Nonclinical Barriers to Care for Neurogenic Patients Undergoing Complex Urologic Reconstruction

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OBJECTIVE To identify nonclinical factors affecting postoperative complication rates in patients with neurogenic bladder undergoing benign genitourinary (GU) reconstruction.

METHODS Adult patients with neurogenic bladder undergoing benign GU reconstruction between October 2010 and November 2015 were included. Patients were excluded if a diversion was performed for malignancy, if patients had a history of radiation or if a new bowel segment was not utilized at the time of the operation. Clinical and nonclinical factors were abstracted from the patients' electronic medical records. Health literacy was assessed via the Brief Health Literacy Screen (BHLS), a validated 3-question assessment. Education, marital status, and distance from the medical center were also queried.

RESULTS Forty-nine patients with a neurogenic bladder undergoing complex GU reconstruction met inclusion and exclusion criteria. On average, patients lived 111 miles (standard deviation 89) from the hospital. Overall, mean BHLS score was 10.4 (standard deviation 4.6) with 35% of patients scoring a BHLS of ≤9. Mean years of educational attainment was 9.7, and only 31% of patients completed high school education. In the first month after surgery, 37 patients (76%) experienced a complication, and 22% were readmitted; however, analysis of complication data did not identify an association between any nonclinical variables and complication rates.

CONCLUSION Nonclinical factors including unmarried status, poor health literacy, and marked distance from quaternary care are prevalent in patients with neurogenic bladder undergoing complex GU reconstruction. To mitigate these potential risk factors, the authors recommend acknowledgment of these factors and multidisciplinary support perioperatively to counteract them. UROLOGY 124: 271–275, 2019. © 2018 Elsevier Inc.

BACKGROUND

Genitourinary (GU) reconstruction for benign indications is performed for refractory lower urinary tract dysfunction, which encompasses a wide breadth of etiologies including inflammatory, infectious, and neurogenic causes.[1,2] At the time of diversion, patients have exhausted a variety of management strategies and many have undergone multiple operations. In addition to a myriad of complicating clinical factors, reconstruction in this population is often confounded with intensive postoperative self-care regimens. For patients with neurogenic bladder specifically, postoperative care becomes even more complex as patients are often reliant on caregivers in the setting of impaired mobility.

Benign GU reconstruction encompasses both continent and incontinent urinary diversions and augmentation enterocystoplasties. The decision regarding the timing and type of reconstruction performed involves shared decision-making and is dependent on both the patient's underlying medical conditions combined with their ability for self-care following surgery. Patients undergoing bladder augmentation or continent diversions are expected to comply with stringent catheterization and irrigation schedules and patients undergoing incontinent diversions must be able to perform stoma care.[3] In the perioperative period, both groups of patients must be able to recognize signs of postoperative complications and have the resources to seek care in a timely fashion. Implicit in the decision to proceed with reconstructive surgery is an assessment of a patient's health literacy, compliance, and access to necessary resources.

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It is well established that sociodemographic factors impact patients' perioperative care and convalescence.[4-6] Within the urologic oncology literature, nonclinical factors including health literacy and education level are associated with increased complication rates, increased utilization of discharge services, and decreased understanding of clinical information.[7-9] To date, there are few studies examining nonclinical patient factors in patients with neurogenic bladder undergoing benign reconstructive surgery. The authors hypothesize that there exists a high prevalence of nonclinical sociodemographic barriers in patients undergoing benign complex GU reconstruction. This study aimed to quantify these factors and assess their association with 30-day complication rates.

METHODS

Following institutional review board approval, a retrospective review was performed of all patients 18 years of age or older undergoing benign GU reconstruction using an intestinal segment between October 2010 and November 2015. Using Current Procedural Terminology codes for benign urinary diversion with bowel segment or enterocystoplasty (51590, 50825, 50845, 51960, 44312, 44314, and 50820). Only patients with a neurogenic etiology of bladder dysfunction were included. Patients were excluded if a diversion was performed for malignancy or if a new bowel segment was not utilized at the time of the operation. Additionally, patients with a history of abdominal or pelvic radiation secondary to non-GU malignancy were excluded. Forty-nine patients met inclusion and exclusion criteria. Sociodemographic and clinical information was extracted from the patient's electronic medical record. Demographic data included age, sex, body mass index, and ethnicity. Clinical data including history of prior abdominal surgery, indication for surgical intervention, and type of diversion were recorded. Comorbidities were classified using the age-adjusted Charlson comorbidity index.[10] Complications reported within 30 days of the surgical procedure were abstracted from the medical record and classified using Clavien-Dindo grading system.

