



Mobility, hydrocephalus and quality of erections in men with spina bifida

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Summary

Introduction

Little is known about erectile dysfunction (ED) among men with spina bifida (SB). The goal of this study was to determine quality of erections and possible factors affecting erections in this population. It was hypothesized that men who ambulate and do not have a ventriculoperitoneal shunt (VPS) are more likely to have erections sufficient for intercourse.

Methods

An online survey was administered over an 18-month period to men aged ≥ 18 years and with SB. Participants were recruited through local, national and international SB organizations via social media. Exclusion criteria were: poor English proficiency, not completing the questionnaire or missing information regarding erections, VPS or ambulation. Data were collected on demographics, previous surgeries and function. Ambulatory status was classified using the Hoffer classification (Hoffer et al., 1973). Those able to walk at least at home, with or without crutches/braces, were classified as "ambulators." Erections were assessed using a single question from the validated Expanded Prostate Cancer Index Composite questionnaire (e.g. normal: "firm enough for intercourse"). Logistic regression was used for statistical analysis.

Results

The median age of 122 participants was 33 years, 53.3% were ambulators and 70.5% had a VPS.

Overall, 41.0% reported normal erections. Ambulators were more likely to report normal erections than non-ambulators (63.1% vs 15.8%, $P < 0.001$) (Table). Those with and without a VPS reported similar rates of normal erections (37.9% vs 48.6%, $P = 0.32$). On multivariate analysis, ambulators were more likely to have normal erections (OR ≥ 8.65 , $P \leq 0.001$) after correcting for age and VPS status. Age and VPS status were not correlated with normal erections on multivariate analysis ($P \geq 0.32$ and $P = 0.62$, respectively).

Discussion

Approximately 59% of men with SB reported ED, with ambulators being far more likely to have normal erections. This suggests that ambulatory status, similar to neurological lesion level, is a confounder of erectile function in the SB population. A limitation of the study was that a single item was used to assess erectile function. Rather than performing a comprehensive analysis of sexual health, the study aimed to gauge the prevalence of normal erections and assess possible risk factors. It did not assess sexual activity, erection duration or ED treatments. However, this is the largest study, to date, on SB and erectile quality with international participants.

Conclusion

About 40% of men with SB reported normal erections. Ambulatory status, rather than hydrocephalus, appeared to be the primary factor associated with erectile function. Approximately 2/3 of ambulators and 1/6 of non-ambulators reported normal erections.

Summary table Self-reported erection quality stratified by ambulatory status.

| Erection quality | Ambulatory status | | | | |
|-----------------------------|-------------------|---------------------------|-----------------------|-----------------------|--------------------|
| | None (n = 53) | Non-functional (n = 4) | Household (n = 11) | Community (n = 33) | Normal (n = 21) |
| Firm enough for intercourse | 8 (16.0%) | 1 (25.0%) | 8 (72.7%) | 20 (60.6%) | 13 (61.9%) |

Introduction

Spina bifida (SB), a birth defect that affects closure of the neural tube, affects 1 in 3000 births [1]. Recent medical advances, including closure of myelomeningocele defects, shunting of hydrocephalus when indicated, and a focus on renal preservation, have led to many of these individuals living into adulthood [2]. As children, urologic SB care is mostly centered on renal preservation and quality of life issues such as urinary and fecal continence. However, as boys with SB reach adulthood, care should also include other important functional and quality of life issues, such as sexual health.

Being born with SB often curtails psychosexual development, which can impair sexual function. It has been shown that those born with congenital disabilities have impaired sexual development due to diminished self-esteem, dependence of caregivers and lack of privacy [3]. However, little is known about erectile quality and erectile dysfunction (ED) in men with SB. Studies of ED in men with SB have tended to be small single-institutional series, with the largest one reporting on 52 participants [4–8].

