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The National Spina Bifida Patient Registry: What We Have Learned about Four Outcomes

Benchmark Project Team:

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To build a better and brighter future for all those impacted by Spina Bifida

BENCHMARK PROJECT: PURPOSE

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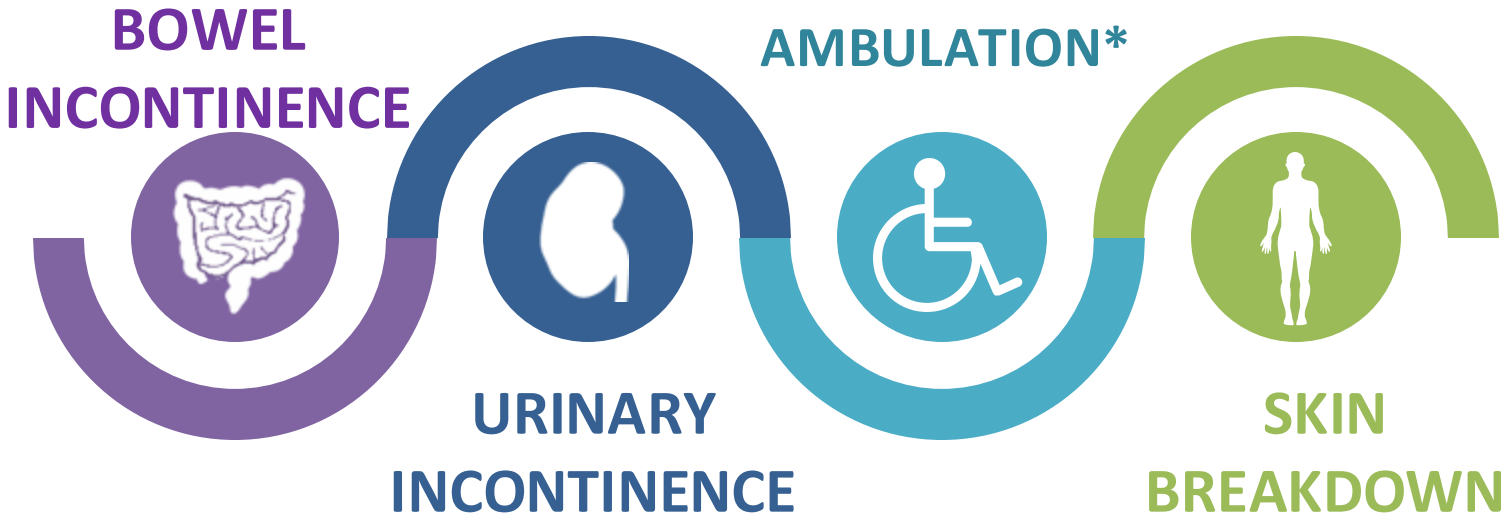
EVALUATE

FOUR CLINICALLY RELEVANT OUTCOMES



*Variance pattern- Some variance across clinics; but pediatric clinic clustered similarly and adult clinics clustered similarly. This outcome was not used to choose clinics bt was evaluated at each clinic.

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Previously Reported

- Results of the pre-visits survey
- Selection of sites to visit
- Analytic process of the interviews
- General findings from all sites

Findings Reported Today

- Characteristics of high-performing programs, challenges experienced by programs and recommendations for each outcome

Components of the Project that Informed our Findings Reported Today

- ✔ Survey of NSBPR clinics: Described all clinics
- ✔ Virtual Interviews with clinical staff across clinics visited: Identified themes
- ✔ Observations across clinics visited: Further defined, validated themes
- ✔ Post visit survey results

Bowel Incontinence Introduction

All clinics visited indicated that bowel incontinence was one of the **most impactful and important outcomes** to individuals with SB

Bowel Continence Clinic Characteristics

- Timely follow up (FU) for any new or changed BP (1-3 weeks minimum)
  - FU by telehealth, telephone, MyChart or in person
  - Conducted by a variety of professionals
- Rapid access to team for any concerns
- Listening to the situation and tailoring the program accordingly – “that's where we're going to get our best success”
- At least one key person connected to families has longevity
- Strong family attachment/fidelity to program
- Strong care coordination between clinic visits
- Psychology and/or child life on site for clinic

Bowel Incontinence
Challenges & Recommendations

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Challenges

- Availability of insurance coverage for TAI in some clinics
- Consistent personnel for follow-up
- Colostomy; rarely used but effective

Recommendation

- Assure aggressive and timely follow up (1-3 weeks) for any new or changed components of the bowel program
- Focus on care coordination between clinic visits to optimize bowel outcomes

Skin Breakdown Introduction

Skin breakdown was the second most impactful outcome

Three levels of prevention result in fewer recorded skin breakdowns in the Registry

- **Primary –** stopping skin breakdown before it occurs
- **Secondary –** early identification and prompt intervention
- **Tertiary –** preventing recurrences

Highest performing skin breakdown clinics were all pediatric; however, variance between pediatric and adult clinics was not large

Low Rate of Skin Breakdown Clinic Characteristics

- Total skin assessment with specific attention to high-risk areas at each annual visit
- Aggressive education approach beginning in the NICU
- Rapid response to skin concerns; timely and aggressive follow-up of any skin breakdown
- Easy access to staff and notable care coordination between visits
- Active skin initiatives (“Did you Look” or similar)
- Involvement of multiple team members addressing skin (MD, APPs, Nurses, Nutrition, PT, OT)
- Low no-show rate with high patient loyalty
- Aggressive and Innovative practices – (e.g., casting, pressure mapping, pre-surgical skin consultation)

