

The Past, Present and Future of Cancer Survivorship and the Importance of the Urologist

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Abstract

Introduction: Cancer survivorship is a concept that focuses on the complete medical and holistic care of the patient with cancer from the time of diagnosis to the time of death. In 2015 the number of cancer survivors in the United States was expected to exceed 14.5 million people and a significant portion of these patients have malignancies that affect the genitourinary health of the survivor. In this review we describe the concept of cancer survivorship and review the important role of the urologist in cancer survivor care.

Methods: A literature search concerning cancer survivorship and urogenital neoplasms was performed. We systematically searched Medline® from inception until July 2015 with the objective of identifying studies specifically targeting broad survivorship care concerns for genitourinary neoplasms. We also included nonsystematically identified publications, and governmental and agency produced reports that are currently available through various government entities and organizations.

Results: Systematic searching yielded 35 articles and 7 reports for inclusion in our literature review. Urology relevant Medline findings were categorized into review articles, biopsychosocial aspects of cancer care, guidelines or society recommendations, diet and exercise related materials, models or coordination of care, or other. We found that the development of guidelines and recommendations for survivorship care in urology has been limited by the quality of the studies published to date.

Conclusions: More patients are surviving cancer and living with the consequences of treatment of the primary disease. Awareness of the components of survivorship will be critical as more national organizations require specific survivorship care programs to address these issues. Given that a large number of cancer survivors in the United States have survived urological malignancy or have urological side effects of treatment, the urology community must be familiar with the global concept of survivorship.

Key Words: urogenital neoplasms, prostatic neoplasms, survivors, adverse effects, patient care planning

Abbreviations and Acronyms

ACS = American College of Surgeons

ASCO = American Society of Clinical Oncologists

IOM = Institute of Medicine

PCP = primary care provider

SCP = survivorship care plan

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97 Since the signing of the National Cancer Act of 1971, the
 98 “War on Cancer” has been marked by significant advances
 99 in the treatment and cure of multiple types of malignancy.
 100 Coupled with an older and growing population, the number
 101 of cancer survivors in the United States has risen substan-
 102 tially. From 1971 to 2001 the number of cancer survivors
 103 increased from 3 million (1.5% of the population) to 9.8
 104 million people (3.5% of population).¹ It is now estimated
 105 that almost 14.5 million Americans with a history of cancer
 106 were alive as of January 2014. Furthermore, future pro-
 107 jections estimate that nearly 19 million cancer survivors will
 108 be alive in 2024.²

109 The role of the urologist in the care of the cancer survivor
 110 is significant. Prostate, bladder, testis and kidney cancer
 111 account for approximately 57% of all male cancer survivors.
 112 In women, while bladder and kidney cancer tend to be less
 113 prevalent, all pelvic malignancies that may affect the geni-
 114 tourinary tract (uterus, ovaries, colon and rectum) account
 115 for up to 24% of all female survivors.² Furthermore, more
 116 than 80% of childhood patients with cancer survive more
 117 than 5 years³ and many of them have significant side effects
 118 such as fertility concerns that will often fall to the urologist
 119 to treat.

120 In this review we describe the concept of cancer survi-
 121 vorship and review the role of the urologist in the cancer
 122 survivor care to promote awareness of the medical and
 123 surgical needs of this group, in addition to the new re-
 124 quirements being placed on cancer programs in the United
 125 States.

127 **Materials and Methods**

129 We systematically searched Medline from inception until
 130 July 2015 with the objective of identifying studies specifi-
 131 cally targeting broad survivorship care concerns for genito-
 132 urinary neoplasms. With the assistance of a medical librarian
 133 we searched for human subject studies with available text in
 134 English using the Medline search terms cancer survivorship
 135 [TIAB] AND urogenital neoplasms [Majr]. We categorized
 136 the results into nonurology related or urology related with the
 137 urology related articles as the focus of this review. Titles and
 138 abstracts were then scanned for relevant studies. We excluded
 139 any studies that we deemed were commentary or otherwise
 140 irrelevant to the review. The resultant studies were then
 141 subcategorized based on broad topics.

142 Additionally, we nonsystematically identified articles
 143 relevant to this review. We included governmental and
 144 agency produced reports as well as studies that focused on
 145 nonurological survivor concerns that are currently available
 146 through various government entities and organizations with
 147 which we were familiar.

148 **Results**

149 A total of 84 reports or articles were identified that met
 150 search criteria. They were ultimately filtered into 35 articles
 151 and 7 reports for review (fig. 1). Urology relevant Medline [F1]
 152 articles were categorized into review articles, bio-
 153 psychosocial aspects of cancer care, guidelines or society
 154 recommendations, diet and exercise related, models or co-
 155 ordination of care, or other. These articles were coupled with
 156 the nonsystematically identified literature to generate a
 157 narrative synthesis of information.
 158
 159

160 **History of Cancer Survivorship**

161 There is a decades-old recognition of the burden of cancer
 162 treatment on the quantity and quality of life of cancer sur-
 163 vivors. This recognition continues to evolve with the goal of
 164 improving health care in this population. In 1986 NCCS
 165 (Coalition for Cancer Survivorship) was founded with the
 166 goal to advocate for and improve the care of the cancer
 167 “survivor,” a term created to replace the term, cancer
 168 “victim.”⁴ Originally, a patient was defined as a survivor
 169 from the time of diagnosis to the time of recurrence of the
 170 primary disease. This definition has been significantly
 171 broadened to include patients, family, friends and all care-
 172 givers. The time frame has evolved as well and now in-
 173 cludes all patients from the time of diagnosis and for the
 174 balance of life as well as care during hospice and at the end
 175 of life.⁴
 176

177 Work in the realm of cancer survivorship has continued
 178 to evolve in the last 3 decades. However, it took almost 20
 179 years after NCCS was formed before The President’s Cancer
 180 Panel, in accordance with the National Cancer Act of 1971,
 181 published its report in 2004 entitled *Living Beyond Cancer:
 182 Finding a New Balance*.⁵ The panel highlighted the growing
 183 needs of the community of cancer survivors in the United
 184 States and laid out recommended action steps to “help
 185 alleviate the severe burdens experienced by cancer survivors
 186 and their families.”⁵ In complementary fashion IOM pub-
 187 lished a seminal report entitled *From Cancer Patient to
 188 Cancer Survivor: Lost in Translation* in 2005.⁶ This report
 189 highlighted the relative inadequacy of education, clinical
 190 practice and research in cancer survivorship and made rec-
 191 ommendations for how to fill these gaps. IOM also recom-
 192 mended using SCPs as a mechanism to enhance
 193 communication and improve care.
 194

195 In response to the IOM report⁶ in 2006 and again in 2010
 196 the Livestrong Foundation performed a comprehensive
 197 survey of cancer survivors in the United States to understand
 198 the gap between the care that cancer survivors receive and
 199 the care that they want.⁷ Of the approximately 2,300

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