**Appendix Table A1.** Frequency distribution of criterion treatment modalities by age for all patients with myelomeningocele and neurogenic bowel dysfunction by age in the National Spina Bifida Patient Registry, November 2013 – December 2017

|  | **n (%) by age at last visit** |  |
| --- | --- | --- |
| **Variables** | **Overall n (%)or statistics(N=3670)** | **5 - 11(n=1445)** | **12 - 19(n=1240)** | **20 and older(n=985)** | **P-value+** |
|  |  |  |  |  |  |
| **Criterion treatment modality**  |  |  |  |  | <0.001 |
| No intervention | 519 (14.1) | 214 (14.8) | 142 (11.5) | 163 (16.5) |  |
| Timed defecation | 122 (3.3) | 49 (3.4) | 54 (4.4) | 19 (1.9) |  |
| Oral medications only | 828 (22.6) | 313 (21.7) | 262 (21.1) | 253 (25.7) |  |
| Digital rectal stimulation | 117 (3.2) | 23 (1.6) | 28 (2.3) | 66 (6.7) |  |
| Suppositories | 214 (5.8) | 110 (7.6) | 73 (5.9) | 31 (3.1) |  |
| Mini-enemas | 168 (4.6) | 106 (7.3) | 54 (4.4) | 8 (0.8) |  |
| Standard rectal enemas | 128 (3.5) | 54 (3.7) | 29 (2.3) | 45 (4.6) |  |
| Manual disimpaction | 92 (2.5) | 32 (2.2) | 30 (2.4) | 30 (3.0) |  |
| Cone/balloon large volume enemas | 371 (10.1) | 235 (16.3) | 74 (6.0) | 62 (6.3) |  |
| Peristeen transanal irrigation | 76 (2.1) | 46 (3.2) | 25 (2.0) | 5 (0.5) |  |
| Antegrade enemas | 971 (26.5) | 256 (17.7) | 458 (36.9) | 257 (26.1) |  |
| Pouched fecal diversion | 64 (1.7) | 7 (0.5) | 11 (0.9) | 46 (4.7) |  |

 **+** Chi-square test

**Appendix Table A2.** Frequency distribution of criterion treatment modalities by lesion level in individuals ≥5 years of age with myelomeningocele and neurogenic bowel dysfunction in the National Spina Bifida Patient Registry, November 2013 – December 2017

|  | **n (%)by level of motor function** |  |
| --- | --- | --- |
| **Variables** | **Overall n (%)or statistics(N=3670)** | **Thoracic(n=799)** | **High-Lumbar(n=457)** | **Mid-Lumbar(n=1161)** | **Low-Lumbar(n=622)** | **Sacral(n=631)** | **P-value+** |
|  |  |  |  |  |  |  |  |
| **Criterion treatment modality**  |  |  |  |  |  |  | <0.001 |
| No intervention | 519 (14.1) | 102 (12.8) | 62 (13.6) | 172 (14.8) | 86 (13.8) | 97 (15.4) |  |
| Timed defecation | 122 (3.3) | 11 (1.4) | 11 (2.4) | 49 (4.2) | 22 (3.5) | 29 (4.6) |  |
| Oral medications only | 828 (22.6) | 172 (21.5) | 93 (20.4) | 256 (22.0) | 135 (21.7) | 172 (27.3) |  |
| Digital rectal stimulation | 117 (3.2) | 48 (6.0) | 17 (3.7) | 32 (2.8) | 14 (2.3) | 6 (1.0) |  |
| Suppositories | 214 (5.8) | 49 (6.1) | 35 (7.7) | 51 (4.4) | 45 (7.2) | 34 (5.4) |  |
| Mini-enemas | 168 (4.6) | 38 (4.8) | 24 (5.3) | 39 (3.4) | 25 (4.0) | 42 (6.7) |  |
| Standard rectal enemas | 128 (3.5) | 36 (4.5) | 12 (2.6) | 37 (3.2) | 24 (3.9) | 19 (3.0) |  |
| Manual disimpaction | 92 (2.5) | 26 (3.3) | 13 (2.8) | 32 (2.8) | 13 (2.1) | 8 (1.3) |  |
| Cone/balloon large volume enemas | 371 (10.1) | 58 (7.3) | 33 (7.2) | 133 (11.5) | 75 (12.1) | 72 (11.4) |  |
| Peristeen transanal irrigation | 76 (2.1) | 7 (0.9) | 12 (2.6) | 27 (2.3) | 19 (3.1) | 11 (1.7) |  |
| Antegrade enemas | 971 (26.5) | 228 (28.5) | 133 (29.1) | 314 (27.0) | 158 (25.4) | 138 (21.9) |  |
| Pouched fecal diversion | 64 (1.7) | 24 (3.0) | 12 (2.6) | 19 (1.6) | 6 (1.0) | # (<1.0) \*\* |  |

