

Quality of life related to urinary continence in adult spina bifida patients

Joceline S. Liu¹, Caroline Dong¹, Jessica T. Casey¹, Alyssa Greiman¹, Shubhra Mukherjee², Stephanie J. Kielb¹

¹Department of Urology, Northwestern University Feinberg School of Medicine, Chicago, USA

²Physical Medicine and Rehabilitation, Northwestern University Feinberg School of Medicine, Chicago, USA

Citation: Liu JS1, Dong C1, Casey JT, Greiman A, Mukherjee S, Kielb SJ. Quality of life related to urinary continence in adult spina bifida patients. Cent European J Urol. 2015; 68: 61-67.

Article history

Submitted: Oct. 10, 2014

Accepted: Dec. 21, 2014

Published on-line:

March 13, 2015

Corresponding author

Joceline S. Liu
303 E Chicago Avenue
Tarry 16
60654 Chicago, USA
phone: +1 512 587 2238
joceline-liu@northwestern.edu

Introduction To analyze the correlations of bladder management technique, ambulatory status and urologic reconstruction on quality of life (QOL) as affected by urinary symptoms in adult spina bifida (SB) patients.

Material and methods Sixty-six adult SB patients completed the RAND 36-Item Health Survey (mSF-36) and Incontinence Quality of Life (I-QOL). Demographic information, history of urinary reconstruction, and bladder management techniques were reviewed and analyzed with respect to survey scores.

Results Mean age of patients was 32.3 (SD \pm 7.2) years and 44 patients (66.7%) were female. Forty-five patients (68.2%) were mainly ambulatory, 21 (31.8%) use a wheelchair and 10 (15.2%) had urologic reconstruction, while 56 (83.3%) did not. Twelve patients (18.2%) void, 42 (63.6%) perform clean intermittent catheterization (CIC), 4 (6.1%) use an indwelling catheter, 3 (4.5%) have an ileal conduit (IC) and 5 (7.6%) mainly use diapers. Mean mSF-36 General Health score was 56.5 (SD \pm 22.9) and mean I-QOL Sum score was 50.9 (SD \pm 21.7), where lower scores reflect lower QOL. mSF-36 and I-QOL scores did not significantly correlate with bladder management technique, ambulatory status or urologic reconstruction. A correlation was noted between I-QOL scales and most mSF-36 scales (all $p < 0.02$).

Conclusions In our cohort study of adult SB patients, bladder management technique and urologic reconstruction did not correlate with urinary (I-QOL) or general health (mSF-36) domains, although I-QOL and mSF-36 scores correlated closely, suggesting urinary continence is significantly related to general QOL. However, we are unable to identify a single factor that improves either urinary or general QOL.

Key Words: quality of life \leftrightarrow spina bifida \leftrightarrow urinary continence

INTRODUCTION

Spina bifida (SB) is one of the most common birth defects, occurring in 3.05 of every 10,000 live births in the United States in 2006, with an estimated 166,000 affected individuals nationally [1, 2, 3]. Though historically associated with high mortality, survival beyond childhood in patients with SB has steadily increased, with 75–85% of patients reaching adulthood [4]. With continued advances in understanding and care for SB, this number will only continue to grow [5, 6]. Urologists play a critical part within the larger continuum

of care for SB patients to preserve renal function, prevent adverse sequelae such as infection or stones, and minimize social embarrassment by improving urinary continence. Significantly, SB necessitates lifetime urological care; in patients lacking follow-up, severe and permanent damage to the native renal function may result [7]. Renal deterioration is a major cause of mortality for SB patients of all ages, as a result of chronically elevated bladder pressures with filling and incomplete or infrequent emptying [8]. Urinary incontinence also proves to be a significant cause of morbidity, limiting patients' social indepen-

dence and quality of life [9]. Medical management of bladder dysfunction with anticholinergic medication and more newly available treatments, including mirabegron and onabotulinumtoxin A, as well as intermittent catheterization has decreased associated morbidity [10]. However, when medical management fails, urinary diversion (with ileal conduit or continent urinary diversion) or bladder reconstruction (with enterocystoplasty) can be employed. Advances in urologic reconstruction and bladder management have led to improved renal preservation and urinary continence.

