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Editorial

Survival and quality of life following a cardiac arrest: Capturing what really matters to survivors



Increasingly embraced across a range of critical illnesses, and most notably following cancer [<https://www.cancer.gov/about-cancer/coping/survivorship>], survivorship has been described as the defining goal of critical care for the 21st Century.¹ Core to survivorship is an appreciation of a survivor's health and well-being – or their health-related quality of life. These are complex and multifaceted concepts that embrace the emotional, physical, social and economic challenges associated with life during and after a critical illness, and up until the end of an individual's life.

Survivors' of cardiac arrest, or where necessary a proxy such as a close companion or carer, are uniquely positioned to report on their post-arrest health and well-being, providing a perspective that no other can provide. Such evidence may be captured quantitatively using well-developed questionnaires, or patient-reported outcome measures (PROMs), which seek to assess either specific aspects of, or the overarching concept of health-related quality of life.^{2,3} However, until recent years, such survivor-reported assessment has been relatively absent in the cardiac arrest literature.⁴ In the absence of a condition-specific measure for this population,² recent international guidance in the form of the Core Outcome Set for Cardiac Arrest (COSCA) has recommended the use of generic PROMs for the assessment of health-related quality of life in future clinical trials up to, as a minimum, 3-months post-arrest.⁵ PROMs have also been included as supplementary outcomes in the updated Utstein Statement and reporting framework.⁶ However, the choice of PROM, and its interpretation is crucial to the way in which we seek to better understand survivorship in this growing population of survivors,² and thus influence the timely provision of appropriate care.

A study in this issue of the journal,⁷ provides a clear depiction of the potential limitations of reporting 'index' or summary scores which, due to the lack of granularity in their presentation, may underestimate the needs of survivors. This is in comparison to the relative benefit to be gained from a more nuanced 'profile-based' assessment that provides a more refined illustration of the impact of survival. The study reports the 6-month follow-up assessment of 442 survivors in the international Targeted-Temperature Management (TTM) trial, adopting the Short-Form 36-item Health Survey (SF-36 version 2), a widely used generic measure of health status, as a measure of health-related quality of life.² The 36-items provide a broad ranging 'profile' assessment of health status, including multiple questions pertaining to mental well-being, physical function, and fatigue. Scores may be presented as two summary scores — summarising

mental or physical health — or as eight domain scores (physical function, role-limitation physical, bodily pain, general health, vitality, social functioning, role-emotional, mental health). It also benefits from a normative-based scoring system, supporting comparison of scores with the general population. In reporting the summary scores, Bohm et al.⁷ illustrated that the physical and mental health of 53% of survivors were 'within normal range', suggesting a good outcome at 6-months for the 'majority' of survivors, and a general health status that was comparable to the general population (albeit with 47% of survivors with a general health status falling below normative values).

However, when the authors delved into the individual domain scores, a clearer distinction between the health status of survivors and that of the general population was illustrated. Statistically and clinically significant differences, evidencing worse health for survivors, were reported for domains reflecting both physical (physical function, role-physical) and emotional (role-emotional) health. These differences remained even when age was taken into account.

When considered by age (dichotomised by age, $</> 65$ years old), Bohm et al.⁷ report worse mental health and vitality (including fatigue) in the younger group and worse levels of physical health in the older group (older than 65 years). Lower levels of mental health have been reported in a large Australian cohort of young survivors when compared to age-matched members of the general population.⁸ And a deteriorating state of mental well-being has been reported at 12-months on the SF-36 (when compared to that reported at 3-months), with scores significantly lower than that of an age- and gender-matched 'norm' population.⁹ Lower levels of mental well-being have been reported to persist for several years post-arrest.¹⁰ However, Bohm et al.'s study emphasises the importance of considering the impact of survival on an individual's emotional and mental well-being, suggesting that fatigue and cognitive impairment could be important factors alongside the impact of anxiety and depression.

The functional impact of survival post-arrest has received little attention. High levels of fatigue¹¹ are commonly reported, together with muscle wasting in survivors who required intensive care admission.¹² Lower levels of physical functioning have been reported in survivors at 12-months,^{9,13,14} three-years^{15,16} and five-years^{8,17} when compared to age and gender-matched members of the general population. Survivors report greater limitations in their ability to reintegrate into society than non-cardiac patients, with almost half reporting significant difficulties at 6-months.¹⁸

It is evident that survivors are experiencing significant limitations in their daily life due to physical and emotional problems that should be taken into consideration in the provision of appropriate aftercare. An intervention targeting the emotional and cognitive needs of survivors reported improvements in their general and mental well-being, captured on the SF-36, at 12-months.¹⁹ However, the physical needs of survivors were not addressed.

