-related factors including type of loss [10, 12, 15, 16, 18, 28] and time since loss [7, 18]. Fewer studies examined interpersonal risk factors (e.g., social support [7, 10, 12, 15, 28], or attachment) [18] or intrapersonal vulnerability (previous psychological distress [15–17, 28], financial adequacy [10, 28], or coping appraisal/strategies) [7, 15, 17, 18, 28], and fewest explored circumstance of death (perceived nature of the death or preparedness for the death) [7, 10, 28]. Of note, no existing studies identified factors associated with membership in distinct PGD-symptom trajectories among ICU bereaved family members. Post-ICU family bereavement commonly follows an intense deterioration and dying process [1, 2]; thus, opportunities to prevent long-lasting PGD occur both during and after the end-of-life (EOL)-ICU care period. These opportunities can be seized by targeting modifiable clinical factors. Therefore, the purpose of this study was to characterize factors associated with ICU bereaved family surrogates' membership in the distinct PGD-symptom trajectories drawing from the integrative framework of predictors for bereavement outcomes [30] emphasizing factors modifiable by high-quality EOL-ICU care.

Methods

Design, context, and participants

This study extends our prior identification of distinct comorbid (PGD, posttraumatic stress disorder, depressive) symptom trajectories for family surrogates of ICU decedents [31] by focusing on PGD-symptom

trajectories using data from our primary longitudinal, observational study on effects of quality of EOL ICU care on family surrogates' bereavement adjustment [32, 33]. We have reported sampling strategy and characteristics of patients, family surrogates, and study settings [31–33]. We consecutively recruited the primary family-surrogate decision maker of critically ill patients (Acute Physiology and Chronic Health Evaluation [APACHE] II score > 20 at enrollment) from level III medical ICUs at two academically affiliated Taiwanese hospitals from January 2018 to March 2020 and followed them through December 2022. Enrolled surrogates signed informed consent for participation and for reviewing their patient's medical record. The study was approved by the study site's research ethics committee (201700343B0). This study was reported according to the Strengthening the Reporting of Observational Studies in Epidemiology reporting guideline for cohort studies.

Outcome variable: PGD-symptoms trajectories

Symptoms of PGD were measured by 11 items of the Prolonged Grief-13 scale [8], including one separation distress symptom, nine cognitive and emotional symptoms, and one functional impairment symptom. The two dichotomous items of the original PG-13 regarding duration and impairment criteria were excluded because these items measure dimensions other than grief symptoms. Frequency of symptoms in the preceding month was rated on a 5-point Likert scale (1 = never, 5 = always). Only data collected since 6 months post loss were used in modeling PGD-symptom trajectories to accommodate the PGD duration criterion [8].

We previously identified three latent PGD-symptom trajectories using latent growth mixture modeling by the best combination of model fit indices, highest entropy, smallest class size > 5% of the total sample, and clinical meaningfulness either individually for PGD symptoms or simultaneously with PTSD and depression symptoms [31] (Online Data Supplement 1). These trajectories were classified as resilient ($n = 242$, 83.2%), recovery ($n = 35$, 12.0%), and chronic ($n = 14$, 4.8%) PGD-symptom trajectories [31]. PGD-symptom levels for the resilient trajectory were low and decreased significantly throughout the first two years of bereavement. The recovery PGD-symptom trajectory indicates moderately high PGD symptoms at 6 months post loss and a steep initial decline followed by decreases in the rate of resolution of PGD symptoms over the first two years of bereavement. A chronic trajectory had high PGD symptoms at 6 months post loss that persisted throughout the first two years of bereavement.

Independent variables

Factors associated with family surrogates' membership in PGD-symptom trajectories were examined based on the integrative framework of predictors for bereavement outcomes [30], except for appraisal and coping which was not assessed in this study. Details on measurement of each risk factor are in Online Data Supplement 2.

