Complicated grief after death of a relative in the intensive care unit

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ABSTRACT   An increased proportion of deaths occur in the intensive care unit (ICU).

We performed this prospective study in 41 ICUs to determine the prevalence and determinants of complicated grief after death of a loved one in the ICU. Relatives of 475 adult patients were followed up. Complicated grief was assessed at 6 and 12 months using the Inventory of Complicated Grief (cut-off score >25). Relatives also completed the Hospital Anxiety and Depression Scale at 3 months, and the Revised Impact of Event Scale for post-traumatic stress disorder symptoms at 3, 6 and 12 months. We used a mixed multivariate logistic regression model to identify determinants of complicated grief after 6 months.

Among the 475 patients, 282 (59.4%) had a relative evaluated at 6 months. Complicated grief symptoms were identified in 147 (52%) relatives. Independent determinants of complicated grief symptoms were either not amenable to changes (relative of female sex, relative living alone and intensivist board certification before 2009) or potential targets for improvements (refusal of treatment by the patient, patient died while intubated, relatives present at the time of death, relatives did not say goodbye to the patient, and poor communication between physicians and relatives).

End-of-life practices, communication and loneliness in bereaved relatives may be amenable to improvements.

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Introduction

Over the last two decades, the use of intensive care at the end of life has increased significantly [1–3]. Studies have described intensive care unit (ICU) practices at the end of life [3–7], shed light on treatment-limitation decisions [8], identified specific needs of bereaved relatives, and determined what affects the quality of the dying experience for relatives, physicians and nurses [9–17].

Relatives of patients who die in the ICU experience a considerable burden of harm [18]. Immediately after the loss, they frequently exhibit symptoms of anxiety and depression [19]. 3 months later, half of them have post-traumatic stress disorder (PTSD) symptoms [20] and quality-of-life alterations [21]. Ill effects identified within the year following the death include financial difficulties [11–13] and psychiatric illness [22]. Studies have identified targets for improving the quality of dying and death, as well as the relatives' experience of bereavement [14, 15, 23]. Nevertheless, specific data are needed on the grieving process after the death of a relative in the ICU.

Sadness, anger, and symptoms of depression are normal manifestations of grief that usually resolve within a few months [24, 25]. Complicated grief, a well-defined syndrome of grief manifestations persisting >6 months [24, 25], occurs in ~10% of bereaved relatives [26, 27] and adversely affects quality of life [25, 28–31]. The persistent manifestations may include intense yearning for the deceased, a sense of disbelief regarding the death, anger, bitterness, intrusive preoccupying thoughts of the deceased, avoidance of reminders of the loss and difficulty in moving on with life [24, 25]. Features of depression and PTSD may exist in relatives with or without complicated grief, raising diagnostic challenges [32], although some distinctions have been established. For example, one of the key distinguishing features of complicated grief is that it tends to come in waves, unlike depression, which tends to be unremitting and persistent. Complicated grief can result in physical and mental health problems or in the worsening of these problems. In a study by PRIGERSON et al. [25] outside the intensive care setting, complicated grief after the death of the spouse predicted negative health outcomes such as cancer, heart trouble, high blood pressure, suicidal ideation and changes in eating habits at 13- or 25-month follow-up. Complicated grief is also associated with substantial impairment of work and social functioning, sleep disturbance, suicidal ideations and behaviour, increase use of tobacco and alcohol, and impairment in relationship functioning [33]. Many studies have focused on complicated grief in elderly patients [34, 35]. Complicated grief is considered more common in those experiencing disasters [33]. It has also been found to be overrepresented in family members of patients with life-threatening illnesses and suicides or homicides [36]. Few studies have assessed complicated grief during the year following the death of an adult relative in the ICU. In two small, single-centre studies based on the Inventory of Complicated Grief (ICG), the prevalence of complicated grief was 5% (two out of 41) after 3–12 months [22] and 46% (six out of 13) after 6 months [37]. However, these studies provide no information on potential links between complicated grief and other components of the post-ICU burden in bereaved relatives, nor do they indicate how specific ICU practices may affect the risk of complicated grief.

Here, we report a prospective observational study in 41 ICUs that was designed to determine the prevalence and risk factors of complicated grief during the first year following the death of an adult relative in the ICU. We also evaluated links between complicated grief and symptoms of PTSD and depression.

Patients and methods

The study was approved by the institutional review board of the Paris North Hospitals (IRB00006477, approval number 11–019), Paris 7 University, Paris, France, and informed consent was obtained from each relative.

