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Long term outcome in babies born with open spina bifida and big heads

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Background

Hydrocephalus is common in spina bifida. There have been no prospective studies to mean age 35 of babies born with open spina bifida and a birth head circumference ≥ 90th centile. This study was supported by ASBAH (Association of Spina Bifida and Hydrocephalus).

Objective

To investigate long term outcome in terms of survival, CSF shunt history, disability and lifestyle in babies born with open spina bifida and big heads.

Design

Prospective cohort study,

Participants

Well-documented cohort of 117 consecutive cases of open spina bifida whose backs were closed non-selectively at birth between 1963 and 1971.

Materials and Methods

Survivors (mean age 35) and their carers were surveyed by postal questionnaire and telephone interview in 2002.

Results

Ascertainment was 100%. Of 54 survivors, 11 were born with a birth head circumference ≥ 90th centile and 43 with a birth head circumference <90th centile. Survival at age 35 was similar in the two groups: 40% (11/28) compared with 51% (43/89) respectively (NS). All 11 survivors born with big heads had had a CSF shunt inserted compared with 81% (35/43) of the remainder (NS). However 73% (8/11) had needed their shunt revised after the age of 2 compared with 30% (13/43) of the remainder ($P < 0.05$). All 11 survivors born with big heads had visual defects compared with 53% (23/43) of the remainder ($P < 0.01$). Six (55%) were on treatment for epilepsy compared with 4 (9%) of the remainder ($P < 0.01$); four of the eleven had suffered CNS infection. Lifestyles were restricted with only one of the eleven survivors born with a big head living independently in the community compared with 49% (21/43) of the remainder ($P < 0.05$). Only one of the eleven drove a car and none worked in open employment.

Conclusion

Although survival at age 35 was similar, long term outcome in babies born with big heads was worse than in the remainder with two of the eleven survivors totally blind, and only one living independently in the community. Birth head circumference ≥ 90th centile may be a predictor of worse long term outcome in open spina bifida.