Associations Between Surrogates’ Decisional Regret Trajectories and Bereavement Outcomes

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Background
Caregivers’ uncompensated support1 during end-of-life (EoL) cancer care is an important societal asset that attenuates patient suffering and dependence on formal services for which our society would otherwise pay.1 However, caregivers bear sizable physical,2 psychological,3,4 and financial5 costs. Such profound EoL caregiving impact does not end with the patient’s death but extends into bereavement,6 a period well-known for depression and prolonged grief disorder (PGD)7 that burden personal health,8,9 and subsequently, healthcare systems.10,11

Family caregivers act as surrogate decision-makers for most patients at EoL, who face physical deterioration or mental incapacity.12 Surrogate EoL decisions are especially difficult, emotion-laden, urgent, and potentially life changing.13 EoL surrogate decision-making can have both short-term14 and long-term15,16 negative impacts on caregivers, including anxiety, depression, posttraumatic stress disorder, and regret. Regret is central to decision-making and a common consequence of value-laden/preference-sensitive decisions such as surrogate EoL decisions.17,18 Cognitive processes throughout the decision-making period aim to reduce postdecisional regret, particularly for unfavorable outcomes,19 and to avoid negative bereavement outcomes that can last several months or years.15,16 Indeed, higher decisional regret is associated with worse bereavement outcomes, including increased symptoms of anxiety,20 depression,21 and PGD.21

Still, findings on the relationship between regret and bereavement outcomes are mixed. No associations were observed between regret and parental depression or anxiety.22 A study23 using a newly developed regret instrument

ABSTRACT

Background: Family surrogates experience heterogeneous decisional regret and negative long-lasting postdecisional impacts. Cross-sectional findings on the associations between decisional regret and surrogates’ bereavement outcomes are conflicting and cannot illustrate the direction and dynamic evolution of these associations. In this study, we sought to longitudinally examine the associations between 4 previously identified decisional-regret trajectories and bereavement outcomes among family surrogates of terminally ill patients with cancer. Patients and Methods: This prospective, longitudinal, observational study included 377 family surrogates. Decisional regret was measured using the 5-item Decision Regret Scale, and 4 decisional regret trajectories were identified: resilient, delayed-recovery, late-emerging, and increasing-prolonged. Associations between bereavement outcomes (depressive symptoms, prolonged grief symptoms, and physical and mental health-related quality of life [HRQoL]) and decisional-regret trajectories were examined simultaneously by multivariate hierarchical linear modeling using the resilient trajectory as a reference. Results: Surrogates in the delayed-recovery, late-emerging, and increasing-prolonged trajectories experienced significantly higher symptoms of prolonged grief ($\beta$ [95% CI], 1.815 [0.782 to 2.848]; 2.312 [0.834 to 3.790]; and 7.806 [2.681 to 12.931], respectively) and poorer physical HRQoL ($-1.615 \pm 2.844$ to $-0.386$); $-1.634 \pm 3.226$ to $-0.042$; and $-4.749 \pm 9.380$ to $-0.118$, respectively) compared with those in the resilient trajectory. Membership in the late-emerging and increasing-prolonged trajectories was associated with higher symptoms of depression ($\beta$ [95% CI], 2.942 [1.045 to 4.839] and 8.766 [2.844 to 14.668], respectively), whereas only surrogates in the increasing-prolonged decisional-regret trajectory reported significantly worse mental HRQoL ($-4.823 \pm 8.216$ to $-1.430$) than those in the resilient trajectory. Conclusions: Surrogates who experienced delayed-recovery, unresolved, or late-emerging decisional regret may carry ceaseless doubt, guilt, or self-blame for patient suffering, leading to profound symptoms of prolonged grief, depressive symptoms, and worse HRQoL over their first 2 bereavement years.