Granularity of assessment is clearly important in providing a clearer illustration of the needs and experiences of survivors. However, the feasibility of data collection may conflict with the need for a measure that is relevant and acceptable.⁵ Bohm et al.⁷ describe hour-long face-to-face interviews to support SF-36 completion, which clearly considered both the length of the questionnaire and the potential challenges of self-completion in a population in which up to 75% may experience some degree of cognitive impairment.¹⁸ Whilst costly and time-consuming, this was rewarded with high completion rates (90%) with survivors and proxies (7%). However, non-respondents at 6-months (10%; 49/491) had poorer health (worse Cerebral Performance Checklist (CPC) scores). Evidence that cognitive impairment and worse mental well-being correlate strongly with worse health-related quality of life in this group,¹⁸ highlights the challenge that the non-inclusion of survivors with a worse outcome may further seek to under-estimate the health-related quality of life and post-resuscitation health and social care needs of this group. There is a clear methodological imperative to seek to ensure that the views of survivors with a worse outcome are captured in future research.⁵

A benefit of generic measures is the broad-based assessment that supports comparison of health state between patients and the general population. However, even where such domain-based assessment as described by the SF-36 is available, such measures are often deemed to have less relevance to a patient's health experience⁵ and are generally less responsive to important change in health than well-developed condition-specific measures. A combination of both generic and specific measures is recommended.²⁰ Whilst domain-specific measures are available, which could usefully supplement the assessment of general health status as recommended by the COSCA guidance,⁵ there remains an imperative to work in collaboration with survivors and their carers to co-produce a high quality, relevant and acceptable measure of survivor-reported outcome that further captures what really matters to all survivors in the aftermath of cardiac arrest.

