Outcomes of Urinary Diversion in Children With Spinal Cord Injuries

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Abstract

Purpose: To gain a better understanding of the outcomes of the Mitrofanoff procedure for urinary diversion in children with spinal cord injury (SCI).

Design: Descriptive retrospective.

Participants/Methods: Individuals 6 to 27 years of age with SCI with at least 1 year follow-up after the Mitrofanoff procedure. Objective data collected via retrospective chart review include general demographics and medical/surgical history. Data collected via structured telephone interview include history of adverse urological events, bladder management, bladder management independence scores, patient satisfaction, and quality of life.

Results: Sixteen subjects (13 female, 3 male) with a mean age of 19 years (range 6–27 y) who underwent the Mitrofanoff procedure were interviewed. Length of postoperative follow-up ranged from 1 to 8 years (mean 4.25 y). Complications included stomal stenosis 25% (n = 4) with a mean of 19 months to first occurrence of stenosis; urethral incontinence 75% (n = 12); renal/bladder calculi 19% (n = 3); and stomal leakage 44% (n = 7). Independence scores for bladder management after the Mitrofanoff procedure improved in 84% of subjects with tetraplegia and 25% of subjects with paraplegia. Eighty-eight percent (n = 14) were satisfied with the procedure, while 12% (n = 2) were somewhat satisfied. A thematic analysis of quality of life revealed that freedom (35%) and independence (35%) were most commonly cited.

Conclusion: While some subjects experienced complications, satisfaction was relatively high and level of independence in bladder management was greatly improved. This study demonstrates that the Mitrofanoff procedure is a beneficial option to improve independence and ease of bladder management in children with SCI.

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Key Words: Spinal cord injuries; Spina bifida; Neurogenic bladder; Mitrofanoff procedure (appendicovesicostomy); Urinary diversion; Vesicosphincteric dyssynergy; Tetraplegia; Paraplegia

INTRODUCTION

Urologic function is usually affected after spinal cord injury (SCI). Loss of cerebral control in suprasacral SCI leads to detrusor hyperreflexia, while loss of control of the pontine micturition center leads to vesicosphincteric dyssynergy. The loss of sensation, motor control, and ability to relax the bladder outlet can leave an individual with the inability to both store and evacuate urine.

Continence is a social expectation in the school arena and is an essential component for the development of confidence and self-esteem in children (1,2). Proper neurogenic bladder management for children and adults with SCI is paramount to maintain optimal health and avoid life-threatening complications, including renal failure. The most common method utilized by children and adolescents with SCI is clean intermittent catheterization (3,4). However, patients (particularly female patients) who are dependent upon wheeled mobility, who have limited hand function, who are obese, or who experience severe lower extremity spasticity often find accessing the urethral meatus for

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intermittent catheterization a cumbersome and challenging process.

Background

In 1980, Mitrofanoff proposed a technique for creating a continent urinary channel that could be catheterized. This technique, also called appendicovesicostomy (5), utilizes the appendix to gain access to the bladder from outside the body. The appendix is isolated with its blood supply intact and is tunneled submucosally into the bladder wall. The colonic end of the appendix is then brought to the skin and used as a stoma for catheterization (6). Variations and refinements of this procedure have since been made by Mitrofanoff and others using alternative conduits such as gastric segments, ileum, and even the ureter and fallopian tube (7). The appendix still remains the best source for the conduit (8, 9). Continent urinary diversion has been performed in patients with bladder dysfunction caused by myelomeningocele and SCI. The use of this procedure has been noted to improve accessibility so that clean intermittent catheterization (CIC) can be performed independently and efficiently (8,10,11).

The Mitrofanoff principle was documented in the pediatric population as early as the mid 1980s (7). Most series have reported the use of the Mitrofanoff technique in patients with spina bifida (12–16), with far fewer reports in patients with suprasacral SCI (17). This is presumably due to the lower frequency of pediatric SCI as compared to the number of children living with spina bifida (18).

Over the last decade, Shriners Hospitals for Children in Philadelphia has performed the Mitrofanoff procedure on children or adolescents with SCI. The purpose of this study was to evaluate the outcomes of continent catheterizable urinary stoma in children and adolescents with SCI who were at least 1-year post procedure.

MATERIALS AND METHODS

A review of medical records indicated that 37 individuals had the Mitrofanoff procedure and met the inclusion criteria of SCI, being at least 1-year post procedure, and having no history of gastrointestinal disease. Of the 37 individuals, 5 did not respond and 16 were lost to follow-up, leaving 16 subjects who consented to participate. Institutional review board approval for this study was obtained. Data were numerically coded to protect subject anonymity and were kept in a secure location.