Intrapersonal risk factors were surrogates' sociodemographics and personal vulnerabilities, e.g., financial hardship, preexisting health problems, and anxiety symptoms. Anxiety was measured by the anxiety subscale of the Hospital Anxiety and Depression Scale [34]. This subscale has 7 items measuring anxiety symptoms and a total score ranging from 0 to 21; higher scores indicate more anxiety symptoms. Depressive symptoms were not included because we previously modeled PTSD-symptom trajectories with PGD and depression symptoms simultaneously which showed high co-occurrence of the three symptom trajectories [31].

Interpersonal risk factors were indicated by perceived social support measured by the Medical Outcomes Study Social Support Survey [35].

Bereavement-related stressors included type of loss (indicated by patient-surrogate relationship) and the decedents' demographics and clinical characteristics.

Death circumstances were indicated by surrogate-perceived quality of the patient's dying and death in ICUs [36]. Quality of dying and death in ICUs was measured by the Quality of Dying and Death (QODD) questionnaire [36] across six domains: symptoms and personal care, family concerns, preparation for death, treatment received, whole person concerns, and moment of death [36]. We previously conducted latent class analysis to examine the frequency component evaluated from none to always or existence (yes or no) with options of "don't know" to identify four QODD latent classes [37]: high, moderate, poor to uncertain, and worst QODD class (Online Data Supplement 3). QODD classes differ by physical symptom control, emotional preparedness for death, and amount of life-sustaining treatments received [38].

Data collection

Intrapersonal risk factors (surrogate demographics and preexisting health problems) and bereavement-related stressors were collected at enrollment, except for APACHE scores which were abstracted from medical records throughout the patient's ICU stay. Patient quality of dying and death was assessed at 1 month post loss by phone interviews. Surveys of surrogates' anxiety symptoms and perceived social support were conducted by phone interviews at 1, 3, 6, 13, 18, and 24 months post loss, whereas PGD symptoms were assessed at 6, 13, 18,

and 24 months post loss to comply with the duration criterion for $PGD \geq 6$ months [8] and to avoid measuring the anniversary effect at 12 months post loss.

Data analysis

Factors associated with membership in PGD-symptom trajectories were identified by a multinomial logistic regression model in MPlus using resilient trajectory as reference. Each participant was assigned to their most probable trajectory determined by the posterior probabilities of trajectory membership. Lagged time-varying variables of anxiety symptoms, perceived social support, and surrogate-perceived quality of dying and death were measured at 1 month post loss to establish a clear time sequence of associations with the outcome variable. The effect of each independent variable was represented as adjusted odds ratio (AOR) with 95% confidence interval (CI).

Results

Participant characteristics

A total sample of 291 bereaved family surrogates provided complete data on the independent variables and any data on the outcome variable from 6 months post loss. Detailed characteristics of the whole sample and across the three PGD-symptom trajectories are in Table 1. Most surrogates were female (59.1%), married (74.6%), the patient's adult child (54.0%), and on average (standard deviation) 49.63 (12.53) years old. Few had preexisting physical-mental problems that required pain medications (12.0%), emergency room visits (6.9%) or hospitalization (4.8%). Overall anxiety symptoms measured at the first month post loss were low (3.92 [3.66] out of 21) but higher in the recovery and the chronic trajectories than the resilience trajectory. Four distinct QODD classes (prevalence) were identified: high (40.9%), moderate (20.3%), poor-to-uncertain (22.3%), and worst (16.5%) QODD classes.

Factors of PGD-symptom trajectories

Surrogate demographics were generally not associated with PGD-symptom trajectories, except for age and marital status (Table 2). Increasing age was associated with decreased (AOR [% CI]: 0.918 [0.849, 0.993]) membership in the recovery trajectory and increased (1.230 [1.010, 1.498]) membership in the chronic trajectory relative to the resilient trajectory. Being married significantly decreased surrogates' membership in the recovery trajectory (0.186 [0.047, 0.729]).

