



## In response to: Families' experiences of ICU quality of care: Development and validation of a European questionnaire (euroQ2)



### To the Editor:

With great interest we read the article by Jensen et al [1]. Addressing the needs of relatives in the Intensive Care Unit (ICU) is a contemporary issue, and measuring their experiences is an important work assessment for healthcare providers and organizations. Therefore, the work from Jensen et al might be helpful to provide high valued care in ICUs. However, to our opinion, there are some relevant theoretical and methodological problems concerning this study that we would like to explain in this letter.

As stated by the authors, the euroQ2 is based on items from the “Quality of Dying and Death” (QODD) questionnaire [2] and the “Family Satisfaction in the ICU survey” (FS-ICU) [3]. However, only 32% of the original items in the QODD and 37% of the FS-ICU have been used as originally formulated. The euroQ2 should therefore be considered as a new questionnaire. The development process is not well described by the study, leading to indistinct questions. For example, the initial draft of the euroQ2 was primarily reviewed in English, then adjusted, and subsequently translated into Danish and Dutch. Items corresponding to end-of-life often elicit a semantic discussion, for that reason it seems difficult to judge these items in English for non-native speakers. Yet, another striking disadvantage of these instruments is the elaboration in ICUs outside Denmark and The Netherlands. It seems reasonable that items will be experienced as more or less important by relatives from different countries or even different continents [4]. The authors argue that the items have been adapted to the European environment, although it remains a mystery how and what they have done to scientifically underpin this proposition. The validation of the euroQ2 in two countries of different cultures and language requires a profound analysis of sensitivity and specificity.

Moreover, there is no reasoning behind the choice for the aforementioned measurement instruments. For example, why did the authors not use the “Critical Care Family Needs Inventory”, which measures the needs of relatives in the ICU [5] or the “Care Family Satisfaction Survey” to measure the satisfaction of relatives [6]. Both have been assessed in former studies as reliable and valid. Furthermore, the QODD has been recognized with many limitations; the developers themselves even stated that the questionnaire was not ready for use as a primary outcome measure in intervention studies after studying over 4,000 patient deaths [7]. Then, the items of the FS-ICU were based on an existing framework to measure patient satisfaction, in a combination with items related to end-of-life care. Quite apart from the fact that satisfaction of patients might not at all correlate with the satisfaction of the relatives, it is preferable to measure experiences rather than satisfaction as they give more objective and specific information for quality improvement [8]. The authors misuse the concepts of “satisfaction”,

“experiences”, and “quality of care” as one and the same and without further explanation.

In the Netherlands, the government introduced a national framework for evaluating quality of care that contains a set of indicators referring to experiences of consumers of care [9]. A Consumer Quality Index was subsequently developed as the measurement standard, and since then it has been applied to the experiences of special target groups. The recently established Consumer Quality Index “Relatives in the ICU”, which has been developed according to these national standards to assess the quality of care through the perspectives of relatives in the ICU, proved to be valid and reliable in a pretest [10]. A sample of 564 respondents from six ICUs and nearly 1400 respondents of more than 20 ICUs in general and academic hospitals in the Netherlands, has been analysed to establish the psychometric characteristics and discriminative power, in respective. The authors do not mention this European instrument focusing on the same topic and target group, nor discuss why it was not integrated in the euroQ2 instead of the American FS-ICU.

Undoubtedly, it is basic knowledge that professionals should meet and integrate relatives' needs in the provided care. Assessing these policies from the perspective of relatives is necessary to consolidate and further improve the process of caring. However, the items of the euroQ2 mostly relate to the care for the patient, for example “pain under control”, “emotional support for patient”, and “end-of-life care according to wishes”. The authors do not explain how these items correspond to the needs of the relatives themselves. Furthermore, the assumption that these items correlate with post-ICU symptoms of anxiety, depression, and post-traumatic stress disorder (PTSD) of relatives, is short-sighted and need further theoretical explanation.

The PTSD diagnostic criteria were revised in the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-V) and require persistence of symptoms for more than one month [11]. Thus, three weeks after discharge from the ICU or the death of a relative is far too early to assess PTSD. In the same way, to measure some symptoms of anxiety or depression in mourning relatives, is within the normal range of emotions after three weeks and not a psychopathological process. The impact of the ICU period can indeed have negative consequences in the long run, which are currently described in the Post Intensive Care Syndrome-Family [12].

In conclusion, we agree with the authors that assessing the needs of relatives of ICU patients is of utmost importance. However, due to the abovementioned arguments, we question the added value of the euroQ2 above existing, validated instruments, like the Consumer Quality Index “Relatives in the ICU”. Especially as the instrument is only validated in two European countries in relatively small samples with several methodological errors.

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