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instead of the common and well-established Decision Regret Scale (DRS)\textsuperscript{19} found bereaved family members’ health-related quality of life (HRQoL) is influenced only by regret frequency, not magnitude.\textsuperscript{23} In contrast, higher decisional regret was consistently associated with poorer physical and psychological health, and lower overall HRQoL for diverse populations making their own treatment decisions.\textsuperscript{19,24–26}

These differences may be attributable to study design. Among these studies,\textsuperscript{19,24–26} regret and HRQoL were concurrently measured once several months or years after the decision, thereby introducing recall bias and precluding the inference of directional associations between decisional regret and HRQoL. When bereavement symptoms of anxiety,\textsuperscript{20} depression,\textsuperscript{21} and PGD\textsuperscript{21} were measured, the same methodological insufficiencies applied. Moreover, existing studies\textsuperscript{19,20,24–26} are all cross-sectional, which cannot reveal the dynamics or heterogeneity of surrogate decisional regret from EoL care decision-making to bereavement. Indeed, we previously identified 4 distinct decisional regret trajectories: resilient, delayed-recovery, late-emerging, and increasing-prolonged.\textsuperscript{27} To extend this line of research and address the current limitations in knowledge on the relationship between regret and bereavement, this study aimed to examine the associations between these 4 decisional-regret trajectories with family surrogates’ symptoms of depression and prolonged grief as well as their HRQoL over their first 2 bereavement years.

**Patients and Methods**

**Study Design and Sample**

This study was part of a prospective, longitudinal, observational study aimed at characterizing the distinct decision-regret trajectories\textsuperscript{27} and their impact on bereaved surrogates of terminally ill patients with cancer in Taiwan. Sampling strategy, participant characteristics, and identification of distinct decisional-regret trajectories have been reported.\textsuperscript{27} Family surrogates were primary surrogate decision-makers for terminally ill patients with cancer. Participants completed surveys when they made an EoL care decision (eg, initiation of a new chemotherapy or immunotherapy, life-sustaining treatments [admission to ICU, intubation with mechanical ventilation support, cardiopulmonary resuscitation, administration of vasopressors, artificial nutritional support, dialysis], or palliative care) between August 2016 and March 2020 and were followed for 2 bereavement years through October 2022. Study procedures were in accordance with the ethical standards of the responsible committee on human experimentation (institutional) and the Helsinki declaration of 1975. The study site’s research ethics committee approved the research protocol (104-9388B) and each participant signed an informed consent.

**Measures**

**Primary Independent Variable**

Decisional regret was measured by the 5-item DRS\textsuperscript{19} to assess whether regret is felt to be present, the decision is right for the patient, the surrogate will make the same decision again in the same circumstances, the decision is wise overall, and the decision has resulted in harm. Final DRS scores are the average of these 5 items (reversing when appropriate) transformed to a 0–100 scale.

We previously identified through latent class growth analysis 4 distinct decisional regret trajectories: resilient (n=100; 26.5%), delayed-recovery (n=212; 56.3%), late-emerging (n=39; 10.2%), and increasing-prolonged (n=26; 6.9%).\textsuperscript{27} These trajectories differ by timing, intensity, and duration of decisional regret. Further details on identification and description of trajectories are available\textsuperscript{27} (supplemental eAppendix 1, available with this article at JNCCN.org).

**Outcome Measures**

**Depressive Symptoms**

Depressive symptoms were measured using the 20-item Center for Epidemiologic Studies Depression Scale (CES-D),\textsuperscript{28} with 4 subscales: positive emotions, depressive emotions, physical activities, and social difficulties. Items were scored for frequency during the past week using a 4-point Likert scale from 0 (rarely/less than 1 day per week) to 3 (most or all of the time/5–7 days). The total score range was 0 to 60; scores ≥16 indicate severe depressive symptoms.\textsuperscript{28}

**Prolonged Grief Symptoms**

Prolonged grief symptoms were measured using the 11 grief symptom items of the Prolonged Grief-13 scale (PG-13),\textsuperscript{29} without the 2 dichotomous items regarding duration and impairment criteria because they measured dimensions other than grief symptoms. Respondents rated the frequency and intensity of feelings about specific grief symptoms over the past month on a Likert scale from 1 (not at all) to 5 (several times per day/overwhelmingly). Scores on the 11 grief symptom items of the PG-13 scale ranged from 11 to 55, with higher scores indicating higher levels of prolonged grief symptoms.

