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Prenatal counseling for myelomeningocele: prognoses, decisions and outcomes

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Background

In 2007, we reported the outcomes of 238 patients counseled by pediatricians following ultrasound (US) diagnosis of a nervous system defect (Avellino et al.). Here, we compare a subset of these patients diagnosed with myelomeningocele (MM) to a group of patients not counselled by a pediatrician. We have gathered data regarding prenatal prognoses and outcomes for these two groups.

Materials and methods

We report 39 patients who were prenatally diagnosed with MM between 1996 and 2003 and either saw a Neurodevelopmental Pediatrician (NDVP) for counseling or relied on obstetrical and genetic counselling only. We added to this study review of 1925 ultrasound reports. There were 12 patients counseled by a NDVP and 27 who were not. We restricted analysis to patients diagnosed with MM before 24 weeks gestational age. This included 9 of 12 counseled patients and 23 of 27 non-counseled patients. We analyzed severity of prognoses and outcomes using Fisher's Exact Test. Poor prognosis was defined as a high level lesion with minimal hip movement or less and a 50% chance for mental retardation. Good prognosis was defined as knee movement or more and an 85% chance of normal IQ.

Results

Poor prognoses were noted for 0 of 9 (0%) counseled and 4 of 14 (29%) non-counseled patients (P = 0.13). High-level lesions (L3 and above) were diagnosed in 6 of 9 counseled patients and 10 of 22 non-counseled patients (P = 0.43). A diagnosis of severe hydrocephalus (>15 mm) was no more or less likely in either group (P = 0.58). In the counseled group, 1 of 9 (11%) patients terminated while 18 of 23 (78%) of non-counseled patients terminated their pregnancy (P = 0.0009). Amongst survivors in the counseled group, 1 of 6 (17%) had motor outcomes of L3 or above, while 1 of 4 (25%) of survivors in the non-counseled group were L3 or above (P = 1.0). No differences were found in education level or hospital stay.

Conclusion

Only 31% of MM patients between 1996 and 2003 were seen for counseling by a NDVP. Patients in the non-counseled group terminate more often, but were no more or less likely to have a poor prognosis, high lesion level, or severe case of hydrocephalus. Motor level, education and length of hospital stay were no different among survivors. A larger study group is needed to better understand outcomes for pregnancies counseled only by a genetic counselor and obstetrician as compared to patients counseled by a NDVP in addition.