

Shavelle RM, Strauss DJ, Katz RT (2008). Survival of persons with locked-in syndrome: A correction. Archives of Physical Medicine and Rehabilitation, 89:1005.

In a 1987 study, Haig et al¹ reported on 27 patients with locked-in syndrome (LIS). A slightly expanded group of 29 patients was studied by Katz² and Doble³ and colleagues. To our knowledge, these are the largest follow-up studies of persons with LIS, and the only ones to report survival probabilities. Their findings on longevity were summarized by Doble as follows: “Five-, 10-, and 20-year survival were 83%, 83%, and 40% respectively.”^{3,p438}

Unfortunately, these probabilities reflect a methodologic problem. Survival time was counted from the first anniversary of the onset of LIS. However, in some instances, follow-up began many years later, and thus subjects were “guaranteed” to survive until the beginning of follow-up: those who died in the interim never entered the study. As an illustration of the problem, figure 1 of Doble³ shows survival over a 25-year period even though the subjects were followed for only 11 years.

To correct the survival probabilities, we counted each person’s survival time only from the time at which they were “exposed” to death (ie, if they died they would still have been included in the study). Then a Kaplan-Meier analysis⁴ gave survival probabilities of 84% at 5 years and 56% at 10 years. The 20-year survival probability cannot be computed directly from the observed data, but the use of some standard actuarial assumptions leads to an estimate of 31%.

In addition to the above correction, 2 additional facts should be noted: (1) the subject population included primarily elective admissions to a world-class facility, and this may have led to an overestimate of survival; and (2) any advances in medical care since the study period would suggest that these figures underestimate survival.

Nevertheless, the above figures are compatible with those derived for other types of neurologic injury and comparable physical disabilities. Examples are the permanent vegetative state,⁵ traumatic brain injury,⁶ and cerebral palsy.⁷

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