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CAESAR: a new tool to assess relatives' experience of dying and death in the ICU

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Abstract

Purpose: To develop an instrument designed specifically to assess the experience of relatives of patients who die in the intensive care unit (ICU).

Methods: The instrument was developed using a mixed methodology and validated in a prospective multicentre study. Relatives of patients who died in 41 ICUs completed the questionnaire by telephone 21 days after the death, then completed the Hospital Anxiety and Depression Scale, Impact of Event Scale-Revised and Inventory of Complicated Grief after 3, 6, and 12 months.

Results: A total of 600 relatives were included, 475 in the main cohort and 125 in the reliability cohort. The 15-item questionnaire, named CAESAR, covered the patient's preferences and values, interactions with/around the patient and family satisfaction. We defined three groups based on CAESAR score tertiles: lowest (≤ 59 , $n = 107$, 25.9 %), middle ($n = 185$, 44.8 %) and highest (≥ 69 , $n = 121$, 29.3 %). Factorial analysis showed a single dimension. Cronbach's alpha in the main and reliability cohorts was 0.88 (0.85–0.90) and 0.85 (0.79–0.89), respectively. Compared to a high CAESAR score, a low CAESAR score was associated with greater risks of anxiety and depression at 3 months [1.29 (1.13–1.46), $p = 0.001$], post-traumatic stress-related symptoms at 3 [1.34 (1.17–1.53), $p < 0.001$], 6 [OR = 1.24 (1.06–1.44), $p = 0.008$] and 12 [OR = 1.26 (1.06–1.50), $p = 0.01$] months and complicated grief at 6 [OR = 1.40 (1.20–1.63), $p < 0.001$] and 12 months [OR = 1.27 (1.06–1.52), $p = 0.01$].

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Take-home message: A 15-item questionnaire (CAESAR) proved reliable for assessing the experience of relatives with the dying and death of a loved one in the intensive care unit. This instrument should prove useful as the primary endpoint in trials of interventions designed to improve family care.

Conclusions: The CAESAR score 21 days after death in the ICU is strongly associated with post-ICU burden in the bereaved relatives. The CAESAR score should prove a useful primary endpoint in trials of interventions to improve relatives' well-being.

Keywords: Relatives, Intensive care unit, Death, Bereavement, Complicated grief

Introduction

An increasing number of deaths occur in hospitals, particularly in intensive care units (ICUs) [1], where the burden on relatives is heavy [2–5]. This fact, together with the high mortality rates in ICUs, has prompted tremendous efforts to understand the experience of dying and death in the ICU [6]. Studies have identified quality markers [7], targets for improving end-of-life care, and metrics for assessing the effectiveness of ICU interventions. For instance, a communication strategy based on a proactive family conference was shown to diminish the post-ICU burden on relatives, who were less affected by post-traumatic stress disorder (PTSD), anxiety and depression [4]. Identifying meaningful outcomes for patients who die in the ICU has been the focus of specific studies. The components of the post-ICU burden are not necessarily specific to the ICU. Characterising the specific aspects of dying and death in the ICU that are associated with the subsequent burden on relatives is a prerequisite to developing preventive strategies.

A tool designed to measure the quality of dying and death (QODD) in any setting (e.g. hospital, nursing home, home or hospice) from the relatives' perspective has been developed by a group that defined QODD as 'the degree to which a person's preferences for dying and the moment of death agree with observations of how the person actually died as reported by others' [8]. This group used a literature review, patient interviews, focus groups, prior research, existing instruments, and a list of desirable measurement properties to identify six conceptual domains and 31 specific issues [8]. Of these 31 issues, 23 were selected as relevant to a QODD measurement tool for ICU patients [9]. The ICU-QODD has shown valuable psychometric properties [10]. After the death, the ICU-QODD is completed by the physicians and nurses in charge of the patient within a few days or weeks and by the relatives after several months.

The QODD tool centres on the patient. The relatives, however, also require specific attention to ensure that their suffering during and after the death is alleviated to the extent possible. ICU healthcare workers must be able to identify the personal characteristics that affect relatives' coping style and ability, such as the nature of their relationship with the patient, ability to understand medical information, communication style with the ICU staff, beliefs, support system and usual degree of psychological

well-being. The first step towards achieving this objective is to understand the experience of relatives of patients dying in the ICU.

