

Evidence-based life expectancy

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This article is a commentary on Oakeshott et al., pp 749–753 of this issue.

A large amount of research literature shows that persons with severe neurological injuries, whether from cerebral palsy,^{1,2} traumatic brain injury,³ or spinal cord injury,⁴ are subject to greater mortality rates than persons of the same age and sex in the general population. This is especially true when motor function is seriously impaired. It follows as a mathematical consequence that their life expectancy is lower. Although I do not think anyone would seriously challenge this research finding, one still frequently encounters unreasonable optimism about life expectancy of persons with severe disabilities.

All too often one comes across the assertion, based on no evidence whatsoever, that the life expectancy of a particular disabled patient is essentially normal. (Such pronouncements are generally prefaced by the mantra ‘given excellent care.’) In the case of spinal cord injury, for example, Dr Michael DeVivo – a prominent expert on life expectancy in this field – found it necessary to point out that: ‘There is a common misconception, often expressed by many rehabilitation professionals, that as a result of recent medical advances, life expectancy for persons who survive the first postinjury year is either normal or reduced by at most 10%. While much progress has been made, there is clearly no justification for such statements.’⁵

Survival and life expectancy in spina bifida has been studied much less, presumably because the condition is less common than the other neurological conditions noted above. The new study by Oakeshott et al.⁶ is to be welcomed, as it follows a reasonably large cohort of persons ($n=117$) for some 40 years and, in particular, provides a detailed analysis of the causes of death. The authors demonstrated that, as has been well docu-

mented for other forms of disability, the degree of preserved motor function is a key factor for longevity.

The authors point out that unjustified optimism appears in the literature on spina bifida, too: ‘It has been widely suggested that after the initial hazardous years, survival in spina bifida is near normal.’ They show that this assertion, which appears to be based on no evidence at all, is false: in their cohort, mortality rates between the ages of 5 and 40 years were some 10 times the national average. I note that if this ratio persisted throughout the lifespan, the reduction in life expectancy would be some 26 years.

Of particular note was that more than half of the deaths of persons over the age of 5 were sudden and ‘unexpected’ – the cause was not immediately obvious. For example, there were three deaths each due to epilepsy (despite the use of anticonvulsants), pulmonary embolism, acute complications of hydrocephalus, and renal sepsis. The authors commented that the general practitioners and nurses were often shocked at these unexpected deaths.

My impression is that despite the published evidence of high mortality rates in these vulnerable populations, surprise and shock is indeed commonplace. A tragic example is the death, from sepsis related to a pressure sore, of the actor Christopher Reeve, who had become tetraplegic and ventilator-dependent following a spinal cord injury. His death, 9 years after the injury, could hardly have been ‘expected’; but his relatively short survival time was far from unusual among ventilator-dependent persons with spinal cord injury.

Research shows that without epidemiological evidence to rely on, physicians consistently tend to overestimate the survival time of their patients.⁷ Interestingly, the better the doctors knew the patients the more they tended to overestimate survival time. Studies such as Oakeshott et al.’s, which follow actual cohorts and document the mortality and causes of death, may encourage a more evidenced-based approach to life expectancy.

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