

# A new tool to assess relatives' experience of dying and death in the intensive care unit

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Professor Kentish-Barnes and co-workers recently published an article in *Intensive Care Medicine*, in which they presented the results of a questionnaire study aimed at assessing the experience of relatives of patients who died in the intensive care unit (ICU) (1). In the above-mentioned article the French research group known as the FAMIREA network describes the development and validation of a new tool called CEASAR, designed to measure relatives' self-reported experience of the dying and death of a family member in the ICU.

Over the years the FAMIREA study group has published several important works about communication in the ICU (2). The extensive research conducted by the FAMIREA group has highlighted the overall burden experienced by relatives of intensive care patients, as well as the risk of bereaved family members developing anxiety, depression and post-traumatic stress disorder (PTSD) (3). Experiencing the death of a loved one in the ICU or being involved in the decision-making about her/his treatment increases the risk of psychological distress and psychiatric disease. In a previous study (4), the results of which served as the basis for the development of the CEASAR tool, it was demonstrated that 6 months after a loved one's death in an ICU, 52% of the relatives had symptoms of complicated grief. In the same study, potential targets for improvements in end-of-life (EOL) care were also identified.

Based on these findings and previous research, Kentish-Barnes *et al.* (1) highlight the lack of targeted instruments to assess family members' experience of the dying and death of a loved one in the ICU. Available instruments such as the ICU-quality of death and dying (QODD) tool (5) do not

focus on family members' assessment but on the patient's quality of death as estimated by physicians, nurses and families. The CEASAR tool should therefore be requested and welcomed by both clinicians and researchers interested in improving EOL care for dying patients and their families.

The instrument was developed by means of six well defined steps that are partly similar to those of classical test theory. First, three independent sources, namely literature review, clinical experience and in-depth interviews, were used for item generation, from which 50 items were generated and tested. However, it is unclear whether the aim of these initial tests was to ensure face and content validity, which would have been useful. It is also unclear whether items with a large number of missing answers were removed.

Correlation values <40 are often considered too low to include in a factor. After testing the internal validity 18 items were removed, but it is impossible for the reader to judge the appropriateness of this removal as the limit for the internal correlation values are not provided. The fifth step involved factor analysis with varimax rotation, resulting in a three factor solution, i.e., the patient, interactions and family needs and satisfaction. Information about how much of the variance these factors covered would have been useful. When testing an instrument it is commonly argued that five informants are needed for each item. Thus 165 participants are required when testing a questionnaire comprising 33 items. It would therefore be of interest to obtain more information about the reasons for such oversampling (n=546) as well as the two cohorts.

Another important aspect of measurement is the

reliability and homogeneity of the scale. The scale covers five steps both in figures and words. It is unclear how these steps were chosen, e.g., the lower the number the more traumatic the experience? Also no information is provided regarding the reason behind using both words and figures. The use of words suggests an ordinal scale or ordered category data that requires non-parametric statistical analysis. However, the scale is treated as a continuous variable and the figures are added to a sum score. The failure to clearly describe the properties of the data could detract from the quality of the measurement. The 15 items in the final version of the questionnaire are presented in a closed way, requiring a Yes or No response, despite the fact that these response alternatives do not fit the items. If the instrument is aimed at measuring experiences, the questions would benefit from being posed in a different way to fit the descriptive formulations in the scale, e.g., how did you experience the pain control provided to your loved one? Or how did you experience that your loved one's dignity was maintained?

In the actual study (1) the CEASAR questionnaire was sent to one relative of a total of 475 patients admitted to 41 ICUs in France who subsequently died. The relative completed the questionnaire 21 days after the death of her/his loved one and the response rate was over 90%. A quarter of the family members had low CEASAR scores indicating a distressing experience. A longer ICU stay and the use of vasopressor therapy were significantly associated with a lower CEASAR score. It was also demonstrated that although the PTSD-related symptoms decreased over time, relatives with the lowest CEASAR score were at higher risk of complicated grief and PTSD-related symptoms after 6 months compared to those with higher scores.

The results from this study and earlier work published by the FAMIREA-network are cogent regarding the psychological consequences of losing a family member in an ICU. The sudden loss of a loved one for which they are unprepared often characterizes the experience of relatives of patients who die in the ICU. This is a harsh experience and as ICU clinicians we must accept that the loss has a major impact on the bereaved relatives and that grief is a natural response. We must therefore ask ourselves what can be done to help all family members to remember the death of their loved one as dignified, despite the distressing circumstances of dying in the highly technological environment of an ICU. Another question is what can we do to prevent PTSD and unnecessary pathological grief?

Although the results of the study revealed high medium

scores on the items concerning quality of communication with physicians (4.4) and nurses (4.7), the item: "During the days before the death, were you clearly informed that your loved one was dying?", had the lowest mean score (3.2) of all items. This is noteworthy because lack of awareness of a loved one's impending death is correlated with a higher risk of complicated grief (6). The importance of a clear and honest communication with family members about the loved one's prognosis and inevitable death is therefore crucial for helping them to prepare for their coming loss (7). Honest communication requires timely EOL decisions in which the family members and nurses are included (8). Shared decision making is also one of the consensus statements reported in the WELPICUS study, covering the opinions of 1,283 healthcare professionals in 32 countries (9).

The CEASAR study revealed that a long ICU stay before the loved one's death was significantly associated with a lower CEASAR score. In a study by Day *et al.* (10) it was found that a majority of family members of ICU patients experienced fatigue, anxiety and moderate to severe sleep disturbance, and that the severity of the patients' illness correlated with these factors. Family members who spent the night in the ICU waiting room reported more sleep problems than those who never stayed at the hospital overnight. Family members' reported reasons for sleeping at the hospital were that their home was located too far away and that they were too anxious to leave. According to Schmidt and Azoulay (11), sleep deprivation jeopardizes the shared decision model because family members are too exhausted to cooperate. This highlights the ICU environment as a contributory factor to the quality of EOL care. Several studies have stressed family members' need for proximity to ICU patients and unrestricted visiting times (12). The CEASAR study revealed that the possibility to be close when the loved one passed away was one factor associated with a positive experience. Access to a private room at the EOL ensures the family members' need for access, privacy and family reconnection (13,14), which in turn promotes another CEASAR item "Were you able to say good bye and express important feelings to your loved one?"

Family members have reported that a post death follow-up meeting with ICU clinicians is helpful for understanding the causes of the loved one's death and for their overall experience of the loved one's dying trajectory (13,15). Further research is needed to investigate whether a more family-centred ICU-design and routine follow-up meetings can prevent PTSD and complicated grief.

In conclusion, the effort to develop a measurement tool to grasp the relatives' experiences of losing a loved one in an ICU is unquestionably good. However, there are some inconsistencies regarding content validity, face validity, internal validity and the construction of the scale that need amendment in order to provide a valid, reliable and user-friendly tool.

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### Footnote

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*Comment on:* Kentish-Barnes N, Seegers V, Legriell S, *et al.* CAESAR: a new tool to assess relatives' experience of dying and death in the ICU. *Intensive Care Med* 2016;42:995-1002.

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