

# A new instrument for assessing the experience of dying and death in the intensive care units from the perspective of relatives

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Post-traumatic stress disorder (PTSD) is defined as an anxiety disorder that generally follows exposure to extreme stress through either the threat of, or actual violence that can be physically harmful or life-threatening. It may be triggered, among other things, by natural disasters, assault or critical illness. An individual may react with intense fear, a sense of horror and helplessness. This changed state is characterised by three types of symptoms: constantly re-living the experience, evasive behaviour and exaggerated responses. These symptoms last for more than a month and may be accompanied by depression, characterised by feeling low and having no motivation and a lack of interest in things for a period lasting more than two months (1,2).

In the area of healthcare, relating to illness, it is not only the patients who are affected, but also the families, medical and nursing staff.

Patients who present symptoms of PTSD after a severe illness may develop behaviour that affects their subsequent recovery, such as ignoring medical advice, as a form of evasive conduct, and failing to follow their treatment. The prevalence of anxiety symptoms in patients in intensive care units (ICUs) varies between 12% and 47%, symptoms of depression are estimated at 28% and PTSD as high as 64% with a mean of 29% (3-8). Factors affecting patients include fear, lack of sleep, medication, intubation, pain, noise, and an interruption in the daily light-dark cycle.

However, PTSD not only reduces patients' mental, physical and social abilities and their financial situations, it also affects their carers and close family members.

With regard to families, a multicentre study by Pochard in 2005 revealed the widespread existence of symptoms of anxiety (73%) and depression (35.3%) in the relatives

of patients in ICUs. Even 12 months after a traumatic experience in an ICU, a third of family members were still experiencing complicated grief, major depression or anxiety disorders (9).

This highlights that a stay in an ICU is a very traumatic event in a patient's relatives life and can generate important psychological repercussions in the medium and long term (post intensive care syndrome).

As we have discussed, having a patient hospitalised in an ICU puts relatives in a challenging situation. It is considered a crisis for the family since they face an uncertain scenario regarding the prognosis; they must take the lead in decision-making and choosing options for treatment. This takes place in a highly technological environment of life support systems, with medical professionals carrying out complex interventions on their loved ones, and with limited capacity for communication. These totally unfamiliar situations and surroundings are conducive to a high stress levels, and symptoms of anxiety and depression. This is true not only of ICUs but of hospitals more generally, where 32% of families have been found to have developed PTSD symptoms after the death of a hospitalised relative (10).

A recent piece of research on the needs of these families evaluates the variety of factors involved: whether the medical team provided timely and sufficient communication, whether plans to move the patient were made clear, whether there were structured meetings with the ICU medical team and whether relatives were consulted about palliative care. This research can help to improve the prognosis for families and aim to reduce the levels of emotional stress experienced by relatives of patients (11).

With regard to vulnerability, it is known that the

closeness of the relative to the patient affects the extent of the development of PTSD (12). Spouses therefore, are particularly vulnerable. The role and responsibility assumed by the relative also appears as a stress factor (13). The decisions that need to be taken create uncertainty and feelings of guilt, particularly at the end of life, so there is a need for different protocols and coping strategies. This editorial focusses on the CAESAR study (*Intensive Care Medicine*, 2016) (14). In that paper, the authors developed a tool specifically to evaluate the experience of relatives of patients who died in ICUs.

There is published research about previous instruments designed to evaluate the way in which patients die in different environments (hospitals, hospices etc.). However, this study evaluates, from the relatives' perspective, how far the patients' wishes were fulfilled at the moment of death, using observations made by the families, so the Quality of Dying and Death (QODD) was more patient-centred.

Relatives require specific attention, and health personnel should be able to identify certain characteristics that may affect them, such as ways of coping, natural capacity for understanding information, ways of communicating etc. The authors of the study saw the need to understand the experience of relatives of patients who die in ICUs, thus, developing a specific tool.

They created and adapted a questionnaire which they then validated in a prospective multicentre study in 41 French ICUs. The items in the questionnaire were developed through a review of social science literature, and qualitative interviews with the families of intensive care patients and workers in this area. This instrument provided information relating to the experience of relatives with intensive care practices, rather than the practices themselves, presenting the perspective of the family rather than physicians or nurses. This study was therefore able to identify those aspects of end-of-life that correlate with post-traumatic stress in ICUs.

A group of ten researchers consisting of physicians, nurses, sociologists and psychologists, was able to identify eight domains and 50 items regarding the relatives' experiences. After an initial evaluation, the panel eliminated 17 items, leaving 33 items in three domains: (I) the patient; (II) interaction with and around the patient (including the quality of communication between the ICU team and patient and the ICU team and relatives); and (III) family needs and satisfaction. Each item was answered in written form with a scale of five points: 1—traumatic, 2—painful, 3—difficult, 4—acceptable, 5—comforting. Finally, another

18 items were eliminated because they were redundant leaving a questionnaire of 15 items, designated CAESAR.