Study design and setting

We conducted a prospective, observational study in 41 ICUs in France from July 2011 to July 2013. In each ICU, one intensivist was the local investigator and included consecutive patients at the time of death. Eligible patients were adults who died after ≥48 h in the ICU. For each patient, the relative who served as the surrogate (designated as proxy, spouse, adult offspring, sibling or other relative, in that order) was included at the time of death. The only eligibility criteria for relatives were having visited the patient at least once in the ICU and sufficient knowledge of French to complete the assessment tools.

Data collection

All data were collected prospectively. Relatives were assessed 21 days then 3, 6 and 12 months after the death. The day-21 assessment consisted of a telephone interview with completion of a questionnaire on end-of-life practices and on the relative's satisfaction regarding patient management and communication with the staff. After 3 months, the Hospital Anxiety and Depression Scale (HADS) and Revised Impact of Event Scale (IES-R) for PTSD symptoms questionnaires were completed during a telephone interview [18, 38]. Both

instruments have been validated in relatives of ICU patients [19, 20, 39, 40]. All telephone interviews were conducted by the same person (Z. Cohen-Solal), a sociologist with extensive interviewing experience.

After 6 and 12 months, a questionnaire including the ICG [24] and IES-R [41] was mailed to the relative.

Immediately after the death of each study patient, the ICU nurses and physicians completed an electronic case-record form to report the characteristics of the patient, end-of-life process and communication with the relatives. The characteristics of each ICU were recorded.

Outcome measures

The primary outcome measure was the ICG score after 6 months. The ICG is the most commonly used assessment tool for complicated grief. It was developed by PRIGERSON et al. [25], and focuses on symptoms that are distinguishable from symptoms of depression and anxiety. Moreover, the ICG was designed to distinguish between normal reactions and more pathological forms of grief. It consists of 19 first-person statements (such as "Ever since she died it is hard for me to trust people"). Each item is rated from 0 (not at all) to 4 (severe), and scores >25 indicate complicated grief [24, 26, 27]. The ICG is a scale with demonstrated internal consistency, and convergent and criterion validity, which provides an easily administered assessment for symptoms of complicated grief [24]. We used the term complicated grief rather than prolonged grief, as collected symptoms were recorded through the ICG. In addition, labelling the syndrome using "prolonged" or "persistent" grief could include cases where grief was prolonged or persistent in ways that are not complicated or pathological [33]. Secondary outcome measures were the IES-R scores after 3, 6, and 12 months, and HADS subscores after 3 months. The IES-R is a valid and reliable scale [42] that has been used successfully in family members of ICU patients [20, 43]. The instrument contains subscale items on intrusion, avoidance and hyperarousal. The IES-R served to measure PTSD symptoms as opposed to specific symptoms of complicated grief. IES-R scores can range from 0 (no PTSD-related symptoms) to 88 (severe PTSD-related symptoms) [44]. We used 32 as the cut-off indicating a high risk of PTSD [39, 45]. The HADS is valid and reliable [38], easy to administer, and has been successfully used to measure symptoms of anxiety and depression in the general population and in family members of ICU patients [46]. HADS subscores >8 were taken to indicate clinically meaningful symptoms of anxiety or depression [46].

Statistical analysis

Continuous variables are described as median (interquartile range) and categorical variables as proportions.

The prevalence of complicated grief and PTSD-related symptoms was defined as the number of relatives with symptoms of complicated grief (ICG >25) and with symptoms of PTSD (IES-R >32) divided by the number of collected relatives' surveys at 6 and 12 months. To identify factors associated with symptoms of complicated grief or PTSD, we performed univariate logistic regression analyses including all the variables shown in tables 1–3 and in the online supplementary material, corresponding to ICU characteristics (e.g. size of the ICU), circumstances of death (e.g. presence of the relative at the time of death), relative's characteristics (e.g. sex and age) or the physician's and nurse's characteristics (e.g. experience in the ICU >2 years).

We then built a mixed multivariate logistic regression model with 1) variables yielding p<0.20 in univariate analyses and 2) an ICU-specific random effect. The final model was determined with stepwise variable selection using an automatic procedure based on the Akaike Information Criterion and was assessed using the Hosmer–Lemeshow goodness-of-fit test (fig. 1). In order to preserve the sample size in multivariate analyses, multiple imputation by chained equations was used to impute missing data for the explanatory variable, excluding ICG, and IES-R scores [48].