The question of health-related quality of life (HR-QOL) in SB patients is an important one that the current literature is just beginning to explore. While one of the urologist's primary goals is to maintain safe bladder pressures and prevent renal deterioration, one of our goals with less well-defined endpoints should be that of improving patient QOL. Though research has been conducted independently on HR-QOL and urinary status in SB patients, few publications to date have investigated the relationship between these two variables [11, 12]; of these, only one concerns the adult population [13]. As the pediatric population continues to age, it is becoming even more vital to determine how different methods of bladder management effects HR-QOL in older patients. We analyzed the relationship between bladder management techniques, ambulatory status and urologic reconstruction on QOL using validated general health (HR-QOL) and urinary incontinence (I-QOL) questionnaires. In seeking these correlations we hope to pinpoint the factors associated with HR-QOL for adult SB patients.

MATERIAL AND METHODS

We performed an institutional review board approved case series of adult (≥ 18 years old) SB patients. Patients were identified in the clinic setting or by mail and were asked to complete a standardized questionnaire. The questionnaire consisted of the RAND36-Item Health Survey, with or without modification of the Physical Functioning Scale for those with spinal cord injury (mSF-36v1 and mSF-36v2, respectively) depending on ambulatory status [14], Neurogenic Bowel Dysfunction Score (NBD) [15] and Incontinence Quality of Life (I-QOL) [16]. The questionnaires included in this study were chosen to assess QOL related to symptoms of urinary incontinence. Patients were identified by having a clinic visit in the multidisciplinary adult SB clinic at our institution between 2001 and 2013.

Patient demographics including age at the time of the study, gender, type and level of neurologic le-

sion, ambulatory status, bladder management technique and history of urologic reconstruction were collected from a chart review of the electronic record. General quality of life was evaluated using the mSF-36 questionnaire, consisting of eight specific domains (Physical Functioning, Role Limitations Due to Physical Health Problems, Role Limitations Due to Emotional Problems, Vitality, Mental Health, Social Functioning, Bodily Pain, General Health, and Health Transition) [14]. The mean value was calculated for each domain on a scale of 0 to 100, with a lower score indicating a lower quality of life. Bowel dysfunction was assessed using the NBD, with a higher score reflecting worse bowel function [15]. Quality of life related to urinary continence was evaluated using the I-QOL questionnaire, comprised of three domains (Avoidance and Limiting Behaviors, Psychosocial Impact and Social Embarrass-

Table 1. Patient characteristics

Demographics of 66 spina bifida patients		
	Patients (n= 66) n (%)	<i>p</i> *
Age (range)	32.3 (22–54)	
Female	44 (66.7)	
Type of spina bifida		
Myelomeningocele	61 (92.4)	
Lipomeningocele	4 (6.1)	
Isolated Tethered Cord	1 (1.5)	
Level of lesion		
L2 and above	6 (9.1)	
L3–L5	35 (53.0)	
S1 and below	11 (16.7)	
Unknown	14 (21.2)	
Ambulation status		
Ambulatory	45 (68.2)	
Wheelchair	21 (31.8)	
Bladder management		
Void	12 (18.2)	
CIC	42 (63.6)	
Indwelling catheter	4 (6.1)	
Ileal conduit	3 (4.5)	
Diaper	5 (7.6)	
Urologic reconstruction history [†]	10 (15.2)	
Female	8 (80.0)	0.33
Wheelchair	4 (40.0)	0.55

*Fisher's exact test used for calculation of statistical significance.

[†]5 augmentation, 1 augmentation with Mitrofanoff, 1 Mitrofanoff only, 2 ileal conduit, 1 ileovesicostomy

ment) with scores between 0 (poorest quality of life) and 100 (best quality of life) [16].

