



Research Paper

Perception of secondary conditions in adults with spina bifida and impact on daily life

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Abstract

Background: Spina bifida is a congenital defect of the neural tube resulting in motor and sensory disruption. Persons with spina bifida can also experience executive function impairments. Secondary conditions are physical, medical, cognitive, emotional, or psychosocial consequences to which persons with disabilities are more susceptible. Our experience suggested clinicians underappreciate the presence and impact of secondary conditions in adults with spina bifida because they do not specifically ask for this information.

Objective: Describe the presence and impact of secondary conditions on daily life, as perceived by adults with spina bifida.

Methods: A clinic-based sample was recruited from the active patient population of an adult specialty center for spina bifida-related care. All subjects were verbally administered a survey developed through literature review and clinical experience of the researchers. The survey measured the presence and perceived impact of secondary conditions. Recruitment and survey data collection occurred over a 6-month period to maximize age representation. Survey data were stratified by age, gender and lesion level for analysis.

Results: Seventy-two respondents completed the survey. Pain was commonly reported, along with pressure ulcers, bowel & bladder concerns, depression, sleep disturbance, and limited social and community participation. No significant relationships were found between the presence or perceived impact of secondary conditions and age, gender or level of lesion.

Conclusions: Secondary conditions in spina bifida are present by early adulthood. Identifying these conditions during clinical encounters requires specific rather than general questions. Future study should evaluate earlier initiation of preventative measures by pediatric providers. © 2015 Elsevier Inc. All rights reserved.

Keywords: Spina bifida; Secondary conditions; Adults; Impact of disability; Patient perceptions

Spina bifida is a fault (dysraphism) in the development of the spine and spinal cord resulting in a gap or lesion in the spine.^{1,2} Classification is based on the level of the lesion in the spine and the presence or absence of hydrocephalus.³ In general, the higher the spinal lesion, the greater the neurologic and orthopedic impairment.³ This congenital neurodevelopmental disorder is a common disabling birth defect in the United States, and surveillance data aggregated from the National Birth Defect Prevention Network⁴ estimated a prevalence of 3.5 cases per 10,000

live U.S. births.⁵ Overall survival has improved and in the United States over 75% of persons with spina bifida live into early adulthood.⁶ With the growing number of adults with spina bifida, research into long-term health needs is warranted. The purpose of our study was to describe how adults with spina bifida perceive the presence and impact of their secondary conditions on daily life, and to use this information to better screen for secondary conditions during clinical encounters.

Secondary conditions are broadly defined as, “those physical, medical, cognitive, emotional, or psychosocial consequences to which persons with disabilities are more susceptible by virtue of an underlying condition, including adverse outcomes in health, wellness, participation, and quality of life.”^{7(p186)} Adults with spina bifida are at risk for secondary conditions such as bowel and bladder problems, pain, fatigue, injury, depression, obesity and pressure sores or ulcers because of motor and sensory disruption at

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the level of the spinal cord lesion.⁸ The impact of secondary conditions has only recently appeared in disability literature. Secondary data analysis of the Nationwide Inpatient Sample from the 2004–05 Healthcare Cost Utilization Project⁹ found one-third of hospitalizations for adults with spina bifida attributed to potentially preventable secondary conditions.¹⁰ Another retrospective review identified problems associated with aging and spina bifida that included pressure ulcers and resulting amputation, scoliosis, urinary incontinence, social isolation, and limited employment.¹¹ While evidence exists that secondary conditions have negative clinical implications, missing from literature is a description of the perceived impact of secondary conditions on a person's daily life.^{3,12}

Persons with spina bifida are also subject to less visible executive function impairments.^{8,13} Executive dysfunction is a complex phenomenon not limited to spina bifida and more easily characterized than defined. "Executive functions are those involved in complex cognitions, such as solving novel problems, modifying behavior in the light of new information, generating strategies, or sequencing complex actions."^{14(p50)} Failure to attend to the impact of executive dysfunction when interviewing a person with spina bifida will limit a clinician's ability to recognize and attend to early manifestations of problems.

The International Classification of Functioning, Disability, and Health (ICF) is a World Health Organization (WHO) framework for measuring health and disability at both individual and population levels.¹⁵ Since anyone can be at risk for a change in health status that results in some manner of disability, disability is seen as a universal human experience and not something affecting only a minority of the population. The WHO ICF framework serves as a conceptual guide and justification for the current study, which emphasizes the *perceived impact* of secondary conditions as distinct from their clinical severity. The objective of this descriptive study was to explore two related questions: 1) how common are secondary conditions in our patients with spina bifida? and; 2) how do secondary conditions impact people's lives? Survey data collected from consenting adults attending a specialty spina bifida clinic was analyzed to test for a relationship between age, gender and level of lesion on the perceived presence and impact of secondary conditions. The study was designed with attention to executive function challenges to obtain the most accurate information possible without clinical confirmation.

Methods

Setting and respondents

The study was conducted in the outpatient clinic of Gillette Lifetime Specialty Healthcare (GLSH). The research protocol was approved by the governing Institutional Review Board (IRB) and procedures followed were

in accordance with the ethical standards of the IRB and with the Helsinki Declaration of 1975 as revised in 2000.

GLSH was established in 2001 to address the specialty health needs of adolescents and adults with childhood-onset disabilities — including spina bifida — in an adult-oriented, integrated, multi-disciplinary, rehabilitation-focused environment.¹⁶ Our service is distinct from the main pediatric services provided by the parent organization, Gillette Children's Specialty Healthcare.¹⁷ GLSH is one of nine programs serving the longitudinal needs of adults with spina bifida.¹⁸ Clients seen at GLSH come from the surrounding metropolitan area, Greater Minnesota, Iowa and Wisconsin and range from formal physician referrals to self-referrals based on 'word of mouth' within the disability community. Clients with spina bifida vary in degree of impairment. All our clients are adults and while survival to adulthood has improved, an association between level of spinal lesion and survival has been established.^{6,19}

An information packet was sent to all GLSH patients, age 18 or older, with a primary diagnosis of spina bifida ($n = 192$). The packet included a letter describing the study, and copies of consent and survey forms, to allow participants and when applicable, legal guardians, sufficient time to read these materials and formulate questions prior to recruitment. Recruitment was conducted inperson when 97 of the 192 adults with spina bifida presented for clinic appointments during a subsequent six month period. Each potential subject was approached for participation interest and screened for recruitment eligibility, which was the ability to understand and answer questions independently. This criterion was based on clinical judgment and patient/caregiver input. No formal assessment tool was used. Of the 97 persons approached for recruitment, five did not meet screening criteria, 20 declined participation and 72 provided written informed consent.

Data collection

The study used a quantitative survey to collect information about secondary conditions experienced by adults, age 18 and older, with spina bifida. The spina bifida secondary conditions (SBSC) survey tool is specific to adults with this condition. Development of the SBSC incorporated emerging adult milestone domains defined by Zukerman, Devine and Holmbeck,²⁰ review of the current literature, and the clinical experience of our multi-disciplinary study team. We know executive function¹⁴ challenges occur in persons with spina bifida.¹³ During a universal screening program for foot health in our adult spina bifida clinic, we found foot lesions even when patients answered "no problems" to the question, "Do you have any problems?" Our foot screening experience suggested that general questions do not elicit accurate information and we paid particular attention to how we worded the SBSC survey questions, using simple and concrete language to minimize misunderstanding. Face validity of the SBSC was

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