

Evaluation of quality of life and satisfaction in patients undergoing laparoscopic Mitrofanoff procedure

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ABSTRACT

Objectives. The Mitrofanoff principle has been extensively evaluated in terms of associated morbidity and mortality. However, there is limited literature specifically addressing quality of life (QoL), particularly concerning the laparoscopic procedure. The aim of this study was to assess the impact of laparoscopic appendicovesicostomy (LA) on QoL by using a specific questionnaire targeted at patients and their families.

Materials and methods. This observational and descriptive study involved patients who underwent LA between May 2018 and December 2023. A survey consisting of 29 questions, organized into three sections was used: satisfaction with the surgery, outcomes, and current continence status. Responses were graded according to the Likert scale (1-5) (1 = strongly disagree, 5 = strongly agree).

Results. Of the 29 contacted families, 24 (82.8%) responded. The average age was 12.3 years (SD 4.4), with 75.9% being male. The primary indication for surgery was pain during urethral catheterization (69%). Mean postoperative follow-up was 36.5 months. Regarding satisfaction with surgery: overall satisfaction, hospitalization duration and pain control was rated with a score of 5 by 66.7%, 58.3% and 58.3%, respectively. In terms of outcomes: 54.2% rated aesthetic results with a score of 5, and 83.3% rated improvement in QoL with a score of 4 or 5. Concerning current continence status, 66.6% were very satisfied with the results and reported total absence of leakages or on a very specific occasion (score of 4 or 5).

Conclusions. This study supports the improvement in perceived QoL among patients requiring an LA. Overall satisfaction with the procedure and outcomes related to continence were perceived as very good by both patients and their families.

KEY WORDS: Urinary bladder, neurogenic; Urinary catheterization; Quality of life.

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EVALUACIÓN DE LA CALIDAD DE VIDA Y LA SATISFACCIÓN DE LOS PACIENTES OPERADOS MEDIANTE LA TÉCNICA LAPAROSCÓPICA DE MITROFANOFF

RESUMEN

Objetivos. La técnica de Mitrofanoff ha sido objeto de una amplia evaluación en términos de morbimortalidad. Sin embargo, las referencias sobre la calidad de vida (CdV), y en especial con relación al procedimiento laparoscópico, son escasas. El objetivo de este estudio es evaluar la influencia de la apendicovesicostomía laparoscópica (AL) en la CdV empleando un cuestionario específico dirigido a los pacientes y sus familias.

Material y métodos. Estudio observacional y descriptivo en pacientes sometidos a AL entre mayo de 2018 y diciembre de 2023. Se realizó un cuestionario con un total de 29 preguntas, organizadas en tres secciones: satisfacción con la cirugía, resultados, y estado de continencia. Las respuestas se clasificaron según la escala de Likert (1-5) (1 = totalmente en desacuerdo, 5 = totalmente de acuerdo).

Resultados. De las 29 familias con las que contactamos, respondieron 24 (82,8%). La edad media fue de 12,3 años (DT=4,4), y el 75,9% de los pacientes eran de género masculino. La principal indicación quirúrgica fue el dolor durante el sondaje uretral (69%). El seguimiento postoperatorio medio fue de 36,5 meses. En cuanto a la satisfacción con la cirugía, la satisfacción global, la estancia hospitalaria y el control del dolor recibieron una puntuación de 5 por parte del 66,7%, el 58,3% y el 58,3% de los participantes respectivamente. Por lo que respecta a los resultados, el 54,2% calificó los resultados estéticos con una puntuación de 5, mientras que el 83,3% otorgó a la mejora de la CdV una puntuación de 4 o 5. Y en lo referente al estado de continencia actual, el 66,6% se encuentran muy satisfechos con los resultados, con una ausencia total de pérdidas o presencia de pérdidas en ocasiones muy concretas (puntuación de 5 o 4).

Conclusiones. El presente estudio confirma la mejora de la percepción de la CdV por parte de los pacientes sometidos a AL. La satisfacción global con el procedimiento y los resultados en materia de continencia gozan de una muy buena percepción por parte de los pacientes y sus familias.

PALABRAS CLAVE: Vejiga neurógena; Sondaje urinario; Calidad de vida.

