

Letter to the Editor (in response to “Medical research and the ethics of medical treatments: disability-free survival” by Dr Lönnqvist, British Journal of Anaesthesia 118 (3): 286–8)

Title: Survival with disability. Whose life is it, anyway?

Authors: David K. Menon¹, Angelos G. Koliass², Franco Servadei³, Peter J. Hutchinson²

Affiliation:

1. Division of Anaesthesia and Neurosciences Critical Care Unit, Addenbrooke’s Hospital & University of Cambridge, Cambridge, UK
2. Division of Neurosurgery, Department of Clinical Neurosciences, Addenbrooke’s Hospital & University of Cambridge, Cambridge, UK
3. Department of Neurosurgery, Humanitas University and Research Hospital, Milan, Italy

Corresponding author:

Peter J. Hutchinson
Professor Neurosurgery
Division of Neurosurgery
Box 167
University of Cambridge
Cambridge Biomedical Campus
Cambridge
CB2 0QQ
UK
pjah2@cam.ac.uk

Dear Editor

We read with interest the editorial by Dr Lönnqvist entitled “Medical Research and the Ethics of Medical Treatments: Disability-free Survival”.¹

The editorial refers to our study, RESCUEicp that interrogated the effect of secondary decompressive craniectomy in traumatic brain injury (TBI) patients with refractory intracranial hypertension.² The editorial states *‘the conclusion to draw is instead that, despite reducing overall mortality, surgery is not associated with any true long-term benefits in this setting; it only increases the number of patients in a vegetative state or suffering serious disability, and should therefore not be used’*. We have major concerns about this statement with reference to our study, and with the wider premise that underpins the editorial, and we will address each of these in turn.

The objective of the RESCUEicp randomised trial was to assess the comparative effectiveness of craniectomy versus advanced medical management (with the option of barbiturates), thus providing evidence to assist clinicians and families in decision-making. The primary analysis showed a significant between-group difference in the extended Glasgow Outcome Scale (GOS-E) distribution and a substantial reduction in mortality with surgery. The pre-specified sensitivity analysis dichotomised at upper severe disability (independent at home) or better was significant at 12 months (i.e. 45.4% of the patients in the surgical group were at least independent at home, as compared with 32.4% of patients in the medical group; $p=0.01$). Furthermore, we estimated that treating 100 patients with craniectomy as opposed to medical treatment will result in 22 more survivors of whom, at 12 months, almost 60% will be at least independent at home. The rest would be dependent at home or not recover consciousness. While we would concur that vegetative state and lower severe disability relate to substantial dependence, the majority of the extra survivors were at least independent at home or better. Many patients and their families will accept this. We therefore caution against a blanket statement that decompressive craniectomy in this context should not be used. In the past, we never advocated for an indiscriminate use of craniectomy^{3 4} and we are not doing so after the publication of the trial results. However, we believe that the RESCUEicp results have shown that craniectomy can be useful, as long as a thoughtful approach is adopted with involvement of the multidisciplinary clinical team and family members in the decision making process.

Moreover, the corollary of Dr Lönnqvist’s suggestion that the only worthwhile outcome after a TBI (or other conditions) is disability-free survival (i.e. good recovery on the Glasgow Outcome Scale) is that the life of all those patients who have not returned to their pre-injury occupational and social activities is not worth living. There are a few problems with this premise.

First, patients can have varying levels of disability ranging from vegetative state to moderate disability. While vegetative state and lower severe disability (dependent on others for care) tend to be considered unfavourable outcomes by most people, patients classified in upper severe disability are independent at home but require assistance outside (e.g. for shopping or travelling) and patients classified in moderate disability are usually employed in a paid or a voluntary capacity but have not returned to their pre-injury employment. Are these not lives worth living? We would argue, and far more importantly the experience of patients who return for follow up confirms, that they certainly are, and this is supported by evidence that patients can adapt to a level of significant disability that they may have previously regarded as unacceptable.⁵