A retrospective medical chart review was used to obtain general demographics and medical/surgical history. A semistructured telephone interview was conducted by author L.M. to gather history of adverse urological events, independence level in bladder management, satisfaction, and quality of life. Subjects were asked to recall their level of independence related to bladder management before their Mitrofanoff procedure and report on their current level of independence. The subject

response was then assigned an ordinal value using the scale for the Functional Independence Measure (FIM) in which scores from 1 to 4 represent varying degrees of dependency upon another person, scores of 5 and 6 represent modified independence, and a score of 7 reflects complete independence (19). Subjects were also asked to recall the amount of time in minutes they require to empty their bladder from setup to catheter removal pre- and post-Mitrofanoff. In addition to bladder management independence, satisfaction was evaluated using 2 questions developed by the researchers. Subject satisfaction level was scored using a 3-point Likert-type scale. A response of 1 signified “not satisfied” and a response of 3 signified “satisfied.” Subjects were also asked whether they would recommend the Mitrofanoff procedure based on personal experience. Open-ended questions were used to explore how the surgery impacted day-to-day life.

Data Analysis

General demographics, surgical history, and occurrence of medical complications were analyzed by calculating the frequency, percentage, mean, and range.

Independence. Independence data were compared before and after the Mitrofanoff procedure and between subjects with tetraplegia and those with paraplegia. Percentages of subjects whose independence improved were further calculated. Mean time to empty the bladder was also calculated pre- and post-surgery and between subjects (tetraplegia and paraplegia).

Patient Satisfaction. Dichotomous data were analyzed by obtaining the frequency of yes/no responses based on the question pertaining to future recommendation of the Mitrofanoff to others.

Open-ended Questions. A thematic analysis was utilized to assess subject responses. The content of the open-ended responses was analyzed, and the data were coded into descriptive themes. Five general categories were generated from review. The categories were then assigned specific themes.

RESULTS

Subsequent data collection and telephone interviews were obtained in 16 of the 37 subjects; the remaining 21 subjects were unavailable for interview. Table 1 reports patient demographics, and Table 2 reports surgical information. A standard Mitrofanoff procedure using an appendicovesicostomy was performed in subjects with an intact appendix. Concomitant bladder augmentation was performed in 2 subjects using ileum. The source for augmentation in the remaining 2 subjects was not available in the medical records. The decision for augmentation was determined by bladder capacity on preoperative urodynamics. The bladder neck was not closed. Length of postoperative follow-up ranged from 1 to 8 years (mean 4.25 y). Ten of the 12 (83%) subjects with tetraplegia also had a history of upper extremity

Table 1. Demographic Information

Subject No.	Gender	Level of Injury	Age at UD (y)	Age at Interview (y)	Length of Post-op Follow-up (y)
1	M	C5	16	18	4
2	F	C6	18	20	3
3	F	C5	14	17	3
4	F	C5	17	18	2
5	F	C4	14	19	6
6	F	T11	5	6	1
7	F	C8	13	18	6
8	F	T2	17	19	3
9	F	C7	18	21	4
10	F	C5	15	21	7
11	F	C5	20	24	5
12	F	T12	19	22	4
13	M	C4	18	22	5
14	M	T11	12	13	2
15	F	C5	20	27	8
16	F	C5	15	20	5

UD, Urinary diversion.

reconstructive procedures after initial SCI rehabilitation. Upper extremity reconstructive procedures consisted of tendon transfers, totally implantable functional electrical stimulation (Freehand), and a combination of both procedures. These subjects all underwent upper extremity reconstruction prior to the Mitrofanoff procedure.

Complications

All 16 subjects (100%) continue to use their Mitrofanoff. As shown in Table 3 12 subjects (75%) experienced some degree of urethral urinary incontinence, ranging from 2 to 60 times per month. While some subjects experienced urethral urinary incontinence twice per month, other subjects experienced incontinence more than once per day. Ten subjects (62%) were prescribed oxybutynin, and 2 (12%) reported taking tolterodine for management of incontinence. In addition to pharmacological management, 6 (37%) subjects also reported using absorbent products to manage the difficulties of urethral urinary incontinence. Stomal leakage was noted in 7 (43%) of the

subjects. Stomal stenosis occurred in 4 (25%) of the subjects; first occurrence of stomal stenosis ranged from 12 to 40 months (mean 19 months) post-procedure. Two subjects underwent stomal dilation while the remaining 2 subjects required surgical revision. Of the 3 subjects who reported bladder calculi, only 1 had additional bladder augmentation performed; the remaining 2 subjects solely underwent the Mitrofanoff procedure.

Urologic Surveillance

Routine yearly urologic follow-up with renal ultrasound surveillance was reported in 10 (62%) subjects. Of the 4 subjects who experienced calculi, 2 (50%) reported regular urological follow-up, while 2 (50%) did not.