INTRODUCTION

Patients with neurogenic bladder face significant urological challenges. Most of them will require lifelong CIC to preserve renal function, which will deeply affect their quality of life (QoL). Studies have shown that CIC can negatively impact the QoL for both patients and their caregivers, the latter particularly when CIC is required at an early age and they are accountable for the performance⁽¹⁻³⁾. If the impact is already significant in patients who are capable of performing CIC through urethra, it is even more profound in cases where the urethral route cannot be used, either due to technical difficulty in patients with reduced mobility or due to pain in those with urethral sensitivity.

The Mitrofanoff principle was precisely described for these patients as an alternative route to the urethra to perform CIC. This procedure involves the creation of a continent catheterizable channel using the appendix⁽⁴⁻⁶⁾. Thus these patients face a complex surgical procedure to initiate catheterization, which can be related to a significant rate of short and long-term complications^(7,8). Until recently, the approach was mainly performed through a midline laparotomy or, alternatively, through a suprapubic Pfannenstiel incision⁽⁴⁾.

The laparoscopic appendicovesicostomy (LA) is a relatively novel and complex surgical procedure and the literature on its success rates and complications is scarce^(6,9-11). Although some studies evaluate the impact of this procedure on pediatric patients, research on QoL and patient satisfaction specific to the laparoscopic approach is lacking⁽¹¹⁾.

This study aims to fill this gap by evaluating on one hand the impact of the LA on the QoL of pediatric patients, and on the other hand the overall satisfaction with the surgical procedure. A specific questionnaire was used to obtain comprehensive data on these outcomes.

MATERIALS AND METHODS

An observational and descriptive study was conducted including all pediatric patients (< 18 years old), who underwent a laparoscopic or robotic-assisted laparoscopic appendicovesicostomy (LA) at our center between May 2018 and October 2023. Those who required conversion to open surgery were also included.

Criteria for surgery were patients with indication of CIC unable to perform urethral catheterization due to technical difficulties or with intact urethral sensation and therefore pain with catheterization. At our center, all patients who are candidates for LA receive an exhaustive explanation from the surgeon during the consultation. We write-up the surgical technique, as well as the expected duration of their hospital stay, possible complications and

the postoperative process (including the time the catheter remains in place after surgery and the timing to initiate CIC through the conduit). Subsequently, they are referred to our nursing consultation where they receive conduit education sessions. Patients are not scheduled for surgery until they are deemed competent and properly trained in the technique.

LA was performed using a transperitoneal approach. The appendix was reimplanted in the bladder by the modified Shanfield technique, previously described by us⁽⁹⁾. Easy catheterization was checked intraoperatively with a 10-12 French feeding tube which was then secured to the skin and left indwelling for 2-3 weeks.

Patients were identified from the institutional database and data was collected from the medical charts. Exclusion criteria were: patients older than 18 years, patients who underwent concomitant bladder augmentation, inability of parents or guardians to understand the survey due to language or socio-cultural reasons, and refusal to participate.

Parents or responsible adults were contacted first by phone and were invited to participate. In case of consent, the survey was sent and answered via email. An anonymous and non-validated questionnaire in Spanish was used. It consisted of 29 questions divided into three sections. The survey was designed and distributed using Google Forms (Table 1). An introductory section assessed the preoperative training provided to all patients, mainly concerning the information received by the medical staff and nurses.

- **Section 1 – Overall satisfaction with the surgical procedure and hospitalization process:** Participants were asked to rate their satisfaction with the surgery, the quality of discharge information provided regarding warning signs and treatment effects, the appropriateness of the length of hospital stay, and the effectiveness of pain management post-discharge.
- **Section 2 – Perceived quality of life and outcomes after surgery:** This included questions about the aesthetic results, overall QoL, impact on daily activities, satisfaction with health management and medical support, perceptions of long-term QoL with the Mitrofanoff conduit, the likelihood of recommending the procedure, and specific concerns related to the conduit.
- **Section 3 – Continence status following surgery:** We examined whether the child experienced urine leakage during day or night, the source of leakage (conduit or urethra), and the impact of leakage on the child's QoL. Additionally, we explored the child's ability to manage their medical condition, progress in self-care, mobility, self-catheterization, potential for future independent living, and self-confidence.