**Health-Related Quality of Life**

HRQoL was measured using the Medical Outcomes Study 36-item Short Form Health Survey (MOS SF-36).\textsuperscript{30} The SF-36 has 8 subscales: physical functioning, role disability due to physical health problems, bodily pain, vitality, general health perceptions, social functioning, role disability due to emotional problems, and general mental health. Subscales are grouped into the physical component summary (PCS) and the mental component summary (MCS)
Decisional Regret and Bereavement

for physical and mental HRQoL, respectively. The PCS and MCS are standardized to range from 0 to 100.

**Covariates**

Covariates included surrogates’ self-reported time-invariant sociodemographics (gender, age, marital status [married vs unmarried], education level [senior high school or less vs above senior high school], relationship with the patient [spouse, adult child, and others], and financial hardship to make ends meet [yes vs no]) and decision conflict; time-variant preloss variables of prognostic awareness (yes vs no), subjective caregiving burden, depressive symptoms, and HRQoL; and time-variant postloss perceived social support. Also controlled as covariates were patients’ time-invariant demographics (gender and age) and time since diagnosis at enrollment (months), as well as time-variant disease burden measured as symptom distress and functional dependency. Detailed information on instruments for measuring surrogate decision conflict, prognostic awareness, subjective caregiving burden, and perceived social support as well as patient symptom distress and functional dependency are provided in supplemental eAppendix 2.

**Data Collection**

Surrogates’ demographics and caregiving/decision-making experiences were assessed during in-person interviews by trained, experienced oncology nurses at enrollment and approximately monthly until they declined participation or the patient died. Bereaved surrogates were interviewed by phone at 1, 3, 6, 13, 18, and 24 months post loss for decisional regret, symptoms of depression and prolonged grief, and HRQoL.

**Statistical Analysis**

Associations of decisional-regret trajectories with the 4 bereavement outcomes over the first 2 bereavement years were evaluated concurrently using multivariate hierarchical linear modeling (MHLM), whereas covariates were controlled using MPlus. Inflation of type I errors from multiple comparisons of outcomes are controlled by MHLM. Random intercepts were used in MHLM to account for within-subject correlations of repeated observations from each surrogate over the first 2 bereavement years. We arranged preloss lagged patient and surrogate time-variant covariates at the assessment when surrogates made an EoL care decision to ensure a clear time sequence of associations with the decisional-regret trajectories and the 4 bereavement outcomes. We also controlled for the time since loss to evaluate the consistency of associations over the first 2 bereavement years. PGD symptoms must be present at sufficiently high levels ≥6 months post loss; therefore, we explored associations from 6 months post loss while controlling for the postloss lagged outcome measures and perceived social support measured at 3 months post loss. Effects of the delayed-recovery, late-emerging, and increasing-prolonged trajectories on bereavement outcomes in reference to the resilient trajectory were indicated by $\beta$ estimates with 95% confidence intervals.

**Results**

**Study Participants**

A total of 377 family surrogates who made EoL care decisions for their loved one and provided decisional regret data constituted the sample used to estimate decisional regret trajectories from EoL care decision-making to the first 2 years of bereavement. Most participants were female (82.0%), married (89.1%), spousal (79.3%), or adult-child (12.2%) family surrogates with an average age of 56.28 (SD, 11.34) years. Patients were typically male (79.8%) and married (89.9%), with a man average age of 60.96 (SD, 9.39) years. Most patients (90.2%) had metastatic disease, and the most common cancer sites were the pancreas (18.0%), stomach (15.9%), liver (14.3%), esophagus (13.3%), and lung (8.0%). Cancers were diagnosed, on average, 13.96 (SD, 23.33) months before enrollment. Patients survived, on average, 105.22 (SD, 146.24) days after enrollment. Few patients had an advanced care directive (4.0%) or a do-not-resuscitate order (8.8%) issued when the EoL care decision was made, whereas a physician–patient EoL care discussion was reported by 11.9% of patients. EoL care decisions were made primarily for hospice or palliative care (62.5%), followed by anticancer treatments (33.0%) and life-sustaining treatments (4.5%). The decision was made, on average, 53.59 (SD, 47.06; median, 40) days before the patient’s death.