Personal vulnerability (financial hardship to make ends meet, emergency room visits or use of pain medication in the year prior to the patient's critical illness) and interpersonal risk factors (strength of perceived social

Table 1 Independent variables across the three distinct PGD-symptom states (N=291)

PGD-symptom trajectories	Resilient (n = 242, 83.2%)	Recovery (n = 35, 12.0%)	Chronic (n = 14, 4.8%)	Total (N = 291)
<i>Variables</i>				
Family demographics and predisposing vulnerabilities				
Age (M [SD])	49.27 [11.94]	50.63 [16.63]	53.29 [10.68]	49.63 [12.53]
Gender (n [%])				
Male	104 [43.0]	12 [34.3]	3 [21.4]	119 [40.9]
Female	138 [57.0]	23 [65.7]	11 [78.6]	172 [59.1]
Educational attainment (n [%])				
> Senior high school	205 [84.7]	24 [68.6]	10 [71.4]	239 [82.1]
< Senior high school	37 [15.3]	11 [31.4]	4 [28.6]	52 [17.9]
Marital status (n [%])				
Married	182 [75.2]	23 [65.7]	12 [85.7]	217 [74.6]
Unmarried	60 [24.8]	12 [34.3]	2 [14.3]	74 [25.4]
Financial insufficiency to make ends meet (n [%])				
Yes	27 [11.2]	6 [17.1]	8 [57.1]	41 [14.1]
No	215 [88.8]	29 [82.9]	6 [42.9]	250 [85.9]
Hospitalizations (n [%])				
Yes	14 [5.8]	0 [0.0]	0 [0.0]	14 [4.8]
No	228 [94.2]	35 [100.0]	14 [100.0]	277 [95.2]
Emergency room visits (n [%])				
Yes	18 [7.4]	1 [2.9]	1 [7.1]	20 [6.9]
No	224 [92.6]	34 [97.1]	13 [92.9]	271 [93.1]
Use of pain medications (n [%])				
Yes	31 [12.8]	2 [5.7]	2 [14.3]	35 [12.0]
No	211 [87.2]	33 [94.3]	12 [85.7]	256 [88.0]
Anxiety symptoms (M [SD])	2.98 [2.45]	8.00 [4.63]	10.07 [5.40]	3.92 [3.66]
Interpersonal risk factors				
Perceived social support (M [SD])	74.61 [12.65]	63.72 [18.58]	64.95 [18.88]	72.74 [14.38]
<i>Bereavement-related stressors</i>				
Type of loss: relationship with the patient (n [%])				
Spouse	57 [23.6]	17 [48.6]	11 [78.6]	85 [29.2]
Child	143 [59.1]	14 [40.0]	0 [0.0]	157 [54.0]
Others	42 [17.3]	4 [11.4]	3 [21.4]	49 [20.8]
Patient demographics and disease characteristics				
Age (M [SD])	67.62 [13.60]	65.40 [15.23]	48.57 [11.88]	66.43 [14.28]
Gender (n [%])				
Male	157 [64.9]	16 [45.7]	10 [71.4]	183 [62.9]
Female	85 [35.1]	19 [54.3]	4 [28.6]	108 [37.1]
Diagnosis (n [%])				
Cancer	117 [48.3]	18 [51.4]	10 [71.4]	145 [49.8]
Non-cancer	125 [51.7]	17 [48.6]	4 [28.6]	146 [50.2]
APACHE II score before patient death (M [SD])	32.66 [5.81]	32.94 [6.64]	29.00 [4.13]	32.52 [5.88]
Length of ICU stay (M [SD])	14.36 [12.89]	13.60 [11.17]	16.57 [17.54]	14.37 [12.91]
<i>Death circumstances</i>				
Classes of family surrogates' perceived quality of dying and death for ICU patients (n [%])				
High quality of dying and death	108 [44.6]	6 [17.1]	5 [35.7]	119 [40.9]
Moderate quality of dying and death	47 [19.4]	9 [25.7]	3 [21.4]	59 [20.3]
Poor-to-uncertain quality of dying and death	50 [20.7]	14 [40.0]	1 [7.1]	65 [22.3]
Worst quality of dying and death	37 [15.3]	6 [17.1]	5 [35.7]	48 [16.5]