For statistical analysis, Fischer's exact test was used for categorical variables to test for differences in demographic characteristics. General and individual domain scores for each questionnaire were reported. Spearman's rho correlation analysis was used to measure the association between generic HR-QOL (mSF-36, v1 and v2) and disease-specific incontinence-related (I-QOL) scores, with variance analyzed using F-test. Analysis of variance with Scheffe posthoc analysis was employed to test for differences in mean mSF-36 and I-QOL scores across patient groups of interest (ambulatory status, bladder management techniques, bladder reconstructive surgery status). These analyses were also repeated, excluding patients who reported fecal incontinence at least weekly on the NBD questionnaire, in an effort to eliminate patients with incontinence unrelated to urinary symptoms that would cloud their general quality of life. For all statistical analyses, $P < 0.05$ was considered statistically significant. Analysis was performed using SPSS®, version 21.

RESULTS

Of the 255 patients contacted to participate in the study (211 by mail, 23 in clinic), 21 were unable to be contacted (i.e. deceased, incorrect mailing address), 8 patients declined participation (approached

in clinic), and 66 returned the completed the survey in full (66/226, 29.2% response rate). Descriptive characteristics are outlined in Table 1. Mean age at the time of the study was 32.3 years (SD ± 7.2) and 44 patients (66.7%) were female. Etiology of SB was most commonly myelomeningocele, reported in 61 patients (92.4%), and less commonly lipomeningocele in 4 patients (6.1%) and isolated cord tethering in one patient (1.5%). Level of neurologic lesion was above or at the level of L2 in 6 patients (9.1%), between L3-L5 in 35 patients (53.0%), at S2 or below in 11 patients (16.7%), and unknown in 14 patients (21.2%). Forty-five patients (68.2%) were mainly ambulatory, while 21 patients (31.8%) mainly used a wheelchair. Ten patients (15.4%) had undergone urologic reconstruction, while 56 (84.8%) had not. Twelve patients (18.2%) void volitionally, 42 (63.6%) perform clean intermittent catheterization (CIC), 4 (6.1%) use an indwelling catheter, 3 (4.5%) have an ileal conduit (IC) and 5 (7.6%) mainly use diapers. There were no significant differences in demographics between patients with and without a history of urologic reconstruction.

Questionnaire elements specific to urinary and fecal incontinence were analyzed within the I-QOL and NBD, respectively. 44.6%, or 29 patients, endorsed some element of urinary incontinence; the amount and severity of urinary incontinence was not captured in the questionnaires. Four patients (6.2%) reported fecal incontinence daily, and another four pa-

Table 2. Lack of association between general health and urinary incontinence-related quality of life with history of bladder reconstruction and ambulatory status

	Bladder reconstruction		p value	Ambulatory status		p value
	No reconstruction (n=56)	Reconstruction (n=10)		Ambulatory (n=21)	Wheelchair (n=45)	
	mean (SD)			mean (SD)		
IQOL Avoidance behavior	49.7 (22.4)	47.4 (27.4)	0.78	56.5 (22.0)	46.2 (23.0)	0.09
IQOL Psychosocial Impact	58.1 (25.3)	57.6 (22.1)	0.95	64.1 (19.8)	55.3 (26.3)	0.19
IQOL Embarrassment	50.0 (28.7)	54.2 (32.8)	0.67	59.3 (29.2)	46.7 (28.6)	0.11
IQOL Sum	50.9 (21.4)	50.6 (24.4)	0.97	57.6 (20.5)	47.9 (21.8)	0.1
mSF36 Physical functioning	65.1 (26.2)	47.5 (32.5)	0.07	59.8 (31.1)	63.6 (26.3)	0.61
mSF36 Role Lim Phys	69.0 (31.5)	61.7 (39.9)	0.52	66.3 (35.2)	68.7 (31.7)	0.78
mSF36 Role Lim Emo	70.1 (31.6)	73.3 (33.1)	0.77	68.7 (38.7)	71.5 (28.1)	0.74
mSF36 Energy/Fatigue	52.7 (23.3)	62.6 (27.0)	0.23	56.3 (31.5)	53.3 (19.8)	0.63
mSF36 Emotional Well-being	65.8 (22.9)	69.0 (28.5)	0.7	63.2 (32.0)	67.8 (18.8)	0.47
mSF36 Social Functioning	70.1 (31.4)	76.3 (28.5)	0.57	67.3 (36.3)	72.8 (28.2)	0.5
mSF36 Bodily Pain	71.5 (27.3)	75.0 (26.2)	0.71	72.4 (32.3)	71.8 (23.9)	0.94
mSF36 General Health	57.5 (23.1)	51.0 (22.1)	0.41	55.2 (20.6)	57.1 (24.1)	0.76

Role Lim Phys = role limitations due to physical health; Role Lim Emo = role limitations due to emotional problems. *Statistical analysis was performed using univariate analysis of variance with Scheffe posthoc analysis

tients (6.2%) endorse episodes of fecal incontinence at least once per week.

