Beyond the Checkbox: Delivering Meaningful Cancer Survivorship Care in a Community Setting

Crystal Labbato DNP, APRN, AGCNS-BC, AOCNS, NCTTP
Survivorship Program Coordinator
• I have no conflicts of interest to disclose
Objectives

• Review existing paradigms of survivorship care.
• Review CoC and NAPBC Standards for survivorship care.
• Describe considerations programs can include when designing/implementing survivorship programs.
• Describe the development and delivery of survivorship care services at a community cancer center.
• Explore opportunities to address research and practice gaps in survivorship care delivery.
Crystal Labbato DNP, APRN

- BFA 2001 Art Academy of Cincinnati
- BSN 2006 Northern Kentucky University
- DNP 2016 University of Kentucky
- ANCC certified AGCNS-BC
- ONCC certified AOCNS
- Certified Tobacco Treatment Specialist, NCTTP
- Respecting Choices trained in First Steps, Next Steps and Advanced Steps – Shared Decision Making in Serious Illness
- 2017-2018 LGBT Health Certificate with U of L
NCCS Defines a Survivor as:

An individual from the time of diagnosis through the balance of their life.
**survivorship**

(ser-VY-ver-ship)

In cancer, survivorship focuses on the health and well-being of a person with cancer from the time of diagnosis until the end of life. This includes the physical, mental, emotional, social, and financial effects of cancer that begin at diagnosis and continue through treatment and beyond. The survivorship experience also includes issues related to follow-up care (including regular health and wellness checkups), late effects of treatment, cancer recurrence, second cancers, and quality of life. Family members, friends, and caregivers are also considered part of the survivorship experience.
### Cancer treatment and survivorship statistics, 2019

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<thead>
<tr>
<th></th>
<th>Male</th>
<th>Female</th>
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<tbody>
<tr>
<td><strong>Prostate</strong></td>
<td>3,650,030</td>
<td>3,861,520</td>
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<td><strong>Colon &amp; rectum</strong></td>
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<td><strong>Melanoma of the skin</strong></td>
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<td><strong>Non-Hodgkin lymphoma</strong></td>
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<td><strong>Oral cavity &amp; pharynx</strong></td>
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<tr>
<td><strong>All sites</strong></td>
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<td>8,781,580</td>
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<th></th>
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<th>Female</th>
</tr>
</thead>
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<td><strong>Prostate</strong></td>
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<tr>
<td><strong>Lung &amp; bronchus</strong></td>
<td>325,680</td>
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<tr>
<td><strong>Oral cavity &amp; pharynx</strong></td>
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<td>288,710</td>
</tr>
<tr>
<td><strong>All sites</strong></td>
<td>10,995,610</td>
<td>11,174,200</td>
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</tbody>
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Living well with, through and beyond a cancer experience.
Fig. 1. Canadian Hospice Palliative Care Association model.
Fig. 2. Basic model of integrated palliative care.

Fig. 3. Disease management-enhanced model.
Fig. 4. Palliative care-enhanced model.

Fig. 1. Canadian Hospice Palliative Care Association model.
This is where you are now.....

From: The Bow Tie Model and Survivorship NOSM April 2022

Pippa Hawley FRCPC
Clinical Professor, Dept. of Medicine, UBC
Medical Director: BC Cancer Pain & Symptom Management/Palliative Care Program
This is where you are now.....

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Pippa Hawley FRCPC
Clinical Professor, Dept. of Medicine, UBC
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“We can never be 100% certain what will happen”

From: The Bow Tie Model and Survivorship NOSM April 2022

Pippa Hawley FRCPC
Clinical Professor, Dept. of Medicine, UBC
Medical Director: BC Cancer Pain & Symptom Management/Palliative Care Program
Delivery of Survivorship Care
# Evolving Standards

## Comparison of the Commission on Cancer (CoC) and National Accreditation Program for Breast Centers (NAPBC) Survivorship Care Plans with 2016 Revisions