To delineate subsets of relatives according to those predictive factors, we performed a focused principal-component analysis [44]. This is a special type of principal-component analysis designed to describe and understand the relationship between a set of quantitative variables with particular attention to the dependencies of one variable (in this case, complicated grief) with others (in this case, characteristics of patients, relatives, clinicians and centres, and end-of-life practices). The relationships between independent variables must be interpreted as in a principal-component analysis: correlated variables are close or diametrically opposite (for negative correlations), while uncorrelated variables form a right angle with the origin. The relative positions of the predictors may distinguish some clusters of explanatory variables. Variables inside the dotted circle are significantly correlated to the dependent variable with p<0.05. All tests were two-sided and p-values <0.05 were considered significant. These explanatory analyses did not take into account multiple comparisons. Statistical tests were performed using

TABLE 1 Circumstances of death in 475 patients who died in 41 intensive care units (ICUs)

Circumstances of death	Subjects
Death following decision to withhold or withdraw treatments	
No	91 (19.2)
Decision to withhold treatment	152 (32)
Decision to withdraw treatment	232 (48.8)
Decision-making process	
No decision	91 (19.2)
Relatives only informed of the decision	160/384 (42)
Relatives involved in the decision making process	224/384 (58)
Family agreement with EOL decision	373 (78.5)
Disclosure of death	
Family was present at patient's bedside	266 (56)
Family was informed over the phone	152 (32)
Family was informed upon arrival to the ICU	57 (12)
Death and ventilation	
Patient died while intubated	318 (67)
Patient died after recent extubation	69 (14.5)
Patient was never ventilated	88 (18.5)
Who was present in patient's room at the time of death?[#]	
Relatives	266 (56)
Physician at bedside	165 (34.7)
Nurse at bedside	304 (64)
Compliance with quality indicators for EOL care [47]	
Family-centred decision-making/involvement	224 (47.1)
24-h family presence	166 (34.7)
Spiritual support	62 (13)
Emotional support available in ICU	176 (37.1)
Intervention of external palliative care consultant	12 (2.5)

Data are presented as n (%) or n/N (%). EOL: end of life. [#]: the sum exceeds 475 as more than one person could be present at the time of death for the same patient.

R software 2.15.2 (University of Vienna, Vienna, Austria) with the stats, lme4, MICE and psy packages (http://cran.r-project.org/web/packages/psy/index.html).

Results

Figure 2 is a flow chart of the study design. Among the 4607 patients admitted to the 41 participating ICUs during the study period, 875 (19%) died, including 228 who met exclusion criteria, 104 for whom the opportunity for inclusion was missed and 68 for whom the relative refused participation. The remaining 475 (54%) were included. Table 1 presents the circumstances of the deaths. The characteristics of the ICUs (table S1), patients and relatives (table S2) are presented in the online supplementary material.

Response rates were 90.5%, 81.3%, 59.4% and 45.2% on days 21, 90 and 180, and at 1 year, respectively. Among all the collected variables (related to ICUs, centres and patients), none was significantly different between relatives who did not respond and those who actually participated.

Day 21

The proportions of relatives satisfied with pain control, respect of dignity, and medical care were 82.4%, 91% and 91.4%, respectively. Communication with physicians and nurses was considered good by 76.3% and 86.3% of relatives, respectively. Relatives reported discussing the patient's end-of-life preferences with the ICU team in 61.5% of cases. Most relatives understood that the patient was dying, although 18.7% felt unprepared for the death. Among relatives, 68.1% said goodbye to their loved one and 56% were present at the time of death. When relatives were asked whether the patient declined to receive any treatment during their ICU stay, 8.9% responded that patients refused treatments.

3, 6 and 12 months

Among relatives assessed at 6 months, the proportion with symptoms of complicated grief (the primary outcome measure) was 52.1% and the proportion with PTSD-related symptoms was 43.6%. Both scores were below the relevant cut-off in 41% of patients and both were above the relevant cut-off in 37% (fig. 1).

TABLE 2 Complicated grief and other markers of post-intensive care unit burden over the year following the death in 475 bereaved relatives

Complicated grief as assessed by the ICG	
6 months	282/475 (60)
ICG score	27 (16–40)
Presence of complicated grief[#]	147 (52.1)
12 months	215/475 (45.3)
ICG score	26 (14–40)
Presence of complicated grief[#]	113 (53)
PTSD-related symptoms as assessed by the IES-R	
3 months	386/475 (81.3)
IES-R score	29 (13–45)
Presence of significant PTSD-related symptoms	173 (44.8)
6 months	282/475 (60)
IES-R score	29 (16–44)
Presence of significant PTSD-related symptoms	123 (43.6)
12 months	215/475 (45.3)
IES-R score	26 (13–42.5)**
Presence of significant PTSD-related symptoms	78 (36.2)**
Symptoms of anxiety and depression as assessed by the HADS	
3 months	386/475 (81.3)
Global HADS scale	13.5 (7–22)
Global HADS score >18	127 (32.9)
Anxiety subscale score	8 (4–12)
Anxiety subscale score≥8	199 (51.6)
Depression subscale	5 (2–10)
Depression subscale score≥8	139 (36)

Data are presented as n/N (%), median (interquartile range) or n (%). ICG: Inventory of Complicated Grief; PTSD: post-traumatic stress disorder; IES-R: Revised Inventory of Event Scale; HADS: Hospital Anxiety and Depression Scale. [#]: ICG score >25. **: $p < 0.01$ between ICG scores at 6 and 12 months.