Responses were recorded on a Likert scale, ranging from 1 = strongly disagree to 5 = strongly agree⁽¹²⁾. Once the responses were obtained, the statistical analysis was also performed using Google Forms.

Table 1

<i>Section</i>	<i>Question</i>
Introductory questions	How would you rate the experience of receiving the information from your treating physician?
	How would you rate the training received from our nursing team?
	How would you rate the explanation received before the procedure regarding laparoscopic surgery?
	Do you consider it a priority to establish an official association/network that connects families with a diagnosis of neurogenic bladder?
Satisfaction overall the surgery	How would you rate your overall satisfaction with the surgery?
	How would you rate the discharge information regarding warning signs and the effects of the treatment?
	How would you rate the hospital stay in terms of the length of admission?
	How would you rate the pain management after hospital discharge?
Aspects of perceived quality of life after surgery	How would you rate the aesthetic results of the surgery (appearance of the wounds and the stoma)?
	In general, how would you assess your child's quality of life since undergoing the Mitrofanoff procedure?
	Do you believe that the surgery has been a good choice for improving your child's quality of life and your own?
	To what extent has the Mitrofanoff procedure improved your child's ability to perform daily activities?
	How would you rate your child's general health since the intervention?
	On a scale of 1 to 5, how satisfied are you with the management of your child's health and the medical support received for their condition?
	How do you perceive your child's long-term quality of life with the Mitrofanoff conduit?
	Would you recommend this procedure to a patient with characteristics similar to your child's?
Continence status after surgery	Does your child experience urine leakage during the day?
	If you answered 'Yes' to the previous question, please specify whether the leakage is through the conduit or the urethra.
	Does your child experience urine leakage during the night?
	If you answered 'Yes' to the previous question, please specify whether the leakage is through the conduit or the urethra.
	Do urine leaks through the conduit affect your child's quality of life?
	Do you believe that your child feels in control of the situation during medical appointments and treatments?
	Do you believe that your child is learning to cope positively with their medical condition?
	Do you feel your child is becoming appropriately independent in areas of self-care, mobility, and self-catheterization?
	Do you think your child will be able to live independently in the future?
Do you consider that your child has self-confidence?	

RESULTS

Out of 29 contacted families, 24 answered the survey resulting in an 82.8% response rate.

As the survey was anonymous, to report patients characteristics we referred to our database of the total of patients (29 patients). Only one patient specifically requested to respond by phone due to a language barrier and was therefore not anonymous. There were 75.9% male and 24.1% female with a mean age of 12.3 years (SD 4.4 years). Of those 29, primary disease was: posterior urethral

valves in 9 (34.6%), neurogenic bladder (NB) related to MMC or neural tube defects in 14 cases (44.8%), Hinman Syndrome in 2 (6.9%), Ochoa Syndrome in 3 (10.3%) and Cloaca in 1 (3.4%). Indication for surgery was pain during CIC in 20 (69%) and difficulty for CIC in 9 (31%). 14 patients (48.3%) had an urinary diversion before the surgery: vesicostomy in 7 (24.1%), bilateral ureterostomy in 4 (13.8%) and suprapubic catheter in 3 (10.3).

In 7 cases the LA was performed with robotic assistance. Mean age at intervention was 9.23 years (SD: 4.4 years). Median operative time was 223.8 minutes (SD: 86

minutes). In 9 patients additional procedures were performed (4 of them underwent a concomitant MACE). Four patients (15%) experienced early postoperative complications: ileus (1), internal hernia over the mesoappendix with subsequent intestinal obstruction (3). The remainder was related to an additional procedure. Mean hospital stay was 6.5 days (SD:2.3) and mean follow-up after the surgical procedure 36.5 months.

Survey results are shown in Table 2.

Regarding overall satisfaction with the surgical procedure and hospitalization process (Section 1), the satisfaction level with the minimally-invasive procedure was notably high, 87.5% provided positive feedback about their overall experience, highlighting that 66.7% of respondents rated their satisfaction as 5 (indicating the highest level of satisfaction). The quality of information provided at discharge was graded 4 or 5 by 87.5% of participants. The length of hospital stay was considered to be appropriate by 58.3% of respondents, and pain management post-discharge was rated as very good or good by 83.3%.