<table>
<thead>
<tr>
<th>Standard</th>
<th>CoC 3.3 Survivorship Care Plan</th>
<th>NAPBC 2.20 Breast Cancer Survivorship Care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Requirement</td>
<td>A comprehensive survivorship care plan (SCP) and treatment summary including ASCO data elements will be completed on patients with curative intent and have completed therapy (other than hormonal).</td>
<td>A comprehensive breast cancer survivorship care process, including a survivorship care plan (SCP) with accompanying treatment summary, is in place within 6 months of completing active treatment and no longer than 1 year from date of diagnosis. The survivorship care process is evaluated annually by the Breast Program Leadership Committee (BPLC - formerly the Breast Program Leadership [BPL]).</td>
</tr>
<tr>
<td>Documentation Required</td>
<td>Within the SCP processes are policies and procedures (as approved by the Cancer Committee) identifying the appropriate healthcare provider(s) from the patient’s oncology care team who will be responsible for approving and discussing the SCP. Providers who are part of the team that are appropriate include: Physicians, registered nurses, advanced practice nurses, nurse practitioners, physician assistants, credentialed clinical navigators (does not include lay navigators). Numerous specifics to be documented.</td>
<td>SCP approved by the breast program medical director (BPMD) and documented in the minutes. Documentation in the BPLC minutes of the SCP delivery process for (i.e., who delivers, timing). Methodology to monitor percentage of patients receiving SCPs. Annual Breast Program Leadership Committee review of the SCP documented in the minutes. If compliance is less than 100% documentation of the exception must exist in each case. Beginning in 2017, SCPs may be delivered by a credentialed member of the care team such as: oncology certified nurses, advanced practice nurses, nurse practitioners, physician assistants, clinical nurse navigators, and/or the physician. SCPs cannot be delivered by lay navigators or others not part of the care team.</td>
</tr>
<tr>
<td>Phase-in Implementation</td>
<td>January 1, 2015: Implement a pilot survivorship care plan process involving 10% of eligible patients. End of 2016: Provide survivorship plans to 25% of eligible patients. End of 2017: Provide survivorship plans to 50% of eligible patients. End of 2018 and beyond: Provide survivorship plans to 75% of eligible patients. January 1, 2019: Provide survivorship plans to 75% of eligible patients and beyond.</td>
<td>December 2014 to March 2015: No minimum requirement. April 2015 to December 2015: 50% of eligible patients receive a SCP to be compliant with standard. Two charts showing delivery of the SCP will be reviewed. The center will self-select the charts. Surveyor will review as part of the medical record review at on-site visit. January 2016 and beyond: 100% of eligible patients must receive a SCP for standard compliance as of January 2016. Patients who do not receive a SCP must have documentation in their record as to why.</td>
</tr>
<tr>
<td>Key Elements of the SCP</td>
<td>Comprehensive Care/Treatment Summary Follow up care plan</td>
<td>Treatment summary Follow-up care</td>
</tr>
</tbody>
</table>

The 2016 CoC Cancer Program Standards can be found at: [https://www.facs.org/quality-programs/cancer/coc/standards](https://www.facs.org/quality-programs/cancer/coc/standards)

The 2014 NAPBC accreditation standards can be found at: [https://www.facs.org/quality-programs/napbc/standards](https://www.facs.org/quality-programs/napbc/standards)
**Breast Cancer Survivorship Care**

**STANDARD 2.20** A comprehensive process to prepare and disseminate a breast cancer survivorship care plan, with accompanying treatment summary, to all eligible patients within six (6) months of completing active treatment and no later than one year (365 days) from date of diagnosis is developed and implemented.

**DEFINITION AND REQUIREMENTS**

The Institute of Medicine (IOM) report *From Cancer Patient to Cancer Survivor* outlines the importance of providing cancer survivors with a comprehensive treatment summary and follow up plan (in other words, a survivorship care plan) that addresses follow-up care to improve health and quality of life. This document serves as a communication and education tool that survivors can provide to all of their health care providers in various disciplines.

The Survivorship Care Plan (SCP) is the record of a patient’s breast cancer history what transpired during active treatment, current continued long-term treatment (in other words, hormonal and targeted therapy), recommendations for follow-up care and surveillance testing/examination, referrals for support services the patient may need going forward, and other information pertinent to the survivor’s short- and long-term survivorship.

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Ineligible Patients and Timeline Extension

- Patients diagnosed with Stage IV breast cancer are not required to have a SCP, as they are assumed to be under continuous treatment. However, consideration should be given to providing these patients with ongoing treatment summaries for their use and to be shared with their primary care physician (PCP), including a listing of common potential late effects and their possible timing.

