Financial Toxicity among Patients with Bladder Cancer: Reasons for Delay in Care and Effect on Quality of Life



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Abbreviations and Acronyms

COST = Comprehensive Score for Financial Toxicity

FACT = Functional Assessment of Cancer Therapy

FACT-GP = FACT-General Population

FT = financial toxicity

HR/CSC = Health Registry/Cancer Survivorship Cohort

HRQOL = health related quality of life

PROMIS = Patient-Reported Outcomes Measurement Information System

QOL = quality of life

UNC = University of North Carolina

Purpose: Costly surveillance and treatment of bladder cancer can lead to financial toxicity, a treatment related financial burden. Our objective was to define the prevalence of financial toxicity among patients with bladder cancer and identify delays in care and its effect on health related quality of life.

Materials and Methods: We identified patients with bladder cancer in the University of North Carolina Health Registry/Cancer Survivorship Cohort. Financial toxicity was defined as agreement with having "to pay more for medical care than you can afford." Health related quality of life was measured using general and cancer specific validated questionnaires. Statistical analyses were performed using the Fisher exact test and the Student t-test.

Results: A total of 138 patients with bladder cancer were evaluated. Median age was 66.9 years, 75% of the patients were male and 89% were white. Of the participants 33 (24%) endorsed financial toxicity. Participants who were younger (p = 0.02), black (p = 0.01), reported less than a college degree (p = 0.01) and had noninvasive disease (p = 0.04) were more likely to report financial toxicity. On multivariable analysis only age was a significant predictor of financial toxicity. Patients who endorsed financial toxicity were more likely to report delaying care (39% vs 23%, p = 0.07) due to the inability to take time off work or afford general expenses. On general health related quality of life questionnaires patients with financial toxicity reported worse physical and mental health (p = 0.03 and <0.01, respectively), and lower cancer specific health related quality of life (p = 0.01), physical well-being (p = 0.01) and functional well-being (p = 0.05).

Editor's Note: This article is the first of 5 published in this issue for which category 1 CME credits can be earned. Instructions for obtaining credits are given with the questions on pages 1360 and 1361.

Accepted for publication October 31, 2017.

No direct or indirect commercial incentive associated with publishing this article.

The corresponding author certifies that, when applicable, a statement(s) has been included in the manuscript documenting institutional review board, ethics committee or ethical review board study approval; principles of Helsinki Declaration were followed in lieu of formal ethics committee approval; institutional animal care and use committee approval; all human subjects provided written informed consent with guarantees of confidentiality; IRB approved protocol number; animal approved project number.

Supported by CEHS Grant P30 ES010126.

^{*} Financial interest and/or other relationship with Grand Rounds.

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Presented at annual meeting of Southeastern Section of American Urological Association, Austin, Texas, March 23-26, 2017. Presented at annual meeting of American Urological Association, Boston, Massachusetts, May 12-16, 2017.

Conclusions: Financial toxicity is a major concern among patients with bladder cancer. Younger patients were more likely to experience financial toxicity. Those who endorsed financial toxicity experienced delays in care and poorer health related quality of life, suggesting that treatment costs should have an important role in medical decision making.

Key Words: urinary bladder neoplasms, health care costs, patient outcome assessment, quality of life, surveys and questionnaires

The United States health care system prioritizes cutting edge technology and innovative pharmaceuticals, of which the costs have been progressively redirected to individual patients. The maintenance of our high quality of care and our use of expensive treatments must be balanced with patient QOL, which can be negatively impacted by financial stress. Interest in this problem has been growing since 2013, when the phrase FT was coined. FT, defined as treatment related financial distress, has been particularly relevant in the field of oncology, which often requires expensive treatments and long-term surveillance. ¹

FT is a particular concern for patients with bladder cancer because of its high prevalence² and significant cost. Bladder cancer is the most expensive cancer from diagnosis to death^{3,4} due to long-term survival and ongoing surveillance.⁵ Surveillance includes imaging and cystoscopy at frequent intervals for years, contributing up to 60% of the cost of bladder cancer care.⁵ In addition to the direct costs of care, indirect costs of cancer treatment such as time away from work⁶ also contribute to the burden of treatment. The negative impact of FT has garnered national attention from features on CBS 60 Minutes⁷ to articles in *The Washington Post*⁸ and *The Wall Street Journal*®.⁹

Patients with cancer are 2.65 times more likely to declare bankruptcy than those without cancer. Decomposed beyond obvious monetary consequences FT can also have negative long-term effects on cancer outcomes. FT requiring bankruptcy was recently linked to early mortality in patients with cancer. Patients who report FT also show medication non-adherence, skip doctor appointments and refuse necessary procedures to offset costs.

While the prevalence and impact of FT have been studied in many common cancers such as breast¹² and lung¹³ cancers, the effects of FT on patients with bladder cancer remain unknown. The objective of our study was to 1) assess the prevalence of FT and associated patient level factors among patients with bladder cancer, 2) evaluate patient reported delays in care and the reasons for those delays, and 3) examine the relationship between FT and HRQOL. To our knowledge this is the first study to evaluate the prevalence and impact of FT in the bladder cancer population.

MATERIALS AND METHODS

We performed a cross-sectional study of 138 patients with bladder cancer identified in the UNC HR/CSC, an incident prevalent cohort of oncology patients recruited from August 2010 to August 2016. To be eligible for HR/CSC patients were required to be an English or Spanish speaking adult 18 years old or older, and have a North Carolina mailing address and an upcoming oncology appointment in the UNC Health Care System.

After screening for eligibility patients were recruited in person during a visit to UNC and informed consent was obtained at that time. A baseline questionnaire was administered, typically within 2 weeks of enrollment, by a computer assisted telephone interview that lasted approximately 1 hour. The baseline questionnaire was extensive, including information on demographics, previous health care access and services, diagnosis and treatment, FT and HRQOL. Among this cohort we identified patients with pathologically confirmed, primary cancer of the bladder.

Patients enrolled in HR/CSC were clinically annotated with diagnostic pathology and first course of treatment data via the UNC Hospital Tumor Registry. This was linked to more extensive clinical data in CDW-H (Carolina Data Warehouse for Health), where information is gathered from the electronic medical record. Additional patient details were manually abstracted from the electronic medical record, including important treatment information (eg chemotherapy cycles and intravesical treatments).

We defined FT as the patient selection of agree or strongly agree with the statement, "You have to pay more for medical care than you can afford," on PSQ-18 (Patient Satisfaction Questionnaire-18), which was also used in other FT analyses. ¹⁴ We examined the association between baseline FT and HRQOL using general and cancer specific scales with FACT, ¹⁵ including a bladder cancer specific FACT questionnaire and the PROMIS ¹⁶ questionnaire.

Descriptive statistics were used to summarize all study variables. Patients were categorized into 2 groups based on FT endorsement. The Fisher exact test and the Student t-test were used to evaluate differences in demographic, diagnostic and treatment characteristics between the FT groups. All analyses were completed with SAS®, version 9.3. This study was reviewed and approved by the UNC institutional review board.

RESULTS

Among 144 patients with bladder cancer enrolled in HR/CSC 138 (96%) completed the baseline

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