



# HHS Public Access

Author manuscript

*Urol Oncol.* Author manuscript; available in PMC 2023 May 14.

Published in final edited form as:

*Urol Oncol.* 2022 April ; 40(4): 117–119. doi:10.1016/j.urolonc.2019.06.016.

## The impact of health literacy on urologic oncology care

Amy N. Luckenbaugh, M.D. \*

Kelvin A. Moses, M.D., Ph.D.

Department of Urology, Vanderbilt University Medical Center, Nashville, TN

### Abstract

Health literacy is the ability to access, comprehend, and act upon medical information to make health care decisions. In the United States, 12% of adults have proficient health literacy. Low health literacy has been associated with worse outcomes in several chronic medical conditions. In addition, low health literacy has been associated with longer hospital stays. In the urologic oncology literature low health literacy is associated with increased minor complications following radical cystectomy. There remains sparse data on health literacy and its impacts on prostate, kidney, testicular and penile cancer care. Going forward, in order to provide the best urologic oncology care to our patients it is critical to account for patients' health literacy status.

### Keywords

Health literacy; Oncology

## 1. Background

Inequities in urologic oncology care are multifactorial, and another contributing factor to inequities may be health literacy. Health literacy is defined as the ability to access, understand, and act on medical information to make informed health care decisions [1]. Health literacy is measured with a variety of validated screening tools, including the Rapid Estimate of Adult Literacy in Medicine, Test of Functional Health Literacy in Adults, and the Brief Health Literacy Screen to name a few. In the United States, 36% of adults are considered to have “below basic” or “basic” health literacy, while only 12% are considered to have proficient health literacy [2]. Low health literacy also has higher association with certain demographic characteristics such as: older age, African American race, lower education level, and female gender [2].

Unfortunately, it has also been established that the majority of patient education materials are written at a 10th-grade reading level or higher despite the fact that the majority of adults read at the 8th-grade level [3]. Further widening the gap between patients and providers, providers often overestimate patient's health literacy, which has the potential to impact patient's health care decisions and in turn can result in disparities in patient care.

\*Corresponding author. Tel.: +615-322-2101; fax: 615-322-8990. amy.n.luckenbaugh@vanderbilt.edu (A.N. Luckenbaugh).

Manuscript type: Invited for: (In)equities in Urologic Cancer Care

Disclosure: No funding to disclose.

Specifically physicians were found to overestimate patient's literacy in 54% of African American patients and 11% of Caucasian patients [4]. This overestimation may result in inadequate patient education and may impact patient outcomes.

### 1.1 Health literacy and medical care

The impact of health literacy on health outcomes is well-documented in the medical literature. Patients with low health literacy tend to have worse outcomes in the setting of chronic medical conditions such as hypertension [5], diabetes [5], asthma [6], congestive heart failure [7] and end stage renal disease [8,9]. For instance, 92% of patients with adequate health literacy were able to identify the blood pressure cutoff for hypertension, while only 55% of those with low literacy knew this information. Similarly, amongst diabetic patients, 94% and 50% of patients with adequate and low literacy, respectively, knew symptoms of hypoglycemia [5]. Additionally, patients with low health literacy were found to have increased risk of death following hospital admission for acute heart failure [7]. Knowing this data it is therefore not surprising that patients with inadequate health literacy are also twice as likely to be hospitalized [10].

### 1.2. Health literacy and surgical care

The disparity in care amongst patients with low health literacy has been recapitulated in the surgical literature. Amongst patients who were undergoing major abdominal surgery, patients with lower health literacy were found to have prolonged index hospital admission postoperatively (a median of 1 day longer). Interestingly, low health literacy was not associated with increased rates of 30-day emergency department visits or 90-day hospital readmissions [11]. Health literacy also demonstrates an effect on outpatient surgery recovery and health care-related quality of life. Patients undergoing outpatient surgery with inadequate health literacy were more likely to report reduced quality of recovery and lower health-related quality of life [12].

### 1.3. Health literacy and urologic oncology care

Consistent with findings in the general medical and surgical literature, health literacy is important in the urologic patients. For patients with nonmuscle invasive bladder cancer health literacy may be critical for patient follow-up and treatment continuation. One study demonstrated that 80.5% of patients with adequate health literacy were adherent to follow-up cystoscopies and intravesical therapies, while only 56.6% of those with low health literacy were adherent [13]. High grade nonmuscle invasive bladder cancer is a disease that can both recur and progress, and it is thus critically important that patients maintain their surveillance schedule and intravesical therapy. The fact that those with low health literacy have decreased adherence to follow-up has the potential to result in increased rates of progression for those with low health literacy.

