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Bladder Cancer



Living with Bladder Cancer: Self-reported Changes in Patients' Functional and Overall Health Status Following Diagnosis

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Abstract

Background: Bladder cancer affects life quality, overall health, and mortality negatively. The effect of bladder cancer on activities of daily living (ADLs) is not well established.

Objective: To examine the effect of bladder cancer diagnosis on ADLs, in addition to physical, mental, and overall health measures.

Design, setting, and participants: Using data from the Surveillance, Epidemiology, and End Results (SEER)-Medicare Health Outcomes Survey (MHOS) registry, responses regarding ADLs and overall health were evaluated in bladder cancer patients over time. The Short Form 12 health survey responses were analyzed to determine the change in physical and mental health scores following bladder cancer diagnosis.

Outcome measurements and statistical analysis: Changes in self-reported ability to perform ADLs and health outcomes following bladder cancer diagnosis were evaluated. Chi-square statistics were used to determine whether the baseline and follow-up surveys were statistically independent for each ADL. Composites scores for physical health (PCS12) and mental health (MCS12) were compared with two-sample *t* test.

Results and limitations: A total of 498 patients with surveys before and after bladder cancer diagnosis were identified. An increased percentage of patients reported difficulty in all ADL tasks following bladder cancer diagnosis; this increase was statistically significant for bathing (p = 0.02) and using the toilet (p = 0.03). These patients also reported a significant decline in overall health status (p = 0.0002). A significant reduction in the mean PCS12 and mean MCS12 composite scores was observed (p < 0.0001 and p = 0.0003, respectively).

Conclusions: Patients with bladder cancer report a significant decline in functional status and overall health, including both physical and mental well-being after diagnosis. Further study is needed for factors that may be most predictive of the decline in functional independence for this population.

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Patient summary: There is a decreased ability to perform daily activities following bladder cancer diagnosis, and patients report a decrease in their physical and mental health. This information can help patients and their caregivers anticipate patient needs following bladder cancer diagnosis, in addition to helping manage their expectations when making decisions regarding treatment options. © 2020 The Author(s). Published by Elsevier B.V. on behalf of European Association of Urology. This is an open access article under the CC BY-NC-ND license (http://crea-

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1. Introduction

Bladder cancer is a heterogeneous disease with high associated costs and significant morbidity. It currently carries the greatest lifetime treatment cost for patients among all forms of cancer [1]. A total of 18 000 bladder cancer–related deaths are estimated to occur in 2020 in the USA alone, representing 3% of all cancer–related deaths [2]. The majority of new cases affect male patients aged 65 yr and older, and mortality increases with age. Advanced age appears to be the greatest overall risk factor for developing bladder cancer, with a seven- to 10-fold increase in the risk observed in those >70 yr old [3–5].

Owing to the mental and physical impact of a cancer involving the urogenital tract, the negative influence of bladder cancer on patients' quality of life and psychological health is profound. Following the diagnosis of bladder cancer, patients report reduced social functioning [6]. Psychological ailments including depression, anxiety, and suicidality are apparent shortly after the diagnosis of bladder cancer. In elderly patients diagnosed with bladder cancer, psychological factors have been linked to increased mortality and worsened morbidity [7–10]. Less is known about the functional impact of bladder cancer diagnosis in regard to activities of daily living (ADLs). Essential to selfcare, ADLs include eating, bathing, dressing, and tasks related to continence, including hygiene and control. The ability to perform ADLs has been shown to correlate with quality of life, overall health, hospital readmissions, and mortality in many patient populations [11–13].

It is important to understand how the diagnosis of bladder cancer impacts ADLs in order to maximize treatment efforts and long-term patient-centered outcomes in these patients [14]. To the best of our knowledge, no prior study has collected information from before and after bladder cancer diagnosis to investigate the impact of this diagnosis on the ability to perform ADLs. Using data collected from the Surveillance, Epidemiology, and End Results (SEER) registries and Medicare Health Outcomes Survey (MHOS), the objective of this study was to examine the overall effect of bladder cancer diagnosis on ADLs. Additionally, physical and mental health outcomes were examined both before and after bladder cancer diagnosis using responses from the Short Form 12 (SF-12) health survey.

