MEASURING LOCOMOTOR DISABILITY: A NEW SCORING MECHANISM FOR SOME FAMILIAR ITEMS

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Background: Locomotor disability is a critical measure for studying functional decline in later life and has featured in several major epidemiological studies. Yet measurement has mostly been confined to single items or ordinal scales rather than truly unidimensional measures with interval properties, thereby limiting the detection of which have been infrequently reported previously. This information will be valuable for families, genetic counsellors and other health care professionals when a congenital anomaly is detected, and will assist in planning for the future care needs of affected individuals.

Results: Survival among children with at least one congenital anomaly was 88.8% (95% CI 88.2 to 89.4) and 85.5% (95% CI 84.8 to 86.3) at one year and 20 years respectively. Twenty year survival among the most common anomaly groups was 89.5% (95% CI 88.4 to 90.6) for cardiovascular, 79.1% (95% CI 76.7 to 81.3) for chromosomal, 93.2% (95% CI 91.6 to 94.5) for urinary, 83.1% (95% CI 79.6 to 86.0) for digestive system, 97.7% (95% CI 96.1 to 98.7) for orofacial clefts, and 66.2% (95% CI 61.5 to 70.4) for nervous system anomalies. Survival varied considerably between subtypes, even within the same anomaly group. The proportion of terminations for fetal anomaly increased throughout the study period, and, together with year of birth, was an independent predictor of survival.

Conclusions: This study presents robust estimates of survival, uniquely to age 20 years, for a range of congenital anomaly groups and subtypes, some of which have been infrequently reported previously. This information will be valuable for families, genetic counsellors and other health care professionals when a congenital anomaly is detected, and will assist in planning for the future care needs of affected individuals.