 **+** Chi-square test

\*\* Exact test was performed when expected cell count was 5 or less; cell count of 5 or less not shown (#)

**Appendix Table A3.** Percent distribution of key demographic and clinical characteristics of individuals with myelomeningocele and bowel impairment according to bowel intervention in the National Spina Bifida Patient Registry, November 2013 – December 2017

|  | **n (%)by bowel intervention** |  |
| --- | --- | --- |
| **Variables** | **Overall n (%)or statistics(N=3670)** | **No intervention(n=519)** | **Any intervention(n=3151)** | **P-value+** |
|  |  |  |  |  |
| **Age (years) group** |  |  |  | 0.002 |
| 5 to <12 | 1445 (39.4) | 214 (14.8) | 1231 (85.2) |  |
| 12 to <20 | 1240 (33.8) | 142 (11.5) | 1098 (88.5) |  |
| 20 or older |  985 (26.8) | 163 (16.5) |  822 (83.5) |  |
|  |  |  |  |  |
| **Sex** |  |  |  | 0.002 |
| Male | 1782 (48.6) | 286 (16.0) | 1496 (84.0) |  |
| Female | 1888 (51.4) | 233 (12.3) | 1655 (87.7) |  |
|  |  |  |  |  |
| **Race/Ethnicity (N=3653)** |  |  |  | <0.001 |
| Non-Hispanic White | 2301 (63.0) | 279 (12.1) | 2022 (87.9) |  |
| Non-Hispanic Black | 291 (8.0) |  70 (24.1) |  221 (75.9) |  |
| Hispanic or Latino |  831 (22.7) | 129 (15.5) |  702 (84.5) |  |
| Other | 230 (6.3) |  37 (16.1) |  193 (83.9) |  |
|  |  |  |  |  |
| **Level of motor function** |  |  |  | 0.62 |
| Thoracic |  799 (21.8) | 102 (12.8) | 697 (87.2) |  |
| High-Lumbar |  457 (12.5) |  62 (13.6) | 395 (86.4) |  |
| Mid-Lumbar | 1161 (31.6) | 172 (14.8) | 989 (85.2) |  |
| Low-Lumbar | 622 (16.9) |  86 (13.8) | 536 (86.2) |  |
| Sacral | 631 (17.2) |  97 (15.4) | 534 (84.6) |  |
|  |  |  |  |  |
| **Health insurance** |  |  |  | <0.001 |
| Any private | 1574 (42.9) | 168 (10.7) | 1406 (89.3) |  |
| Non-private | 2096 (57.1) | 351 (16.7) | 1745 (83.3) |  |

**+** Chi-square test

**Appendix Table A4.** Prevalence of fecal continence++ by criterion treatment modality and level of motor function in individuals ≥5 years of age with myelomeningocele and neurogenic bowel dysfunction in the National Spina Bifida Patient Registry, November 2013 - December 2017

