Quality of Life After Traumatic Brain Injury: Results of the Australian Arm of the International QOLIBRI Study

Abstract:

The effect of traumatic brain injury (TBI) can be devastating and, in some cases, lifelong. Although health-related quality of life (HRQoL) is accepted as an outcome measure in TBI, there are no international HRQoL instruments with a TBI focus. The QOLIBRI study is developing such an instrument. Based on work in 15 countries worldwide a preliminary version has been published, but there are acknowledged limitations and further work is needed to refine it. This paper reports the first use of the QOLIBRI in an Australian sample. Former patients of the Royal Melbourne Hospital who were admitted with TBI were randomly sampled and 66 participants were administered the QOLIBRI alongside a standard quality of life instrument, the AQoL.

The results reported in this paper include an overview of the structure and development of the QOLIBRI, and its performance in the Australian study when compared with that of the AQoL. The results of this study suggest that, when compared with population norms, those who suffer TBI do not fully recover even after 5 years following trauma, but that they experience a quality of life significantly worse than that of those without TBI. The particular areas of life affected will be delineated, as will issues around social isolation, labourforce participation and on-going need for caregiving. The results of this study confirm previous reports that there are long-term outcomes for people who suffer TBI and that there is scope for the better co-ordination of post-treatment health care.

Australia is participating in the next study phase, which is to finalise the descriptive system of the QOLIBRI, to harmonise its scoring so that it possesses international and local validity, and to undertake a full validation of it. The Australian study has three parts. Part 1 involves a cross-sectional study (n=60 randomly sampled TBI patients) for finalisation of the descriptive system, Part 2 a detailed examination of the QOLIBRI against measurement theory and to develop a short version for use with the cognitively impaired, and Part 3 is a larger study (n=200 randomly sampled TBI patients) aimed at (a) validating the QOLIBRI for Australian use and (b) examining, over time, HRQoL recovery from TBI. This research will enable the further development of TBI collaborations between Australian and overseas researchers. Once validated, the QOLIBRI will be used worldwide, including in Australia, as the standard HRQoL outcome measure in TBI research. QOLIBRI scores will have the potential to (a) directly improve patient care through identifying areas of need and (b) to assist with the comparison of competing treatments.