Here, our objective was to develop and validate a tool specifically designed to assess the overall experience of relatives of patients who die in the ICU. We used a mixed methodology to create the questionnaire then validated it in a multicentre prospective study in 41 French ICUs.

Patients and methods

The study was approved by the institutional review board of the Paris-North Hospitals (IRB00006477, approval #11-019), Paris 7 University. Informed consent was obtained from each relative before study inclusion.

Development of the CAESAR instrument

We used three sources of data to develop the initial questionnaire: a review of the medical, nursing and social-science literature; the experience accumulated by our research group; and in-depth qualitative interviews by a sociologist (NKB) with relatives of patients expected to die in the ICU, bereaved relatives, physicians and nurses.

A panel of ten investigators (five physicians, two nurses and three sociologists/psychologists) held several meetings to discuss the data collected from these three sources. They identified eight domains and 50 items about the experience of relatives (Table S1). The items were then tested twice with relatives of patients, as well as with physicians and nurses, in one ICU (Saint Louis Hospital). The distribution of each item was examined, and a floor or ceiling effect was defined as having more than 85 % of respondents with the lowest or highest item score [11], a characteristic potentially associated with poor discrimination. Items with a large number of missing answers were then identified as potentially unreliable. Finally, a factorial analysis was performed to identify items with a weak representation. On the basis of the results of these analyses, the panel eliminated 17 items. The remaining 33 items (Table S2) fell into three domains: the patient (preparation for death, whole person concerns, symptoms, personal care, and treatment preferences); interactions with and around the patient (quality of communication between the ICU team and the patient and between the ICU team and the relatives, particularly whether conflicts arose), and family needs and satisfaction. The items are not arranged by domain on the questionnaire form but

Table 1 Final 15-item CAESAR questionnaire

| Items | Mean score (standard deviation) |
|--|---------------------------------|
| 1. Was your loved one's pain well controlled throughout the ICU stay? Please rate this experience: 1 Traumatic, 2 Painful, 3 Difficult, 4 Acceptable, 5 Comforting | 4.2 (1.2) |
| 2. Do you feel that your loved one's dignity was maintained? Please rate this experience: 1 Traumatic, 2 Painful, 3 Difficult, 4 Acceptable, 5 Comforting | 4.6 (0.9) |
| 3. Do you feel the ICU team was attentive to your loved one? Please rate this experience: 1 Traumatic, 2 Painful, 3 Difficult, 4 Acceptable, 5 Comforting | 4.4 (0.9) |
| 4. Are you satisfied with the quality of medical care received by your loved one? Please rate this experience: 1 Traumatic, 2 Painful, 3 Difficult, 4 Acceptable, 5 Comforting | 4.4 (1.1) |
| 5. During the days before the death, were you clearly informed that your loved one was dying? Please rate this experience: 1 Traumatic, 2 Painful, 3 Difficult, 4 Acceptable, 5 Comforting | 3.2 (1.3) |
| 6. Are you satisfied with the quality of the communication between you and the physicians? Please rate this experience: 1 Traumatic, 2 Painful, 3 Difficult, 4 Acceptable, 5 Comforting | 4.4 (1.1) |
| 7. Are you satisfied with the quality of the communication between you and the nurses? Please rate this experience: 1 Traumatic, 2 Painful, 3 Difficult, 4 Acceptable, 5 Comforting | 4.7 (0.8) |
| 8. Were you in conflict with the ICU team? Please rate this experience: 1 Traumatic, 2 Painful, 3 Difficult, 4 Acceptable, 5 Comforting | 4.6 (0.8) |
| 9. Were you given the opportunity to discuss your loved one's wishes, as well as your own preferences, with the ICU team? Please rate this experience: 1 Traumatic, 2 Painful, 3 Difficult, 4 Acceptable, 5 Comforting | 4.1 (1.1) |
| 10. Did your loved one refuse any of the suggested treatments? Please rate this experience: 1 Traumatic, 2 Painful, 3 Difficult, 4 Acceptable, 5 Comforting | 4.1 (0.8) |
| 11. Do you believe the ICU team went too far in the treatment given to your loved one? Do you believe the ICU team used unnecessary treatments? Please rate this experience: 1 Traumatic, 2 Painful, 3 Difficult, 4 Acceptable, 5 Comforting | 3.9 (1.3) |
| 12. Were you able to say goodbye and express important feelings to your loved one? Please rate this experience: 1 Traumatic, 2 Painful, 3 Difficult, 4 Acceptable, 5 Comforting | 3.9 (1.3) |
| 13. Were you present when your loved one died? Please rate this experience: 1 Traumatic, 2 Painful, 3 Difficult, 4 Acceptable, 5 Comforting | 4.5 (0.9) |
| 14. Are you satisfied with the support you received while your loved one was dying? Please rate this experience: 1 Traumatic, 2 Painful, 3 Difficult, 4 Acceptable, 5 Comforting | 3.9 (0.6) |
| 15. During your loved one's stay in the ICU, did you receive counselling, for instance from a psychologist? Please rate this experience: 1 Traumatic, 2 Painful, 3 Difficult, 4 Acceptable, 5 Comforting | 4.2 (0.8) |