2. Patients and methods

Institutional Review Board exempt approval was obtained from our local institution to perform analysis on deidentified data provided from the SEER-MHOS linked registry. Data include a total of 15 935 records related to 9423 bladder cancer patients from cohort 1 through cohort 15. Each cohort consists of a baseline survey and a 2-yr follow-up survey for patients. Within this survey, patients reported ADLs (ie, bathing, dressing, eating, getting in and out of chairs, walking, and toileting) with one of three responses: inability to complete the task, completing the task with difficulty, performing task without difficulty. Patients are also asked to rate their overall general health. Cancer staging based on American Joint Committee on Cancer seventh edition, gender, age, and comorbid conditions were identified for these patients as well.

We identified a group of patients with bladder cancer who had completed surveys both before and after bladder cancer diagnosis. The baseline characteristics of the study samples were summarized, and cross-tabulation analyses were performed for each ADL measure to obtain the joint frequency distribution of baseline and follow-up surveys. Chi-square and Fisher's exact tests were used to determine whether the baseline and follow-up surveys were statistically independent. Selfreported changes in physical and mental health were evaluated using responses to the SF-12 survey before and after bladder cancer diagnosis. This survey consists of health-related questions with separate composites scores for physical health (PCS12) and mental health (MCS12). A two-sample *t* test was used to compare the PCS12 and MCS12 scores before and after diagnosis.

A stratification analysis by gender, age at the time of survey, bladder cancer staging, and comorbidities was performed to reveal potential confounding factors. Comorbidities included in the analysis were cardiovascular disease, pulmonary disease including chronic obstructive pulmonary disease, diabetes mellitus, cerebrovascular accidents, and second primary malignancies.

The same analysis was also conducted for baseline and follow-up responses to the SEER-MHOS general health question, which asks patients to rate their general health from excellent to poor on a scale of 1–5. Statistical significance was maintained at p < 0.05 for all analyses, and statistical analysis software was used.

3. Results

A total of 498 patients with bladder cancer were identified who met the inclusion criteria of having a survey results both before and after the diagnosis of bladder cancer. The majority were white (82%) and male (73%). The median age was 76.7 yr (interquartile range [IQR]: 72.3–81.7) and the median time from baseline to follow-up survey was 755 d (IQR: 728–771). Of the patients, 31.1% had one comorbid condition, while 22.1% had three or more comorbidities reported. Low-stage disease (stages 0 and 1) and advanced stage disease (stages III and IV) were reported by 68.3% and 9.4% of respondents, respectively. Of them, 10.4% reported having a malignancy in addition to bladder cancer, and 50.2% reported earning an annual income of <\$30 000.

Table 1 shows the results for the percentages of patients reporting difficulty with ADLs stratified by gender, age, and

		Bathing (%)	Dressing (%)	Eating (%)	Chair (%)	Walking (%)	Toilet (%)	
Overall	Before	11.50	10.00	3.90	25.10	34.10	6.80	
	After	16.50 (p = 0.02)	13.40	6.00	29.30	38.90	10.70 (p = 0.03)	
Gender								
Male	Before	10.20	8.20	3.40	24.20	33.60	6.00	
	After	14.50	13.10 (p = 0.03)	4.60	27.90	38.90	10.30 (p = 0.05)	
Female	Before	14.90	14.90	5.20	27.60	35.30	9.00	
	After	21.60	14.20	9.70	32.80	38.80	11.90	
Age (yr)								
<70	Before	10.50	11.40	3.50	27.20	31.90	4.50	
	After	16.20	13.50	5.50	25.20	39.30	11.70 (p = 0.05)	
70 to <80	Before	8.90	8.50	3.90	20.20	31.20	5.00	
	After	11.50	8.90	5.40	26.00	34.10	6.90	
$\geq \! 80$	Before	18.40	12.30	4.40	34.20	43.00	13.20	
	After	28.30	23.90 (p = 0.02)	8.00	40.70	49.60	18.80	
Stage								
0	Before	9.20	9.20	3.10	20.90	29.00	6.80	
	After	12.90	12.40	3.10	26.50	35.60	10.40	
Ι	Before	13.60	11.30	5.70	28.40	37.90	6.80	
	After	13.70	10.30	3.40	29.00	37.90	7.40	
II	Before	16.30	11.60	4.70	32.60	34.90	11.60	
	After	25.60	11.60	14.30	33.30	37.20	14.00	
III	Before	6.90	6.90	0.00	20.70	31.00	6.90	
	After	20.70	13.80	10.30	32.10	48.30	10.30	
IV	Before	5.60	5.60	5.60	16.70	27.80	5.60	
	After	27.80	27.80	16.70	38.90	50.00	22.20	
ADL = activity of daily living								

Table 1 – Patient-reported difficulty with ADLs before and after bladder cancer diagnosis

Only statistically significant p values are listed.

