METHODS: Patients identified as having undergone radical cystectomy for malignancy were interviewed within 6-24 months from the time of surgery and stratified by diversion type. Following written consent, interviews were conducted either in person or over the phone; all interviews were recorded. Interviews were conducted in a semi-structured manner by two urologists, with 9 open-ended questions and additional unscripted follow-up questions based on themes raised by the patients. The interviews were reviewed for common themes, preferences, and recommendations.

RESULTS: A total of 13 interviews were conducted. No patient expressed decision regret about their choice of urinary diversion. 77% specifically stated that they had adequate information about diversion options pre-operatively. Those that did not express this were primarily disappointed by post-operative counseling, specifically for ostomy appliances, not pre-operative surgical counseling. The most striking recurrent theme was the desire for a “buddy system” in which patients could contact and maintain discussion with an experienced patient. The overall impression was that this system would be most useful in the recovery/maintenance phase rather than in the pre-operative decision-making process. 62% of patients reported this would have been the single biggest area for improvement in their experience, with only one patient stating he would not have opted to talk to a peer. Although 46% of patients expressed surprise about complications they experienced, none felt that this was secondary to inadequate pre-operative counseling or that these complications should have been discussed in more detail prior to the surgery.

CONCLUSIONS: This data furnishes a basis to develop more accessible and effective patient centered decision making tools and highlights the need to concentrate on post-surgical maintenance care, including management of urostomy appliances, catheters and reinforcing irrigation technique. Future research should include including management of urostomy appliances, not pre-operative surgical counseling. The most striking recurrent theme was the desire for a “buddy system” in which patients could contact and maintain discussion with an experienced patient. The overall impression was that this system would be most useful in the recovery/maintenance phase rather than in the pre-operative decision-making process. 62% of patients reported this would have been the single biggest area for improvement in their experience, with only one patient stating he would not have opted to talk to a peer. Although 46% of patients expressed surprise about complications they experienced, none felt that this was secondary to inadequate pre-operative counseling or that these complications should have been discussed in more detail prior to the surgery.

CONCLUSIONS: This data furnishes a basis to develop more accessible and effective patient centered decision making tools and highlights the need to concentrate on post-surgical maintenance care, including management of urostomy appliances, catheters and reinforcing irrigation technique. Future research should include repeating similar interviews at other centers, assessing responses to new post-operative care resources, and optimizing a system to coordinate a dynamic peer-peer network.

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SELF-PERCEPTION, QUALITY OF LIFE AND EASE OF CATHETERIZATION IN PATIENTS WITH CONTINENT URINARY DIVERSION WITH THE MITROFANOFF PRINCIPLE
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INTRODUCTION AND OBJECTIVE: Continent urinary diversion (CUD) with the Mitrofanoff principle stands as an alternative to urethral Catheterization by a route other than the urethra when the urethra could not be used or for a patient who will need clean intermittent Catheterization (CIC) lifelong. The aim of the study was to determine self-perception of health related quality of life (HRQoL), ease of Catheterization and global and cosmetic outcomes in patients reliant on Mitrofanoff catheterization for bladder emptying.

METHODS: Cross-sectional study that aims to describe HRQoL with the EuroQol EQ-5D-3L questionnaire, Cosmetic and global satisfaction with a questionnaire designed by the reconstructive urology board and ease of catheterization with a Likert questionnaire adapted from the Intermittent Catheterization Difficulty Questionnaire (ICDQ) validated in patients reliant on retrograde CIC. Records of all patients requiring CUD with the Mitrofanoff principle by three surgeons were reviewed, and data regarding sociodemographic characteristics, complications, diagnosis and follow up were collected from patient medical records.

RESULTS: A total of 25 patients requiring CUD with the Mitrofanoff principle between 2012 and 2018, the group was composed mainly of appendiceal conduits 18 patients (72%) and 7 ileal conduits (Yang-Monti) and three of those requiring Casale (Monti Spiral) and 1 a Double Monti technique. Median follow up was 57 months with an Interquartile Range (IQR) of 9-84 months, median age was 30 years with an IQR of 5-76 years. Visual Analogue Scale (VAS) of the EQ-5D-3L reported a Global health score of 86.5%. 59% of the patients had no pain or bleeding with catheterization. Regarding Global satisfaction and cosmetic perception 91% were satisfied with their CUD, 95% would recommend this procedure to a friend and 64% were satisfied with the cosmetic appearance of their stoma.

CONCLUSIONS: CUD with the Mitrofanoff its associated with good HRQoL, global satisfaction, ease and painless Catheterization, adequate self-perception of cosmetic outcomes and a low complication rate, remaining a safe and viable option for patients reliant on CIC and who’s urethra could not be used for micrurethral or retrograde catheterization. To our Knowledge this is the first study that reports all these outcomes in this setting, with follow up, up to 84 months.

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