Regarding QoL and outcomes after surgery (Section 2), a substantial majority (83.3%) felt the Mitrofanoff procedure had significantly improved their child's QoL and enhanced their daily activities (79.2%) rating the improvement as 4-5 in both responses. The overall health status post-procedure was rated positively by 83.3% of respondents. Aesthetic outcomes were rated as excellent

by 54.2%, and 79.1% would recommend the LA to other patients.

Regarding continence status following surgery (Section 3), 25% of patients experience some degree of leakage during daytime and 31.8% report at night (scores 1 or 2 in both cases). Of the few patients who reported urine leakage during the day, 33.3% leaked through the urethra as well as 33.3% of those who experienced leakage at night. However, episodes of incontinence did not significantly impact their child's QoL. Regarding autonomy, 66.7% of families believed their child is learning to positively cope with their medical condition, with 62.5% feeling their child was generally or completely independent in self-care and catheterization. Looking ahead, 70.8% of families were confident in their child's potential for full autonomy. Self-confidence among children was high, with 29.2% rating their confidence as 5 and another 29.2% as 4.

DISCUSSION

The Mitrofanoff catheterizable conduit has been shown to improve QoL in a subset of patients with neurogenic bladder who have difficulties or are unable to use the native urethra for catheterization⁽¹³⁻¹⁵⁾. This includes patients with reduced mobility (especially wheelchair-bound women),

Table 2

<i>Section</i>	<i>Question</i>	<i>Results</i>
Satisfaction overall the surgery	Overall satisfaction with the surgery	- 5 (Very good): 66.7% - 4 (Good): 20.8% - 3 (Neutral): 8.3% - 2 (Poor): 4.2% - 1 (Very poor): 0
	Discharge information regarding warning signs	- 5 (Very good): 50% - 4 (Good): 37.5% - 3 (Neutral): 8.3% - 2 (Poor): 4.2% - 1 (Very poor): 0
	Length of hospital stay	- 5 (Very satisfied): 58.3% - 4 (Satisfied): 33.3% - 3 (Neutral): 4.2% - 2 (Dissatisfied): 4.2% - 1 (Very dissatisfied): 0
	Pain management after hospital discharge	- 5 (Very good): 58.3% - 4 (Good): 25% - 3 (Neutral): 8.3% - 2 (Poor): 4.2% - 1 (Very poor): 0 - No response: 4.2%

(Continues)

Table 2 (Continued)

<i>Section</i>	<i>Question</i>	<i>Results</i>
Aspects of perceived quality of life after surgery	Aesthetic results of the surgery	- 5 (Very good): 54.2% - 4 (Good): 29.2% - 3 (Neutral): 12.5% - 2 (Poor): 0 - 1 (Very poor): 0 - No response: 4.2%
	Child's quality of life since the Mitrofanoff procedure	- 5 (Very good): 50% - 4 (Good): 33.3% - 3 (Neutral): 12.5% - 2 (Poor): 0 - 1 (Very poor): 0 - No response: 4.2%
	Surgery as a good choice for improving patient's QoL	- 5 (Strongly agree): 58.3% - 4 (Agree): 16.7% - 3 (Neither agree nor disagree): 16.7% - 2 (Disagree): 4.2% - 1 (Strongly disagree): 0 - No response: 4.2%
	Enhanced ability to perform daily activities following the Mitrofanoff procedure	- 5 (Very much improved): 41.7% - 4 (Significantly improved): 37.5% - 3 (Moderately improved): 8.3% - 2 (Slightly improved): 4.2% - 1 (No improvement at all): 4.2% - No response: 4.2%
	General health since the Mitrofanoff procedure	- 5 (Very good): 45.8% - 4 (Good): 37.5% - 3 (Neutral): 12.5% - 2 (Poor): 0 - 1 (Very poor): 0 - No response: 4.2%
	Satisfaction with the management and medical support received	- 5 (Very satisfied): 66.7% - 4 (Satisfied): 25% - 3 (Neutral): 4.2% - 2 (Unsatisfied): 0 - 1 (Very unsatisfied): 0 - No response: 4.2%
	Long-term quality of life perception with the Mitrofanoff conduit	- 5 (Very good): 33.3% - 4 (Good): 29.2% - 3 (Neutral): 33.3% - 2 (Poor): 0 - 1 (Very poor): 0 - No response: 4.2%
	Recommendation of the procedure to other similar patients	- 5 (I would definitely recommend it): 58.3% - 4 (Yes, I would recommend it): 20.8% - 3 (I Don't know, I'm unsure): 8.3% - 2 (Probably not): 4.2% - 1 (Not at all): 0 - No response: 8.3%