Mean mSF-36 General Health score was 56.5 (SD \pm 22.9) and mean I-QOL Sum score was 50.9 (SD \pm 21.7), where lower scores reflect lower QOL. The individual eight mSF-36 and three I-QOL domains were not significantly different in patients with and without history of urologic reconstruction or based on ambulatory status (Table 2). No I-QOL scales significantly differed based on bladder management technique (Table 3). Similarly, no mSF-36

domains significantly differed based on bladder management technique, although the specific question regarding general health rating differed significantly, ($p = 0.03$) with highest scores in patients managed with voiding (68.8), followed by CIC (58.3), IC (58.3) and diapers (45.0); the lowest scores were in patients with indwelling catheters (25.0) (Table 3). When comparing the QOL measures from mSF-36 and I-QOL, a moderate correlation was noted between I-QOL scales and most mSF-36 scales (outlined in Table 4). Eight patients reported fecal incon-

Table 3. Limited association between general health and urinary incontinence-related quality of life with bladder management technique. A single element regarding general health perception correlated with bladder management technique performed using univariate analysis of variance with Scheffe posthoc analysis

Questionnaire	Bladder management technique					p value*
	Voiding (n=12)	CIC (n=42)	Catheter (n=4)	Ileal Conduit (n=3)	Diaper (n=5)	
	mean (SD)					
IQOL Avoidance Behavior	47.8 (26.5)	52.7 (21.8)	34.7 (31.4)	50.3 (33.9)	38.0 (14.1)	0.56
IQOL Psychosocial Impact	59.3 (20.3)	60.5 (26.1)	47.9 (28.6)	61.5 (27.1)	44.2 (20.4)	0.57
IQOL Embarrassment	57.8 (28.9)	53.1 (28.3)	31.7 (30.9)	62.2 (40.2)	24.0 (13.9)	0.12
IQOL Sum	52.1 (21.7)	53.6 (21.3)	38.0 (27.8)	54.7 (30.5)	36.2 (13.9)	0.37
mSF36 Physical functioning	68.6 (24.6)	63.5 (28.8)	53.3 (41.8)	44.4 (34.0)	54.3 (18.8)	0.76
mSF36 Role Lim Phys	77.1 (18.9)	67.5 (34.7)	66.7 (31.5)	41.7 (52.0)	69.2 (35.8)	0.68
mSF36 Role Lim Emo	71.5 (30.5)	73.2 (32.3)	63.9 (33.7)	66.7 (31.2)	63.3 (27.4)	0.61
mSF36 Energy/Fatigue	58.5 (17.7)	52.8 (25.3)	39.6 (32.1)	84.0 (15.6)	50.0 (15.3)	0.22
mSF36 Emotional Well-being	67.9 (21.8)	67.8 (23.7)	51.7 (28.9)	81.7 (31.8)	56.0 (18.5)	0.38
mSF36 Social Functioning	74.0 (29.4)	71.4 (31.9)	58.3 (36.1)	87.5 (21.7)	67.5 (30.1)	0.6
mSF36 Bodily Pain	62.1 (26.1)	72.6 (28.0)	89.2 (18.8)	88.3 (20.2)	69.5 (28.6)	0.6
mSF36 General Health	59.2 (18.6)	55.2 (25.2)	65.0 (0)	65.0 (8.7)	48.0 (27.1)	0.84
mSF36 Health trans	68.8 (21.7)	58.3 (22.5)	25.0 (0)	58.3 (38.2)	45.0 (27.4)	0.03

CIC = clean intermittent catheterization; Role Lim Phys = role limitations due to physical health; Role Lim Emo = role limitations due to emotional problems.