Bold denotes statistical significance.

cancer stage as well as overall results. There was an overall association between bladder cancer with worsening functional status, demonstrated by an increased percentage of patients reporting difficulty in each individual task from before to after diagnosis; this increase was statistically significant in bathing (from 12% to 17%, p = 0.02) and using the toilet (from 7% to 11%, p = 0.03). Strong trends toward increased difficulties with dressing, eating, walking, and transferring to and from a chair were also noted, although these were not quite statistically significant.

Stratification by gender found that male patients reported significant increase in difficulty with dressing (from 8% to 13%, p = 0.03) and using the toilet (from 6% to 10%, p = 0.04). Both males and females reported increased difficulty with all other ADLs following diagnosis, but these differences did not reach statistical significance. Stratification by age found that younger patients (<70 yr) had a significant increase in difficulty with using the toilet (from 5% to 12%, p = 0.05) and older patients (\geq 80 yr) had a significant increase in difficulty with dressing (from 12% to 24%, p = 0.02). Albeit these are the ADL categories that demonstrated statistically significant difference, all ages reported increased difficulty with all ADLs following bladder cancer diagnosis, with the only exception being younger patients getting up from a chair. Stratification by income revealed that earning an annual income of <\$30 000 resulted in an increased odds of decline in ADLs including bathing (odds ratio [OR] 2.3), dressing (OR 3.0), eating (OR 3.3), walking (OR 1.8), and using the toilet (OR 2.7).

Table 2 – Patient responses	to PCS12	and	MCS12	at	baseline	and
follow-up surveys						

	Mean	95% CI	p value				
PCS12							
Before	40.4	39.4-41.4	< 0.0001				
After	36.8	35.7-37.8					
MCS12							
Before	52.3	51.4-53.2	0.0003				
After	49.9	48.9-50.9					
CI = confidence interval; MCS12 = composites scores for mental health; PCS12 = composites scores for physical health.							
PCS12 and MCS12 were significantly lower at follow-up (after bladder							
cancer) than at baseline (before bladder cancer).							

The result of the t test comparing pre- and postdiagnosis physical and mental component scores show an overall reduction. There is a significant reduction in the mean PCS12 from 40.4 (confidence interval [CI]: 39.4-41.4) to 36.8 (CI: 35.7-37.8) and mean MCS12 from 52.3 (CI: 51.4-53.2) to 49.9 (CI: 48.9–50.9), with p < 0.0001 and p = 0.0003, respectively (Table 2).

Figure 1 shows the percentages of patients who rated their general health as poor when responding to the SEER-MHOS general health question on baseline and follow-up surveys. There is an overall significant increase in patients reporting poor general health following bladder cancer diagnosis (from 3.7% to 9.6%, p = 0.0002). Stratification by



Poor General Health

Fig. 1 – Percentages of patients reporting general health as poor in baseline and follow-up surveys. BC = bladder cancer. * = Denotes statistical significance.

gender found that this association was significant in both males (3.3-8.7%, p = 0.0028) and females (4.6-12.0%, p = 0.0261). Additionally, significantly more patients between 70 and 80 yr of age (p = 0.0056) and those diagnosed with stage 0 disease (p = 0.0424) reported their general health as being poor.

4. Discussion

The ever-increasing life expectancy provided by advances in medicine underscores the need for greater attention to the understanding of how diagnosis and management of disease processes impact patient outcomes and the daily lives of patients. Despite the high prevalence of bladder cancer, its effect on the ability of patients to perform ADLs has yet to be reported. Using the SEER-MHOS linked database, this population-based study compared patients' ability to perform ADLs before and after bladder cancer diagnosis. Within this population, we found a significant increase in reported difficulty with complex ADLs including bathing and toileting. While not quite statistically significant, strong trends toward increased difficulties with dressing, eating, walking, and transferring to and from a chair were also noted. A stratified analysis revealed that other factors associated with worsening ADL function following diagnosis included male gender and age > 80 yr, both being common demographics associated with bladder cancer.