are instead asked in the order believed to be easiest and least traumatic for the relatives. Each item is answered by both a written description and a score on a 5-point scale (1, traumatic; 2, painful; 3, difficult; 4, acceptable; and 5, comforting). A questionnaire was also developed for the physicians and nurses and used for a separate analysis. Finally, 18 additional items were eliminated because they were redundant, as determined on the basis of inter-item Spearman's correlation coefficients [12]. This produced the 15-item questionnaire shown in Table 1 and designated CAESAR. Relatives need approximately 20 min to complete the instrument.

Validation of the CAESAR questionnaire

The 33-item questionnaire was validated in a multicentre prospective study conducted from July 2011 to July 2013 in 41 French ICUs belonging to the FAMIREA network, as described elsewhere [13]. In each ICU, one of the intensivists included consecutive adults who died after at least 48 h in the ICU. For each patient, we included the

relative who served as the surrogate at the time of death (designated proxy > spouse > adult child > sibling > other relative, in that order). Eligibility criteria for relatives were having visited the patient at least once in the ICU and having sufficient knowledge of French to complete the assessment tools.

The data shown in the tables and figures were collected prospectively. The relatives completed the 33-item questionnaire during a telephone interview 21 days after the patient's death. To validate the questionnaire, a reliability cohort of relatives of patients who died in the same 41 ICUs was recruited. During a telephone interview 3 months after the death, each relative in the cohort completed the Hospital Anxiety and Depression Scale (HADS) and Impact of Event Scale-Revised (IES-R) for PTSD symptoms. All telephone interviews were conducted by the same sociologist with extensive interviewing experience (ZCS). Finally, 6 and 12 months after the death, a questionnaire including the Inventory of Complicated Grief (ICG) and IES-R was mailed to each relative.

