Perceptions of Healthcare
By Adults Living with Spina Bifida
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Healthcare Perceptions of Adults Living with Spina Bifida

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• Does not intend to discuss commercial products or services.
• Does not intend to discuss non-FDA approved uses of products/providers of services.
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• In a study published in 1964 Laurence stated the life expectancy of an infant born with Spina Bifida was 35%.


• “Today, at least 75–85% of children born with SB are expected to reach their early adult years. However, the life expectancy of those with SB cannot be accurately determined from the current data available.”

“Before 1975, a major contributor to decreased survival is death during infancy. The presence of cerebral spinal fluid shunting is a major contributor to increased survival”.

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• “In 1952 Nilsen and Spitz, working in conjunction with John Holter, the father of a child with hydrocephalus, reported the successful use of a ventriculojugular shunt regulated by a spring and ball valve”.

• “Between 1955 and 1960, four independent groups invented distal slit, proximal slit, and diaphragm valves almost simultaneously. Around 1960, the combined invention of artificial valves and silicone led to a worldwide therapeutic breakthrough”.
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• In addition to the advent of ventricular shunts other advances in treatment such as improved bladder management have led to an increase of life expectancy of children born with Spina Bifida.

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• “In general, there is a lack of comprehensive and lifelong care available to the adult with SB”.

  Dicianno, Brad E., et al. "Rehabilitation and medical management of the adult with spina bifida."  
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• Focus has been on the healthcare community’s perceptions of what needs the adult living with Spina Bifida has

• A review of the literature, published to date, revealed that there are no studies that address the perception of healthcare by adults living with Spina Bifida
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• 150 Adults living with Spina Bifida attended the National Conference of the SBAA in June, 2016

• Ages ranged from 18 to 78 years old.

• Each participant voluntarily agreed to share their story.

• Interviews were casual and informal.
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• Common themes emerged:

  • Lack of knowledge by clinicians
    • Lack of experience with adults living with Spina Bifida
    • Misconceptions/ Preconceived notions about adults living with Spina Bifida
    • Ableist attitudes of clinicians
    • Focusing only on SB related issues
    • Lack of preventative care in areas not effected by SB
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• Difficulty accessing healthcare
  • Payor source issues
  • Transportation issues
  • Physical Accessibility Issues
  • Availability of clinicians (i.e., Pediatric vs Adult)
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• Care needs not being met
  • Non-holistic treatment
  • Non-involvement in developing a plan of care
  • Focus on the caregiver’s needs not the patient’s needs
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• Social Concerns
  • Interference with other aspects of their lives
  • Fear of loss of function
  • Isolation from friends
  • Lack of self determination
Interesting notes:

• The majority of adults living with Spina Bifida interviewed felt that they were aging faster than their non Spina Bifida contemporaries.

• Of those who were 40+ they were concerned about how they will meet their parents medical needs as the age along with their own. About half reported being mistaken as being the patient when they were, in fact, the caregiver of an aging parent.

• Basic woman’s healthcare was often neglected.
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• Overall impressions
  • We as clinicians are failing to serve the adult spina bifida community adequately
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Change is needed:

- Shift from Pediatric and Adult to Aging with Spina Bifida
  - A holistic lifespan approach to care of patients living with Spina Bifida
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Change is needed:

• Research
  • Aging with Spina Bifida
  • Best Practices
  • Care delivery models beyond the clinic model
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Change is needed:

• Education

  • Update curriculums to include aging with Spina Bifida
  • Disseminate knowledge of research results, standards of care, etc. beyond the Spina Bifida Community
  • Utilize technology as a resource to clinicians who do not regularly care for adults living with Spina Bifida
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Change is needed:

- Care
  - Elicit input from patients living with Spina Bifida about their healthcare needs and perceptions
  - Embrace “transition begins at birth”
  - Provide tools that empower patients with Spina Bifida to independently manage their healthcare
  - Advocate