Functional Independence

Increased levels of independence with bladder management were noted among the majority of subjects. Table 4 reports bladder management independence scores for subjects pre- and post-surgery. Improvement in time to empty the bladder was also noted. Table 5 reports mean scores for time in minutes to empty the bladder for subjects with tetraplegia and paraplegia.

Satisfaction Level

Fourteen subjects (88%) were satisfied with their Mitrofanoff; 2 (12%) were somewhat satisfied. No subject was dissatisfied with the procedure. When asked if the Mitrofanoff procedure has impacted the number of social outings in a positive way, 10 subjects (62.5%) responded “yes”; the remaining 6 (37.5%) felt the number of social outings were not impacted by the Mitrofanoff. All subjects were asked, based on their personal experience

Table 2. Surgical Information

Surgical Information	Total (%)
Urinary diversion	16 (100%)
Appendix	12 (75.0%)
Tubularized ileum	2 (12.5%)
Colon	1 (6.3%)
Unknown	1 (6.3%)
Umbilical stoma site	16 (100%)
Urinary diversion revision	2 (12.5%)
Augmentation	4 (25.0%)

Table 3. Complications

Adverse Event	Total (%)
Urethral incontinence	12 (75%)
Stomal incontinence	7 (43%)
Stomal stenosis	4 (25%)
Calculi	4 (25%)
Bladder	3 (75%)
Renal	1 (25%)

with the procedure, whether they would recommend the procedure to others. All subjects (100%) would recommend the procedure.

The two most common themes that emerged from the open-ended responses were “freedom” and “independence.” Freedom and independence were described in the following quotes:

“I am now living on my own; I never could have before. I don’t have to get out of the wheelchair to catheterize. It allows me to travel easier. I don’t have to worry about getting home to cath. I can go out anywhere now. I don’t have to rely on my parents anymore to help me empty my bladder.”

Likewise, other themes were “discretion,” “decreased time,” and “convenience” and were illustrated by the following comments:

“I can cath anywhere now. It takes much less time; it has given me more privacy. I don’t have to plan ahead

anymore before I go out. It’s not as personal anymore; I can just lift up my shirt. It is so simple now that even a friend could help me. I don’t spend nearly as much time in the bathroom anymore.”

DISCUSSION

Other published series report successful catheterization of the stoma in 91% to 100% of patients, which is consistent with this series (16,20–23). Stomal continence has been reported in other series from 93% to 100% (16,21–23); our series reports 56% continence. Previous studies (12,13,16,20–25) note bladder calculi to range from 5% to 100%; 25% of our patients developed bladder/renal calculi. Stenosis has been reported to range from 7% to 24% in other series (12,13,20–25), which is consistent with stenosis reported in this series (25%). The Mitrofanoff procedure has been shown to have a positive impact on the level of functional independence in bladder management and the time required to perform bladder management.

All subjects with tetraplegia improved in bladder management independence scores except for two (Table 4). The goal of surgery for the subjects who remained dependent was ease and convenience of the caregiver to complete bladder management tasks. Although this subject had the physical capability to become independent with bladder management, it was not a goal of the procedure. Another subject with tetraplegia scored a 5 in independence before surgery. This male subject was implanted with the Freehand system before undergoing the Mitrofanoff procedure. Male patients with this device encounter ease in access of the perineal area for bladder management more so than female patients (26). Ease in

Table 4. Independence Scores Pre- and Postsurgery*

	Independence Scores	No. of Subjects Independence Scores Presurgery	No. of Subjects Independence Scores Postsurgery	Percentage of Improved Scores Postsurgery
Tetraplegia	1	10	2	84
	2	1	0	
	3	0	0	
	4	0	0	
	5	1	2	
	6	0	8	
	7	0	0	
Paraplegia	1	1	1	25
	2	0	0	
	3	0	0	
	4	1	0	
	5	0	0	
	6	2	3	
	7	0	0	

*1 = total assistance; 2 = caregiver performing most of the tasks; 3 = caregiver performing some of the tasks; 4 = contact assistance; 5 = supervision or set-up; 6 = modified independence; 7 = complete independence.

Table 5. Mean Time to Empty Bladder

	Mean Before Surgery (min)	Range	Mean Postsurgery (min)	Range
Tetraplegia	11	5–30	6.2	2–15
Paraplegia	14	7–20	4.7	4–19

perineal access may account for the lack of significant improvement in scores displayed pre- and post-urinary diversion in this particular subject.