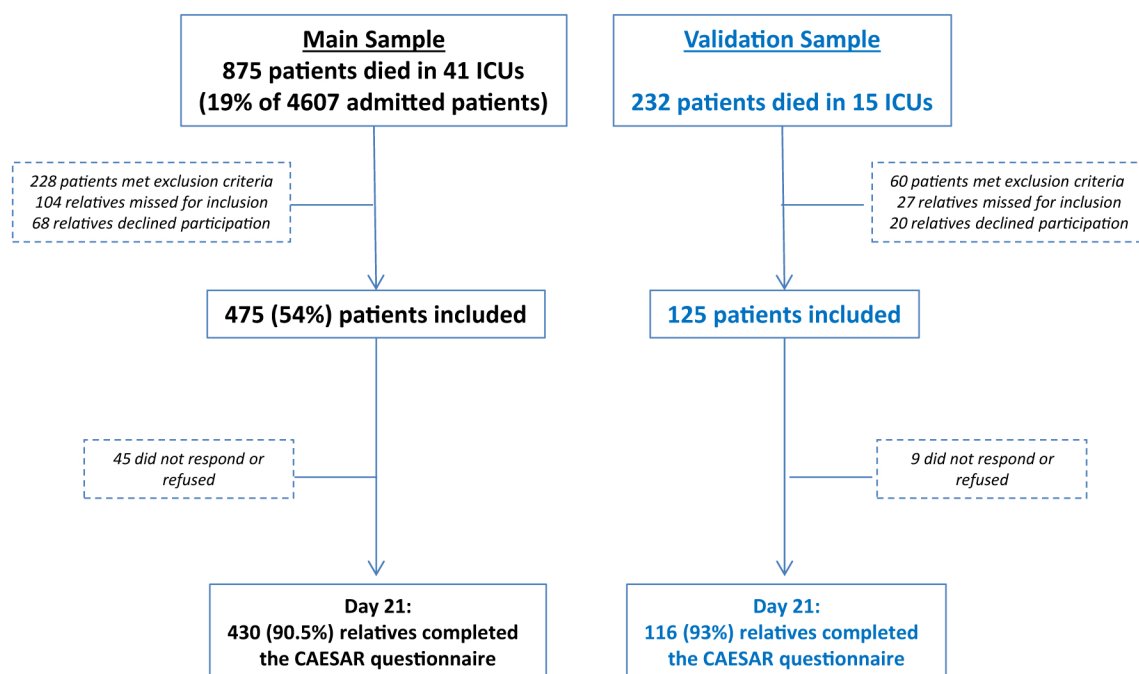


Fig. 1 Recruitment flow chart for the development and reliability cohorts

Factorial validity was assessed in the main sample by determining the dimensional structure of the 33-item questionnaire and final 15-item CAESAR questionnaire. To this end, we used maximum likelihood factor analysis with varimax rotation. The number of factors was determined from the observation of the screen plots and value of simulations [14–16]. Internal consistency was deemed acceptable when Cronbach's alpha [17] was in the 0.70–0.95 range [18]. Confidence intervals (CIs) were computed on the basis of 1000 bootstrap replicates. Factorial validity was assessed in the reliability sample using the same methodology.

For the final 15-item tool, the item scores (range 1–5) were summed to obtain a global score (15–75).

Statistical analysis

Statistical analyses were performed using the R 3.1 package with the “psy” package [19]. Quantitative data were described as median (interquartile range) and binary and categorical data as number (%). All statistical tests were two-sided and p values of 0.05 or less were considered significant.

Results

Study population

Figure 1 is the study flow chart. 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 whose relatives refused participation. For

each of the remaining 475 (54 %) patients, one relative was included. On day 21, 430 (90.5 %) relatives completed the 33-item instrument. A different group of 232 relatives was included in the reliability cohort; 116 (93 %) of these relatives completed the 33-item instrument on day 21.

Table 2 reports the main characteristics of the relatives and end-of-life circumstances according to CAESAR scores.

CAESAR scores

Of the 430 33-item questionnaires completed on day 21, 413 (96 %) had no missing data for the 15 CAESAR items and were therefore used to determine the global score. The median score was 66 (range 21–75, interquartile range 59–69). Of the score values, 107 (25.9 %) were in the lowest tertile (≤ 59), 185 (44.8 %) in the middle tertile and 121 (29.3 %) in the highest tertile (≥ 69). Table 3 reports the prevalence of symptoms of post-ICU burden according to CAESAR score tertiles.

Figure S1A depicts the distribution of individual item scores and Fig. S1B the distribution of the global CAESAR score. The factorial analysis of the main sample, assessed by screen plots, was consistent with a single dimension, as 42.1 % of the variance was explained by the first principal component (Fig. S2A). Cronbach's alpha was 0.88 (95 % CI 0.85–0.90). Similarly, in the reliability sample, the results suggested a one-dimensional structure, with 35.9 % of the variance explained by the first principal component