*Statistical analysis was

Table 4. Spearman rho correlations between general health (mSF-36) and urinary incontinence-related (I-QOL) questionnaire scores

	IQOL Avoidance Behavior	IQOL Psychosocial Impact	IQOL Embarrassment	IQOL Sum
	Spearman's rho correlation (p)			
mSF36 Physical functioning	0.11 (0.40)	0.28 (0.02)	0.13 (0.29)	0.22 (0.08)
mSF36 Role Lim Phys	0.35 (0.004)	0.45 (0.00)	0.34 (0.006)	0.41 (0.001)
mSF36 Role Lim Emo	0.33 (0.008)	0.36 (0.004)	0.33 (0.008)	0.35 (0.005)
mSF36 Energy/Fatigue	0.38 (0.002)	0.46 (0.0)	0.37 (0.002)	0.43 (0.0)
mSF36 Emotional Well-being	0.37 (0.002)	0.40 (0.001)	0.36 (0.003)	0.39 (0.001)
mSF36 Social Functioning	0.40 (0.001)	0.51 (0.0)	0.41 (0.001)	0.47 (0.0)
mSF36 Bodily Pain	0.31 (0.01)	0.29 (0.02)	0.30 (0.02)	0.29 (0.02)
mSF36 General Health	0.12 (0.35)	0.16 (0.21)	0.16 (0.20)	0.15 (0.23)

Role Lim Phys = role limitations due to physical health; Role Lim Emo = role limitations due to emotional problems. Spearman's rho correlation was utilized in statistical analysis

tinence at least weekly. In the remaining 57 patients, mSF-36 and I-QOL domains were again not correlated with bladder management technique or history of urologic reconstruction, but ambulatory status was correlated with I-QOL Avoidance Behavior ($p = 0.04$), I-QOL Embarrassment ($p = 0.03$) and overall I-QOL Sum ($p = 0.04$).

DISCUSSION

Prior studies have explored the factors influencing HR-QOL in SB patients, but the data thus far primarily reflects the experience of pediatric patients; these studies are often conducted as comparisons of children with SB versus children with other neurological deficits, or pediatric patients versus a smaller sample of adult SB patients. [17–21] Often these studies are difficult to compare directly, as there is large variation in methodology for evaluating quality of life. While some studies distill results to a single value, other studies find more significant conclusions when components are evaluated independently (i.e. physical, mental, and social QOL). There is no clear consensus regarding management and goals of care that correlate well and consistently with validated QOL measures in a large adult SB population. Sawin et al. reported a meta-analysis examining data on QOL in both pediatric and adult SB patients and noted a lack of coherence in published results, specifically conflicting conclusions on which factors correlate to QOL in SB patients [22]. Though this is due in part to different research objectives, a significant cause of this incoherence is the variety of instruments used in the different studies, including condition-specific measures such as the health-related QOL tool for SB patients (HRQOL-SB) [23], as well as five different generic tools, including the mSF-36 questionnaire used in our study. The inconsistent methodology in these similar studies prevents results from being easily compared and demonstrates that an appropriate standard for evaluating these patients is yet to be determined. Of particular note, the authors note a complete absence of “a psychometrically strong, SB-specific measure of HR-QOL” and suggest inclusion or expansion of a continence domain as a potential solution. While a few studies have explored this particular relationship since the aforementioned review, they have mostly dealt with the pediatric population. This reflects both the relatively new presence of an adult SB population as well as an increasing need to study their health status [11, 12]. Our study not only focuses specifically on adult SB patients, but also hones in on this niche question of urinary management and continence status and how it may impact HR-QOL and

I-QOL in these patients, for whom social independence is perhaps even more significant compared to their younger counterparts.

Only one similar study of HR-QOL and continence has been conducted with the adult population [13]. Lemelle et al. utilized the mSF-36 questionnaire and assessed both urinary and fecal continence as well as ambulatory status, creating their own scales for the latter assessments. Twenty-six patients (10.3%) of 252 adult patients were incontinent of urine and had significantly lower scores for the mSF-36 Bodily Pain domain. The authors also reported higher scores in the mSF-36 General Health and Role Limitations Due to Physical Health Problems scales in patients who had undergone bladder reconstruction with and without continence mechanism, respectively. No other significant associations between HR-QOL and urinary continence or bladder management were demonstrated.