APACHE: Acute Physiology and Chronic Health Evaluation; ICU: intensive care unit; M: mean; PGD: prolonged-grief disorder; SD: standard deviation

Table 2 Factors associated with PGD-symptom trajectories for bereaved surrogates of ICU decedents

PGD-symptom trajectories	Recovery			Chronic				
	AOR	95% CI	<i>p</i>	AOR	95% CI	<i>p</i>		
<i>Intrapersonal risk factors</i>								
Family demographics and preexisting mental health or medical conditions in the year before the patients' critical illness								
Gender (Male vs Female)	1.229	0.401	3.769	0.918	0.044	0.001	1.582	0.087
Age	0.918	0.849	0.993	0.033	1.230	1.010	1.498	0.040
Educational attainment (> vs ≤ senior high school)	0.321	0.102	1.007	0.051	0.519	0.079	3.387	0.493
Marital status (Married vs unmarried)	0.186	0.047	0.729	0.016	0.005	0.000	1.343	0.063
Financial insufficiency to make ends meet (Yes vs no)	0.499	0.136	1.836	0.296	2.326	0.364	14.873	0.372
Emergency room visits (Yes vs no)	0.354	0.017	7.381	0.503	5.985	0.179	199.788	0.317
Use of pain medications (Yes vs no)	0.503	0.072	3.515	0.488	0.239	0.023	2.287	0.231
Anxiety symptoms	1.520	1.256	1.840	<0.001	2.022	1.444	2.831	<0.001
<i>Interpersonal risk factors</i>								
Perceived social support	0.970	0.931	1.010	0.137	1.020	0.927	1.122	0.690
<i>Bereavement-related stressors</i>								
Type of loss: Relationship with the patient (vs Others)								
Spouse	9.056	1.086	75.507	0.042	575.620	1.244	+	0.042
Child	0.133	0.021	0.844	0.032	0.002	0.000	0.353	0.019
Patient demographics and disease characteristics								
Age	1.044	0.993	1.096	0.091	0.779	0.614	0.988	0.039
Gender (Male vs Female)	0.249	0.061	1.017	0.053	0.110	0.009	1.373	0.087
Diagnosis (Cancer vs non-cancer)	1.447	0.499	4.195	0.496	5.577	0.443	70.231	0.184
APACHE II score before patient death	1.035	0.955	1.122	0.402	0.939	0.777	1.135	0.516
Length of ICU stay	1.017	0.978	1.057	0.393	1.032	0.943	1.128	0.497
<i>Death circumstances</i>								
Classes of family surrogates' perceived quality of dying and death for ICU patients (vs high quality of dying and death)								
Moderate	0.677	0.117	3.911	0.663	0.119	0.008	1.761	0.122
Poor-to-uncertain	4.342	0.980	19.248	0.053	0.364	0.008	16.437	0.603
Worse	2.625	0.496	13.904	0.256	7.671	0.184	319.809	0.284

Bold indicates significant associations; Bold with italics indicates nearly significant associations

AOR: adjusted odds ratio; APACHE: Acute Physiology and Chronic Health Evaluation; CI: confidence interval; ICU: intensive care unit; PGD: prolonged-grief disorder

support) were not associated with surrogates' membership in PGD-symptom trajectories (Table 2). In contrast, higher anxiety symptoms measured at the first month of bereavement increased membership in the recovery (1.520 [1.256, 1.840]) and chronic (2.022 [1.444, 2.831]) trajectories.

Bereavement-related stressors were not associated with surrogates' membership in PGD-symptom trajectories (Table 2), except type of loss (spousal or parental losses vs losses other than spousal or adult-child relationship with the patient) and patient age. Spouses were more likely and adult-child surrogates were less likely than other relationships to be in the two more profound PGD-symptom trajectories. Bereaved surrogates of older patients

were less likely to be in the chronic trajectory. Membership in the chronic trajectory decreased (0.779 [0.614, 0.988]) with each year increase in patient age.

