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Appendix S1: Myelomeningocele and spina bifida aperta.

Myelomeningocele, perhaps better called spina bifida aperta, is caused by failure of closure of the caudal neuropore during embryologic neurulation. This results in a midline defect in mesoderm-derived tissue (bone, muscle, dura), through which the abnormally formed spinal cord and leptomeninges protrude. In some cases, leptomeninges are intact, and a fluid filled sac is present. In other cases, leptomeninges are not completely intact, and the open spinal placode is visible on the surface of the back. Historically, the form with a fluid-filled sac has been called "myelomeningocele," whereas the naked placode is called "myeloschisis" [1, 2]. No distinction between the two is made in evaluating candidates for fetal surgery. Myelomeningocele therefore refers to the condition itself and to a form of a lesion, whereas spina bifida aperta just refers the name of the condition. Myelomeningocele is the more commonly used to refer to all open neural tube defects, which why it is the term used herein.

Appendix S2: Methods

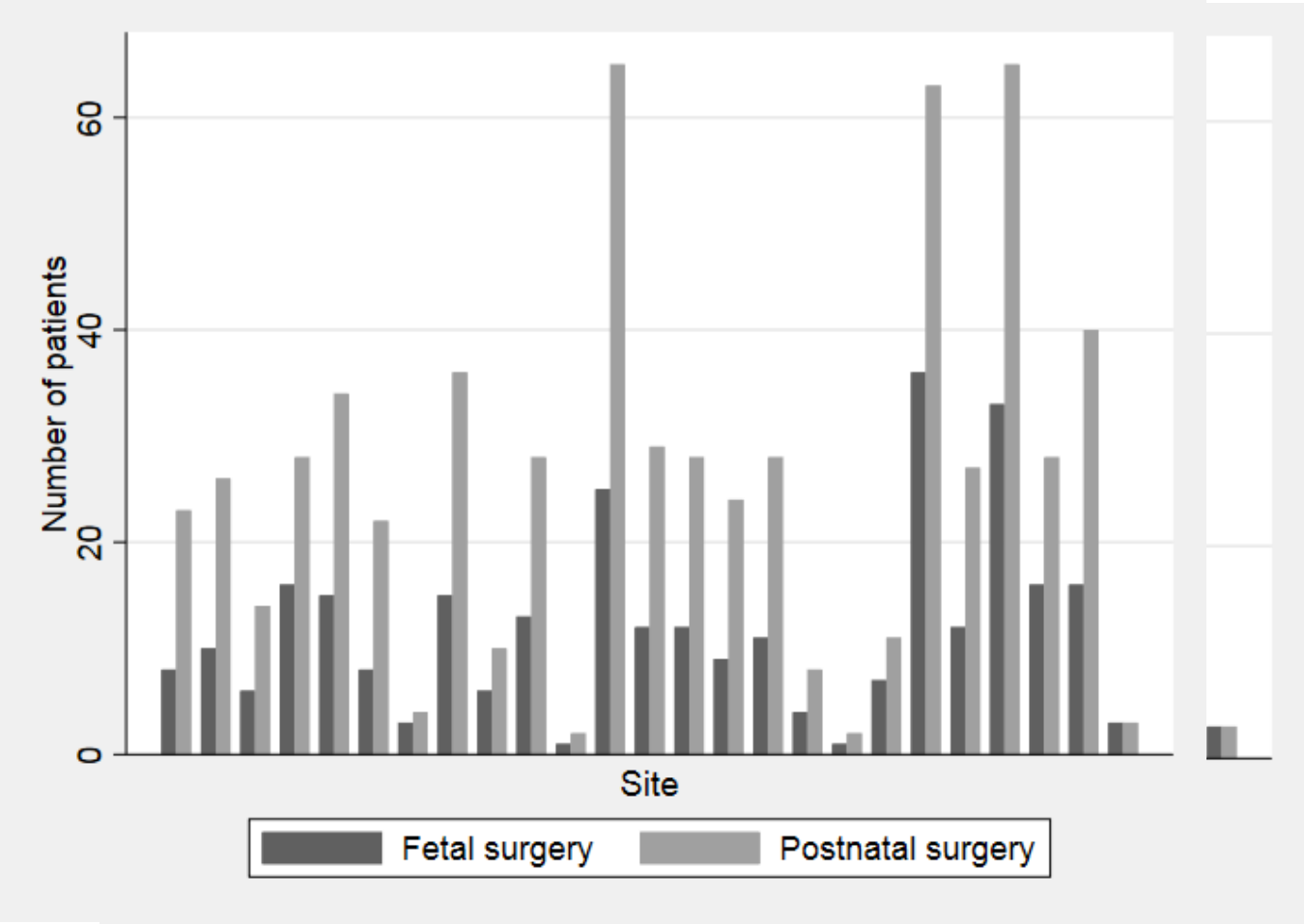
The study was approved by the Institutional Review Board at each spina bifida clinic site. Written, informed consent for participation in the NSBPR was obtained from adults or from parents or legal guardians for minors and adult dependents. Assent for participation was obtained from children and from adults with intellectual disability, where appropriate.

Researchers from all spina bifida clinic sites were trained to use standard methods to collect data by interviews of patients and/or parents at patient care visits and by review of the medical record [16]. Data were collected on enrollment regarding past medical and surgical histories, demographics and current condition, and then yearly at routine clinic visits regarding interval treatments, surgeries, and clinical outcomes[11-14]. The categories used for patients' self-assigned race or ethnicity were non-Hispanic/Latino White race, non-Hispanic/Latino Black race, or Hispanic/Latino ethnicity[13], the same as in previous NSBPR studies. Data from the last visit recorded in the NSBPR were used for analysis.

