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Review

Cancer survivorship for primary care: Annotated bibliography

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ABSTRACT

Long-term cancer survivorship care is a relatively new and rapidly advancing field of research. Increasing cancer survivorship rates have created a huge population of long-term cancer survivors whose cancer-specific needs challenge healthcare infrastructure and highlight a significant deficit of knowledge and guidelines in transitional care from treatment to normalcy/prolonged survivorship. As the paradigm of cancer care has changed from a fixation on the curative to the maintenance on long-term overall quality of life, so to, has the delineation of responsibility between oncologists and primary care physicians (PCPs). As more patients enjoy long-term survival, PCPs play a more comprehensive role in cancer care following acute treatment. To this end, this annotated bibliography was written to provide PCPs and other readers with an up-to-date and robust base of knowledge on long-term cancer survivorship, including definitions and epidemiological information as well as specific considerations and recommendations on physical, psychosocial, sexual, and comorbidity needs of survivors. Additionally, significant information is included on survivorship care, specifically Survivorship Care Plans (SCPs) and their evolution, utilization by oncologists and PCPs, and current gaps, as well as an introduction to patient navigation programs. Given rapid advancements in cancer research, this bibliography is meant to serve as current baseline reference outlining the state of the science.

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Background

Survival is the new normal in cancer care. There are nearly 15 million cancer survivors in the United States. Clinically, this new paradigm of cancer survivorship is still in its infancy. As described by several Institute of Medicine (IOM) reports, including “From Cancer Patient to Cancer Survivor: Lost in Transition,” there is a

significant shortfall of knowledge, research, and attention to long-term cancer survivorship. Even in the past decade, attitudes have shifted from exclusive fixation on disease eradication to maintenance of long-term well-being, including a new emphasis on comprehensive primary care after acute treatment. Needless to say, research continues to progress swiftly and the latest developments often raise more questions than they answer. To that end, this bibliography serves two interconnected purposes; to give the reader a base of knowledge which will assist him or her in navigating the frontier of cancer survivorship clinical care, and to outline the numerous research directions underway.

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Methods

The purpose of this annotated bibliography was to conduct a thorough review of the current cancer survivorship literature and condense it into a useful resource. We utilized multiple sources to identify the core articles for review. First, we conducted a literature review from the online database PubMed.gov, accessed through the Department of Family Medicine at the University of Colorado at Denver Anschutz Medical Campus. The initial search criteria “cancer survivorship” yielded over 300,000 individual publications. The search was narrowed to specific survivor needs using the term “patient needs”, in combination with terms like “psychosocial”, “physical”, and “sexual” following “cancer survivorship”. Each specific search yielded 50–300 articles, subsequently narrowed to “English language” in the final selection. Initial screening of articles was completed by the authors and only recent articles, general interest, and those representing national organizations (e.g., IOM) were included in the final report.

Second, based on early findings of the emerging importance of survivorship care planning, a separate literature search was completed for “cancer survivorship care planning” yielding over 1000 articles. Narrowing the search term to “cancer survivorship care plans” yielded 298 articles.

Third, additional articles were identified through the references and endnotes of published manuscripts and reports, suggestions from colleagues and recommendations from collaborating cancer experts. Finally, these same search terms were cross referenced for additional scholarly articles and gray literature in Google and Google Scholar.

The combined searches included over 250 articles on cancer survivorship. The authors reviewed these to identify the seminal papers, those essential to primary care providers, and articles of duplicate or similar topic. The final selection included in this annotated bibliography includes 31 articles that provide the reader with a broad understanding of the current state-of-the-science in cancer survivorship. The annotations include an analysis of the research, ideas, and recommendations to inform the reader about clinical care, research gaps, and best practices for survivorship care. By selecting and describing a collection of articles that includes some general and specific topics, this bibliography provides a guided tour through the topic. The annotations provide a core understanding of cancer survivorship and an accessible resource for learning more about cancer survivorship.

Results

Seven broad rubrics emerged from analysis related to various aspects of cancer survivorship.

- I. General background on cancer survivorship
- II. Epidemiology of cancer survivorship
- III. Psychosocial considerations in cancer survivorship
- IV. Physical and medical considerations in cancer survivorship
- V. Special populations in cancer survivorship
- VI. Survivorship Care Plans (SCPs)
- VII. Other issues in cancer survivorship

I. *General background on cancer survivorship.* This section introduces several seminal reports from the *Institute of Medicine (IOM)* which have been critical to our changing understanding and strategy for addressing cancer care and long-term survivorship. Given the length of these resources, adequate summary and analysis is outside the scope of this annotated bibliography. Nonetheless, they will be included and alluded to throughout because of their foundational influence. They provide a valuable baseline for understanding

the field of cancer survivorship, the scope of cancer survivorship, and the numerous gaps in our knowledge and care for cancer survivors.

Hewitt, Maria, Susan L. Weiner, and Joseph V. Simone, eds. *Childhood cancer survivorship: improving care and quality of life.* National Academies Press, 2003 [1].

This IOM report on childhood cancer survivorship played an important preliminary role in changing the conversation of cancer care from “curing” the initial disease to long-term quality of life care. Recognizing childhood cancer survivors are a unique population given the longstanding impacts cancer can have on their lives, the IOM called for increased post-treatment surveillance and interventions to address long-term complications. This report was an early turning point in the approach to cancer care, emphasizing the need for improved quality care for survivors past acute treatment and into the future.

Hewitt, Maria, Sheldon Greenfield, and Ellen Stovall, eds. *From cancer patient to cancer survivor: lost in transition.* National Academies Press, 2005 [2].

This hallmark report from the IOM has played an instrumental role in garnering attention and support for improving long-term cancer survivorship care. It is fundamental to the changing paradigm of cancer care from exclusively acute treatment and disease eradication to the maintenance of general well-being.

Levit, Laura, et al. “Delivering high-quality cancer care: charting a new course for a system in crisis.” *Institute of Medicine. Washington, DC: Institute of Medicine (2013) [3].*

This most recent IOM cancer care report outlines the systematic failures of cancer care and articulates the systematic changes necessary to avoid a crisis in clinical care for cancer survivors. Specifically, the committee proposed improved patient engagement and provider coordination, utilization of evidence-based care, increased emphasis on health care information technology, translation of evidence into clinical practice, and guaranteed accessibility and affordability.

II. *Epidemiology.* The following articles provide a helpful starting place for understanding the scope of cancer survivorship. Included are resources that articulate the **definition** of cancer survivorship and describe the **demographics**, the **epidemiology**, and the changing **paradigm** of long-term cancer survivorship.

Siegel, Rebecca, et al. “Cancer treatment and survivorship statistics, 2012.” *CA: a Cancer Journal for Clinicians* 62.4 (2012): 220–241 [4].

This highly cited article by Siegel and colleagues offers a wide array of general background information and statistics on cancer and survivorship including prevalence, survival, and treatment statistics on selected cancers. This article contains a large amount of demographic information and statistics and is a highly useful starting point for cancer survivorship research.

Siegel et al. define cancer survivorship as, “any person who has been diagnosed with cancer, from the time of diagnosis through the balance of life. They further describe 3 distinct phases of survivorship: (1) the time from diagnosis to the end of initial treatment, (2) the transition from treatment to extended survival, and (3) long-term survival. In 2012, there were 13.7 million cancer survivors in the United States, estimated to grow to 18 million by 2022. Prostate cancer accounts for 43% of male survivors, while colorectal cancer

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