CLINICAL RISK

Estimating life expectancy in children with neurological disabilities

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INTRODUCTION

Extensive epidemiological information has accrued over the course of the last 20 years with regard to the average life expectancy for people with neurological disabilities.

In medicolegal practice statisticians, epidemiologists and clinicians are asked to apply this information in individual cases. These estimates are frequently contentious as they are a major determinant of the extent of financial compensation.

Nevertheless, it would appear that some degree of consensus is evolving as a consequence of there being a reasonably general acceptance of those factors that constrain longevity. These are particularly mobility limitations, nutritional status, other health factors including aspiration, scoliosis and epilepsy, and profound cognitive impairment.

The degree of constraint that each of these produces alone and together has to be estimated against a background of what would be considered to be a 'normal' life expectancy for unimpaired individuals of the same age. Thereafter it is considered reasonable that the specific clinical or other characteristics that make an individual unique should be used to fine tune the estimate so that it can be applied to the specific case.

However this potentially harmonious approach faces hazards, some of which are inherent to the methodology that is used, some due to there being an unavailability of relevant data, some being due to misunderstanding of what this approach entails on the parts of both the courts, lawyers acting for one side or the other and experts. One obtains the impression that at times this misunderstanding may be wilful.[1]

It must be emphasized that this described approach is not the same as merely attempting to apply available statistical and epidemiological data without there being careful consideration of particular circumstances. It is also not the same as arbitrary and empirical assumptions on how survival might be constrained that are still sometimes made by clinicians 'from their own experience'.

METHODOLOGICAL DIFFICULTIES

The two databases that offer most useful information in UK litigation practice are those from California and from Liverpool. Other epidemiological information that offers a broadly similar perspective can be derived from Canadian, Australian and other UK studies.

Strauss and Shavelle[2] have used the California database in a number of publications whilst Hutton, Pharaoh and Cooke[3] have published their Liverpool findings and attempted to keep them up to date.

The major point that these and other databases have in common is that they correlate life expectancy with aspects of functional impairment in individuals who are considered to have cerebral palsy. They do not correlate their findings with specific diagnoses.

The California database is larger, is continuously updated and has more categories of dysfunction. The quality and accuracy of the input, the completeness of the ascertainment, the possibility that some individuals identified as having cerebral palsy have progressive neurological disorders and the particular statistical methods used in providing data have all been questioned and responded to.

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The Liverpool database has fewer subjects and for each of those has very many fewer functional categories so that distinguishing between survival for those who are profoundly disabled as compared to those who are less severely disabled can be difficult. In addition, because follow up has been shorter, statistical inferences have to be made when survival beyond around 40 years of age is thought likely. However one novel aspect of this database is the suggestion which derives from recent work that severe visual impairment acts as an additional constraint upon longevity in children with disabilities.

These and other databases have functions that extend far beyond offering opinions on the life expectancy of individual people with disabilities. Their value in providing epidemiological data for service provision and in generating clinical hypotheses that can be tested is very significant.

Comments are also required on the relevance and significance of clinical observations that are used both to inform databases and also to indicate in their own right an individual's potential for survival. The first of these relates to gross motor functioning and specifically to independent mobility. Both clinical experience and epidemiological data suggest that in order of increasing severity an inability to walk unaided, an inability to sit unaided and a failure to achieve head control are very potent indicators for early demise. Indeed the majority of children with cerebral palsy who do not achieve head control do not survive beyond around 20 years of age. By contrast those who retain independent mobility as adults are unlikely to have a constraint on a normal life expectancy of more than around 20 years.

There has also been some controversy and confusion with regard to the relevance of the need for gastrostomy feeding to life expectation in disabled children with cerebral palsy. Here the issues are far more complex than whether or not a gastrostomy is in place, and life expectation appears to be primarily related to the child's nutritional status. Specifically, it is reasonable to anticipate that a child who has a gastrostomy but is adequately nourished and free from risk of aspiration is likely to have a longer life expectancy than one who is orally fed but is failing to thrive and has recurrent respiratory infections.

By contrast the significance of cognitive impairment is not particularly great other than when individuals have a profound degree of mental retardation.

It follows that when clinicians are asked to give an opinion on the prognosis for survival in medical negligence or personal injury litigation that figures that are statistically derived from the epidemiological studies can and should be weighted for clinical factors. What is less certain is whether it is appropriate to weigh statistically derived figures in relation to assumed future quality of care. Whilst it is intuitive to attempt to do this there is hitherto no supportive published evidence.

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The final point to be considered by clinicians is that they should know what exactly they are estimating. For example should this be a mean or median survival time. Whilst it is likely to be somewhat unsound statistically, convention in English courts is to equate life expectation estimates with what would be considered to be the mean survival for a population of individuals who are of the same age and who have the same range of abilities and disabilities.

It is beyond the scope of this review to provide an opinion on the soundness of determining an important component of quantum in high value claims in this way. The inevitable inaccuracy of the bulk of these estimates must however be as powerful an argument as there can be for advocating a system of periodic payments rather than a lump sum to successful claimants.

References

1 Braithwaite B. Professor Strauss on life expectancy in cerebral palsy babies. Quantum 2003; 5: 1–3
2 Strauss D, Shavelle R. Life expectancy of adults with cerebral palsy. Developmental Med Child Neurol 1998; 40: 369–375
3 Hutton J, Cooke T, Pharaoh P. Life expectancy in children with cerebral palsy. BMJ 1994; 309: 431–435