Intensive Care Med (2019) 45:1163–1164
https://doi.org/10.1007/s00134-019-05611-3

LETTER

Post-resuscitation EQ-5D-3L scoring by the patient or caregiver/legal guardian versus the medical professional: a sub-study of the Jerusalem District Resuscitation Study

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Dear Editor,

The metrics most often used to evaluate the risk–benefit ratio of healthcare interventions are quality-adjusted life years (QALYs, i.e. years in perfect health gained) and disability-adjusted life years (DALYs, i.e. years in perfect health lost).

One of the tools required to calculate QALY and DALY is the European Quality of Life (EuroQol) Group's five-dimensional health status questionnaire (EQ-5D-3L). The EQ-5D-3L scores five aspects of daily living—mobility, self-care, usual activities, pain/discomfort and anxiety/depression—where each can be scored at three levels (no problems, some problems, or extreme problems) [1, 2]. However, patients with low scores may be particularly difficult to assess because of their disabilities. The correlation between subjective (i.e. patient or caregiver/legal guardian) and objective (i.e. professional) score in this context remains unknown [3].

We conducted long-term follow-up on a 2-year cohort of survivors of out-of-hospital cardiac arrest (OHCA) as a sub-study of the Jerusalem District resuscitation cohort (IRB approval 0271-15-SZMC) [4], with the aim of comparing patient or caregiver/legal guardian to professional EQ-5D-3L scores. Patients who survived to hospital discharge ($n=54$) were sought for assessment of survival and EQ-5D-3L at a median of 2.8 years after the arrest (interquartile range 1.8–3.8). Eighteen patients had died and were no longer available for interview. Four patients declined participation (two directly and two via a legal guardian). After informed consent was obtained, EQ-5D-3L questionnaires were completed first directly by 30 patients or legal guardians (mailed forms), and then by a single trained medical professional who performed the interviews. The professional was blinded to the forms that had been completed by the person being interviewed. We used Cohen's kappa coefficient (κ) to measure inter-rater agreement between sets of forms, with Fleiss criteria to classify $\kappa > 0.75$ as highly correlated, 0.40–0.75 as intermediate and $\kappa < 0.40$ as a marked lack of association.

Strong associations were found between respondent–interviewer sets of questionnaires in dimensions relating to physical activity; κ scores were 0.942 for mobility, 0.801 for self-care and 0.754 for usual activities ($n=30$). However, the correlations between respondent–interviewer sets of questionnaires in the dimensions relating to mental well-being were poor: 0.160 for pain/discomfort and 0.300 for anxiety/depression. These were perceived as better by the interviewer than by the patient/legal guardian ($n=28$, as two legal guardians also felt unqualified to assess either pain/discomfort or anxiety/depression).

This report is a pilot study. Our cohort is very small but also quite sick (23% were still alive, with a cerebral performance categories [CPC] score of 3–4 almost 3 years after the event) [5]. Collecting such data on these patients is challenging. Our patients were assessed by a single interviewer; thus standardization may have been overshadowed by bias. However, previous studies assessing

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QoL after intensive care unit (ICU) admission in general and specifically after OHCA have not mentioned how EQ-5D scores were assessed [1]. Our preliminary findings suggest that before conclusions are reached regarding the risk–benefit ratios of interventions employed in the ICU, there is a need to further assess the impact of the method employed when gathering data on QoL after ICU discharge.

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Acknowledgements
The Jerusalem District study and all of its sub-studies would never have taken place without the professional guidance and moral support of Prof. Jeremy Kark, may he rest in peace. We stand on the shoulders of a giant, and for his legacy we are grateful.

Compliance with ethical standards

Conflicts of interest
All authors declare that they have no conflict of interest.

Publisher's Note

Accepted: 26 March 2019
Published online: 1 April 2019

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