- The one-year-from-diagnosis requirement to provide a SCP is extended to 18 months for patients receiving hormonal and targeted therapy.
Measure of Compliance

Each calendar year, the program fulfills all of the following compliance criteria:

1. The cancer committee identifies a survivorship program team, including its designated coordinator and members.
2. The survivorship program is monitored and evaluated. A report is given to the cancer committee, contains all required elements, and is documented in the cancer committee minutes.
NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®)

Survivorship

Version 2.2021 — July 1, 2021

NCCN.org

NCCN Guidelines for Patients® available at www.nccn.org/patients

Continue
Survivorship Care Plan (SCP)

• The record of a patient’s cancer history:
  – current continued long-term treatment (ie hormonal and targeted therapy).
  – recommendations for follow-up care and surveillance testing/examination.
  – referrals for support services the patient may need going forward, and other information pertinent to the survivor’s short and long-term survivorship care.
  – It is to stipulate specifically what surveillance is to be performed, at what frequency, by whom, and when.
ASC0 Treatment Summary and Survivorship Care Plan

General Information

Patient Name: [Redacted]  Patient DOB: [Redacted]
Patient phone: [Redacted]  Email: [Redacted]

Health Care Providers (Including Names, Institution):

Primary Care Provider: [Redacted]
Surgeon: [Redacted]
Radiation Oncologist: [Redacted]
Medical Oncologist: [Redacted]
Other Providers:

Treatment Summary

Cancer Type/Location/Histology Subtype: [Redacted]
Diagnosis Date (year): [Redacted]
Stage: □ I □ II □ III □ Not applicable

Treatment

Surgery □ Yes □ No
Surgery Date(s) (year): [Redacted]

Surgical procedure/locations/findings:

Radiation □ Yes □ No
Body area treated: [Redacted]
End Date (year): [Redacted]

Systemic Therapy (chemotherapy, hormonal therapy, other) □ Yes □ No
Names of Agents Used
End Dates (year)

Persistent symptoms or side effects at completion of treatment: □ No □ Yes [enter type(s)]: [Redacted]

Familial Cancer Risk Assessment

Genetic/hereditary risk factor(s) or predisposing conditions:

Genetic counseling □ Yes □ No
Genetic testing results:

Follow-up Care Plan

Need for ongoing (adjuvant) treatment for cancer □ Yes □ No
Additional treatment name
Planned duration
Possible Side effects

Schedule of clinical visits

Coordinating Provider
When/How often

ASC0 Survivorship Care Plan

Updated based on consensus conference held on 9/27/13 and the ASC0 Survivorship Committee

Cancer surveillance or other recommended related tests

Coordinating Provider

What/When/How Often

Please continue to see your primary care provider for all general health care recommended for a (man) (woman) your age, including cancer screening tests. Any symptoms should be brought to the attention of your provider:
1. Anything that represents a brand new symptom;
2. Anything that represents a persistent symptom;
3. Anything you are worried about that might be related to the cancer coming back.

Possible late- and long-term effects that someone with this type of cancer and treatment may experience:

Cancer survivors may experience issues with the areas listed below. If you have any concerns in these or other areas, please speak with your doctors or nurses to find out how you can get help with them.

□ Emotional and mental health  □ Fatigue  □ Weight changes  □ Stopping smoking
□ Physical functioning  □ Insurance  □ School/Work  □ Financial advice or assistance
□ Memory or concentration loss  □ Parenting  □ Fertility  □ Sexual functioning
□ Other

A number of lifestyle/behaviors can affect your ongoing health, including the risk for the cancer coming back or developing another cancer. Discuss these recommendations with your doctor or nurse:

□ Tobacco use/cessation  □ Diet
□ Alcohol use  □ Sun screen use
□ Weight management (loss/gain)  □ Physical activity

Resources you may be interested in:

Other comments:

Prepared by: [Redacted]  Delivered on: [Redacted]

* This Survivorship Care Plan is a cancer treatment summary and follow-up plan is provided to you to keep with your health care records and to share with your primary care provider.
* This summary is a brief record of major aspects of your cancer treatment. You can share your copy with any of your doctors or nurses. However, this is not a detailed or comprehensive record of your care.
Who Should Be Offered Survivorship Services?