Skin Breakdown
Challenges and Recommendations

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Challenges

- Lack of psychologist, neuropsychologist or nutritionist
- Difficulties accessing wheelchair seating specialists, many of which are located outside clinic
- Implementation of a standardized approach to skin care

Recommendations:

- Assure Systematic and comprehensive approach to prevention
  - Skin assessment and education
- Develop aggressive approach to treatment

Urinary Incontinence Introduction

- Urinary incontinence was bothersome, but less impactful than bowel incontinence or skin breakdown
- Urinary continence can conflict with kidney function and infection
  - Goals of care: “Kidneys, then infections, then dryness”
- Achieving continence remain important if desired
  - "I think our goals are continence for all –[but] that doesn't mean that every child and every family is going to want that, but we should be setting them up for that opportunity”
- Independence when feasible

Urinary Continence Clinic Characteristics

- Timely FU for any new or changed plan (1-3 weeks minimum)
  - FU by telehealth, telephone, MyChart or in person
  - Conducted by a variety of professionals (MD, AAP, Nurses)
- Rapid access to team for any concerns
- Listening to the situation and tailoring the program – “that's where we're going to get our best success”
- At least one key person connected to families has longevity
- Strong family attachment/fidelity to program
- Strong care coordination between clinic visits
- Psychology and/or child life on site for clinic

Urinary Incontinence
Challenges and Recommendations

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Challenges:

- Continence may not be a priority for all individuals or families
- Continence may be in-conflict with family culture, kidney health, or independence
- The culture of dependence for those with a physical disability in some families may negatively impact continence and independence

Recommendations:

- Kidney function, infection, and family/patient preference all influence continence and may merit inclusion in the registry
- Independence merits inclusion as an outcome

Ambulation Introduction

Ambulation was the least impactful outcome across all clinics
Clinics indicated that their focus was on mobility not necessarily ambulation:

- "Our interest is in functional mobility for all, which sometimes is ambulation [walking], but not always”
- "We don't really see community ambulation [walking] as sort of the gold standard”

The consistent theme: “Least restrictive device while optimizing function and independence”

Ambulation
Clinic Characteristics: Pediatric

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Pediatric clinics had higher rates of community ambulation

- Aggressively supported walking throughout life even if focused on household /therapeutic walking
- Clinics' approach was based on repeat muscle testing and/or gait analysis
- Multidisciplinary collaboration, strong care coordination was evident and crucial
- As children age, a shift from ambulation to mobility was increasingly evident
  - Preservation of mobility/ prevention of overuse injuries became a focus
- Community mobility was identified as foundational to full participation in society

Ambulation
Clinic Characteristics: Adult

Adult clinics had lower rates of community ambulation

- Transition to wheelchairs/scooters was more common
- Focus was on fitness, function in society, joint-sparing and prevention of overuse injury
- Innovative technology was used to support mobility, function and participation in society

Ambulation Challenges

- Weight management
- Insurance coverage for needed equipment
- Periods of immobility
  - “Anytime, there's a significant medical issue. If they end up in the hospital and are relatively immobile for a period of time, they can get deconditioned so quickly that it really is difficult for them to resume ambulation”
  - “During the pandemic--many of our patients have said that they feel like they aren't walking as well, and they aren't as strong as they were, because they had reduced their activities”
- Families' hesitancy / investment in walking

Ambulation Recommendations

- Mobility should be seen as the gold standard
  - **Clinics visited and the Benchmark Team recommend that "loss of community ambulation [walking]" although a variable of interest, should not be used as a quality outcome**
- Weight management should be considered a critical component of clinic services
- Walking as a form of exercise, if feasible, throughout life should be supported to enhance overall health.
  - Equipment needed for this activity should be available and covered by insurance

Other Findings of Interest that Appeared to Enhance Outcomes

- Presence of a strong voice of those with SB
- Presence of nutritionist in clinic – especially for treatment of skin problems
- State programs (Title V) that allow programs to apply for their unique needs
- Innovative practices that facilitated communication (e.g., posters of personnel, newsletters)

Overall Findings that Facilitated Outcomes

- Aggressive intentional follow-up for any change in program or new goal (e.g., 1-3 weeks)
- Consistency of site staff
- Presence of psychologist, neuropsychologist, or child life specialists that focused on child/family adaptation to treatment demands
- Although not present at each site, when the voice of individuals with SB was evident it clearly made an impact

Final Thoughts
The Circular Effect

Providers across clinics commented about the importance of the interaction of outcomes

- Skin breakdown reduces mobility which increases weight which puts more pressure on skin
- Bowel and bladder issues can impact skin
- Weight and mobility affect bladder, bowel, and skin health

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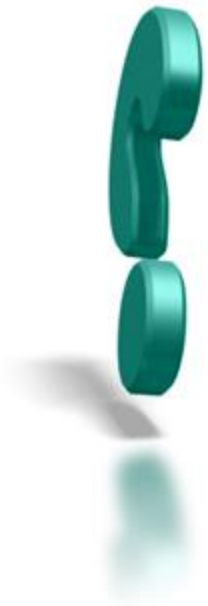
Benchmark

Project



QUESTIONS

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THANK YOU!

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