Nonclinical variables assessed among this population included level of education, marital status, and living distance from the medical center. Level of education was measured in years of completed formal education. Marital status was classified as married, single, or unknown. Both variables were assessed on patient intake by nursing staff and were patient reported. Distance to quaternary care center, both in miles and in minutes, was calculated based on the mapped distance using global positioning system from a patient's home zip code, as listed in the medical record, to the hospital. Health literacy, which is defined as the ability to obtain, comprehend and act on medical information was assessed via the Basic Health Literacy Screen (BHLS) score.[11] The BHLS is a validated 3-question assessment of health literacy administered by nursing staff upon admission to the hospital and documented in the patient's electronic medical record. The following questions are included in the survey: (1) "How confident are you in filling out medical forms by yourself?"; (2) "How often do you have someone help you read hospital materials?"; and (3) "How often do you have problems learning about your medical condition because of difficulty understanding written information?". Patient responses are scored on a 5-point Likert scale with composite scores ranging from 3 to 15 and lower scores indicating poorer health literacy. While there is no predetermined score defining low and high health literacy, the median score at our institution on prior studies has ranged from 12.2 to 13 with a score ≤9 considered poor.[7,9]

Continuous variables were found to be normally distributed with no skewness, therefore parametric testing with Student's t-test was performed. Categorical variables were analyzed using chi-squared or Fischer's exact tests. All statistical analyses were performed using SPSS statistical software (IBM SPSS Statistics for Windows, version 24.0; IBM, Armonk, NY).

RESULTS

Forty-nine patients with a neurogenic bladder undergoing complex GU reconstruction met inclusion and exclusion criteria. Table 1 shows the demographic and clinical data of the cohort, and Table 2 describes nonclinical barriers to care. Of patients, 69% had a prior history of abdominal surgery. Twenty percent (n = 10) of patients underwent continent reconstruction, which included either enterocystoplasty, continent urinary diversion, or both. This compares to 79.6% of patients (n = 39) who underwent incontinent diversion, specifically ileal conduit. Concomitant cystectomy was performed in 77.5% (n = 38) of patients and 36.7% (n = 18) of patients underwent concomitant bowel diversion at the time of urinary reconstruction. In the 30 days following surgery, 75.5% (n = 37) of patients experienced a complication and 22.4% (n = 11) of patients were readmitted. Some patients experienced more than 1 complication, totaling 65 complications for this patient population. Complication data, characterized by the Clavien-Dindo classification system, are summarized in

Table 1. Demographics

Patient Characteristic	
No. patients	49
Age, mean (SD)	42.7 (14.8)
Sex (male), no. (%)	26 (53.1)
BMI, mean (SD)	28.1 (7.0)
CCI, mean (SD)	0.83 (1.1)
Marital status, no. (%)	
Single	30 (61.2)
Married	11 (22.4)
Unknown	8 (16.3)
Ethnicity, no. (%)	
Caucasian	48 (98.0)
Other	1 (2.0)
Prior abdominal surgery, no. (%)	34 (69.4)
Diversion, no. (%)	
Continent or augment	10 (20.4)
Conduit	39 (79.6)
Length of stay, days (SD)	7.0 (3.1)
Type of neurologic condition, no. (%)	
Spina bifida	12 (24.5)
Spinal cord injury	25 (51.0)
Demyelination	6 (12.2)
Other	6 (12.2)

BMI, body mass index; CCI, Charlson comorbidity index; SD, standard deviation.

Table 2. Nonclinical barriers

Health literacy	
BHLS, mean (SD)	10.4 (4.6)
BHLS 9 or below, no. (%)	17 (34.7)
Education level, mean (SD)	9.7 (5.7)
Education >12 years, no. (%)	15 (30.6)
Miles to hospital, mean (SD)	110.7 (89.9)
Minutes to hospital, mean (SD)	104.0 (75.8)

BHLS, Brief Health Literacy Screen.