Interestingly, disease stage did not prove to be a reliable indicator of decline in ADLs at any stage. One possible explanation is that patients diagnosed with more advanced stages of bladder cancer do not necessarily experience worse decline in ADL function compared with those with earlier stages. This information is important because it can be relayed appropriately to patients diagnosed with bladder cancer and aid in subsequent treatment decisions for patients diagnosed with bladder cancer at all stages. However, the MHOS survey is administered every 2 yr only, and those with advanced stages may not have the followup to show a potential quicker decline in ADLs. Since prior data have shown a correlation between ADL performance and mortality in the elderly [11], those who survive despite advanced disease are likely to have better functional status. As a result, patients with advanced disease who had the greatest decline in ADLs are potentially underrepresented.

The negative influence that bladder cancer imposes on patients' quality of life, mental health, and social functioning has been shown to be significant [6–10]. This study further supports this notion by demonstrating that a significant number of patients self-reported their overall general health as "poor" following bladder cancer diagnosis, with only 3.7% using this designation before diagnosis while 9.6% using it afterward. Additionally, the significant reduction in PCS12 and MCS12 scores highlights the detriment in physical and mental health following bladder cancer diagnosis. Patient-reported outcomes such as those provided in these data sets offer a unique opportunity to evaluate how the diagnosis of bladder cancer changes patients' abilities to function and care for themselves. As functional status and level of dependency have been shown to predict survival [15], the understanding of the negative impact that bladder cancer has on ADLs allows for better counseling of patients and their caregivers regarding the disease course and expected outcomes. By identifying which patients are most at risk of functional decline, this information could facilitate improved anticipation of future needs and refined expectation management when making decisions regarding how to proceed with the management and treatment options.

A number of limitations are intrinsic to the SEER-MHOS data set. The data are limited to Medicare Advantage Organization beneficiaries, excluding the majority of Medicare beneficiaries due to their enrollment in fee-forservice coverage. Patients enrolled in Medicare Advantage have improved baseline health status when compared with fee-for-service beneficiaries and tend to be slightly younger than fee-for-service enrollees [16–19]. This suggests that these data actually represent a slightly younger and healthier population of patients with bladder cancer. It is reasonable to hypothesize that this study possibly underestimates the magnitude of ADL decline in bladder cancer patients. Although it has been shown that there is no difference in the decline in functional status between Medicare Advantage and fee-for service enrollees [20], it is unclear whether this holds true for the subgroup of patients diagnosed with bladder cancer.

The intent of this study was to examine the changes in ADL function associated with bladder cancer diagnosis, but there are some limitations to this study. As our aim was to assess the effect of diagnosis of bladder cancer on selfreported ADL functions, we used chi-square analysis to determine whether the baseline and follow-up survey responses were statistically independent. At the time of this writing, the SEER-MHOS linked database includes cohorts 1-15, with the last entries being from 2014. If more recent advances in bladder cancer management have led to improved functional outcomes, these data may not reflect such changes adequately. The data rely on both an initial and a follow-up survey. By virtue of this methodology, this excludes any patient who passed away prior to completing the follow-up survey, potentially excluding patients with more severe disease. Furthermore, specific information regarding treatment type and timing with respect to surveys is not available. This information would be useful in stratifying the population to better define which treatment factors may be associated with an increased risk of functional decline. Nevertheless, this study is a useful addition to the literature on functional status in bladder cancer patients. It provides some baseline data on ADLs of bladder cancer patients, so future studies can prospectively be designed to monitor these ADL trajectories and implement interventions to improve ADL function and trajectories.

5. Conclusions

In patients diagnosed with bladder cancer, there is a significant decline in self-reported ability to perform ADLs and overall health status. In an effort to better anticipate patient's health care needs and manage their expectations following diagnosis, health care providers must recognize and support the functional decline experienced by this patient population. Further study is needed to elucidate factors that may be most predictive of the decline in functional independence in patients diagnosed with bladder cancer.