(Continues)

Table 2 (Continued)

<i>Section</i>	<i>Question</i>	<i>Results</i>
Continence status after surgery	Urine leakage during the day	- 1 (Constantly every day, needs to wear a diaper): 16,7% - 2 (Approximately 2-3 times a week, needs to wear a diaper): 8,3% - 3 (Approximately once a week, wears a pad): 4,2% - 4 (Occasionally, very rarely): 58,3% - 5 (Not at all): 8,3% - No response: 4,2%
	Specification of whether the leakage is through	- The leakage is through the conduit: 50% - The leakage is through the urethra: 33,3% - No response: 16,7%
	Urine leakage during the night	- 1 (Constantly every night, needs to wear a diaper): 29,2% - 2 (Approximately 2-3 times a week, needs to wear a diaper): 4,2% - 3 (Approximately once a week, wears a pad): 8,3% - 4 (Occasionally, very rarely): 20,8% - 5 (Not at all): 33,3% - No response: 4,2%
	Specification of whether the leakage is through	- The leakage is through the conduit: 33,3% - The leakage is through the urethra: 33,3% - No response: 33,3%
	Urine leaks through the conduit affect patient quality of life	- 1 (Yes, a lot): 12,5% - 2 (Yes, but only slightly): 8,3% - 3 (Only occasionally): 12,5% - 4 (Generally, no): 16,7% - 5 (Not at all): 20,8% - No response: 29,2%
	Feeling control of medical appointments and treatments	- 1 (Not at all): 0 - 2 (Generally, no): 12,5% - 3 (Only occasionally): 16,7% - 4 (Generally, yes): 25% - 5 (Yes, absolutely): 41,7% - No response: 4,2%
	Positively learn to cope with their medical condition	- 1 (Not at all): 4,2% - 2 (Generally, no): 12,5% - 3 (Only occasionally): 12,5% - 4 (Generally, yes): 16,7% - 5 (Yes, absolutely): 50% - No response: 4,2%
	Becoming independent in self-care, mobility, and self-catheterization	- 1 (Not at all): 8,3% - 2 (Generally, no): 4,2% - 3 (Only occasionally): 20,8% - 4 (Generally, yes): 33,3% - 5 (Yes, absolutely): 29,2% - No response: 4,2%
	Capability to live independently in the future	- 1 (Not at all): 8,3% - 2 (Generally, no): 4,2% - 3 (Only occasionally): 8,3% - 4 (Generally, yes): 20,8% - 5 (Yes, absolutely): 50% - No response: 8,3%
	Child's self-confidence	- 1 (Not at all): 4,2% - 2 (Generally, no): 4,2% - 3 (Only occasionally): 29,2% - 4 (Generally, yes): 29,2% - 5 (Yes, absolutely): 29,2% - No response: 4,2%

patients who experience sensitivity and pain with catheterization, and finally anatomical issues such as urethral strictures, a closed bladder neck, or other anomalies like a urogenital sinus or cloaca, etc.^(1,4,16,17).

