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The quality of quality-of-life outcome data: the challenge of data interpretation

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In this edition of Resuscitation, Kimmoun and colleagues describe a secondary analysis of the FROG-ICU study, in which they compare one-year outcomes of a cohort of cardiac arrest intensive care unit (ICU) survivors and a cohort of non-cardiac arrest ICU survivors.[1, 2] Across 21 European ICUs, 1561 (1447 non-cardiac arrest; 114 cardiac arrest) patients were enrolled. For the primary outcome, a propensity-matched analysis identified cardiac arrest patients, compared with non-cardiac arrest patients, had a higher rate of one-year survival. The authors are to be congratulated for building on this primary analysis by collecting and analysing health-related quality of life (HRQoL) outcomes from this patient cohort.

Traditionally, HRQoL outcomes have been infrequently reported in the cardiac arrest literature.[3] In recent years, however, key studies have highlighted the importance of collecting these data by describing the challenges experienced by survivors during their recovery from cardiac arrest.[4-11] The need to collect HRQoL in cardiac arrest studies was described in the International Liaison Committee on Resuscitation (ILCOR) Core Outcome Set for Cardiac Arrest Group (COSCA) statement.[12] In addition, Utstein cardiac arrest registry templates support the collection, where feasible, of HRQoL outcome data.[13, 14]

There is a lack of consensus in the cardiac arrest community as to the most appropriate HRQoL tool, such that COSCA supports the use of several tools.[12] A systematic review of HRQoL tools has highlighted the need for more evidence as to the most appropriate HRQoL tool for use in the cardiac arrest population.[15] Survival and, to a certain extent, neurological outcomes can be derived from administrative databases and medical records.[12] In contrast, a common characteristic of all HRQoL outcome measures is the need for the patient to be willing to complete the tool.

The study by Kimmoun et al highlights the challenge of collecting these data.[1] Participants completed the Short Form-36 (SF-36), revised Impact of Event Scale (IES-R), and Hospital Anxiety and Depression Scale at 3-months, 6-months, and 12-months following discharge. Completion rates were relatively consistent over time- at 12-months, approximately 48% of the non-cardiac arrest group survivors and 67% of the cardiac arrest group survivors completed HRQoL surveys. In propensity-matched groups, the study reported that the mental component score (MCS) of the SF-36 was

similar between groups, whilst the physical component score (PCS) was higher in the cardiac arrest population. These data, however, should be interpreted with caution due to percentage of non-responders and the imbalance in percentage of non-responders between groups. It is particularly noteworthy that HRQoL tool completion was limited to direct completion by the patient.

The reported completion rate of HRQoL tools of approximately 67% in the cardiac arrest population compares favourably with other studies, including well-resourced randomised controlled trials, although some studies have reported completion rates of around 90%.[6, 16, 17] Evidence from both the wider literature and cardiac arrest literature indicates that individuals who complete HRQoL outcome tools are often systematically different to responders.[5, 7, 8, 18]

In cardiac arrest survivors, a key concern is that non-responders may be more likely to have neurological impairment than responders, and therefore experience a worse quality of life. On this basis, it is attractive to collect data through a proxy. In one Australian study, it was necessary to undertake almost one in four interviews on HRQoL outcomes through a proxy.[11] International guidance describes how the decision to include HRQoL data from proxies requires researchers to carefully balance the selection bias that may result from excluding important sub-groups against the risk of proxy bias.[18] This includes consideration as to the validity of proxy responses to the HRQoL outcome tool being used.[19, 20]

Contrasting the results of the Kimmoun et al with that of Bohm et al provides an insight in to the potential effect of including data from proxy responders.[1, 17] In particular Bohm et al, who permitted proxy responses and thereby achieved a response rate of about 90%, reported PCS and MCS values in cardiac arrest survivors that were markedly lower than those reported in the current study.

For patients and clinicians, the optimum outcome following cardiac arrest is one that, as far as possible, mirrors the patient's baseline quality of life. Studies that add to our understanding of HRQoL after cardiac arrest, such as the study by Kimmoun and colleagues, are important drivers to optimise outcome and highlight gaps in current clinical care. The challenge for the resuscitation community is how we interpret these data both within and across studies. We need to be mindful of the implications of collecting data from the patient's proxy. Equally, we need to be mindful of the implications of systematically excluding patients with the poorest outcomes from our knowledge of post-arrest HRQoL. These patients and their families may be in the greatest need for support and rehabilitation.

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