We report the general health and urinary incontinence-related quality of life in adult SB patients, in relation to bladder management technique, ambulatory status and history of bladder reconstruction. Bladder management techniques are aimed towards an ultimate goal of protecting renal function while optimizing continence, patient independence and quality of life. While first line methods of management include medical treatment, when these measures are inadequate, surgical interventions are the next step. Bladder reconstruction often includes bowel segment use with subsequent anastomosis, which may contribute to morbidity in this population, which often at baseline has significant bowel symptoms. These results demonstrate a close correlation between urinary incontinence-related and general health quality of life, implying that incontinence plays a significant role in perception and satisfaction with general health in adult SB patients. However, a correlation between bladder management technique, ambulatory status and history of bladder reconstruction are not correlated with either I-QOL or mSF-36 measures. Goals of increased independence and continence with specific bladder management techniques and bladder reconstruction were not correlated with either QOL tool. When subgroup analysis of patients with fecal incontinence at least weekly were excluded from the analysis in an effort to eliminate patients with health-related symptoms that might overshadow urinary symptoms, I-QOL and mSF-36 scores remained uncorrelated with bladder management technique or bladder reconstruction. There was a correlation between ambulatory status and several I-QOL domains (avoidance behavior, embarrassment and overall sum), suggesting that perhaps urinary incontinence plays a more

significant role in I-QOL in patients who are mainly ambulatory, or independent at baseline, when compared to patients confined to a wheelchair.

Despite the advantages of this study in a relatively infrequently studied population, limitations of this study include the small number of patients ($n = 66$), which may limit the ability to detect a statistically significant difference in QOL measures based on bladder management technique and urologic reconstruction. In this study, the I-QOL was used as a tool to assess urinary-related QOL, but may not be optimized to the specialized population of adult SB, in whom incontinence occurs due to neurogenic lesions. Furthermore, objective observation and reporting of volume and frequency of urinary incontinence was not included in the patient-reported surveys. This study was also limited by a 29% response rate, likely multi-factorial in etiology including mailed questionnaire, incorrect home address, and disqualification due to incomplete survey completion. Different methods of contact for the questionnaire (via mail versus clinic) may also introduce selection bias in response rates. Additionally, this study compares QOL in adult SB patients over a range of representative urologic management and surgical his-

tory, and provides an important snapshot of patient reported urinary incontinence and health-related QOL. Future directions for research in this realm should address pre- and post-intervention HR-QOL in patients undergoing changes in bladder management technique or reconstruction in a prospective manner.

CONCLUSIONS

Urologic reconstruction and bladder management techniques have evolved in SB patients and affect patients' daily urinary regimens. In our cohort of adult SB patients, although bladder management technique and urologic reconstruction did not affect scores in the urinary (I-QOL) or general health (mSF-36) domains, I-QOL scores correlated with mSF-36 scores. Thus, urinary-related QOL is significantly related to general HR-QOL. However, we are unable to identify a single factor that improved either urinary or general HR-QOL. We need to continue to study the effect of bladder management technique pre- and post-operatively, over time with urologic reconstruction on general health-related and urinary QOL in the SB population.