Second, we would be keen to know whether Dr Lönnqvist's views are based on the experience of long term follow up in the patient groups that he cites, or simply on his impression of their short-term outcome in hospital. As RESCUEicp shows, patients with TBI (especially those who undergo decompressive craniectomy) continue to improve beyond the "conventional" 6 months outcome assessment point. With regards to emergency AAA repair, even a decade ago the survival was 70% and health-related quality of life for survivors was similar to baseline by 6 months.^{6,7} Finally, while we hesitate to take issue with a paediatric anaesthetist about outcomes of prematurity, it would be remiss of us not to direct his attention to authoritative reviews, which show that, of neonates born at 22 and 24 weeks gestational age, up to 40% and 70% of survivors experience little or no disability.⁸ Further, when these cohorts reach adolescence and young adulthood, despite health problems, they rate their health-related quality of life, self-esteem, and expectations for economic and social goals the same as full-term comparators.⁹ Current trends for more aggressive care in each of these settings could mean more disabled survival. However, a substantial recent report¹⁰ suggests that this is not the case in preterm infants, and while long term outcomes from emergency endovascular repair of ruptured aneurysms are still emerging, minimally invasive management approaches might arguably accelerate return to baseline.⁷ Notwithstanding this discussion, we would be entirely in agreement with Dr Lönnqvist that it is inappropriate to undertake repeated and burdensome interventions in very sick neonates (and for that matter, adults) when the expected outcome is bleak. However, we would take issue about how and when such outcomes are defined, and how frequently they occur.

Third, if we accept the premise on which his discussion is based, is Dr Lönnqvist also prepared to say that the lives of patients with chronic progressive conditions (e.g. diabetes, dialysis-dependent renal failure etc) are not worth living if they develop any form of disability? Should we deny anything but palliative care to any individual with such a condition presenting with an acute

illness that may result in a significant increase in their burden of disability? We certainly would not support such an approach, and to be fair to Dr Lönnqvist, we believe that neither would he – the treatment and support of a society’s disabled members is a measure of its maturity of civilisation.

Finally, and most importantly, it is important to acknowledge that the perspective of patients and their families need to be taken into account when determining the degree of “acceptable” disability and subsequently whether a craniectomy (or other intervention) should be considered. It is not for clinicians to unilaterally decide whether a given degree of disability is “acceptable” or otherwise – the person who needs to accept an outcome is the patient. Therefore, we believe that the indirect input of the patient (as best as is possible), and of families, is critical when determining the degree of acceptable disability, and consequently whether a craniectomy should be considered. We believe that the concept of shared decision making can play a fundamental role in this respect.¹¹

These are not easy questions, and we need to acknowledge that all of our answers are imperfect ones – often resulting in the choice of a least-worst, rather than best option. We agree that we should resist the urge to intervene just because we can, and avoid prolonging the process of dying in contexts where the outcome is likely to be uniformly bleak. However, any discussion of these issues should be grounded in hard data, recognise improvements in outcome that accompany changes in management, and (most importantly) take into account the wishes of patients and families.

Conflicts of interest: The authors were involved as investigators with the RESCUEicp trial and are also involved as investigators with the RESCUE-ASDH trial (www.rescueasdh.org). No other relevant conflicts of interest.

References

1. Lönnqvist P-A. Medical research and the ethics of medical treatments: disability-free survival. *Br J Anaesth* 2017; **118**: 286–8
2. Hutchinson PJ, Kolias AG, Timofeev IS, et al. Trial of Decompressive Craniectomy for Traumatic Intracranial Hypertension. *N Engl J Med* 2016; **375**: 1119–30
3. Kolias AG, Kirkpatrick PJ, Hutchinson PJ. Decompressive craniectomy: past, present and future. *Nat Rev Neurol* 2013; **9**: 405–15
4. Servadei F. Clinical value of decompressive craniectomy. *N Engl J Med* 2011; **364**: 1558–9
5. Honeybul S, Janzen C, Kruger K, Ho KM. Decompressive craniectomy for severe traumatic brain injury: is life worth living? *J Neurosurg* 2013; **119**: 1566–75
6. Dick F, Grobety V, Immer FF, et al. Outcome and quality of life in patients treated for abdominal aortic aneurysms: a single center experience. *World J Surg* 2008; **32**: 987–94
7. Aljabri B, Al Wahaibi K, Abner D, et al. Patient-reported quality of life after abdominal

- aortic aneurysm surgery: a prospective comparison of endovascular and open repair. *J Vasc Surg* 2006; **44**: 1182–7
8. Patel R. Short- and Long-Term Outcomes for Extremely Preterm Infants. *Am J Perinatol* 2016; **33**: 318–28
 9. McCormick MC, Litt JS, Smith VC, Zupancic JAF. Prematurity: An Overview and Public Health Implications. *Annu Rev Public Health* 2011; **32**: 367–79
 10. Younge N, Goldstein RF, Bann CM, et al. Survival and Neurodevelopmental Outcomes among Periviable Infants. *N Engl J Med* 2017; **376**: 617–28
 11. Muehlschlegel S, Shutter L, Col N, Goldberg R. Decision Aids and Shared Decision-Making in Neurocritical Care: An Unmet Need in Our NeuroICUs. *Neurocrit Care* NIH Public Access; 2015; **23**: 127–30