However, we must bear in mind that this is an additional surgical procedure for patients who, due to their characteristics, have often already undergone multiple interventions, and that the rate of short- and long-term complications related to this surgery is not negligible^(4,9,18). The Mitrofanoff procedure itself, open or minimally invasive, can be related to complications in up to 25-30% of patients, with a reoperation rate of as high as 14%^(4,9). Moreover, in the subgroup of patients for whom the indication is pain with catheterization due to urethral sensitivity (mainly males with posterior urethral valves and closed neural tube defects), the surgery must often be performed as a first step before initiating CIC. Thus, the announcement to the patient and their caregivers that they have to start a likely lifelong CIC is aggravated by the fact that a complex surgical procedure will be required to initiate it and this may significantly impact on their QoL. The availability of a minimally invasive technique for this procedure that reduces the morbidity of a midline laparotomy of Pfannenstiel incision (which is the traditional access) can represent a substantial change. For this reason, we wanted to study the impact on QoL in our patients undergoing LA and assess their overall satisfaction with the procedure. We had previously published our surgical technique and the preliminary results from our first 15 patients⁽⁹⁾. Our experience has now been expanded to 29 patients, consistently yielding positive results with minimal complications. The laparoscopic approach offers advantages such as early recovery and excellent cosmetic outcomes.

Because of the lack of a validated questionnaire to assess the satisfaction and QoL in pediatric patients who require CIC and have a catheterizable conduit created laparoscopically, we ultimately decided to design a specific questionnaire to more accurately assess the items we intended to evaluate. We incorporated questions from pre-existing questionnaires that we believed would effectively assess the key items relevant to our study⁽¹⁹⁻²²⁾.

Regarding overall satisfaction with the surgical procedure and hospitalization process 87.5% of our patients and parents reported a high overall satisfaction (score of 4 or 5). This is consistent with the literature indicating satisfaction rates of 88-96.5% across studies of both the open Mitrofanoff procedure in pediatric patients and the laparoscopic approach in adults^(23,24). Blanc et al. reported a global health score of 86.5% using the EuroQol EQ-5D-3L questionnaire⁽⁶⁾. Despite complications such as stomal stenosis (19-27%) and occasional incontinence (14.6%), different studies report that 95 to 96.5% of patients highly value the procedure for its hygienic and psychological benefits^(7,23,25).

Our patients provided notably positive feedback about their overall experience, the quality of information provided at discharge and length of hospital stay. It is our belief that this positive perception is unreservedly related to the information provided before the surgery and during the hospital stay. As described by others, thorough training provided by both the surgeon and the nursing team is key to guarantee the success of the procedure and the patient's satisfaction⁽²⁶⁾. Ensuring that patients and caregivers understand the process and feel comfortable with the CIC technique is essential before proceeding with surgery, and obviously this will require more attention for those patients who have not yet been catheterized via the urethra. It is also crucial for them to be prepared to leave the hospital with a permanent catheter through the conduit for a period of 2-3 weeks. All of this as a whole, facilitates postoperative adaptation and prevents complications in the postoperative period.

When we evaluate continence in the group of patients included in our study, we must bear in mind that the LA by itself does not improve continence; rather, it provides an alternative route to facilitate CIC. The continence in these patients is achieved through proper bladder emptying and requires time. This is particularly important for those patients who were previously unable to perform CIC via the native urethra and at the time of surgery had not started treatment to improve bladder emptying yet or had an incontinent diversion. In our series, 20 patients (69%) required the appendicovesicostomy to start CIC. Of those, 14 patients had a urinary diversion before surgery and 6 patients had neither derivation nor yet started CIC and had already high-pressure bladders. We observed a score of 1 or 2 in 25% of patients with daytime leakage and 33.4% with nighttime leakage. Despite these issues, and considering the expectation of long-term improvement once CIC is well established, most families felt that leakage did not significantly impact their child's QoL.

Concerning future prospects and their child's independence 62.5% feel that the patient is achieving complete autonomy in personal care, and in fact, 70.8% rated the patient's potential capability to live on their own in the future with scores of 4 or 5.

This study is limited by its retrospective nature and sample size, though sufficient to detect significant trends, may limit the generalizability of our findings.

In conclusion, this study provides valuable insights into the outcomes in terms of QoL of the LA. Although LA does not elide the challenges of lifelong CIC, patients and caregivers demonstrate a positive perspective towards managing the condition and achieving long-term autonomy. Overall, our results support the effectiveness of the LA in enhancing QoL of patients with neurogenic bladder who are unable to use the native urethra for catheterization.

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