Table 2 Characteristics of the relatives, end-of-life, and ICU by CAESAR score tertile

| | Overall <i>n</i> = 413 (%) | Lowest tertile <i>n</i> = 107 | Middle tertile <i>n</i> = 185 | Highest tertile <i>n</i> = 121 | <i>p</i> value |
|--|----------------------------|-------------------------------|-------------------------------|--------------------------------|----------------|
| Relatives, <i>n</i> (%) | | | | | |
| Gender, <i>n</i> (%) | | | | | |
| Male | 128 (31.0 %) | 38 (35.5 %) | 51 (27.6 %) | 39 (32.2 %) | 0.346 |
| Female | 285 (69.0 %) | 69 (64.5 %) | 134 (72.4 %) | 82 (67.8 %) | |
| Relationship to patient | | | | | |
| Spouse | 140 (33.9 %) | 38 (35.5 %) | 69 (37.3 %) | 33 (27.3 %) | 0.199 |
| Adult child | 188 (45.5 %) | 50 (46.7 %) | 82 (44.3 %) | 56 (46.3 %) | |
| Parent | 13 (3.1 %) | 5 (4.7 %) | 3 (1.6 %) | 5 (4.1 %) | 0.496 |
| Brother/sister | 37 (9.0 %) | 10 (9.3 %) | 16 (8.6 %) | 11 (9.1 %) | |
| Other | 35 (8.5 %) | 4 (3.7 %) | 15 (8.1 %) | 16 (13.2 %) | 0.243 |
| Religious/spiritual beliefs | 280 (67.8 %) | 71 (66.4 %) | 122 (65.9 %) | 87 (71.9 %) | |
| Practice of a religion | 107 (25.9 %) | 22 (20.6 %) | 48 (25.9 %) | 37 (30.6 %) | |
| End-of-life | | | | | |
| Length of ICU stay (days), median (IQR) | 7 (4–17) | 11 (6–24) | 6 (3–16) | 6.5 (4–12) | 0.008 |
| Use of vasopressors, <i>n</i> (%) | 314 (76. %) | 91 (85 %) | 140 (75.7 %) | 83 (68.6 %) | 0.016 |
| Decision to withhold or withdraw life-sustaining therapy, <i>n</i> (%) | | | | | |
| None | 80 (19.4 %) | 26 (24.3 %) | 36 (19.5 %) | 18 (14.9 %) | 0.494 |
| Withholding decision | 134 (32.4 %) | 31 (29 %) | 61 (33 %) | 42 (34.7 %) | |
| Withdrawing decision | 199 (48.2 %) | 50 (46.7 %) | 88 (47.6 %) | 61 (50.4 %) | |
| Family participation in the decision-making process, <i>n</i> (%) | | | | | |
| Actively involved | 198 (47.9 %) | 40 (37.4 %) | 92 (49.7 %) | 66 (54.5 %) | 0.103 |
| Informed of decisions | 135 (32. %7) | 41 (38.3 %) | 57 (30.8 %) | 37 (30.6 %) | |
| Neither involved nor informed | 80 (19.4 %) | 26 (24.3 %) | 36 (19.5 %) | 18 (14.9 %) | |
| How the death was disclosed to the family, <i>n</i> (%) | | | | | |
| At the bedside | 228 (55.2 %) | 65 (60.7 %) | 93 (50.3 %) | 70 (57.9 %) | 0.066 |
| Over the phone | 136 (32.9 %) | 27 (25.2 %) | 72 (38.9 %) | 37 (30.6 %) | |
| Upon arrival at the ICU | 49 (11.9 %) | 15 (14.9 %) | 20 (10.8 %) | 14 (11.5 %) | |
| Mechanical ventilation at the time of death, <i>n</i> (%) | | | | | |
| Intubated | 273 (66.1 %) | 75 (70.1 %) | 125 (67.6 %) | 73 (60.3 %) | 0.572 |
| Recently extubated | 58 (14.0 %) | 13 (12.1 %) | 24 (13 %) | 21 (17.4 %) | |
| Never intubated | 82 (19.9 %) | 19 (17.8 %) | 36 (19.5 %) | 27 (22.3 %) | |
| Involvement of external consultants, <i>n</i> (%) | | | | | |
| Palliative-care team | 12 (2.9 %) | 4 (3.7 %) | 4 (2.2 %) | 4 (3.3 %) | 0.702 |
| Clergyman/chaplain | 51 (12.3 %) | 17 (15.9 %) | 21 (11.4 %) | 13 (10.7 %) | 0.372 |
| ICU characteristics, <i>n</i> (%) | | | | | |
| 24-hour visiting | 151 (36.6 %) | 32 (29.9 %) | 72 (38.9 %) | 47 (38.8 %) | 0.252 |
| Psychologist available | 150 (36.3 %) | 38 (35.5 %) | 69 (37.3 %) | 43 (35.5 %) | 0.933 |

ICU intensive care unit, IQR interquartile range

(Fig. S2). Cronbach's alpha was 0.85 (95 % CI 0.79–0.89). Spearman's correlation coefficients between each item and the global score ranged from 0.39 to 0.79 (Table S3).