At 3 months, 36% of relatives had symptoms of depression (HADS subscore ≥8) and presence of symptoms of depression at 3 months was associated with symptoms of complicated grief at 6 months (OR 4.47, 95% CI 1.95–10.24).

After 12 months, the proportion of assessable relatives with symptoms of complicated grief was unchanged but the proportion with PTSD-related symptoms was significantly lower ($p < 0.0001$) compared with the 6-month assessment. However, when we looked at the individual data, we found that 19% of relatives with symptoms of complicated grief at 6 months no longer present these symptoms at 12 months and that 21.3% who did not present complicated grief symptoms at 6 months did present these symptoms at 12 months. Similarly, for the IES-R, 32.6% of relatives with PTSD- related symptoms at 6 months no longer presented these symptoms at 12 months and 10.5% who did not present PTSD- related symptoms at 6 months did present these symptoms at 12 months. Among relatives assessed at 6 months but not at 12 months, the proportions with symptoms of complicated grief and with PTSD-related symptoms at 6 months were not significantly different from those among relatives assessed at both time-points.

Determinants of complicated grief and PTSD-related symptoms at 6 months

Table 3, table S3 and figure 3 present factors associated with ICG >25 and/or IES-R >32 after 6 months. 6 months after the loss, factors independently associated with complicated grief only were patient-related (*i.e.* patient's refusal of treatment was associated with a decreased risk of presenting complicated grief symptoms) and physicians-related (*i.e.* intensivist board certification before 2009 and relatives reporting poor quality communication with physicians). Interestingly, none of the ICU characteristics predicted complicated grief. Perception by the relative that the patient could not breathe peacefully was only associated with a higher risk of PTSD symptoms. Variables associated with both complicated grief and PTSD related symptoms were family-related (relative of female sex and relative living alone), related to end-of-life management (patient died while intubated, the relative being present at time of death and the relative not having said goodbye to the patient). In the bivariate analyses, involvement of the relative in treatment-limitation decisions was associated with decreased complicated grief whereas disagreement between the relative and intensivist about goals of care was associated with increased PTSD symptoms. However, neither covariate had a significant effect in the multivariate analysis.

TABLE 3 Determinants of complicated grief at 6 months

Variables	Univariate analysis		Multivariate analysis	
	OR (95% CI)	p-value	OR (95% CI)	p-value
ICU characteristics				
Nurse involvement in clinical research	1.57 (0.84–2.92)	0.155	1.75 (0.84–3.66)	0.135
Physician and nurse characteristics				
Intensivist board certification before 2009	3.02 (1.38–6.60)	0.006	3.82 (1.57–9.34)	0.003
Nurses >2 years of ICU experience	0.71 (0.41–1.23)	0.221		
Patient characteristics				
Age	0.98 (0.96–0.99)	0.017		
Length of ICU stay	1.01 (1.00–1.02)	0.101	1.01 (1.00–1.02)	0.155
Need for vasopressors	2.10 (1.20–3.68)	0.009		
Patient died while intubated	2.54 (1.53–4.22)	<0.001	2.12 (1.16–3.89)	0.015
Family involvement in EOL decision	0.57 (0.35–0.92)	0.022		
Family disagreement with EOL decision	3.92 (1.79–8.60)	0.001		
Relative characteristics				
Female sex	2.87 (1.67–4.94)	<0.001	3.07 (1.62–5.80)	0.001
Being the spouse	1.96 (1.19–3.23)	0.008		
Living alone	1.64 (1.01–2.70)	0.044	1.97 (1.10–3.51)	0.022
Relative reports that				
Patient's dignity was not respected	3.18 (1.13–8.92)	0.028		
Death was not anticipated	2.33 (1.18–4.6)	0.015		
Communication with physician was unsatisfactory	3.64 (1.92–6.91)	<0.001	3.27 (1.42–7.50)	0.005
Communication with nurses was unsatisfactory	3.21 (1.5–6.85)	0.003	2.26 (0.84–6.10)	0.106
Patient refused treatments[#]	0.38 (0.17–0.86)	0.021	0.24 (0.08–0.69)	0.008
They did not say good bye to loved one	2.28 (1.35–3.85)	0.002	2.47 (1.30–4.68)	0.006
They were present at the time of death	1.89 (1.18–3.03)	0.009	2.91 (1.62–5.21)	<0.001

Uni- and multivariate analyses are shown. Univariate logistic regression was performed to estimate odds ratios; p-values were calculated using the Wald test. Mixed multivariate logistic regression with intensive care unit (ICU) as a random effect was performed to estimate adjusted odds ratios and p-values. Hosmer–Lemeshow goodness of fit test: p=0.764. EOL: end of life. [#]: patient decision to withhold or withdraw treatment for themselves.