Death-circumstance factors indicated as surrogate-perceived patient QODD class was associated with trajectory membership. Surrogates in the poor-to-uncertain and worst QODD classes were generally more likely to be in the two more profound PGD trajectories than the high QODD class (Table 1). However, only the association between the poor-to-uncertain QODD class and membership in the recovery trajectory nearly reached statistical significance: surrogates' perception of their loved one's quality of dying and death in ICUs as poor to uncertain increased membership in the recovery trajectory

(4.342 [0.980, 19.248], $p=0.053$) compared to the resilient trajectory.

Discussion

Our longitudinal study confirmed the utility of the integrative framework of predictors for bereavement outcomes [30], except for interpersonal risk factors, in characterizing ICU bereaved family surrogates' membership in the three distinct PGD-symptom trajectories over their first two bereavement years. We observed that membership in the PGD-symptom trajectories was associated with surrogate age, marital status, anxiety symptoms 1 month post loss, kinship with their loved one, patient age, and surrogate perception of their loved one's quality of dying and death in the ICU.

Older surrogates saw decreased likelihood for the recovery trajectory and increased likelihood for the chronic PGD-symptom trajectory relative to the resilient trajectory. Existing studies generally observed no association between bereaved persons' age and their membership in PGD-symptom trajectories [7, 12, 16, 28]. Still, younger bereaved caregivers of dementia patients were more often found in the high-grief than the low-grief trajectory [10], and younger caregivers predominantly of cancer patients were more likely to be in a trajectory characterized by preloss moderate-to-high grief symptoms which declined significantly after the patient's death until three years post loss [13]. Both studies align with our observation that younger surrogates were more likely to be in the recovery trajectory than were elderly surrogates. Younger individuals may initially experience higher levels of grief symptoms due to inexperience with death of a loved one and struggle with multiple responsibilities in family and work, but they may have greater resources to gradually cope with and recover from the loss [13, 39]. Furthermore, bereaved surrogates' membership in the chronic trajectory increased with their age. Age may bring on health vulnerabilities [40] that complicate coping with the loss of a long-term meaningful relationship, thereby increasing their likelihood of being in the chronic PGD-symptom trajectory.

Marriage is significantly associated with lower likelihood of membership in the recovery PGD-symptom trajectory relative to the resilient trajectory. This has never been reported in previous studies. Marital status is of vital importance for health [41], including physical [42, 43] and psychological [44] well-being. We extend this line of evidence to the protective effect of marriage in buffering more profound PGD symptoms at the early stage of bereavement for ICU surrogates.

We found the personal vulnerability of higher anxiety symptoms at the first month post loss significantly increased bereaved surrogates' membership in

the recovery and chronic PGD-symptom trajectories. This aligns with literature on the role of more depressive symptoms [15, 28] and lower mental health [13, 17] before loss. Compromised mental health like higher anxiety symptoms at early bereavement incapacitates surrogates' acceptance of and adequate adjustment to the loss, thereby increasing risk of more profound and long-lasting PGD-symptom trajectories as in the recovery and chronic PGD-symptom trajectories.

In the bereavement-related stressors domain, we confirmed previous reports that a spousal loss increased membership in the recovery [28] and chronic [16] PGD-symptom trajectories, whereas adult-child surrogates were less likely to be in the two more profound and long-lasting PGD-symptom trajectories [28]. However, no relationship was observed [10, 15], whereas losing a child was associated with more profound and chronic trajectories [12, 18] which could not be detected in our study due to the small sample of parental surrogates. Spousal surrogates' increased membership in recovery and chronic trajectories may be attributable to the mutual dependency and long-lasting intimacy common to spousal relationships, whereas adult-child surrogates may be more likely to accept the death of an elderly parent, thereby decreasing intensity and duration of grief reactions.