Factors associated with the CAESAR score

A longer ICU stay length was significantly associated with a lower CAESAR score indicating a more difficult experience with dying and death [11 (6–24), 6 (3–16) and 6.5 (4–12) days in the low, middle and high tertiles, respectively, *p* = 0.008]. Vasopressor therapy was also

associated with a lower CAESAR score (85, 75.7 and 68.6 % of patients received vasopressors in in the low, middle and high tertiles, respectively, *p* = 0.016).

At 3 months, 370 (86 %) relatives completed the HADS and IES-R. Among them, 190 (51.4 %) had symptoms of depression and 129 (34.9 %) symptoms of anxiety. At 6 and 12 months, 268 (64.9 %) and 209 (50.6 %) relatives completed the ICG and IES-R. Among them, 139 (51.9 %) met criteria for complicated grief at 6 months and 113 (54.1 %) at 12 months. Complicated grief at 6 months was

Table 3 Post-ICU burden according to CAESAR score tertile

| Median (IQR) or numbers (%) | Overall | Lowest tertile <i>n</i> = 107 | Middle tertile <i>n</i> = 185 | Highest tertile <i>n</i> = 121 | <i>p</i> value |
|---------------------------------------|--------------|-------------------------------|-------------------------------|--------------------------------|----------------|
| At 3 months (<i>n</i> = 385) | | | | | |
| HADS score | 13 (7–22) | 18 (9.5–24) | 13 (7–20) | 10 (5–17.75) | <0.001 |
| Relatives with symptoms of anxiety | 198 (51.4 %) | 58 (61.1 %) | 83 (50.3 %) | 49 (44.5 %) | 0.058 |
| Relatives with symptoms of depression | 137 (35.6 %) | 49 (51.6 %) | 57 (34.5 %) | 23 (20.9 %) | <0.001 |
| IES-R score | 30 (13–45) | 38 (25–54) | 28 (14–45) | 17 (5.25–17.75) | <0.001 |
| Relatives with PTSD symptoms | 173 (44.9 %) | 57 (60.0 %) | 74 (44.8 %) | 34 (30.9 %) | <0.001 |
| At 6 months (<i>n</i> = 267) | | | | | |
| ICG score | 27 (16–40) | 37 (24.5–49) | 25 (17–39.75) | 22 (10.5–35.5) | <0.001 |
| Relatives with complicated grief | 140 (52.4 %) | 49 (73.1 %) | 54 (49.1 %) | 36 (39.6 %) | <0.001 |
| IES-R score | 29 (16–43) | 35 (21–49.5) | 28 (17–45.75) | 25 (12–36) | 0.004 |
| Relatives with PTSD symptoms | 116 (43.4 %) | 37 (55.2 %) | 47 (42.7 %) | 31 (34.1 %) | 0.029 |
| At 12 months (<i>n</i> = 207) | | | | | |
| ICG score | 27 (14–41) | 31 (21–45) | 29 (19–42) | 22 (9.75–34.25) | 0.003 |
| Relatives with complicated grief | 112 (54.1 %) | 29 (64.4 %) | 53 (60.2 %) | 31 (40.8 %) | 0.013 |
| IES-R score | 26 (13–43) | 31 (21–46) | 30 (13.75–45) | 20.5 (10–30.25) | 0.002 |
| Relatives with PTSD symptoms | 76 (36.7 %) | 21 (46.7 %) | 38 (43.2 %) | 18 (23.7 %) | 0.011 |

Lowest, middle and highest CAESAR tertiles were scores ≤ 59 , between 60 and 68, and ≥ 69 , respectively
ICU intensive care unit, IQR interquartile range, HADS Hospital Anxiety and Depression Scale, IES-R Impact of Event Scale-Revised, PTSD post-traumatic stress disorder, ICG Inventory of Complicated Grief

more common in the lowest CAESAR score tertile than in the middle tertile [odds ratio (OR) 1.27, 95 % CI 1.10–1.47, $p = 0.002$] or highest tertile (OR 1.40, 95 % CI 1.20–1.63, $p < 0.001$) (Fig. 2). Corresponding figures at 12 months were as follows: OR 1.04, 95 % CI 0.87–1.24, $p = 0.64$; and OR 1.27, 95 % CI 1.06–1.52, $p = 0.011$, respectively. Table S4 reports associations between CAESAR score tertiles and clinical endpoints at 3, 6 and 12 months.