REFERENCES

- Iwashyna TJ. Survivorship will be the defining challenge of critical care in the 21st century. *Ann Intern Med* 2010;153:204–5, doi:<http://dx.doi.org/10.7326/0003-4819-153-3-201008030-00013>.
- Haywood KL, Pearson N, Morrison LJ, et al. Assessing health-related quality of life (HRQoL) in survivors of out-of-hospital cardiac arrest: a systematic review of patient-reported outcome measures. *Resuscitation* 2018;123:22–37, doi:<http://dx.doi.org/10.1016/j.resuscitation.2017.11.065>.
- Andrew E, Nehme Z, Bernard S, Smith K. Comparison of health-related quality of life and functional recovery measurement tools in out-of-hospital cardiac arrest survivors. *Resuscitation* 2016;107:57–64, doi:<http://dx.doi.org/10.1016/j.resuscitation.2016.07.242> Epub 2016 Aug 10.
- Whitehead L, Perkins GD, Clarey A, Haywood KL. A systematic review of the outcomes reported in cardiac arrest clinical trials: the need for a core outcome set. *Resuscitation* 2015;88:150–7, doi:<http://dx.doi.org/10.1016/j.resuscitation.2014.11.013> Epub 2014 Dec 9.
- Haywood K, Whitehead L, Nadkarni VM, et al. COSCA (Core outcome set for cardiac arrest) in adults: an advisory statement from the international liaison committee on resuscitation. *Circulation* 2018;137:e783–801, doi:<http://dx.doi.org/10.1161/CIR.0000000000000562> Epub 2018 Apr 26.
- Perkins GD, Jacobs IG, Nadkarni VM, et al. Cardiac arrest and cardiopulmonary resuscitation outcome reports: update of the Utstein Resuscitation Registry Templates for Out-of-Hospital Cardiac Arrest: a statement for healthcare professionals from a task force of the International Liaison Committee on Resuscitation (American Heart Association, European Resuscitation Council, Australian and New Zealand Council on Resuscitation, Heart and Stroke Foundation of Canada, InterAmerican Heart Foundation, Resuscitation Council of Southern Africa, Resuscitation Council of Asia); and the American Heart Association Emergency Cardiovascular Care Committee and the Council on Cardiopulmonary, Critical Care, Perioperative and Resuscitation. *Circulation* 2015;132:1286–300, doi:<http://dx.doi.org/10.1161/CIR.0000000000000144> Epub 2014 Nov 11.
- Bohm M, Lilja G, Finnbogadottir H, et al. Detailed analysis of health-related quality of life after out-of-hospital cardiac arrest. *Resuscitation* 2019;135:97–204.
- Deasy C, Bray J, Smith K, et al. Functional outcomes and quality of life of young adults who survive out-of-hospital cardiac arrest. *Emerg Med J* 2013;30:532–7, doi:<http://dx.doi.org/10.1136/emered-2012-201267>.
- Orbo M, Aslaksen PM, Larsby K, Schafer C, Tande PM, Anke A. Alterations in cognitive outcome between 3 and 12 months in survivors of out-of-hospital cardiac arrest. *Resuscitation* 2016;105:92–9, doi:<http://dx.doi.org/10.1016/j.resuscitation.2016.05.017> Epub 2016 May 30.
- Gamper G, Willeit M, Sterz F, et al. Life after death: posttraumatic stress disorder in survivors of cardiac arrest—prevalence, associated factors, and the influence of sedation and analgesia. *Crit Care Med* 2004;32:378–83, doi:<http://dx.doi.org/10.1097/01.CCM.0000108880.97967.CO>.
- Kim YJ, Rogers JC, Raina KD, et al. Solving fatigue-related problems with cardiac arrest survivors living in the community. *Resuscitation* 2017;118:70–4, doi:<http://dx.doi.org/10.1016/j.resuscitation.2017.07.005>.
- Puthuchery ZA, Rawal J, McPhail M, et al. Acute skeletal muscle wasting in critical illness. *JAMA* 2013;310:1591–600, doi:<http://dx.doi.org/10.1001/jama.2013.278481>.
- Beesems SG, Wittebrood KM, de Haan RJ, Koster RW. Cognitive function and quality of life after successful resuscitation from cardiac arrest. *Resuscitation* 2014;85:1269–74, doi:<http://dx.doi.org/10.1016/j.resuscitation.2014.05.027> Epub 2014 Jun 6.
- Smith K, Andrew E, Lijovic M, Nehme Z, Bernard S. Quality of life and functional outcomes 12 months after out-of-hospital cardiac arrest. *Circulation* 2015;131:174–81, doi:<http://dx.doi.org/10.1161/CIRCULATIONAHA.114.011200> Epub 2014 Oct 29.
- Wachelder EM, Moolaert VR, van Heugten C, Verbunt JA, Bekkers SC, Wade DT. Life after survival: long-term daily functioning and quality of life after an out-of-hospital cardiac arrest. *Resuscitation* 2009;80:517–22, doi:<http://dx.doi.org/10.1016/j.resuscitation.2009.01.020> Epub 2009 Mar 17.
- Moolaert VR, Wachelder EM, Verbunt JA, Wade DT, van Heugten CM. Determinants of quality of life in survivors of cardiac arrest. *J Rehabil Med* 2010;42:553–8, doi:<http://dx.doi.org/10.2340/16501977-0547>.
- Graf J, Muhlhoff C, Doig GS, et al. Health care costs, long-term survival, and quality of life following intensive care unit admission after cardiac arrest. *Crit Care* 2008;12:R92, doi:<http://dx.doi.org/10.1186/cc6963> Epub 2008 Jul 18.
- Lilja G, Nielsen N, Bro-Jeppesen J, et al. Return to work and participation in society after out-of-hospital cardiac arrest. *Circ Cardiovasc Qual Outcomes* 2018;11:e003566, doi:<http://dx.doi.org/10.1161/CIRCOUTCOMES.117.003566>.
- Moolaert VR, van Heugten CM, Winkens B, et al. Early neurologically-focused follow-up after cardiac arrest improves quality of life at one

- year: a randomised controlled trial. *Int J Cardiol* 2015;193:8–16, doi: <http://dx.doi.org/10.1016/j.ijcard.2015.04.229> Epub 2015 Apr 30.
20. Devlin NJ, Appleby J. Getting the most out of PROMs. Putting health outcomes at the heart of NHS decision-making. The King's Fund; 2010 ISBN: 978 1 85717 591 2.

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Received 21 December 2018

<http://dx.doi.org/10.1016/j.resuscitation.2018.12.021>
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