Older age of the ICU decedents decreased surrogates' membership in the chronic PGD-symptom trajectory. In Chinese/Taiwanese culture, dying young defies filial piety, subverts family expectations of growing up healthy, and prevents one from fulfilling major life milestones like parenting and employment [45]. Death at this age is "premature," thus, bereaved surrogates of younger ICU decedents may suffer persistent, profound PGD symptoms such as lack of acceptance and sense-making of their loved one's death throughout their first two bereavement years. In contrast, age brings greater acceptance of progressing illness and impending mortality, and death in older age is seen as "nature taking its course" [45], thereby decreasing the likelihood of being in the chronic PGD-symptom trajectory.

Our most novel findings concerned the associations between death-circumstance factors evaluated as QODD classes and bereaved surrogates' membership in the PGD-symptom trajectories. Poor-to-uncertain or worst QODD classes generally led to the recovery and chronic PGD-symptom trajectories (Table 1), but due to the small sample size of the chronic trajectory (4.2%), only the association between the poor-to-uncertain QODD class and recovery trajectory neared statistical significance. Surrogates of ICU patients in the poor-to-uncertain QODD latent class perceived that their loved one suffered more from inadequate control of pain and dyspnea, insufficient/uncertain emotional preparedness for

death, and more life-sustaining treatments than those in the high QODD latent class [37, 38]. Ott and colleagues [7] reported that bereaved spouses in the recovery and chronic trajectories perceived the death as less peaceful than those in the resilient trajectory. Cancer caregivers who perceived their loved one as better prepared for death and with greater symptom control suffered less intense PGD symptoms [46], whereas a recent systematic review of QODD for ICU decedents indicated that effective management of patient pain and physical symptoms was associated with higher QODD [47]. Painful memories of unrelieved pain or dyspnea, uncertain or insufficient patient emotional preparedness for death, and patient suffering from frightening life-sustaining treatments may preclude bereaved surrogate acceptance and sense-making of the patient's death, leading to more profound PGD symptoms, especially at early bereavement.

Several limitations should be acknowledged. Recruiting surrogates of critically ill patients from two medical centers in Taiwan may limit representativeness of (inter) national target populations and those who experience unnatural causes of loss. Our sample size may not have sufficient power to precisely estimate associations of the recovery and chronic trajectories with several independent variables (e.g., personal vulnerability [financial hardship to make ends meet, emergency room visits or use of pain medication in the year prior to the patient's critical illness], strength of perceived social support, and the worst QODD class) in our multinomial logistic regression model. In this observational study, a causal relationship cannot be inferred between predictors and PGD-symptom trajectories, nor can we exclude the potential impact of unmeasured covariates, especially considering that predictors from the appraisal and coping domain were excluded in this study. Future research should explore the role of surrogates' appraisal of the loss (e.g., negative cognitive appraisal) [18], quality of relationship [7, 10, 18], and their coping strategies (e.g., optimism, neuroticism) [17, 18].

Conclusion

Clinically modifiable factors associated with bereaved ICU surrogates' membership in the two more distressed PGD-symptom trajectories included anxiety symptoms at early bereavement and surrogate-perceived QODD in the ICU. These two variables point to valuable strategies for supporting at-risk ICU family surrogates and reducing risk of profound and/or long-lasting PGD symptom trajectories. First, ICU clinicians should screen and identify at-risk family surrogates (e.g., older, unmarried, or spouse of younger patients), be sensitive to their psychological needs, and refer them for appropriate psychosocial care early while

their patient is dying in ICUs. Most importantly, ICU clinicians should enhance critically ill patients' QODD by providing high-quality EOL care through adequate symptom management, facilitating emotional preparedness for death, and avoiding potentially inappropriate life-sustaining treatments. Primary care professionals should promptly identify and refer bereaved surrogates who early in bereavement suffer high anxiety symptoms (at 1 month post loss) or profound/persistent PGD-symptoms (for 6 months post loss) for psychological support. Such high-quality ICU EOL and bereavement care actions not only benefit critically ill patients when they are dying in ICUs but also facilitate surrogates' bereavement adjustment by avoiding profound and long-lasting PGD-symptoms.