The prevalence of PTSD-related symptoms as assessed by the IES-R decreased over time, from 44.6 % ($n = 165/370$) at 3 months to 42.9 % ($n = 115/268$) at 6 months and 36.8 % ($n = 77/209$) at 12 months. At 6 months, relatives in the lowest CAESAR score tertile were at higher risk for PTSD-related symptoms compared to those in the middle tertile (OR 1.13, 95 % CI 0.98–1.32, $p = 0.102$) or highest tertile (OR 1.24, 95 % CI 1.06–1.44, $p = 0.008$) (Fig. 2). Corresponding figures at 12 months were as follows: OR 1.04, 95 % CI 0.87–1.23, $p = 0.69$; and OR 1.26, 95 % CI 1.06–1.50, $p = 0.011$, respectively.

Discussion

This study performed in 41 ICUs belonging to the FAMIREA network allowed us to develop and validate a new tool, the 15-item CAESAR questionnaire, designed to measure the self-reported experience of relatives with the dying and death of a family member in the ICU. The CAESAR score 21 days after the patient’s death correlated strongly with the presence in the following months of symptoms of anxiety, depression, PTSD and complicated grief.

This tool should prove useful in assessing the efficacy of interventions designed to improve the quality of relatives’ experience with dying and death of ICU patients. Furthermore, it can serve to identify areas where improvements are most needed. These expected benefits are of considerable importance, as high levels of post-ICU burden continue to be documented despite recent advances in communication strategies, training, incorporation of palliative care in the ICU and recognition of relatives’ vulnerability [20–22].

To determine how to improve end-of-life care in the ICU, we need objective and subjective information on the process of dying, the management of this process in the ICU, and the effects of specific features of the process on relatives’ well-being. The items of the CAESAR questionnaire were derived from studies in the field of social science and from qualitative interviews of relatives of ICU patients and of ICU workers. CAESAR provides information on the relatives’ experience with ICU practices rather than on the practices themselves. This approach sheds light on the aspects of end-of-life care that are important to families, as opposed to physicians and nurses. Moreover, as shown in a previous publication [13], our study identified features of end-of-life care that correlated with major components of the post-ICU burden such as PTSD and complicated grief. Thus, an individualized determination of the part each specific patient wants to play and the opportunity for the relatives to say goodbye and to be present at the time of death are particularly important to the relatives [13].