In order to confirm these results, and to analyse the relationship between complicated grief and the explanatory variables, a focused principal-component analysis was performed (fig. 4). Three clusters of explanatory variables are depicted in this figure. First, the year of intensivist's board certification and the fact that patients died intubated are positively correlated. A second cluster (patient's refusal of treatment, female relative, relative living alone following the loss and patient could not breathe peacefully) is diametrically opposite and therefore negatively correlated to the first one. The third cluster includes the fact that relatives witnessed the death and did not say goodbye to the dying patient.

Figure S1 shows the end-of-life process and its relationships with complicated grief and PTSD symptoms.

Discussion

This multicentre study is the first to report the incidence of complicated grief in a large number of relatives of patients who died in the ICU. Sadly, over half of these bereaved family members presented with complicated grief symptoms at 6 months, a proportion that persisted essentially unchanged for a total of 12 months. This result is alarming considering that complicated grief is a condition that exposes bereaved relatives to additional burden, such as symptoms of yearning and failure to adapt. PTSD was also high in this study, with 43.6% of relatives presenting symptoms after 6 months, but, unlike complicated grief ,this proportion diminished significantly in the following 6 months. Among study variables, some were associated with complicated grief only and some with both complicated grief and PTSD. This study is important because it provides new targets for improving end-of-life practices with the ultimate goal of decreasing the burden on bereaved relatives: taking into account patients' wishes, timely extubation, closure at the end of life and high-quality communication.

Complicated grief is distinct from depression and PTSD, yet may produce symptoms of both. In this study, presence of symptoms of depression at 3 months was associated with complicated grief at 6 months.