Table 3. Complication data classified by Clavien-Dindo standardized scale

Readmission within 30 days, n (%)	11 (22.4)
No. of patients with any complication at 30 days, n (%)	37 (75.5)
Total number of complications within 30 days, n	65
Clavien I	14 (21.5)
Clavien II	34 (52.3)
Clavien III	
Clavien IIIa	2 (3.1)
Clavien IIIb	2 (3.1)
Clavien IV	13 (20.0)
Clavien V	0

Table 3. The majority of these complications (n = 48, 73.8%) were classified as Clavien-Dindo grade I or II. Analysis of complication data did not identify an association between any of the nonclinical variables (BHLS, education level, marital status, or distance from hospital) and complication rates.

DISCUSSION

The purpose of this investigation was to quantify the prevalence of nonclinical patient factors in a cohort of patients with neurogenic bladder undergoing benign GU reconstruction. Our findings demonstrated a lower education level, health literacy score, and percentage of married patients, as well as a longer distance from hospital, than has been previously published on other populations undergoing major GU surgery. This confirms that in addition to complex clinical factors, this population faces several nonclinical barriers that only further complicate their care, and are necessary to account for postoperatively.

The study population had a mean BHLS of 10.4 and a mean educational attainment of only 9.7 years that was lower in contrast to a cohort of patients undergoing radical cystectomy with diversion for malignancy with a median health literacy of 13 and median education attainment of 13.3 years.[9] Additionally, in the study of radical cystectomy patients, 84.3% of patients with high health literacy were married compared to 69.4% of patients with low health literacy. Using marriage as a surrogate for social support systems, this implies that patients with poor literacy may lack needed support.

Previous studies have investigated the association of health literacy on discharge services following radical cystectomy and found that lower health literacy was associated with increased need for discharge services such as home health care, skilled nursing facilities, or rehabilitation services.[7] Similarly, in another study of patients undergoing radical cystectomy, there was an increased utilization of home health services for those who reported a single, divorced, or widowed marital status with an odds ratio as high as 4.49.[8] It follows then, that with a married status rate of 22% overall utilization of discharge services is likely increased. Future studies may serve to further elucidate the increased use of discharge services for this particular group of patients with poor social support.

The mean distance from a patient's residence to our institution was 111 miles. This compares to a retrospective review of over 93,000 Medicare files demonstrating median distance to index hospital for a major operation of 7.4 miles.[12] Another study found that with every 10-minute increase in travel time from a patient's residence to the nearest hospital, there was an associated 9% increase in the probability of hospital readmission following surgery.[13] Since many patients undergoing complex surgery live long distances from the hospital, ensuring that community-based providers are knowledgeable and adept at caring for these multifaceted patients is critical as it may not be possible for patients to see their surgeon when complications arise.

In an effort to mitigate these potential issues, our institution has a multistep, multidisciplinary process in place to begin education early in the decision-making process. After discussion of potential surgical management options, patients are contacted by clinic nursing staff to review expectations for perioperative and postsurgical care. Patients are evaluated by a wound-ostomy clinical nurse who also conducts a clinical assessment of patient's ability to self-manage in addition to providing educational instruction and literature. Perioperatively, mid-level providers conduct teaching for patients and caregivers in conjunction with wound-ostomy clinical nurse. This includes 3 daily postoperative visits in which patients and caregivers must demonstrate self-care tasks. Following surgery, patients are contacted at home for follow-up assessment. Patients have a specific mid-level provider as a point of contact should issues arise. Furthermore, the authors seek to engage local community-based support and practitioners to help facilitate care when complications arise, which may help to overcome the barrier of long distance from the hospital experienced by many.

It was expected that patients with high health literacy would have fewer complications as demonstrated in the study by Scarpato et al in a population undergoing radical cystectomy.[9] Interestingly, there was no correlation between nonclinical variables and 30-day complication rates in this study. Perhaps, with a larger sample size and prospective collection of complication data, an association would be identified.

The study is limited by its retrospective nature. Additionally, given the long distance from the main hospital, patients may have presented to local hospitals with

complications rather than the institution in which surgery was performed. This may have led to under-reporting of complications at follow-up.

Patients with neurogenic bladder undergoing complex GU reconstruction require both clinical and social support for long-term success. The decision regarding the surgical intervention should be made in the context of the patient and their sociodemographic factors, including their ability to understand self-care and recognize signs and symptoms of complications that may arise. The process of transitioning care from the inpatient setting to home is a critical period in which hospital readmissions are common and may be prevented.[5] Key processes to improve the discharge process include medical reconciliation and coordinating with community-based providers to ensure that patients are equipped with the resources to manage their condition and postoperative care.[5] Overall, this study emphasizes the many nonclinical barriers experienced by the population of patients with neurogenic bladder undergoing benign GU reconstruction and highlights the importance of establishing support systems perioperatively.