- Patients who have finished all of their treatment?
- Patients without metastatic or advanced disease?
- Patients whose only treatment is surgery?
- Patients experiencing distress after treatment ends?
- Patients who we “know” will “survive”?
Treatment Summary Visit

• Billable service
• Arrive a few minutes early to complete Distress Tool, PHQ9, GAD7
• History and brief physical exam
• Review of treatment summary and care plan document
• The rest of the visit is tailored to the patient needs:
  – Discussion of common late or long term effects of treatment or illness.
  – Discussion of serious late or long term effects of treatment, prevention and management
  – Individualized discussion of patient needs identified on Distress Tool, PHQ9, GAD7
  – Discussion of NCCN guidelines for surveillance of treated cancer.
  – Prevention and screening of other cancers, and healthy lifestyle.
Survivorship Care Plan (SCP)

- The record of a patient’s cancer history:
  - what transpired during active treatment.
  - current continued long-term treatment (i.e., hormonal and targeted therapy).
  - recommendations for follow-up care and surveillance testing/examination.
  - referrals for support services the patient may need going forward, and other information pertinent to the survivor’s short and long-term survivorship care.
  - It is to stipulate specifically what surveillance is to be performed, at what frequency, by whom, and when.
Treatment Summary & SCP Visit

- Referrals to resources available at Baptist:
  - Lymphedema clinic
  - Physical/Occupational Therapy
  - Oncology Nutrition
  - Smoking Cessation
  - Psychiatry and psychosocial oncology
  - Oncology Social Work
  - Genetics (it’s back!)
  - Exercise programs (CARE at Milestone)
  - Sleep medicine
  - Primary Care referral line
  - Massage/Reiki Therapy
  - Cancer screening
  - Support groups and psychoeducation (Cancer University)
    - Sharing Our Stories
    - Young Women’s Series: Living Beyond Breast Cancer
    - Grief support group
Treatment Summary & SCP Visit

– Referrals to community resources
  • Kentucky Cancer Program
  • Kentucky African Americans Against Cancer
  • Kentucky Cancer Link
  • Gilda’s Club
  • American Cancer Society
  • Leukemia and Lymphoma Society
  • Friend for Life
  • Go2 Foundation
  • Acupuncture
  • Community Mental Health Services
  • LiveStrong at the YMCA
  • Cancer and Careers
  • A Time to Heal
    – Survivorship
    – Brain Fog Program
  • Queering Cancer
  • Kentucky Trans Health Advocacy Program
  • Sex therapy referrals for individuals and partners
  • Pelvic floor therapy (BH FLO)
NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®)

Older Adult Oncology

Version 1.2021 — May 24, 2021

NCCN.org

Continue
Chronological Age = 82
Older Adult Functional Assessment

• A multidimensional, interdisciplinary patient evaluation that leads to the identification of patient problems and the development of a plan for resolving these problems

• Reasons to perform a geriatric assessment:
  – Detection of unidentified problems
  – Better estimation of residual life expectancy
  – Prediction of adverse outcomes
  – Improvement of care quality
Older Adult Functional Assessment

– Billable service.
– Eligible patients are age 65 or older with a cancer diagnosis, or younger than 65 with multiple co-occurring physical, psychosocial or spiritual concerns.
– Patients will receive a comprehensive geriatric assessment with special focus on any of the following:
  • Prediction of chemotherapy treatment toxicity for medical decision making
  • Functional and/or cognitive assessment
  • Psychosocial assessment
  • Tobacco use assessment
  • Advance care planning and goals of care assessment
– Follow up visits are completed as appropriate for continuity of care.
Older Adult Functional Assessment

– Minimum assessment dimensions for older adults:
  • Social Resources
  • Functional Status
  • Physical Function
  • Nutrition Status
  • Psychological reserve
  • Medications
  • Medical conditions
Advance Care Planning

• Can be facilitated by Supportive Onc APRNs or Social Work:
  – Completing Kentucky or Indiana Living Will directive
  – MOST/POLST shared decision making
  – Monthly one hour class offered via zoom
    • 4th Wednesday of the month from 1pm-2pm
  – Individual appointments
These guidelines are focused on smoking cessation recommendations for patients with cancer and cancer survivors. There are health benefits to smoking cessation even after a cancer diagnosis, regardless of site, stage, or prognosis, namely improvement in cancer treatment outcomes, primary cancer recurrence, and secondary cancers. It is never too late for patients with cancer to stop smoking cigarettes and experience health benefits. Nicotine addiction is a chronic relapsing disorder. People with cancer who smoke often demonstrate high-level nicotine dependence. The NCCN Panel recommends that treatment plans for all people with cancer who smoke include the following:

- Evidence-based motivational strategies and behavior therapy,
- Evidence-based pharmacotherapy, and
- Close follow-up with retreatment as needed.