**Bereavement Outcomes Over First 2 Years of Bereavement**

Among the 377 surrogates, 341 participated in bereavement surveys. Data on bereavement outcomes were available for 317, 252, 229, 193, and 179 surrogates at 1, 3, 6, 13, 18, and 24 months post loss, respectively. Raw data for the 4 bereavement outcomes for the whole sample and across the 4 distinct decisional-regret trajectories over the first 2 bereavement years are shown in Figure 1. Bereaved family surrogates’ symptoms of depression and prolonged grief and mental HRQoL improved, whereas physical HRQoL remained stable (Table 1). In reference to 3 months post loss, prolonged grief symptoms significantly decreased from 6 months post loss onward ($\beta$ [95% CI] ranging from $-1.519 \text{[} -2.885 \text{ to } -0.153 \text{]}$ to $-5.311 \text{[} -8.068 \text{ to } -2.553 \text{]},$ whereas depressive symptoms decreased ($-4.526 \text{[} -6.774 \text{ to } -2.278 \text{]}$ to $-5.319 \text{[} -8.473 \text{ to } -2.165 \text{]})$ and mental HRQoL significantly improved ($2.698 \text{[} 0.238 \text{ to } 5.158 \text{]}$ to $3.440 \text{[} 1.788 \text{ to } 5.092 \text{]}$) from 13 months post loss onward.
Associations of Distinct Decisional-Regret Trajectories With Bereavement Outcomes

Family surrogates’ membership in the 4 decisional-regret trajectories was significantly associated with their bereavement outcomes (Table 1). Surrogates in the 3 higher and long-lasting decisional-regret trajectories experienced significantly higher symptoms of prolonged grief ($\beta$ [95% CI], 1.815 [0.782 to 2.848]; 2.312 [0.834 to 3.790]; and 7.806 [2.681 to 12.931]; for delayed recovery, late-emerging, and increasing-prolonged trajectories, respectively) than those in the resilient trajectory. In addition, surrogates in late-emerging and increasing-prolonged decisional-regret trajectories reported significantly higher symptoms of depression ($\beta$ [95% CI], 2.942 [1.045 to 4.839] and 8.766 [2.864 to 14.668], respectively). Surrogates in the 3 higher and long-lasting decisional-regret trajectories reported significantly poorer physical HRQoL ($-1.615 [-2.844 to -0.386]$, $-1.634 [-3.226 to -0.042]$, and $-4.749 [-9.380 to -0.118]$), whereas only the increasing-prolonged decisional-regret trajectory reached a statistically significant level for worse mental HRQoL ($-4.823 [-8.216 to -1.430]$) than those in the resilient trajectory.

Discussion

Our findings indicated that bereaved surrogates of terminally ill patients with cancer endured profound grief reactions immediately post loss but adjusted gradually over their first 2 years of bereavement (Figure 1). These findings align with the literature on evolution of bereavement outcomes, including decreased symptoms of depression$^{32-34}$ and prolonged grief$^{34-36}$; improved mental HRQoL and functioning$^{35,36}$; and stable, high physical HRQoL$^{35}$.

Our findings not only confirmed that surrogates experience notable psychological distress lasting several months or years$^{15,16}$ but also showed that heterogeneous decisional-regret experiences were significantly differentiated by bereavement outcomes. In reference to the resilient trajectory, surrogate membership in the 3 higher

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Figure 1. Course of changes in bereavement outcomes over the first 2 bereavement years. (A) Symptoms of depression, measured with the CES-D. The horizontal black line over the depression score at 16 indicates the threshold for severe depressive symptoms. (B) Symptoms of prolonged grief, measured with the 11 grief symptom items of the PG-13. Abbreviations: CES-D, Center for Epidemiologic Studies Depression Scale; PG-13, Prolonged Grief-13 scale. (continued on next page)
and long-lasting decisional-regret trajectories was associated with significantly higher levels of prolonged grief symptoms (Table 1). Surrogates who experience delayed-recovery, unresolved, or late-emerging decisional regret may carry ceaseless doubt and concern about whether they made the right decisions, guilt over the decisions they made,15,16 and a worst-case scenario perception that their decision precipitated the patient’s death.14 Subsequently, they may experience painful grief reactions of yearning and longing for or persistent preoccupation with thoughts and memories of the deceased, a marked sense of disbelief, difficulty accepting the loss, and anger about the death of the loved one—characterized as symptoms of prolonged grief.29,37