References

- Parekh AD, Trusler LA, Pietsch JB, Byrne DW, DeMarco RT, Pope JC 4th, et al. Prospective, longitudinal evaluation of health related quality of life in the pediatric spina bifida population undergoing reconstructive urological surgery. *J Urol*. 2006; 176: 1878–1882.
- Parker SE, Mai CT, Canfield MA, Rickard R, Wang Y, Meyer RE, et al. Updated National Birth Prevalence estimates for selected birth defects in the United States, 2004–2006. *Birth Defects Res A Clin Mol Teratol*. 2010; 88: 1008–1016.
- Fletcher JM, Brei TJ. Introduction: Spina bifida—A multidisciplinary perspective. *Dev Disab Res Rev*. 2010; 16: 1–5.
- Liptak GS, Garver K, Dosa NP. Spina bifida grown up. *J Dev Behav Pediatr*. 2013; 34: 206–215.
- Lloyd JC, Wiener JS, Gargollo PC, Inman BA, Ross SS, Routh JC. Contemporary epidemiological trends in complex congenital genitourinary anomalies. *J Urol* 2013; 190: 1590–1595.
- Kaufmann Rauen K, Sawin KJ, Bartelt T, Waring WP 3rd, Orr M, Corey O'Connor R. Transitioning adolescents and young adults with a chronic health condition to adult healthcare – an exemplar program. *Rehabil Nurs*. 2013; 38: 63–72.
- Ahmad I, Granitsiotis P. Urological follow-up of adult spina bifida patients. *Neurourol Urodyn*. 2007; 26: 978–980.
- Malakounides G, Lee F, Murphy F, Boddy SA. Single centre experience: long term outcomes in spina bifida patients. *J Pediatr Urol*. 2013; 9: 585–589.
- Clayton DB, Brock JW. The urologist's role in the management of spina bifida: a continuum of care. *Urology*. 2010; 76: 32–38.
- Weld KJ, Dmochowski RR. Effect of bladder management on urological complications in spinal cord injured patients. *J Urol*. 2000; 163: 768–772.
- Freeman KA, Smith K, Adams E, Mizokawa S, Neville-Jan A; West Coast Spina Bifida Consortium. Is continence status associated with quality of life in young children with spina bifida? *J Pediatr Rehabil Med*. 2013; 6: 215–223.
- Olesen JD, Kiddoo DA, Metcalfe PD. The association between urinary continence and quality of life in paediatric patients with spina bifida and tethered cord. *Paediatr Child Health*. 2013; 18: e32–38.
- Lemelle JL, Guillemin F, Aubert D, Guys JM, Lottmann H, Lortat-Jacob S, et al. Quality of life and continence in patients with spina bifida. *Qual Life Res*. 2006; 15: 1481–1492.
- Luther SL, Kromrey J, Powell-Cope G, Rosenberg D, Nelson A, Ahmed S, Quigley P. A pilot study to modify the SF-36V physical functioning scale for use with veterans with spinal cord injury. *Arch Phys Med Rehabil*. 2006; 87: 1059–1066.
- Krogh K, Christensen P, Sabroe S, Laurberg S. Neurogenic bowel dysfunction score. *Spinal Cord*. 2006; 44: 625–31.
- Patrick DL, Martin ML, Bushnell DM, Yalcin I, Wagner TH, Buesching DP. Quality of life of women with urinary incontinence: further development of the incontinence quality of life instrument (I-QOL). *Urology*. 1999; 53: 71–76.

17. Young NL, Sheridan K, Burke TA, Mukherjee S, McCormick A. Health outcomes among youths and adults with spina bifida. *J Pediatr*. 2013; 162: 993–998.
18. Sibinski M, Synder M, Higgs ZC, Kujawa J, Grzegorzewski A. Quality of life and functional disability in skeletally mature patients with myelomeningocele-related spinal deformity. *J Pediatr Orthop B*. 2013; 22: 106–109.
19. Padua L, Rendeli C, Rabini A, Girardi E, Tonali P, Salvaggio E. Health-related quality of life and disability in young patients with spina bifida. *Arch Phys Med Rehabil*. 2002; 83: 1384–1388.
20. Tezcan S, Simsek TT. Comparison of Health-Related Quality of Life between children with cerebral palsy and spina bifida. *Res Dev Disabil*. 2013; 34: 2725–2733.
21. Flanagan A, Kelly EH, Vogel LC. Psychosocial outcomes of children and adolescents with early-onset spinal cord injury and those with spina bifida. *Pediatr Phys Ther*. 2013; 25: 452–459.
22. Sawin KJ, Bellin MH. Quality of life in individuals with spina bifida: a research update. *Dev Disabil Res Rev*. 2010; 16: 47–59.
23. Parkin PC, Kirpalani HM, Rosenbaum PL, Fehlings DL, Van Nie A, Willan AR, King D. Development of a health-related quality of life instrument for use in children with spina bifida. *Qual Life Res*. 1997; 6: 123–132. ■