Abbreviations

AOR	Adjusted odds ratio
APACHE	Acute physiology and chronic health evaluation
CI	Confidence interval
EOL	End of life
ICU	Intensive care unit
PGD	Prolonged grief disorder
QODD	Quality of dying and death

Supplementary Information

The online version contains supplementary material available at <https://doi.org/10.1186/s13054-024-05160-2>.

Additional file 1

Author contributions

WFH, PHG, CLP, HTH, HCC, CWC, and TST contributed substantially to the study conception and design. CLP, HTH, HCC, CWC contributed by providing study patients. CLP, HTH, HCC, CWC, and TST contributed to collection and/or assembly of data. WFH, CLP, HTH, HCC, CWC, and TST contributed to data analysis and interpretation. WFH, PHG, CLP, HTH, HCC, CWC, and TST contributed to the writing and final approval of the manuscript. The corresponding author (Tang ST) takes responsibility for the content of the manuscript, has full access to all of the data in the study, and is responsible for the integrity of the data, the accuracy of the data analysis, including and especially any adverse effects. Other contributors: Language Editor: Erica Light.

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Availability of data and materials

The sharing of anonymized data from this study is restricted due to ethical and legal constrictions. Data contains sensitive personal health information, which is protected under The Personal Data Protection Act in Taiwan, thus making all data requests subject to Institutional Review Board (IRB) approval. Per Study Hospital IRB, the data that support the findings of this study are restricted for transmission to those in the primary investigative team. Data sharing with investigators outside the team requires IRB approval. All requests for anonymized data will be reviewed by the research team and then submitted to the Study Hospital IRB for approval. Upon approval from the IRB, the data supporting the findings of this study are available from the corresponding author upon reasonable request.

Code availability

Specifications for MPlus codes for statistical analyses are available from the first and corresponding authors upon reasonable request.

Declarations

Ethics approval and consent to participate

This study was conducted with the approval for human subject research of the central Institutional Review Board of the study sites (Chang Gung Medical Foundation, Institutional Review Board; approval number: 201700343B0; approval date: March 20, 2017; study title: Impact of end-of-life care quality in intensive care units on adjustment of bereaved family members). Study procedures were followed in accordance with the ethical standards of the responsible committee on human experimentation (institutional) and with the Helsinki Declaration of 1975. Each family surrogate signed informed consent for participation.

Competing interests

The authors declare no competing interests.

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Author details

¹Department of International Business, Soochow University, Taipei City, Taiwan, ROC. ²Department of Radiology, Weill Cornell Medicine, New York City, NY, USA. ³Department of Medicine, Weill Cornell Medicine, New York City, NY, USA. ⁴Department of Internal Medicine, Division of Pulmonary and Critical Care Medicine, Chang Gung Memorial Hospital at Linkou, Tao-Yuan, Taiwan, ROC. ⁵Department of Internal Medicine, Division of Hepato-Gastroenterology, Chang Gung Memorial Hospital at Kaohsiung, Kaohsiung, Taiwan, ROC. ⁶Department of Respiratory Therapy, Chang Gung University, Tao-Yuan, Taiwan, ROC. ⁷Division of Hematology-Oncology, Chang Gung Memorial Hospital at Linkou, Tao-Yuan, Taiwan, ROC. ⁸School of Medicine, Chang Gung University, Tao-Yuan, Taiwan, ROC. ⁹School of Nursing, Medical College, Chang Gung University, 259 Wen-Hwa 1st Road, Kwei-Shan, Tao-Yuan 333, Taiwan, ROC. ¹⁰Department of Nursing, Chang Gung University of Science and Technology, Tao-Yuan, Taiwan, ROC. ¹¹Department of Nursing, Chang Gung Memorial Hospital at Kaohsiung, Kaohsiung, Taiwan, ROC.

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