

Letter to the Editors

Sir,

NeuroRehabilitation recently published an article by Thomas and Barnes (TB) [1] entitled “Life expectancy for people with disabilities.” Designated a “review article,” its main arguments were that (1) there are major limitations in the world’s published studies on life expectancy of persons with neurological disabilities, and (2) one should therefore rely instead on what TB describe as a “pragmatic approach.” According to this, the life expectancy for a given individual “is based on clinical judgement and clinical experience,” rather than on the evidence from scientific studies.

We recognise that all research studies have limitations. Nevertheless, the scientific/medical research literature represents the systematically recorded experiences of thousands of clinicians and their patients. Further, and despite TB’s assertions to the contrary, when persons with similar disabilities are compared, studies of life expectancy from around the world demonstrate a high degree of consistency. For example, the survival curves for children with cerebral palsy in Western Australia and California have been shown to be similar [2], as is also true for those in the UK and California [3]. TB also suggest that there is an absence of cohort studies, and that follow-up is too short to compute median survival times. This, too, is wrong. In the case of spinal cord injury, for example, in the US Spinal Cord Injury Statistical Center database the overall median survival time is 32 years. This is sufficient to compute the median for most subgroups.

No doubt it is reasonable to make adjustments to estimates of life expectancy based on positive and negative

factors specific to the individual (e.g., presence or absence of respiratory problems, pressure sores, and risk of aspiration). But as there is substantial and consistent evidence from the cohort and period studies, this research evidence is the only legitimate starting point for a rational discussion and estimation of life expectancy.

As authors of many of the published studies that TB have reviewed, we categorically reject their assertion this literature supports their “pragmatic approach.” We do not believe that it is reasonable to offer estimates of life expectancy without a firm scientific basis, and TB’s label “clinical judgement” does not legitimize such estimates.

Sincerely,

Dr. Robert Shavelle, Dr. Richard T. Katz,
Dr. Ross MacKenzie, Dr. Lewis Rosenbloom,
Dr. Michael DeVivo, Dr. Jane Hutton,
Dr. David Strauss, Dr. Steven Day,
and Mr. Jordan Brooks

References

- [1] R. Thomas and M. Barnes, Life expectancy for persons with disabilities, *NeuroRehabilitation* **27** (2010), 201–209.
- [2] R.M. Shavelle, D.J. Strauss and S.M. Day, Comparison of survival in cerebral palsy between countries [letter], *Developmental Medicine & Child Neurology* **43** (2001), 574.
- [3] D.J. Strauss, R.M. Shavelle, L. Rosenbloom and J.C. Brooks, Update: Life expectancy in cerebral palsy, *Developmental Medicine & Child Neurology* **50** (2008), 487–493.