

The Need for Survivorship Care in Genitourinary Cancers: Considerations from SUO and LUGPA

Hamed Ahmadi,* Michael A. S. Jewett,[†] Neal D. Shore,[‡] Nour Alkazaz,* Ashraf Almatar,* David M. Latini,* Laura Legere,* Ed Messing,* J. Brantley Thrasher[§] and Cheryl T. Lee*^{||} on behalf of the Society of Urologic Oncology and the Large Urology Group Practice Association

From the Oregon Health and Science University (HA), Portland, Oregon, University of Toronto (MASJ, AA), Toronto General Hospital (NA) and Princess Margaret Cancer Centre (LL), Toronto, Ontario, Canada, Carolina Urologic Research Center (NDS), Myrtle Beach, South Carolina, Baylor College of Medicine (DML), Houston, Texas, University of Rochester School of Medicine and Dentistry (EM), Rochester, New York, University of Kansas Medical Center (JBT), Kansas City, Kansas, and University of Michigan (CTL), Ann Arbor, Michigan

Abstract

Introduction: A quarter of American cancer survivors have genitourinary malignancies that are largely managed by urologists. We explored urologist perceptions about survivorship care for genitourinary malignancies.

Methods: A total of 701 SUO (Society of Urologic Oncology) and 1,746 LUGPA (Large Urology Group Practice Association) members were invited to complete a web based survey composed of 5 domains, including 1) demographics, 2) current survivorship care practices, 3) perceived barriers, 4) accessibility to survivorship resources and 5) perceptions of advocacy groups.

Results: Of 191 respondents 137 (72%) had no training in survivorship care. Of the 174 respondents 129 (74%) practiced shared care models while 45 (26%) preferred pure specialized followup care. Only 39 of 129 respondents (30%) with a shared care model always provided a written care plan. These plans infrequently included information on lifestyle modifications and educational resources. Routine patient referral to advocacy organizations was highest for prostate cancer at 40% followed by bladder, testicular and kidney cancers at 17%, 10% and 8%, respectively. Lack of time/resources and practice guidelines were considered the 2 most important barriers to survivorship care by 31% and 30% of participants, respectively. Web based information on advocacy groups and best practice guidelines were selected as the most important initiatives to promote survivorship care.

Abbreviations and Acronyms

GU = genitourinary

PCP = primary care practitioner

U.S. = United States

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^{||} Correspondence: Department of Urology, 7303 CCGC, 1500 East Medical Center Dr., Ann Arbor, Michigan 48109 (telephone: 734-615-6662; FAX: 734-647-9480; e-mail address: ctlee@umich.edu).

Conclusions: Despite the low response rate this study highlights important practice gaps in survivorship care for patients with genitourinary malignancies. In collaboration with advocacy organizations professional societies should initiate programs to better educate and train their members in survivorship care guidelines and consensus best practices.

Key Words: urogenital neoplasms, survivors, physician's practice patterns, aftercare, questionnaires

In the U.S. malignancy will develop in half of all men and a third of all women in their lifetime.¹ The expanding and aging American population, attributable to enhanced cardiovascular and nutritional care as well as the plethora of therapeutic advances in GU oncology, have contributed to an expansion in the number of cancer survivors, which is currently estimated at almost 14 million.² Consequently the care and well-being of cancer survivors, especially following active cancer treatment, has become a priority for national health policy. Through a series of reports IOM (Institute of Medicine) has addressed several key deficiencies along the continuum of cancer survivorship care.³⁻⁵ These reports have shaped public policy, spurred new funding sources at NCI (National Cancer Institute) and cancer foundations, and also promoted enhanced communication and coordinated care among providers, patients and caregivers.

Cancer survivorship encompasses a distinct phase of the cancer continuum including not only disease management, surveillance and issues of recurrence but also physiological and psychosocial aspects of cancer recovery, which can permit reintegration into routine daily life as well as health promotion and disease prevention for cancer survivors.⁶ Many oncology providers have struggled with efforts to develop and improve survivorship care due to clinic pressures, lack of knowledge, insufficient survivorship tools and a dearth of best practices to guide them. Suboptimal coordination among oncologic providers from various specialties and a lack of institutional resources have posed further challenges.^{7,8}

This issue is particularly germane for clinicians who manage GU malignancies, which affect men and women spanning several decades of life. A quarter of all cancer survivors and more than half of male cancer survivors in the U.S. have GU malignancies.³ In fact it was estimated that by 2022 prostate cancer survivors will represent the largest cancer population in the U.S. with 3.9 million survivors (45% of all American male cancer survivors).⁹ Bladder, kidney and testicular cancer survivors will represent more than 650,000, 500,000 and 295,000 American cancer survivors, respectively, which means that almost a third of all cancer survivors will have had a GU malignancy.⁹

While a growing body of literature addresses the unmet needs of cancer survivors,^{4,10,11} there remains a lack of information regarding urological practitioner knowledge,

insight and attitudes about survivorship planning. Improved understanding of practitioner attitudes regarding GU cancer survivorship as well as current patterns of followup would highlight key gaps in education and clinical practice that require attention, resources and initiatives. This study represents an international collaboration aimed at identifying physician perceptions about GU cancer survivorship.

Materials and Methods

Study Population

In March 2013 members of SUO and LUGPA were asked to complete a web based survey. Initial invitations to complete the survey along with 2 subsequent reminders were delivered via electronic mail to 701 SUO and 1,746 LUGPA members. Participation was entirely voluntary. A research waiver was obtained from the University of Michigan institutional review board.

Survey Structure

The supplementary Appendix (<http://www.urologypracticejournal.com/>) shows the study instrument. It was based on existing questionnaires from the Roswell Park Institute in Buffalo, New York,¹² and the Electronic Living Laboratory for Interdisciplinary Cancer Survivorship Research, a health, wellness and cancer survivorship center at Princess Margaret Hospital in Toronto, Ontario, Canada. A total of 27 multiple choice and Likert scale questions were developed across 5 domains, including 1) demographics, 2) current survivorship care practices, 3) perceived barriers, 4) accessibility to survivorship resources and 5) perceptions of advocacy groups. The instrument, which was previously used to assess physician practice patterns in Canada, was modified slightly to accommodate minor variation in language and phrasing assumptions between the U.S. and Canada.¹³ Descriptive data analysis was performed with SPSS®, version 19.0.

Results

Demographics

A total of 216 physicians viewed the questionnaire for a 9% participation rate, of whom 191 completed the survey for an

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