Author contributions: Katie S. Murray had full access to all the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

Study concept and design: Murray. Acquisition of data: Golzy. Analysis and interpretation of data: Golzy. Drafting of the manuscript: Ungerer, Anwar. Critical revision of the manuscript for important intellectual content: Murray. Statistical analysis: Golzy. Obtaining funding: Murray. Administrative, technical, or material support: Murray. Supervision: Murray, Golzy. Other: None.

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References

- Yeung C, Dinh T, Lee J. The health economics of bladder cancer: an updated review of the published literature. PharmacoEconomics 2014;32:1093–104.
- [2] Siegel RL, Miller KD, Jemal A. Cancer statistics, 2020. CA Cancer J Clin 2020;70:7–30.
- [3] Griebling TL. Re: Trends in cancer of the urinary bladder and urinary tract in elderly in Denmark, 2008–2012. J Urol 2017;197:317.
- [4] Jensen TK, Jensen NV, Jørgensen SM, Clark P, Lund L. Academy of Geriatric Cancer Research (AgeCare). Trends in cancer of the urinary bladder and urinary tract in elderly in Denmark, 2008–2012. Acta Oncol Stockh Swed 2016;55(suppl 1):85–90.
- [5] Wuethrich PY, Vidal A, Burkhard FC. There is a place for radical cystectomy and urinary diversion, including orthotopic bladder substitution, in patients aged 75 and older: results of a retrospective observational analysis from a high-volume center. Urol Oncol 2016;34:58.e19–2.
- [6] Fung C, Pandya C, Guancial E, et al. Impact of bladder cancer on health related quality of life in 1,476 older Americans: a crosssectional study. J Urol 2014;192:690–5.
- [7] Pham H, Torres H, Sharma P. Mental health implications in bladder cancer patients: a review. Urol Oncol 2019;37:97–107.
- [8] de Lima MM, Tobias-Machado M. Suicide in patients with genitourinary malignancies. Eur J Cancer Care (Engl) 2017;26:e12635.

- [9] Jazzar U, Yong S, Klaassen Z, et al. Impact of psychiatric illness on decreased survival in elderly patients with bladder cancer in the United States. Cancer 2018;124:3127–35.
- [10] Sharma P, Henriksen CH, Zargar-Shoshtari K, et al. Preoperative patient reported mental health is associated with high grade complications after radical cystectomy. J Urol 2016;195:47–52.
- [11] Manton KG. A longitudinal study of functional change and mortality in the United States. J Gerontol 1988;43:S153–61.
- [12] Gillen P, Spore D, Mor V, Freiberger W. Functional and residential status transitions among nursing home residents. J Gerontol A Biol Sci Med Sci 1996;51:M29–36.
- [13] Mor V, Wilcox V, Rakowski W, Hiris J. Functional transitions among the elderly: patterns, predictors, and related hospital use. Am J Public Health 1994;84:1274–80.
- [14] Sylvester RJ, van der Meijden APM, Oosterlinck W, et al. Predicting recurrence and progression in individual patients with stage Ta T1 bladder cancer using EORTC risk tables: a combined analysis of 2596 patients from seven EORTC trials. Eur Urol 2006;49:466–77, [discussion 475–7].

- [15] Reuben DB, Rubenstein LV, Hirsch SH, Hays RD. Value of functional status as a predictor of mortality: results of a prospective study. Am J Med 1992;93:663–9.
- [16] Morgan RO, Virnig BA, DeVito CA, Persily NA. The Medicare-HMO revolving door—the healthy go in and the sick go out. N Engl J Med 1997;337:169–75.
- [17] Pourat N, Kagawa-Singer M, Wallace SP. Are managed care Medicare beneficiaries with chronic conditions satisfied with their care? J Aging Health 2006;18:70–90.
- [18] Maciejewski ML, Dowd B, Call KT, Feldman R. Comparing mortality and time until death for Medicare HMO and FFS beneficiaries. Health Serv Res 2001;35:1245–65.
- [19] Taylor AK, Beauregard KM, Vistnes JP. Who belongs to HMOs: a comparison of fee-for-service versus HMO enrollees. Med Care Res Rev 1995;52:389–408.
- [20] Porell FW, Miltiades HB. Disability outcomes of older Medicare HMO enrollees and fee-for-service Medicare beneficiaries. J Am Geriatr Soc 2001;49:615–31.