FIGURE 1 Symptoms of complicated grief and post-traumatic stress disorder (PTSD) at 6 months in 282 bereaved relatives. Relatives completed the Inventory of Complicated Grief and the Revised Impact of Event Scale questionnaires 6 months after the patient's death. Assessments were performed in 59.4% of the 475 relatives included in the study. Among the 193 relatives who were not assessed for complicated grief and PTSD, 146 never responded to the telephone calls or the letters, 45 refused to respond (after initially agreeing to participate to the study) and two relatives died.
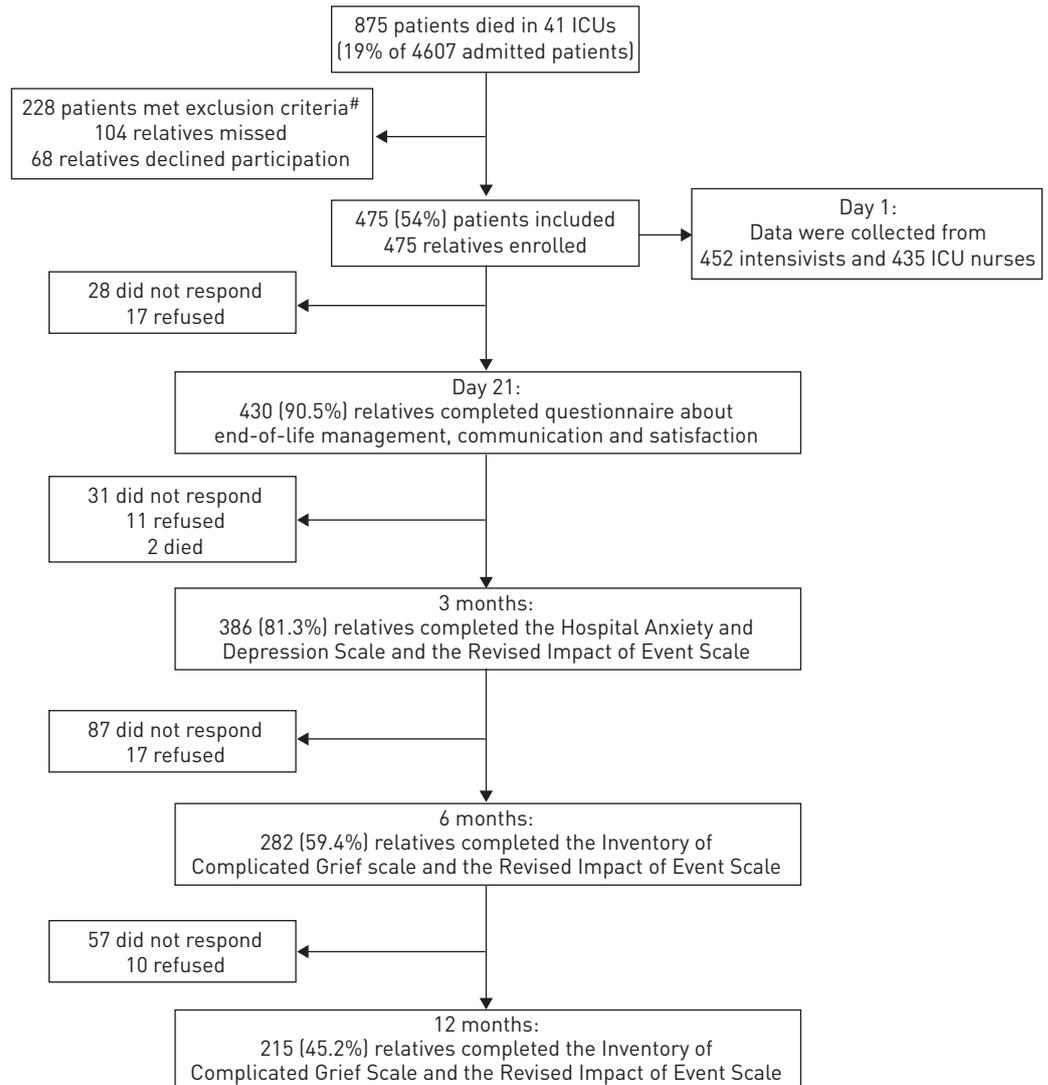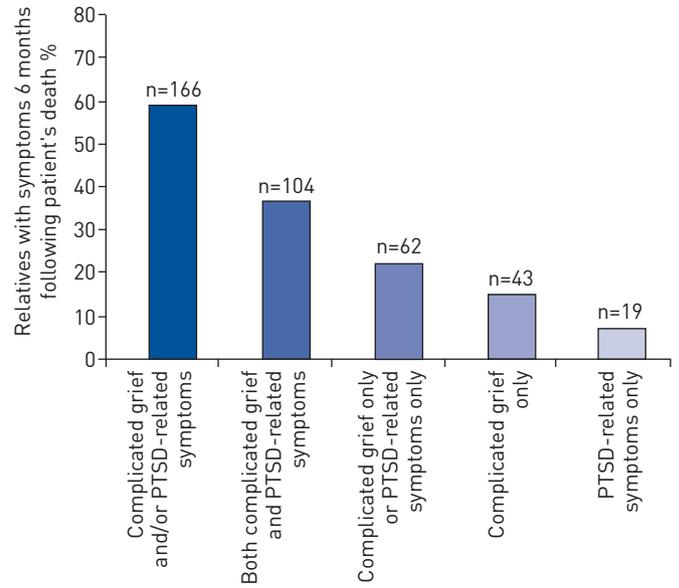
FIGURE 2 Flow chart of patients and relatives. ICU: intensive care unit. #: patients either died before ICU day 3 or did not have a relative visiting them before the time of death.
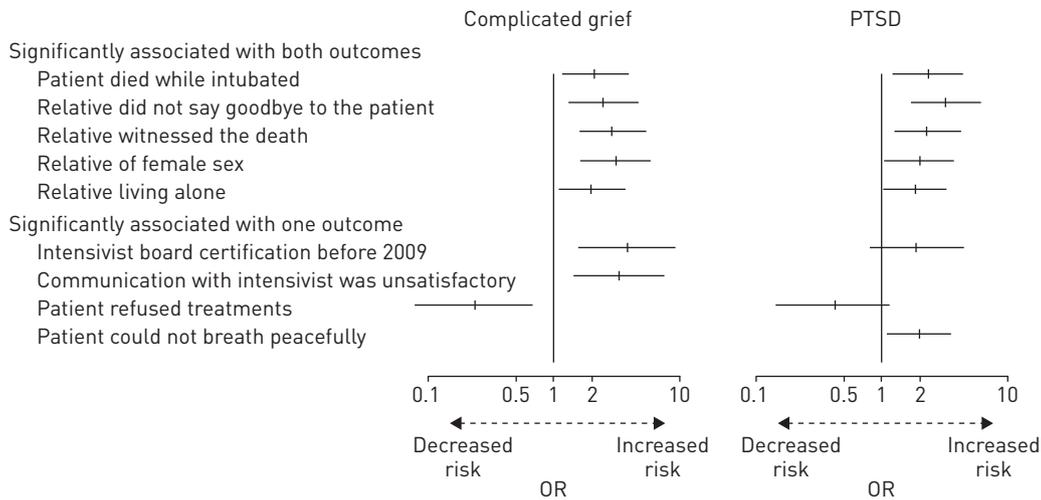
FIGURE 3 Plot distribution of independent determinants of complicated grief and post-traumatic stress disorder (PTSD) symptoms identified by multivariate analysis. Data are presented as odds ratios. Whiskers represent 95% confidence intervals.

