



Key Survivorship Issues

BCAN PATIENT FALL SUMMIT 2023

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Defining Survivor

“An individual is considered a cancer survivor from the time of diagnosis, through the balance of their life. Family members, friends, and caregivers are also impacted and therefore included in this definition “

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Survivorship

Means different things to different people

- Having no signs of cancer after treatment
- Living with, through, and beyond cancer
- Others

The term “survivorship” does not feel right to all people who have experienced cancer

Individual challenges and concerns

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General cancer survivorship data

- 18.1 million people with history of cancer in the U.S.
- Number of cancer survivors is projected to increase by 24.4% (to 22.5 million) by 2032 and 26 million by 2040
- In the next 10 years, the number of people who have lived 5 or more years after their cancer diagnosis is projected to increase approximately 30%, to 16.3 million
- 67% of survivors are 65 or older

American Cancer Society. *Cancer Treatment & Survivorship Facts & Figures 2022-2024*. Atlanta: American Cancer Society; 2022.

National Cancer Institute, Office of Cancer Survivorship

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Defining Bladder Cancer Survivorship

A work in progress with input from different stakeholders

A bladder cancer survivor is someone with a current or past diagnosis of bladder cancer...

Bladder cancer survivorship is holistic, patient-centered, comprehensive care that involves collaboration between multiple health care professionals throughout different phases of the cancer experience...

It takes into consideration the complex and unique experiences of each individual patient, focusing on not only results of diagnostics and follow up schedules, but incorporates health promotion, disease-prevention, treatment-related side effects, emotional and mental well-being, caregivers...

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Summary of 2022 Think Tank

Reviewed survey results

- Identifying how different groups view most important survivorship needs
 - Uncertainty/worry related to recurrence
 - Post-treatment related side effects
 - Emotional/mental health
- Shaping the future of survivorship-focused research
 - Survivorship Clinics
 - Support Groups
 - Survivorship Care Plans

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Summary of 2023 Think Tank

Reviewed survey data

- Health care provider (n=80)
- Patients (n=135)

Takeaways

- Providers
 - Interested in BCSC
 - Identify potential benefits
 - Barriers are similar as barriers for many other aspects of healthcare
 - APPs play a key role
- Patients
 - Large percentage don't know about resources at their centers (40%), including smoking cessation
 - Access to telehealth
 - Not sure about BCSC availability
 - Support groups

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Hot Topic Discussion Items

- Survivorship space on BCAN website
- Care plans
- Guidelines/standardization
- Smoking cessation
- Gaps from survey

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Current Action Items

Dedicated space on BCAN website for survivorship

- Patient and caregiver subcategories
- Health care provider subcategory
- Advocates are going through existing resources

Survivorship Care Plan

- Updating of current iterations
- Providers may use as a template for their institutions/modify to meet the needs of their patients
- Patients can access to take to their provider

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Current Action Items

Survivorship guidelines/standardizing BCSC

- 1-2 page document for providers
- Beyond scans/labs/timeframe for visits
 - Health promotion/disease prevention, smoking cessation, cancer screenings, long-term side effect management, emotional/mental health screening, etc.

Documents that need to be developed

- Emotional/psychological well-being
- Financial toxicity (what is it/resources)
- Volunteers looking at existing documents on BCAN website and identify gaps

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Longer Term

- Icon for survivorship documents that already exist so that they are identified as such
- Expanding Task Force
- Disseminating the work that's being done
- Narrowing focus of future surveys for data collection
- Task force meeting with social work group to get their insights on gaps
- White Paper re: BCAN supported guidelines for bladder cancer survivorship care beyond NCCN guidelines for intervals of imaging/diagnostics

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What are your ideas?



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