

Maryellen S. Kelly¹, Kirsten L. Simmons¹, Leah G. Davis^{1,2}, Jonathan C. Routh¹

¹Department of Surgery, Duke University School of Medicine, Durham, NC, USA

²Duke University Medical Center, Durham, NC, USA

Introduction

- Neurogenic bowel dysfunction affects over 80% of individuals with spina bifida
- **Neurogenic bowel is characterized by bowel incontinence and constipation**
- Health utility states have been increasingly used in healthcare systems to understand how burdensome a population perceives a disease is and to evaluate whether interventions improve quality of life years.

| Causes | Secondary Consequences |
|---|--|
| Decreased ano-rectal sensation | Decreased quality of life |
| Altered blood flow | Decreased school attendance and educational attainment |
| Altered acid secretion | Decreased rates of employment as an adult |
| Altered water and electrolyte transport | Increased depression and anxiety |
| Increased colonic transit time | Increased peer discrimination and bullying |
| Dysmotility | Urine incontinence |
| Relaxation of anal sphincter | Hydrocephalus shunt malfunction |
| | Urinary tract infections |
| | Skin breakdown/hemorrhoids/anal fissures |

Objective

- To elicit health utility scores for neurogenic bowel using an online community sample

Methods

- The time trade-off method was used to estimate a health utility score
- Survey was distributed to Mturk participants
- Participants received \$0.50 if they completed the entire survey



Survey

- Demographics
- Background and management information for neurogenic bowel
- Time trade-off assessment using 3 hypothetical scenarios
- Content validation from convenience sampling: retrospective cognitive interviews

Stats

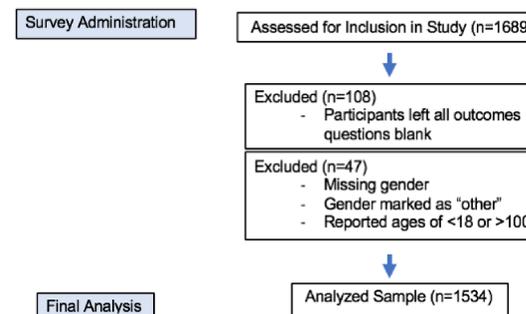
- Outcomes for each scenario were calculated using median and IQR
- Univariate comparisons of distributions of TTO for demographic data were made using Kruskal-Wallis tests
- 2016 Centers for Disease Control and Prevention Life tables were used to calculate the number of expected years of life a participant had left to live, and therefore could donate. Utility scores were calculated using the following formula:

$$1 - \frac{\# \text{ of Health Years Given Up}}{\# \text{ of Years Remaining}}$$

Results

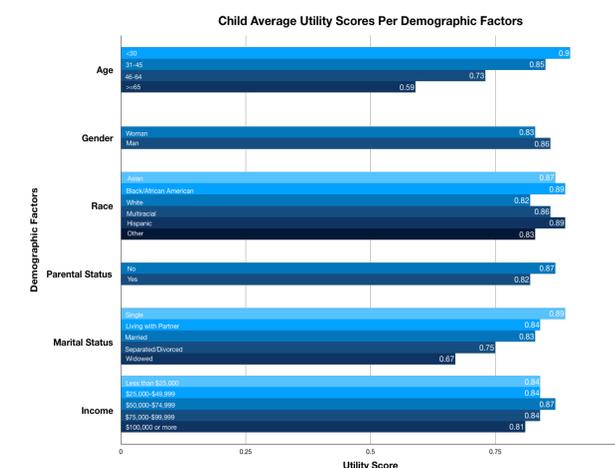
- The median utility score was 0.84 [0.70-0.92]
- Participants reported that they would give up a median of 5 years of their own life, to prevent NBD in themselves or their child

| Scenario | Years Given Up (median [IQR]) | Utility Score (median [IQR]) |
|--------------------------|-------------------------------|------------------------------|
| Child Constipation | 5 [4, 10] | 0.83 [0.67, 0.92] |
| Child Fecal Incontinence | 5 [3, 10] | 0.87 [0.72, 0.93] |
| Self-Fecal Incontinence | 5 [3, 10] | 0.88 [0.76, 0.94] |
| Child Scenario Mean | | 0.84 [0.7, 0.92] |
| Mean of All Scenarios | | 0.84 [0.7, 0.92] |



Participant demographics

| Characteristic | N (%) |
|---|-------------|
| N | 1534 |
| Age (Years)(%) | |
| <=30 | 543 (35.4) |
| 31-45 | 612 (39.9) |
| 46-64 | 327 (21.3) |
| >=65 | 52 (3.4) |
| Gender (%) | |
| Female | 813 (53.1) |
| Male | 714 (46.6) |
| Other | 5 (0.3) |
| Parental Status (%) | |
| No | 631 (41.1) |
| Yes | 903 (58.9) |
| Current Partner Status (%) | |
| Single | 452 (29.5) |
| Living with Partner | 160 (10.5) |
| Married | 777 (50.8) |
| Separated/Divorced | 123 (8.0) |
| Widowed | 19 (1.2) |
| Highest Level of Education Attained (%) | |
| High School or Less | 149 (9.7) |
| Some College | 439 (28.7) |
| Bachelor's Degree | 706 (46.1) |
| Masters or Doctoral Degree | 237 (15.5) |
| Yearly Income (%) | |
| Less than \$25,000 | 237 (15.5) |
| \$25,000-\$49,999 | 436 (28.5) |
| \$50,000-\$74,999 | 405 (26.5) |
| \$75,000-\$99,999 | 238 (15.5) |
| \$100,000 or more | 215 (14.0) |
| Race (%) | |
| Asian | 107 (7.1) |
| Black or African-American | 128 (8.5) |
| White | 1138 (75.5) |
| Multiracial | 40 (2.7) |
| Hispanic or Latino | 95 (6.3) |
| Self-Reported Current Health (%) | |
| Poor | 74 (5.0) |
| Moderate | 712 (48.0) |
| Good | 696 (47.0) |



Discussion

Prior health utility values for spina bifida: 0.85, 0.72, 0.84

Neurogenic bowel dysfunction in this study 0.84, 16% reduction from perfect health.

Similar to moderately severe disease states: severe persistent asthma (0.83); moderate seizure disorder (0.84); mild mental retardation (0.84)

Review of health utility estimates of chronic health conditions in children among parents, patients and pediatricians 0.80