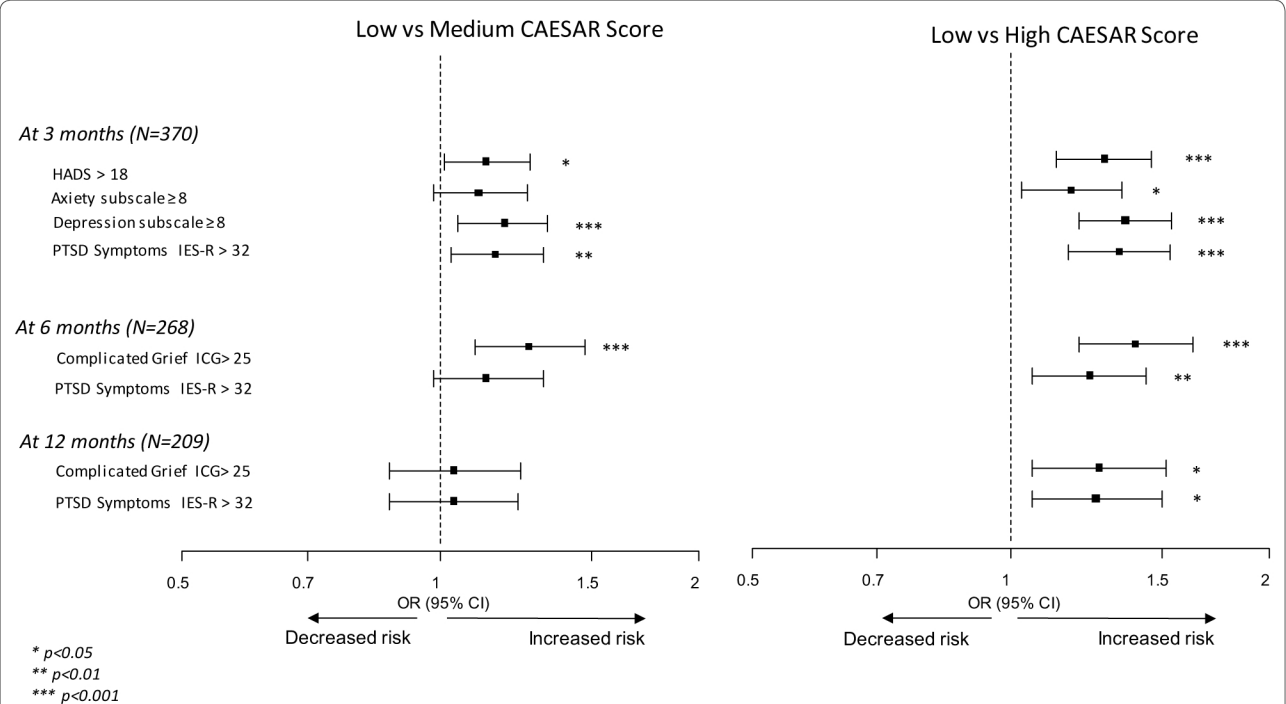


Fig. 2 Association between the CAESAR score and clinical endpoints 3, 6 and 12 months after the patient's death, assessed by logistic regression

The CAESAR scale adds to the ICU-QODD, which relies primarily on data from family members and not from healthcare workers [23]. Furthermore, we focused on relatives and not patients. When developing the CAESAR tool, we eliminated items that often went unanswered in the test administrations. ICU-QODD and CAESAR include shared variables that influence their scores, such as pain control, patient's dignity, family presence at the time of death and discussion of the patient's wish to withdraw life support [24]. Other variables specific to CAESAR, such as quality of communication, are considered by relatives to be among the most highly valued aspects of care [25]. Studies comparing the information supplied by the two tools are warranted. However, discrepancies can be expected, as family members give more favourable ratings of dying and death compared to nurses [26].

The global CAESAR score provides a picture of relatives' experience with end-of-life care in the ICU. By determining this score at regular intervals, ICUs can monitor their performance over time. However, further work is needed to assess the sensitivity of the CAESAR score to interventions designed to improve dying and death in the ICU. The median CAESAR score was 66/75 (21–75), and only 25.9 % of relatives were in the lowest tertile. Whether CAESAR can serve as a benchmarking tool needs further exploration.

This study has several limitations. First, all participating ICUs were in France and the findings may not be applicable to other countries. However, the large number of ICUs and relatives and the validation of the results in a reliability cohort support the robustness of the data. Second, instead of asking the relatives to complete the questionnaire immediately after the death, we waited 3 weeks. We believe that completing the questionnaire immediately may be difficult or even distressful. Compared to earlier studies, the evaluation of the relatives' experience was performed far earlier and using a more uniform approach. Moreover, a single highly experienced sociologist administered the questionnaire during a telephone interview, offering support whenever the items activated distressing emotions. Such support is known to be much appreciated by families [27]. Last, not all relatives could be contacted at 6 and 12 months. However, the response rates at these time points are at the high end of the range reported in earlier studies [4, 9].

In summary, we describe and validate a new instrument for assessing the experience of relatives of patients who die in the ICU. Our study suggests new targets for interventions designed to improve family care in the ICU. Only a quarter of the relatives had low CAESAR scores indicating a distressing experience. However, these low scores were associated with a greater post-ICU burden. The CAESAR score could serve as a primary endpoint in studies of

interventions aimed at improving the experience of relatives with the dying and death of a loved one in the ICU.

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Compliance with ethical standards

Conflicts of interest

None of the authors declare any conflict of interest in relation to this manuscript.

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