The subject with paraplegia who remained dependent in bladder management was 6 years of age. Fostering of independence in bladder management with self-catheterization is usually initiated around the time the child typically enters school. At the time of the survey, this subject was relying on parental assistance to meet all bladder management needs. Independence scores for 2 subjects with paraplegia remained unchanged pre- and post-surgery. However, these subjects did improve on time to empty the bladder. Lack of improvement in independence scores is likely due to ceiling effects of the scoring as defined by the FIM (27).

Twelve (75%) subjects experienced urethral urinary incontinence after the Mitrofanoff procedure; stomal incontinence was noted in 43%. This does not distinguish limited or infrequent episodes from more chronic incontinence. Small sample size may have also been a factor in the incontinence rate. Future research related to this complication should utilize a multitude of potential subject responses such as “slight/moderate/severe dampness,” with an assessment of the frequency of episodes per day requiring change of garments or absorbency products. An assessment of whether the urinary incontinence was bothersome to the subject is also recommended. This series may have also benefited from subject stratification to better determine the root cause of leakage. Leaking can be secondary to multiple factors. Behavioral causes of incontinence can include failure to catheterize regularly, poor compliance with anticholinergic medications, or a poorly managed bowel program. The bladder neck was not closed in these subjects because they had vesicosphincteric dyssynergy and therefore competent outlets. Also, closing the outlet eliminates a pop-off mechanism that can prevent rupture of an augmented bladder, which is possible with a closed bladder neck. Our unexpectedly high complication rate with regard to both urethral and stomal leakage also suggests that the subjects might have had impaired compliance and capacity. We have endeavored to avoid bladder augmentation whenever possible because of the potential associated complications including neoplasia. This high incontinence rate emphasizes the need to revisit urodynamic evaluation of the subjects as well as the potential role of future bladder augmentation. What is most remarkable is the high level of satisfaction with

the Mitrofanoff procedure even in the face of incomplete continence.

Ten of 12 subjects with tetraplegia (83%) underwent elective upper extremity procedures for restoration of hand function (28–30). The Mitrofanoff principle has been examined with relation to the general procedure of intermittent catheterization in patients with tetraplegia (31,32). Few published studies have specifically examined reconstructive upper extremity surgery and CIC in patients with tetraplegia. In one study (33), after tendon transfer surgery for hand function, 51% to 85% of patients were found to have the ability to perform catheterization independently. It is likely that improvements in satisfaction and independence associated with bladder management are a result of the combination of the Mitrofanoff procedure and upper extremity reconstruction. Further evaluation of the timing of upper extremity reconstruction and the Mitrofanoff procedure and their combined impact is warranted in these subjects. While upper extremity reconstruction alone may afford a patient with tetraplegia greater independence with grasp and insertion of the catheter, typically a degree of dependence remains with managing clothing to access the perineal area for self-catheterization. This is especially challenging for female patients with tetraplegia. The impact that upper extremity reconstruction may have on the satisfaction and independence level in individuals with tetraplegia who have undergone the Mitrofanoff procedure warrants further exploration.

There are several limitations of the study. First, the sample size was a weakness. Sixteen (43%) of the 37 subjects were able to be contacted and enrolled into the study. We encountered difficulty with accessing current contact information for subjects who were older than 21 years of age (the oldest age of treatment within the Shriners system) and no longer under the care of the institution.

The retrospective nature of this study required subjects to reflect on independence levels and quality of life preoperatively; this time span was considerable for some subjects. Relying on subject recollection spanning several years may lead to a recall bias. Assessing subjective experiences closer to the surgical event may provide a more accurate and reliable account. Quality of life was assessed by a researcher-developed telephonic questionnaire. Utilization of a 5-point Likert-type scale rather than a 3-point scale is also more widely utilized and acceptable when formulating surveys. Outcome

measures to assess quality of life related to urinary difficulties in adults with SCI exist (34–36). However, there are currently no pediatric measures that assess quality of life and satisfaction related to neurogenic bladder dysfunction. Future research may benefit from the development of a valid and reliable outcome measure designed to assess health-related quality of life as it relates to bladder dysfunction in children. Utilization of such a measure will help to strengthen such quality of life findings.

CONCLUSION

The Mitrofanoff procedure can afford the child/adolescent with SCI a greater level of independence and function. Patient knowledge of the procedure as well as benefits and potential complications are fundamental for patients and their families to make an informed decision on the best urinary treatment options possible.

Although the sample is relatively small, the subjects in this study demonstrated enhanced satisfaction and quality of life, as evidenced by their recommendation of the procedure to others and their responses to open-ended questions. They also described improvement with regard to efficiency and ease of bladder management. This study demonstrates the potential of the Mitrofanoff procedure as an option to improve independence and ease of bladder management in children with SCI. Consideration of study limitations noted by this series is necessary for future work. Further prospective research on continent urinary diversion with larger sample sizes focusing specifically on long-term outcomes of children and adolescents with SCI is recommended.

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