Following radical cystectomy with urinary diversion for muscle invasive bladder cancer there are a number of complex care issues that require education, such as stoma care for incontinent diversions, and catheterization for patients undergoing continent diversion. Each of these requires detail teaching prior to discharge from the hospital, including hands-on training and written instructions. One study demonstrated that 50.6% of patients

required home health care following radical cystectomy with urinary diversion. On bivariate analysis, patients with lower health literacy were more likely to require discharge services; however, on multivariable analysis health literacy score was not associated with higher use of discharge services [14]. It should be considered though that many patients undergoing cystectomy are of older age and with older age there is a higher likelihood of lower health care literacy. Hence, these results may be attenuated by the older age among most of the cystectomy patient population.

Further analysis was performed to determine the relationship between postoperative complications following radical cystectomy with urinary diversion and health literacy. Patients with low health literacy were found to have higher T-staging at the time of diagnosis, and also were found to have poorer nutritional status as indicated by a lower preoperative albumin [15]. Overall complication rates following cystectomy were 42.7%, with 34.2% of those being classified as a minor complication (Clavien I, II, including ileus, urinary tract infection, need for total parenteral nutrition, wound infection, deep venous thrombosis, pneumonia, abscess, and lymphocele). Minor complications were experienced in 39.4% of patients with low health literacy vs. 28.9% of patients with high health literacy ( $P=0.034$ ) [15]. In multivariate analysis low health literacy was the only factor found to be associated with having a minor complication [15]. Despite higher rates of minor complications, health literacy was not associated with increased risk of emergency department visit or readmission following radical cystectomy with urinary diversion.

For patients with other genitourinary malignancies such as prostate, kidney, testicular and penile cancer there is sparse data about the impact of health literacy on postoperative complications, readmission rates, and emergency department visits. An on-going study performed at Vanderbilt University Medical Center and Nashville General Hospital evaluated the effects of health care literacy on knowledge of prostate anatomy and treatment regret. Although the results remain unpublished, patients with lower health literacy had higher levels of dissatisfaction with their treatment choice [16].

Patient education is a critical part of providing comprehensive oncologic care. To assist with this, the National Comprehensive Cancer Network has guidelines designed for patients for most cancer diagnoses, including urologic malignancies. The guidelines for the most common malignancies, including both prostate and kidney cancer, were evaluated using four tools to assess literacy levels. For prostate cancer the patient centered guidelines were found to be at the 10th-grade reading level and considered to be highly complex. Similarly, for kidney cancer the patient centered guidelines were found to be nearly at the 10th grade reading level (9.9 grade) and considered to be moderately complex [3]. Currently, the recommended reading level for patient centered reading material is the 6th-grade reading level. Therefore, despite efforts to create patient centered guidelines the current NCCN material is likely not beneficial for patients with low health literacy. Improving patient access to information is vital, but it is also important to ensure that this influx of knowledge does not result in increased confusion for patients and their families.

An additional area for potential improvement is pathology reports for genitourinary malignancies. Many patients now have access to their medical records; however, typical

pathology reports may exceed the health literacy of many patients. Working with patient centered focus groups the University of Washington developed patient centered pathology reports for bladder biopsy pathology results. Patients were then randomized to receive standard pathology report and the patient centered pathology report. Patients receiving the patient centered pathology report were more likely to be able to identify the cancer stage. In addition, although not statistically significant, correct identification of grade and provider communication were improved for those receiving patient centered pathology reports [17].

Pathology reports represent only a small piece of the patient experience. Hence, there are a number of other ways to improve patient understanding of health information including: 1. improving access and content of online electronic medical records. 2. Utilization of patient support groups involves multiple care providers such as nurses, urologists, psychologists, and urologic cancer survivors. 3. Finally, the use of patient advocacy websites as sources for patient information. These sources should take into account health literacy as they develop strategies for patient centered care.

## 2. Conclusion

As described low health literacy is associated with poorer outcomes for chronic medical conditions, prolonged hospitalization for surgical procedures, increased minor complications and higher rates of treatment dissatisfaction. Although physicians have developed patient education materials many of these materials are well-above the recommended 6th-grade reading level. Going forward working to improve patient education materials would be beneficial to improve patient education prior to and following treatment for genitourinary malignancies.