The assessment for spinal segmental level of motor function (motor level) categories was based on neurologic examination at the last visit. Motor level was defined as the most caudal segmental level with intact motor function. Categories were thoracic (flaccid lower extremities); high lumbar (hip flexion present); mid lumbar (knee extension present); low lumbar (foot dorsiflexion present); and sacral (foot plantar flexion present) [11-14].

Anonymized patient data were transmitted to the CDC. At the CDC, data were incorporated into the NSBPR database, and data quality checks were performed[16].

Figure SI: Number of fetal surgery (n=298) and postnatal surgery (n=648) patients included in the matched sample by spina bifida clinic site of care*. The 25 sites had a median (25^{th}-75^{th} percentile) of 39 (18-44) total patients, with a median of 11 (6-15) prenatal surgery patients and 27 (11-29) postnatal surgery patients.



Legend:* All patients had myelomeningocele, were born 1997 through 2017, and were enrolled in the National Spina Bifida Patient Registry 2009 through 2017.

Table S1. Unadjusted associations between demographic and clinical characteristics and neurosurgery procedure outcomes in the study population of fetal surgery (N=248) and matched postnatal surgery (N=698) patients*

	Neurosurgery procedure outcomes			
Covariate	CSF diversion	Shunt revision† IRR, (95% CI) P value	Chiari Decom-pression††† IRR, (95% CI) P value	Tethered cord release††† IRR, (95% CI) P value
Male sex (reference: Female)	1.00 (.88-1.13) .96	1.00 (.81, 1.25) 0.98	.93 (.51, 1.69) 0.81	.92 (.68, 1.25) 0.58
Non-Hispanic o White (reference: not non-Hispanic/Latino White)	.94 (.82-1.07) .34	1.45 (1.12, 1.87) 0.01	2.28 (1.05, 4.95) 0.04	1.67 (1.14, 2.43) 0.01
Non-Hispanic o Black (reference: not non-Hispanic/Latino Black)	1.12 (.93-1.34) .23	.80 (.54, 1.18) 0.26	.15 (.03, .77) 0.02	.48 (.25, .89) 0.02
Hispanic ethnicity (reference: not Hispanic/Latino)	1.12 (.95-1.32) .18	.72 (.52, 1.00) 0.05	.82 (.32, 2.10) 0.68	.64 (.39, 1.05) 0.08
Private insurance (reference: no private insurance)	.84 (.73-.96) .01	1.11 (.86, 1.43) 0.42	1.33 (.70, 2.53) 0.38	1.50 (1.03, 2.19) 0.03
Age at last visit in NSBPR	.97 (.92-1.02) .19	1.21 (1.07-1.36) .002	1.13 (.84-1.53) .41	1.17 (1.02-1.36) .03

Table S2 Unadjusted associations between motor function spinal segmental level categories and neurosurgical procedure outcomes in the study population of fetal surgery (N=298) and postnatal surgery (N=648) patients*

Category of segmental level of motor function	CSF diversion	Shunt revision† IRR, (95% CI) P value	Chari decompression ††† IRR, (95% CI) P value	Tethered cord release ††† IRR, (95% CI) P value
Sacral level (reference population)	_____	_____	_____	_____
Low lumbar level	1.45 (1.18-1.80) <.01	1.29 (.89, 1.86) 0.18	1.67 (.65, 4.32) 0.29	.95 (.61, 1.50) 0.84
Mid lumbar level	1.58 (1.29-1.93) <.01	1.13 (.81, 1.57) 0.47	2.35 (.94, 5.84) 0.07	.93 (.59, 1.44) 0.73
High lumbar level	1.67 (1.30-2.13) <.01	1.29 (.84, 1.98) 0.24	3.27 (1.23, 8.71) 0.02	.89 (.53, 1.51) 0.68
Thoracic level	1.72 (1.40-2.12) <.01	.96 (.63, 1.48) 0.86	2.80 (1.01, 7.77) 0.05	.85 (.51, 1.41) 0.53

Legend:
* All patients had myelomeningocele, were born 1997 through 2017 and were enrolled in the National Spina Bifida Patient Registry (NSBPR) 2009 through 2017. Outcomes were assessed at last visit recorded in the Registry. Significance of differences was assessed by univariable Poisson regression.
IRR= Incidence rate ratio

CI= confidence Interval
Shunt=ventriculoperitoneal shunt
ETV=endoscopic third ventriculostomy
† In matched patients ≥12 months old at last visit
†† In shunted patients, all ages
††† In the whole study population

Table S3. Unadjusted associations of distributions of categories of spinal segmental levels of motor function (motor levels) with frequencies of CSF diversion in fetal surgery patients and separately in matched postnatal surgery patients

A. Relationship of distribution of motor levels to CSF diversion frequency in fetal surgery patients (P<0.001)

Category of most severe motor level	No CSF diversion N=174 (%)	CSF diversion N=124 (%)
Sacral	74 (43)	28 (23)
Low-lumbar	48 (28)	33 (27)
Mid-lumbar	41 (24)	38 (31)
High-lumbar	8 (5)	8 (6)
Thoracic	3 (2)	17 (14)

B. Relationship of distribution of motor levels to CSF diversion frequency in postnatal surgery patients (P<0.001)

Category of most severe motor level	No CSF diversion N=150 (%)	CSF diversion N=498 (%)
Sacral	71 (47)	92 (18)
Low-lumbar	27 (18)	124 (25)
Mid-lumbar	29 (19)	147 (30)
High-lumbar	13	74

	(9)	(15)
Thoracic	10 (7)	61 (12)

Fisher’ exact test was used for comparisons of distributions.