In addition, up to 36.9% of the patients presented with both complicated grief and PTSD, suggesting that detecting complicated grief does not add to PTSD. However, some clinical symptoms are specific to complicated grief (such as symptoms of yearning and failure to adapt) and may require different coping strategies. Also, high levels of PTSD symptoms have been identified for over 10 years and still remain high,
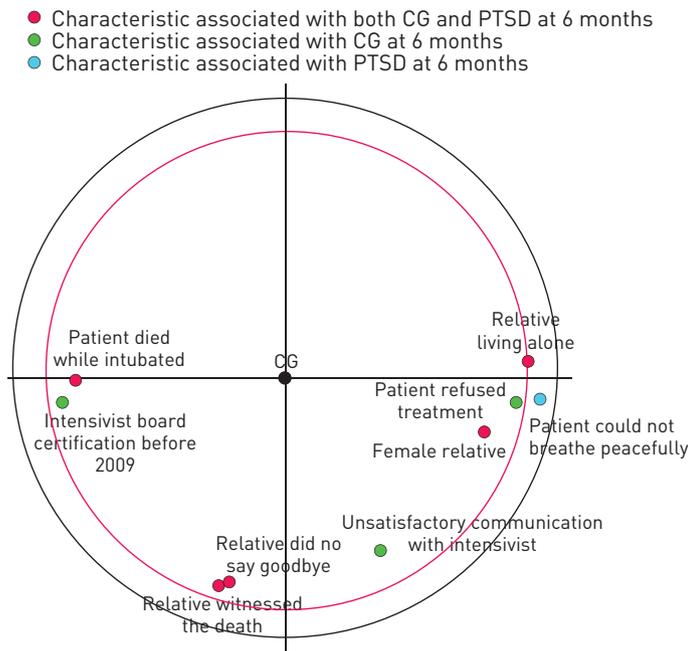
FIGURE 4 Focused principal-component analysis of determinants of post-traumatic stress disorder (PTSD) symptoms and symptoms of complicated grief (CG) at 6 months. This graphical display is focused on CG and its correlation with other variables. This representation allows both the pattern of relationships between CG and the dependencies between the responses to be seen. The relative positions of the predictors may distinguish some clusters of explanatory variables. CG is at the center of the diagram and the distance of this point to another variable may be translated into correlation. When two points are close to one another, then the two underlying variables are positively correlated. When two points form a right angle with the origin, the two underlying variables are uncorrelated. When two points are diametrically opposed, then the two underlying variables are negatively correlated. The variables inside the red circle are significantly correlated with the dependent variable at the 5% level. Three clusters of explanatory variables are depicted in this figure: first, the year of intensivist's board certification and the fact that patients died while intubated are positively correlated; a second cluster (patient's refusal of treatment, female relative, relative living alone following the loss and patient who could not breathe peacefully) is diametrically opposite and therefore negatively correlated to the first one; the third cluster includes the fact that relatives witnessed the death and did not say goodbye to the dying patient.

suggesting that current ways of preventing PTSD may not be effective. This study clearly shows that if up to one-third of relatives present with both complicated grief and PTSD, ~15% present complicated grief only and 6% PTSD only. Interestingly, some of the patients who had both complicated grief and PTSD after 6 months showed an improvement in one of these two scores and not in the other. In keeping with the relative's follow-up after an ICU stay, our data report some differences in PTSD prevalence based on the time of assessment (3 months *versus* ≥6 months), the difference between bereaved and nonbereaved relatives, and study designs (control groups from interventional studies) [20, 22, 23, 37].