Surrogates in the 2 most worrisome late-emerging and increasing-prolonged decisional-regret trajectories experienced more depressive symptoms than those in the resilient trajectory, and these elevated depressive symptoms were compounded with worse mental HRQoL for those in
the increasing-prolonged trajectory (Table 1). Unresolved and new development of decisional regret late in the 2-year bereavement period may signify that bereaved surrogates ceaselessly questioned whether they made the right decision for their loved one and felt guilty about their decision, particularly if it caused suffering from unnecessary treatments such as initiation of new chemotherapy, immunotherapy, or life-sustaining treatments. Doubt about the EoL care decision\textsuperscript{15,16} compounded with internalized guilt and self-blame\textsuperscript{38} may induce feelings of helplessness, meaninglessness, and negative beliefs about oneself, the world, and the future,\textsuperscript{39} manifesting as more depressive symptoms and worse mental HRQoL. However, our speculation about the mechanism of associations between membership in late-emerging and increasing-prolonged decisional-regret trajectories and experiencing more depressive symptoms and worse mental HRQoL warrants further validation, preferably by qualitative studies.

Furthermore, our findings showed that surrogates in the 3 higher and long-lasting decisional-regret trajectories had poorer physical HRQoL. These findings are congruent with the association between higher decisional regret and the increasing-prolonged trajectory (Table 1).

### Table 1. Associations of Distinct Decisional Regret Trajectories With Bereaved Family Caregivers’ Psychological Distress and QoL Over First 2 Bereavement Years

<table>
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<tr>
<th>Outcome Variables</th>
<th>Depressive Symptoms*</th>
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<th>Prolonged Grief Symptomsb</th>
<th>P Value</th>
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<td>95% CI</td>
<td></td>
<td>β</td>
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<td>Ref</td>
<td>Ref</td>
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<td>Ref</td>
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<tr>
<th>Decisional regret trajectories</th>
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<th>Delayed recovery</th>
<th>Late-emerging</th>
<th>Increasing-prolonged</th>
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<tr>
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<th>Delayed recovery</th>
<th>Late-emerging</th>
<th>Increasing-prolonged</th>
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<td>−9.380</td>
<td>−0.118</td>
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Family surrogates’ self-reported time-invariant demographics (age, gender, relationship with patient, marital status, educational attainment, and status of financial sufficiency) and decision conflict; time-variant lagged preloss variables of prognostic awareness, subjective caregiving burden, depressive symptoms, and health-related QoL measured when they made an end-of-life care decision; and time-variant lagged postloss variable of perceived social support and bereavement outcomes (scores of CES-D, 11 grief symptom items of the PG-13, and PCS and MCS of the MOS SF-36) were controlled. Patients’ self-reported time-invariant demographics (age and gender), time since diagnosis at enrollment, and time-variant lagged preloss variables of symptom distress and functional dependency were also controlled. Bold indicates statistical significance.

Abbreviations: CES-D, Center for Epidemiologic Studies Depression Scale; MCS, mental component summary; MOS SF-36, Medical Outcomes Study 36-Item Short Form Survey; PCS, physical component summary; PG-13, Prolonged Grief-13 scale; QoL, quality of life.

*Measured with the CES-D.

bMeasured with the 11 grief symptom items of the PG-13.

cMeasured using the PCS of the MOS SF-36.

dMeasured using the MCS of the MOS SF-36.
poorer physical health for patients who make treatment decisions for themselves. These findings suggest that the consequences of regret for family surrogates during first 2 years of bereavement may not just be psychological.

