Epidemiology/Genetics Abstracts

Title: MORTALITY ASSOCIATED WITH SPINA BIFIDA IN THE UNITED STATES, 1979-2005

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Background: Spina bifida occurs in 1,300-1,500 births annually in the United States. Treatment for spina bifida and related conditions has improved to the point that most infants born with spina bifida now live into adulthood. As survival increases, there is a great need to understand causes of mortality among all age groups of people with spina bifida in order to provide direction for care and evaluate risk factors for mortality.

Method: We identified all death certificates from 1979 to 2005 that included a diagnosis of spina bifida as a primary or underlying cause of death (ICD9 code 741 for 1979-1998 and ICD10 code Q05 for 1999-2005). We calculated the median and distribution of age at death by death cohort. We constructed a control sample of death certificates that did not contain spina bifida matched on age at death, sex, race, and year of death. We then calculated proportionate mortality ratios to identify which conditions were more likely to be identified among those with spina bifida using death certificates from 1999 to 2005.

Results: From 1979 to 2005, there were 8,497 death certificates that included a diagnosis of spina bifida. Overall, the median age at death was 8 years; however there was a major increase in median age at death from 1 month during the earliest death cohort (1979-1984) to 30 years in the latest cohort (2000-2005). The conditions that were observed significantly more frequently compared to the general population were those involving skin infections (PMR=5.5) and the urinary/renal system (PMR=2.2).

Conclusion: This population-based analysis of mortality associated with spina bifida provides an important look at when and why people with spina bifida die. We noted a significant increase in the age at death over time, along with identifying conditions contributing most frequently to death among people with spina bifida.