

Poster Presentation

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## Expectation of life and unexpected death in open spina bifida

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Improvements in the care of patients with spina bifida has led to a tendency to underestimate the high mortality associated with the condition. There are few really long term reviews and those that exist have a high proportion of patients lost to follow up some of whom may in fact be dead We present a cohort of 117 consecutive cases of open spina bifida who were treated from birth irrespective of severity, between 1963 and 1971. Every case was accounted for in 2002 when the mean age was 35. The causes and circumstances of the 66 deaths were obtained from hospital records, post mortem reports and the Office of National Statistics, supplemented by information from medical and other carers. In the 1960s the early mortality was high and one in three of the children died before the fifth birthday. Thereafter deaths were fewer and of 77 who survived to age 5, 10% died every 10 years. Although some of the deaths were predictable many occurred suddenly and unexpectedly without the patient reaching hospital. These include 2 cot deaths, 3 cases of acute hydrocephalus, 3 epileptic seizures, 3 cases of pulmonary embolism and 2 of acute sepsis in diabetic patients. By being aware of the high prevalence of unpredictable and largely unpreventable deaths, doctors may avoid giving overoptimistic forecasts.