Limitations
Our study longitudinally and simultaneously evaluated the associations of surrogates’ decisional-regret trajectories with their depressive symptoms, prolonged grief symptoms, and physical and mental HRQoL over the first 2 bereavement years while controlling for time-invariant and lagged time-variant patient and surrogate covariates to establish a clear time sequence of associations. However, several study limitations should be acknowledged. Generalizability to (inter-)national target populations and bereaved surrogates who lose their loved one as a result of other diseases or sudden/traumatic death may be limited, and the representativeness of targeted patients with cancer may be biased by our convenience sampling of surrogates of terminally ill patients with cancer from a single medical center in Taiwan. Despite our longer follow-up than the quantitative studies included in the 2 systematic reviews (commonly within 6 months post decision), we followed surrogates only for the first 2 bereavement years; therefore, our findings cannot robustly generalize to the relationships between decisional regret and bereavement outcomes more than 24 months post loss. The present study only considered surrogates’ symptoms of depression and prolonged grief and HRQoL, thereby overlooking other bereavement outcomes, such as psychological distress (eg, anxiety, posttraumatic stress disorder) and healthcare resource utilization. We used screening tools and not “gold standard” diagnostic measures to assess bereaved surrogates’ psychological distress, thereby likely overestimating bereaved surrogates’ psychological distress but avoiding overlooking their need for emotional support. Despite our large sample, some categories of our primary independent variable (ie, decisional-regret trajectory) may not have had sufficient power to precisely estimate associations with the outcome variables in our MHLTM. We cannot infer a cause-and-effect relationship between the 4 distinct decisional-regret trajectories and the examined bereavement outcomes, nor can we exclude the possible impact of unmeasured variables (eg, surrogate preferred and actual decision roles, patient-surrogate EoL care discussions). Furthermore, factors associated with membership in the decisional-regret trajectories, especially for the most worrisome late-emerging and increasing-prolonged trajectories, have not yet been explored.

Conclusions
Surrogates’ membership in the 3 higher and long-lasting decisional-regret trajectories was positively associated with more symptoms of depression and prolonged grief as well as worse physical and mental HRQoL over the first 2 bereavement years. Considering the substantial negative physical, psychological, and social impacts of prolonged grief and depression, addressing the needs of surrogates in the 3 higher and long-lasting decisional-regret trajectories may facilitate bereavement adjustment. Healthcare professionals should be alert for family surrogates who experience heightened decisional regret (DRS >25) right after EoL decision-making, which may or may not resolve within their first 2 bereavement years, as shown by the delayed-recovery and increasing-prolonged trajectories, respectively. Even for family surrogates who report a low decisional-regret level before their loved one’s death, late-emerging decisional regret can develop after the loss and may never resolve completely during the first 2 bereavement years. To prevent poor bereavement outcomes, healthcare professionals should be attentive to the bereavement risks of EoL decision-making, and surrogates who struggle with heightened decisional regret right after making an EoL decision should be referred to psychological care. Healthcare professionals should navigate the complexities of surrogate decision-making and supplement the insufficient information only interventions with attendance to surrogates’ intense emotional and psychological difficulty in making major decisions. Subsequently, surrogates may be supported to make affirming decisions that prevent prolonged, unceasing, or late-emerging decisional regret from EoL care decision-making through bereavement; experience less postloss psychological distress from depressive and prolonged grief symptoms; and experience improved physical and mental HRQoL.

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References


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**eAppendix 1:** Identification and Description of the 4 Distinct Decisional-Regret Trajectories

**eAppendix 2:** Assessments of Covariates
eAppendix 1. Identification and Description of the 4 Distinct Decisional-Regret Trajectories

Latent-class growth analysis (LCGA)\textsuperscript{1} with a continuous latent-trajectory indicator (total Decision Regret Scale [DRS] score) by MPlus (version 8.1) was conducted to identify decisional-regret trajectories in which surrogates comprised a homogenous group sharing a discrete decisional-regret growth pattern\textsuperscript{1} from end-of-life (EoL) decision-making through the first 2 bereavement years. Best model solutions with an increasing number of trajectories were decided by model fit indices, including several information criteria (ICs), such as the highest log-likelihood (LL), smallest Akaike’s information criterion (AIC), Bayesian information criterion (BIC), and sample-size adjusted Bayesian information criterion (SABIC), as well as appropriately high entropy (a measure of certainty in class membership assignment, ranging between 0 and 1, with a higher value indicating that surrogates grouped together have more homogenous decisional-regret patterns).\textsuperscript{2,3} These criteria, a smallest trajectory comprising no less than 5% of the total sample, parsimony, and clinical/theoretical meaningfulness of identified latent trajectories were factored in deciding the optimal number of trajectories.\textsuperscript{1}