While men with higher-level spinal cord lesions are less likely to have any erections [5], erectile quality is rarely described. The lesion level, however, is rarely assessed during routine urological clinic appointments. In addition, several classifications of neurological impairment exist and the actual functional level can change over time after a cord tether [9]. Finally, it is unclear whether erectile function is associated with readily assessable factors, such as ambulatory status or ventriculoperitoneal shunting (VPS), in this population. The present study sought to analyze erectile function and quality of erections in a large contemporary population. It was hypothesized that men with more impaired ambulatory status and a VPS were more likely to report ED.

Methods

An online survey was administered (January 2013–August 2014) to men aged ≥ 18 years and with SB. Participants were recruited through local, national and international SB organizations via social media, as part of a larger international quality of life study [10,11]. Only men answering the questionnaire online were eligible, as this method is associated with the most honest responses when it comes to sensitive topics [12]. Exclusion criteria were the same as for the larger study: poor English proficiency, a primary diagnosis other than SB and surgery in the last month. Additionally, those not completing the questionnaire or missing information on erections, VPS status or ambulatory status were excluded.

Data were collected on demographics, previous surgeries and function. Ambulatory status was classified using the 5-point Hoffer classification [13]. Ambulatory groups included: non-ambulators (mobile only in a wheelchair), non-functional ambulators (walking only during therapy), household ambulators (walking only inside with braces or crutches), community ambulators (walking inside and outside with or without crutches, using wheelchair only for

long trips) and normal ambulators (walking inside and outside without any aids).

Erections were assessed using a single question from the validated Expanded Prostate Cancer Index Composite questionnaire (EPIC, “Thinking about the last 4 weeks, how would you describe the quality of your erections?”) [14]. Four Likert scale answer options were: none at all, not firm enough for any sexual activity, firm enough for masturbation or foreplay only, and firm enough for intercourse. Erections firm enough for intercourse were considered normal.

Mann–Whitney U and Fisher’s exact tests were used to compare variables between participants with different ambulatory status. Logistic multivariable regression was used to analyze predictors of normal erections. No evidence of collinearity was detected. Variables included in the multivariable model were selected *a priori* and included: age (potentially related to ambulatory status, due to increasing weight and/or neurological impairment with age, and an established ED risk factor), VPS status and ambulatory function. It was initially intended to also include a history of bladder neck procedures, particularly bladder neck reconstruction, which may jeopardize sexual function. Given that about 20% of participants did not provide data on these procedures, it was decided to perform the main analysis without the bladder neck procedure variable. This variable was included in a secondary analysis. A critical $P = 0.05$ and SAS software were used (v9.4, SAS Institute, Cary, NC).

Results

Of the 191 males that were assessed, 122 (63.9%) met inclusion criteria (five had poor English proficiency, 39 did not complete the questionnaire, 19 had missing information about erections and six about VPS status).

The median age of 122 participants was 33 years (IQR 27–41), 81.2% were Caucasian and 73.0% lived in the United States. Most patients lived with their parent(s) (41.8%), spouse or partner (24.6%), or alone (23.8%). Most participants were able to eat and dress independently (79.5%) and 24.6% reported having developmental delay. The 34 patients from outside the United States (27.9% of the group) lived in the United Kingdom (10), Canada (nine), Australia (five), Turkey (three), as well as Chile, France, Ireland, Israel, Norway, Sweden and South Africa (one each).

Overall, 24.0% reported complete urinary continence over the last 4 weeks and 74.6% performed CIC. A history of bladder augmentation was reported by 33.6%, catheterizable urinary channel by 14.8% and a Malone antegrade enema by 13.9%. Overall, 19.7% reported having a bladder neck procedure in the past (sling: 2.5%, reconstruction: 4.1%, closure: 3.3%, artificial urinary sphincter: 16.4%, numbers may not add up since some participants reported more than one procedure), while 18.8% of participants did not provide any bladder neck procedure data.

Ambulatory and VPS status

Overall, most patients were wheelchair dependent and never ambulated ($n = 53$, 43.4%), while 21 (17.2%)

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