|  | **n continent (%)** |  |
| --- | --- | --- |
|  | **Thoracic(n=799)** | **High-Lumbar(n=457)** | **Mid-Lumbar(n=1161)** | **Low-Lumbar(n=622)** | **Sacral(n=631)** | **P-value+** |
|  |  |  |  |  |  |  |
| Criterion treatment modality  |  |  |  |  |  |  |
|  No intervention |  -- |  -- |  -- |  -- |  -- |  |
|  Timed defecation |  # (<40) \*\* |  7 (63.6) |  21 (42.9) |  9 (40.9) | 15 (51.7) | 0.64 |
|  Oral medications only |  51 (29.7) | 31 (33.3) |  95 (37.1) |  58 (43.0) | 94 (54.7) | <0.001 |
|  Digital rectal stimulation |  31 (64.6) |  9 (52.9) |  17 (53.1) |  # (<30.0) \*\* |  # (<35.0) \*\* | 0.1465 |
|  Suppositories |  15 (30.6) |  8 (22.9) |  20 (39.2) |  30 (66.7) | 15 (44.1) | <0.001 |
|  Mini-enemas |  17 (44.7) | 16 (66.7) |  19 (48.7) |  11 (44.0) | 20 (47.6) | 0.47 |
|  Standard rectal enemas |  26 (72.2) |  # (<35.0) \*\* |  22 (59.5) |  10 (41.7) | 10 (52.6) | 0.071 |
|  Manual disimpaction |  11 (42.3) |  # (<35.0) \*\* |  13 (40.6) |  # (<20.0) \*\* |  # (<40.0) \*\* | 0.52 |
|  Cone/balloon large volume enemas |  35 (60.3) | 19 (57.6) |  74 (55.6) |  47 (62.7) | 42 (58.3) | 0.90 |
|  Peristeen® transanal irrigation |  # (<60.0) \*\* |  8 (66.7) |  17 (63.0) |  11 (57.9) |  # (<40.0) \*\* | 0.63 |
|  Antegrade enemas | 153 (67.1) | 86 (64.7) | 212 (67.5) | 116 (73.4) | 99 (71.7) | 0.45 |
|  Pouched fecal diversion |  |  |  |  |  |  |

**+** Chi-square test

\*\* Exact test was performed when expected cell count was 5 or less; cell count of 5 or less not shown (#)

++ Fecal continence is defined as having episodes of incontinence less than once a month or never

**Appendix Table A5**. Summary of univariate logistic regression on continence of stool, stratified by level of motor function (excluding those who used pouched fecal diversions or without bowel intervention) according to bowel intervention in the National Spina Bifida Patient Registry, November 2013 – December 2017