Four distinct decisional-regret trajectories were identified as optimal: resilient, late-emerging, delayed-recovery, and increasing-prolonged.\textsuperscript{4} The resilient trajectory showed a generally low decisional-regret level, with mild and transient perturbations around the time of patient death only. For the delayed-recovery group, DRS scores accelerated from 6 to 1 month before loss, thereafter trending slowly downward with an increasing speed since 13 months post loss toward a potentially complete resolution below the cutoff (DRS <25) for heightened decisional regret beyond the second bereavement year. Surrogates in the late-emerging trajectory reported a low decisional-regret level before their loved one’s death, but their decisional regret increased gradually after the loss and never subsided below the cutoff for heightened decisional regret throughout the first 2 bereavement years. The increasing-prolonged trajectory featured a rapid increase in the decisional-regret levels during EoL decision-making, peaking 1 month post loss and thereafter declining steadily but without a complete resolution below the cutoff for heightened decisional regret over the first 2 bereavement years.\textsuperscript{4}

References

eAppendix 2. Assessments of Covariates

1. Decision conflict was measured by the 16-item Decision Conflict Scale (DCS)\(^1\) on a Likert scale ranging from 0 (strongly agree) to 4 (strongly disagree). DCS measures surrogates’ uncertainty in making a health care decision, the modifiable factors contributing to uncertainty, and the quality of the decision made. Final scores multiply the average of the 16 items (reversing when appropriate) by 25. Final scores range from 0 to 100; higher scores indicate greater decisional conflict.

2. Surrogates’ prognostic awareness was measured by asking whether they knew their loved one’s prognosis, and if so, whether the disease (1) was curable; (2) might recur in the future, but their loved one’s life was not currently in danger; or (3) could not be cured, or their loved one would probably die soon. Surrogates were recognized as accurately knowing the patient’s prognostic awareness only if they chose option 3; inaccurate prognostic awareness reflected not knowing their loved one’s prognosis or choosing option 1 or 2.

3. Subjective caregiving burden was measured using the 24-item Caregiver Reaction Assessment (CRA).\(^2\) The CRA measures the impact of end-of-life (EoL) caregiving on caregivers’ schedule, health, and finances, as well as caregiver esteem in providing care (rewarding or causing resentment), and lack of family support. Total scores range from 24 to 120; higher scores indicate stronger perceived EoL caregiving burden.

4. Depressive symptoms were measured with the 20-item Center for Epidemiologic Studies Depression Scale (CES-D).\(^3\) Items were scored for frequency during the past week by a 4-point Likert scale ranging from 0 to 3. Total scores range from 0 to 60; higher scores indicate more depressive symptoms.

5. Quality of life during EoL caregiving was measured using the 35-item Caregiver Quality of Life Index–Cancer (CQOLC).\(^4\) The CQOLC measures the effect that the illness and caregiving needs of a patient with cancer have on caregivers’ physical, emotional, social, and family functioning in 4 subscales. CQOLC scores range from 0 to 140; higher scores indicate better QoL.

6. Caregivers’ perceived social support was measured using the 19-item Medical Outcomes Study Social Support Survey (MOS-SSS).\(^5\) The MOS-SSS assesses emotional, informational, tangible, and affectionate support, as well as positive social interaction. Total scores are computed on a scale of 0 to 100; higher scores indicate stronger perceived social support.

7. Patient distress due to common cancer symptoms (eg, pain, dyspnea, anorexia, insomnia) was measured using the 13-item Symptom Distress Scale (SDS).\(^6\) Scores range from 13 to 65; higher scores indicate greater symptom distress.

8. Patient functional dependency was measured by the 10-item Enforced Social Dependency Scale (ESDS).\(^7\) Scores range from 10 to 51; higher scores reflect greater impairment in personal and social functioning.

References