CONCLUSION

Patients with neurourologic disorders requiring complex GU reconstruction are especially vulnerable with a low education level and health literacy. This complex population also travels significant distances to obtain surgical treatment. When concerns arise postoperatively, resources must exist, such that the appropriate care may be accessed in a timely fashion. While health literacy, marital status, education, and distance from hospital are nonmodifiable, with adequate perioperative systems in place, these barriers can be overcome.

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SUPPLEMENTARY MATERIALS

Supplementary material associated with this article can be found, in the online version, at http://dx.doi.org/10.1016/j.urology.2018.08.047.

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EDITORIAL COMMENT

This manuscript sought to investigate the role of health literacy and a variety of sociodemographic factors and readmission and complication rates after complex GU surgery in a small but high-risk population of patients with neurogenic bladder. Nearly half of the patients were spinal cord injured (SCI), one-fourth had spina bifida (SB), and the remainder either had a degenerative neuromuscular disease or were unspecified. While all of these diseases can result in a similar bladder phenotype, and therefore similar surgical treatments, the populations are vastly different. Onset of disease (congenital or acquired) and acuity of onset (chronic degenerative vs traumatic) dramatically impact patients' expectations surrounding quality of life and acceptance of their disabilities. Moreover, these factors may also substantially influence the number and type of health care assistants surrounding the patient, which in congenital conditions can more often be a parent or adult sibling than a spouse. I cannot help but wonder if further specification of disease type and "primary caregiver" type (spouse, sibling, parent, friend, and none), as well as health literacy measures of those caregivers, would provide further insight.

One study measured health literacy among children with SB. Nearly one-fourth of the parents in the study demonstrated poor or marginal health literacy, not surprising given that demographics impacting health literacy (type of insurance, income, and education) are often shared familially.[1] Importantly, Cooper et al similarly did not demonstrate a relationship between ED/hospital utilization and health literacy. Health literacy among adults with SB is poorly characterized, and measurement may be challenged by the well-described deficit in executive function that many patients with congenital hydrocephalus demonstrate. Executive function is difficult to measure and often not considered an intellectual disability. Even if a patient has adequate health literacy, diminished executive function may impair that

individual's ability to navigate the complexities of health care systems.

Comparatively, Johnston et al measured health literacy among patients with SCI and noted 14% as having marginal or inadequate health literacy.[2] Unlike SB, executive function deficit is not characteristically seen in patients with SCI. In fact, many patients with SCI demonstrate high levels of utilization of technologies for access to health information[3,4] and active self-education through group SCI forums and programs.

In short, this paper is important because it points out that very few of the interventions we employ to impact surgical outcomes extend beyond the hospital. Most of a patient's recovery occurs after discharge, and that is when the greatest opportunity for failure also occurs. Especially for patients with multisystem diseases and disabilities that rely on others for care, we need to continue to think about how we can measure factors that may predict success after discharge and develop programs that can mitigate risk for readmissions and complications. Understanding and addressing the entire web of resources (family members, other care providers, technologies, and local medical providers) and potential liabilities (executive function, health literacy gaps, transportation, financial constraints, and geographic distance) will serve our patients and our limited collective health resources most efficiently.

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AUTHOR REPLY

We agree with the commentator that caregiver and social support needs may vary depending on the etiology of the patient's condition. In fact, both health literacy and social support have demonstrated associations with a patient's ability to self-manage, which is a necessary and often overlooked consideration while formulating postoperative care plans. One study by Chen et al investigated self-management in chronic kidney disease patients, finding that social support conferred an even more important role than the health literacy of the individual.[1]

As an example of this effort to increase social support, 1 pilot program targeted at postoperative ileostomy patients demonstrated a 58% decrease in 30-day readmission rates. By utilizing home health agencies and multidisciplinary clinical care teams, a high frequency of home visits allowed for prompt identification of complications.[2]

While health literacy may be difficult to modify, social support networks and medical liaisons may serve to compensate for low health literacy if utilized correctly. We agree that future efforts should focus on programs to assist this patient population in navigating the health care system.

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