| **Variables** | **n (%)** | **Odds Ratio (95% CI)** | **P-value** |
| --- | --- | --- | --- |
|  |  |  |  |
| ***Thoracic (n=673)*** |
| **Modality category** |  |  | <0.0001‡ |
| Timed defecation † | 11 (1.6) |  |  |
| Oral medications only | 172 (25.6) | 0.74 (0.21 - 2.63) | 0.64 |
| Digital rectal stimulation | 171 (25.4) | 1.90 (0.54 - 6.73) | 0.32 |
| Manual disimpaction | 26 (3.9) | 1.28 (0.30 - 5.49) | 0.74 |
| Retrograde large volume enemas | 65 (9.7) | 2.62 (0.70 - 9.87) | 0.1534 |
| Antegrade enemas | 228 (33.9) | 3.57 (1.01 - 12.58) | 0.0476 |
|  |  |  |  |
| ***High-lumbar (n=383)*** |
| **Modality category** |  |  | <0.0001‡ |
| Oral medications only † | 93 (24.3) |  |  |
| Timed defecation | 11 (2.9) | 3.50 (0.95 - 12.87) | 0.0593 |
| Digital rectal stimulation | 88 (23.0) | 1.45 (0.79 - 2.65) | 0.23 |
| Manual disimpaction | 13 (3.4) | 0.89 (0.25 - 3.12) | 0.85 |
| Retrograde large volume enemas | 45 (11.7) | 3.00 (1.44 - 6.26) | 0.0034 |
| Antegrade enemas | 133 (34.7) | 3.66 (2.09 - 6.40) | <0.0001 |
|  |  |  |  |
| ***Mid-lumbar (n=970)*** |
| **Modality category** |  |  | <0.0001‡ |
| Timed defecation † | 49 (5.1) |  |  |
| Oral medications only | 256 (26.4) | 0.79 (0.42 - 1.46) | 0.45 |
| Digital rectal stimulation | 159 (16.4) | 1.28 (0.67 - 2.45) | 0.45 |
| Manual disimpaction | 32 (3.3) | 0.91 (0.37 - 2.25) | 0.84 |
| Retrograde large volume enemas | 160 (16.5) | 1.76 (0.92 - 3.36) | 0.0871 |
| Antegrade enemas | 314 (32.4) | 2.77 (1.50 - 5.12) | 0.0011 |
|  |  |  |  |
| ***Low-lumbar (n=530)*** |
| **Modality category** |  |  | <0.0001‡ |
| Timed defecation † | 22 (4.2) |  |  |
| Oral medications only | 135 (25.5) | 1.09 (0.44 - 2.72) | 0.86 |
| Digital rectal stimulation | 108 (20.4) | 1.50 (0.59 - 3.80) | 0.39 |
| Manual disimpaction | 13 (2.5) | 0.26 (0.05 - 1.48) | 0.1298 |
| Retrograde large volume enemas | 94 (17.7) | 2.33 (0.90 - 5.99) | 0.0802 |
| Antegrade enemas | 158 (29.8) | 3.99 (1.59 - 10.01) | 0.0032 |
|  |  |  |  |
| ***Sacral (n=531)*** |
| **Modality category** |  |  | 0.0027‡ |
| Timed defecation † | 29 (5.5) |  |  |
| Oral medications only | 172 (32.4) | 1.12 (0.51 - 2.47) | 0.77 |
| Digital rectal stimulation | 101 (19.0) | 0.81 (0.36 - 1.86) | 0.62 |
| Manual disimpaction | 8 (1.5) | 0.56 (0.11 - 2.79) | 0.48 |
| Retrograde large volume enemas | 83 (15.6) | 1.16 (0.50 - 2.71) | 0.73 |
| Antegrade enemas | 138 (26.0) | 2.37 (1.05 - 5.36) | 0.0386 |
|  |  |  |  |

*† Reference group*

*‡ Overall p-value*

**Appendix Table A6.** Frequency distribution of fecal continence by exclusive or conjunctive use of criterion treatment modality (oral agents were not counted as the additive agent) in individuals ≥ 5 years of age with myelomeningocele and neurogenic bowel dysfunction in the National Spina Bifida Patient Registry, November 2013 – December 2017

|  | **n continent** **(rate, %) by exclusive usage** | **P-value+** |
| --- | --- | --- |
| **Variables** | **n (%)(N=3670)** | **Exclusive** | **Conjunctive** |
|  |  |  |  |  |
| **Criterion treatment modality (2)** |  |  |  |  |
| Timed defecation | 122 (3.3) | 55 (45.5) a |  |  |
| Digital rectal stimulation | 117 (3.2) | 58 (54.2) | # (<55.0) \*\* | 1.0 |
| Suppositories | 214 (5.8) | 82 (42.1) | 6 (31.6) | 0.47 |
| Mini-enemas | 168 (4.6) | 79 (49.4) | # (<55.0) \*\* | 1.0 |
| Standard rectal enemas | 128 (3.5) | 61 (56.5) | 11 (55.0) | 1.0 |
| Manual disimpaction | 92 (2.5) | 21 (47.7) | 12 (25.0) | 0.030 |
| Cone/balloon large volume enemas | 371 (10.1) | 193 (57.8) | 24 (64.9) | 0.48 |
| Peristeen transanal irrigation | 76 (2.1) | 38 (56.7) | 6 (66.7) | 0.73 |
| Antegrade enemas | 971 (26.5) | 635 (69.0) | 31 (60.8) | 0.22 |
|  |  |  |  |  |

**+** Chi-square test

\*\* Exact test was performed when expected cell count was 5 or less; cell count of 5 or less not shown (#)

a All patients in this group used timed defecation exclusively; one patient had missing data