Complicated grief is the persistence of specific symptoms >6 months after the death [24–25] and severely affects quality of life [24–27, 49]. Some of the factors significantly associated with complicated grief suggest specific explanations. For instance, relatives of patients who died while intubated may have been unaware of the exact time of death, which may have led to a feeling of disbelief about the death. Relatives of patients who died while not intubated may have perceived the death as more natural and may have received greater support from the ICU staff, in particular during obvious manifestations of respiratory distress, gasps or a need for titrating sedation. Not saying goodbye to the patient may contribute to feelings of yearning for the deceased, as well as to anger and bitterness. Actively helping the relatives understand that the patient is dying and helping them find closure by saying goodbye to their loved one is crucial. Therefore, the ICU staff must regularly assess the relatives' feelings and experience, and offer to remain with the relatives at the patient's bedside. Being present at time of death increased the risk of presenting complicated grief symptoms in our study. This finding may seem surprising, as relatives often express the wish to be with their loved one at the time of death [12] and witnessing the death has been identified as a marker for good-quality end-of-life care [47]. However, relatives may wish to witness the death then find the experience difficult to handle, at least in the ICU setting. Inadequate management of patient comfort and dignity can impact on relatives' experience of the dying process. This puts forward the necessity for improving perceived suffering by patients during the dying process. Furthermore, inadequate preparation related to poor communication and lack of support can adversely affect the relatives 6 months after the death. Relatives who wish to be present at the time of death need compassionate support before, during and after this experience.

We identified three areas for improvement. The first one is relevant to end-of-life practices and affects three domains: taking into account patients' wishes (treatment refusal), timely extubation and closure at the end of life, all three of which are important components of high-quality end-of-life care in the ICU, in keeping with earlier data [15, 16, 50–53]. However, our study is the first to show a significant association between end-of-life practices and complicated grief symptoms up to 1 year after the death. The second area of improvement is communication: interestingly, suboptimal communication with the intensivist was associated with complicated grief symptoms but not with PTSD-related symptoms. High-quality communication involves adequate information that death is imminent, to ensure that the family is aware of the reality of death [23] and can say goodbye to the patient; another component of good communication is adequate support for relatives who wish to witness the death. That intensivist board certification before 2009 predicted complicated grief may reflect recent changes in the critical care curriculum in France, which now includes specific training on care, ethical issues and communication at the end of life. An alternative explanation is that communication with young physicians may be less stressful for the relatives, as suggested by a previous study [54]. The third area of improvement is post-ICU care: living alone after the death was associated with the presence of complicated grief symptoms, underlining the importance of providing bereaved relatives with effective social support. Previous studies reported that complicated grief was increased among subjects with an absent or unhelpful family [55]. Interventions to evaluate the impact of targeting these three domains with the goal of diminishing the frequency of complicated grief are warranted.

This study has several limitations. First, all participating ICUs were in France, and whether our findings apply to other countries is unclear. However, the proportions of relatives with complicated grief and/or PTSD-related symptoms were consistent with earlier data [37]. In addition, previous studies in France, Canada and the USA reported that the prominent model for decision making remains the shared decision-making model [56], with surrogate decision makers empowered to be able to actively be part of the decisions. In addition, the large sample size, varied case-mix and ethnic diversity of our patient population suggest applicability of our findings to other settings. Second, in this study, the lack of a control group of bereaved relatives after the death of a patient outside the ICU meant that we were not able to state that complicated grief occurs more frequently in this setting. However, the present study focused on identifying targets for improvement of end-of-life care in the ICU and to alert hospital clinicians, as well as general practitioners, that these bereaved relatives are at high risk of complicated grief. Third, nearly half the relatives were lost to follow-up before the end of the year, suggesting a potential for estimation bias. However, the 60% response rate at 6 months is among the highest in similar studies

[14, 23, 57]. In addition, the reasons for loss to follow-up indicate clearly that a 100% response rate after 6 or 12 months is not realistic in studies of bereavement. ICG and IES-R scores at 6 months showed no significant differences between the groups with and without assessments at 12 months. Fourth, complicated grief and PTSD were assessed using questionnaires, as opposed to semi-structured interviews with psychologists or psychiatrists. However, these questionnaires have been validated in the ICU setting and proven reproducible across studies [20, 23, 58]. The ICG is a good screening instrument for complicated grief and scores >25 predict a range of negative health outcomes in many studies [26, 27]. We believe qualitative data would help to give meaning to the findings from the present study. Finally, we did not use the Revised ICG as no French translation of the scale was valid at the time of the study.

In practice, this study depicts the grieving process in individuals having lost an adult family member in the ICU. The five-fold higher frequency of complicated grief compared with studies in the general population [24, 25] indicates that community healthcare professionals must maintain a high index of suspicion for complicated grief, and discuss possible treatment and support with psychiatrist and/or psychologist. This conclusion applies also to depression and PTSD symptoms. The manifestations of normal grief and complicated grief should be taught in medical and nursing schools. Identification of risk factors associated with management of end-of-life care in the ICU helps target interventions that may help decrease bereaved families' burdens: encouraging, when possible, extubation; encouraging families to say goodbye; and adequate preparation and support during end-of-life care for families who wish to be present. The end of life in the ICU can still be improved both by enhancing communication strategies and by introducing palliative care at an early stage to help relatives make meaning of the patient's death.

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