It took no more than 20 minutes for relatives to complete the questionnaire. The questionnaire was validated by a multicentre prospective study conducted over two years in 41 French ICUs belonging to the FAMIREA network. Only the relatives of patients who had died after hospitalisation for a period of at least 48 hours in the ICU were included. They had to complete a 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 depression and anxiety scale and the scale for post-traumatic stress. All telephone interviews were conducted by the same sociologist. Finally, 6 and 12 months after the death, a questionnaire was sent out that included a test for complicated grief. Of the 4,607 patients admitted to the 41 participating ICUs during the study period, 875 (19%) died. Of these, 400 were excluded, leaving 475 that could be included in the study, 430 of whose relatives had completed the questionnaire. From the 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.

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.

Reviewing the results: the median CAESAR score was 66. Of the score values, 25.9% were in the lowest tertile, 44.8% in the middle tertile and 29.3% in the highest tertile.

The factors associated with the CAESAR score were: (I) a longer length of stay in an ICU was significantly associated with a lower CAESAR score, indicating more traumatic, painful and difficult experiences; and (II) vasopressor therapy was also associated with a lower CAESAR score.

At 3 months, 370 (86%) relatives completed the questionnaires. Among them, 190 (51.4%) had symptoms of depression and 129 (34.9%) had symptoms of anxiety. At 6 and 12 months, 268 (64.9%) and 209 (50.6%) of relatives completed the ICG and IES-R, respectively. 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 more common in the lowest CAESAR score tertile than in the middle or highest tertile. The prevalence of PTSD-related symptoms decreased over time, from 44.6% at 3 months to 42.9% at

6 months, and 36.8% at 12 months.

At 6 months, relatives in the lowest CAESAR score tertile were at a higher risk of developing PTSD-related symptoms compared to those in the middle tertile or highest tertile.

Thereby, this study performed in 41 ICUs led to the development and validation of 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 intensive care.

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 in the bereaved relatives.

Thus, this tool should prove useful in assessing the efficacy of interventions designed to improve the quality of relatives' experience of dying and death of ICU patients. Furthermore, it can serve to identify areas where improvements are most needed. The data gathered is of considerable importance given the high level of post-intensive care burden documented despite recent advances in communication strategies in ICUs and recognition of relatives' vulnerability.

As previously noted, the CAESAR score adds to the ICU QODD in that it focuses on family members rather than health workers, and more on relatives than patients.

Both tests share variables that impact on the score, such as pain control, patient dignity, family presence at the moment of death and discussion of life support withdrawal. Other variables, specific to CAESAR, such as the quality of communication, were considered by relatives to be among the most important.

It is suggested that this score could be determined at regular intervals to monitor its performance over time.

The authors point out certain limitations to their study. All participants were from ICUs in France and therefore the findings might not be applicable in other countries. However, the study was based on a large number of units and individuals evaluated which support the robustness of the results.

Also, interviews took place three weeks after the patient had died instead of asking the relatives to complete the questionnaire immediately after the death. The authors considered it difficult and stressful to conduct the interviews immediately. They also involved a highly experienced psychologist in the telephone interviews, to offer support whenever an item caused emotional stress. This was very much appreciated by the relatives, and,

moreover, there was a high response rate when relatives were contacted 6 and 12 months later.

In summary, the authors described and validated a new tool to evaluate the experiences of families of patients who die in ICUs. The study suggests new targets for interventions designed to improve the care for families in ICUs.

Only 25% of relatives had a low CAESAR score, which indicates a very stressful experience. However, these scores can be associated with greater psychological burden post intensive care.

This important study will enable the evaluation and implementation of measures and interventions related to relatives at risk of developing PTSD during such a difficult period as being exposed to dying and death of a loved one in an ICU. We should stress, in our experience (15), that relatives of patients who survive also present a high risk of developing PTSD (22.9%). This is possibly because, as a relative of a patient, the environment of ICUs themselves can create a very traumatic experience, and also that relatives' psychological symptoms such as anxiety and depression, present during the month before the patient's hospitalization, are determining factors for symptoms of PTSD after the ICU experience.

Some families are not able to cope with this situation adequately, which affects the functioning and equilibrium of the whole system and each family member. The way a relative manages a loved one's condition is significantly affected by the personal emotional background he or she brings, their gender and educational level, as well as the severity of the patient's illness and length of stay. These elements enable us to identify people at increased risk of PTSD, and to intervene and provide preventative measures to help relatives endure an ICU experience with more ease and comfort, and for it to be a less traumatic ordeal.

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## Footnote

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