Moreover, identifying patients with low health literacy prior to the treatment of genitourinary malignancies may empower providers and their teams to provide targeted perioperative counseling, education, and treatment. Identifying these patients early may ultimately reduce the duration of hospitalization, reduce perioperatively morbidity, improve patient follow-up, and patient satisfaction. In conclusion, when caring for our patients with urologic malignancies it is critical to account for a patient's health literacy status to provide patient-centered comprehensive oncologic care.

## References

- [1]. Nielsen-Bohlman L, Panzer AM, Kindig DA. In: Health literacy: a prescription to end confusion Washington (DC), 2004
- [2]. Kutner MGE, Jin Y, Paulsen C. The health literacy of America's adults US Department of Education; 2006.
- [3]. Tran BNN, Ruan QZ, Epstein S, Ricci JA, Rudd RE, Lee BT, et al. Literacy analysis of National Comprehensive Cancer Network patient guidelines for the most common malignancies in the United States. *Cancer* 2018;124:769. [PubMed: 29178322]
- [4]. Kelly PA, Haidet P. Physician overestimation of patient literacy: a potential source of health care disparities. *Patient Educ Couns* 2007;66:119. [PubMed: 17140758]
- [5]. Williams MV, Baker DW, Parker RM, Nurss JR, et al. Relationship of functional health literacy to patients' knowledge of their chronic disease. A study of patients with hypertension and diabetes. *Arch Intern Med* 1998;158:166. [PubMed: 9448555]

- [6]. Williams MV, Baker DW, Honig EG, Lee TM, Nowlan A, et al. Inadequate literacy is a barrier to asthma knowledge and self-care. *Chest* 1998;114:1008. [PubMed: 9792569]
- [7]. McNaughton CD, Cawthon C, Kripalani S, Liu D, Storrow AB, Roumie CL, et al. Health literacy and mortality: a cohort study of patients hospitalized for acute heart failure. *J Am Heart Assoc* 2015;4.
- [8]. Cavanaugh KL, Osborn CY, Tentori F, Rothman RL, Ikizler TA, Wallston KA, et al. Performance of a brief survey to assess health literacy in patients receiving hemodialysis. *Clin Kidney J* 2015;8:462. [PubMed: 26251719]
- [9]. Dageforde LA, Box A, Feurer ID, Cavanaugh KL, et al. Understanding patient barriers to kidney transplant evaluation. *Transplantation* 2015;99:1463. [PubMed: 25606794]
- [10]. Baker DW, Parker RM, Williams MV, Liu D, Storrow AB, Roumie CL, et al. Health literacy and the risk of hospital admission. *J Gen Intern Med* 1998;13:791. [PubMed: 9844076]
- [11]. Wright JP, Edwards GC, Goggins K, Tiwari V, Maiga A, Moses K, Kripalani S, Idrees K, et al. Association of health literacy with postoperative outcomes in patients undergoing major abdominal surgery. *JAMA Surg* 2018;153:137. [PubMed: 28979989]
- [12]. Halleberg Nyman M, Nilsson U, Dahlberg K, Jaensson M, et al. Association between functional health literacy and postoperative recovery, health care contacts, and health-related quality of life among patients undergoing day surgery: secondary analysis of a randomized clinical trial. *JAMA Surg* 2018;153:738. [PubMed: 29710226]
- [13]. Turkoglu AR, Demirci H, Coban S, Guzelsoy M, Toprak E, Aydos MM, Ture DA, Ustundag Y, et al. Evaluation of the relationship between compliance with the follow-up and treatment protocol and health literacy in bladder tumor patients. *Aging Male* 2018;7:1–6.
- [14]. Kappa SF, Scarpato KR, Goggins KM, Kripalani S, Moses KA, et al. The impact of health literacy and clinicodemographic factors on use of discharge services after radical cystectomy. *J Urol* 2017;198:560. [PubMed: 28396183]
- [15]. Scarpato KR, Kappa SF, Goggins KM, Chang SS, Smith JA Jr, Clark PE, Penson DF, Resnick MJ, Barocas DA, Idrees K, Kripalani S, Moses KA, et al. The impact of health literacy on surgical outcomes following radical cystectomy. *J Health Commun* 2016;21:99. [PubMed: 27661137]
- [16]. Heslop DMK: The Association of Health Literacy with Prostate Cancer Knowledge and Treatment Regret 2019
- [17]. Mossanen M, Macleod LC, Chu A, Wright JL, Dalkin B, Lin DW, True L, Gore JL. et al. Comparative effectiveness of a patient centered pathology report for bladder cancer care. *J Urol* 2016;196:1383. [PubMed: 27211289]