Clinical Recommendations:

- Combining pharmacologic therapy and behavior therapy is the most effective approach and leads to the best results for smoking cessation.
  - The two most effective pharmacotherapy agents are combination nicotine replacement therapy\(^a\) (NRT) or varenicline.
  - Behavior therapy with multiple counseling sessions is most effective, and at least a minimum of brief counseling is highly recommended. Quitlines may be used as an adjunct, especially in lower-resource settings.
- Smoking status should be documented in the patient health record. Patient health records should be updated at regular intervals to indicate changes in smoking status, quit attempts made, and interventions utilized.
- Smoking relapse and brief slips are common and can be managed. Providers, the health care team, and tobacco treatment specialists should discuss this and provide guidance and support to encourage continued smoking cessation attempts. Smoking slips are not necessarily an indication to try an alternative method. It may take more than one quit attempt with the same therapy to achieve long-term cessation.
- Smoking cessation should be offered as an integral part of oncology treatment and continued throughout the entire oncology care continuum, including surgery, radiation therapy, systemic therapy, and end-of-life care. An emphasis should be put on patient preferences and values when considering the best approach to fostering smoking cessation during end-of-life care.
- Despite emerging evidence, there is still insufficient evidence to recommend the use of e-cigarettes in smoking cessation, alone or in combination with evidence-based smoking cessation methods. There is also insufficient evidence regarding the safety and efficacy of e-cigarette use in patients with cancer. Thus, patients should be counseled toward the use of evidence-based smoking cessation methods.

\(^a\) Combination NRT = Nicotine patch + short-acting NRT (ie, lozenge, gum, inhaler, nasal spray).

Note: All recommendations are category 2A unless otherwise indicated.

Clinical Trials: NCCN believes that the best management of any patient with cancer is in a clinical trial. Participation in clinical trials is especially encouraged.
Tobacco Treatment Services

• Individual Consultations
  – In person, by video or phone
  – Billable visit
  – Intake visit (prefer in person)
  – Follow up visits as needed for ongoing monitoring and support
  – Medication management and monitoring
Clinical Case #1

- 72 year old with adenocarcinoma of the prostate Gleason 4+3=7
- Completed radiation treatment course 7/1/2020
- Survivorship visit 4/20/2021
  - CC: dysuria, frequency, dribbling urine, syncopal episodes, frequent falls, incontinence of bowel, poor appetite with 30lb weight loss since completion of XRT, mood disturbance.
Clinical Case #1

- **EXAM:** Orthostatic hypotension, near syncopal episode on scale, weakness, Distress score: 9; PHQ9 score 14; GAD7 score 5.
- **Patient Goals of Care:**
  - 1. Improvement of strength and stamina with target of return to playing golf and spending time with grandchildren and spouse.
  - 2. Urination without pain or passing out.
- **PLAN:**
  - Patient scheduled with urology – indwelling Foley to TURP, residual incontinence, working with pelvic floor therapist
  - Referral to oncology nutrition – gain 17 pounds since July, BMs regular
  - Referral to oncology social work
  - Zoloft per PCP – dose 100 mg daily, mood improved
  - Blood sugars per PCP
  - BP per Cardiology
  - Fall safety at home, education – falls stopped after Foley placed and Flomax stopped
  - Refer to PT/OT – returned to former activities
  - Advance Care Planning – copy requested
Clinical Case #2

- 28 year old patient s/p brachytherapy with 5 cycles cisplatin with concurrent brachytherapy 7/2018, now NED

- Survivorship visit 9/23/2021
  - CC: Early menopause with hot flashes, mood changes (tearfulness), eczema, fatigue, fecal urgency with incontinence, bloating, loss of appetite, weight gain. Single parent. Unsuccessful connection with community based mental health since treatment completion.
  - ESAS: tiredness, nausea, anxiety, drowsiness, lack of appetite, wellbeing, other (fecal incontinence)
Clinical Case #2

• EXAM: A&O, anxious appearing, abd distention noted. Distress score 8, PHQ9 score 14, GAD7 score 11.

• PLAN:
  – Referral to pelvic floor therapy
  – Referral to oncology nutrition
  – Referral to Friend for Life
  – Provided community referrals to mental health
  – Advance care planning
Survivorship is a Team Sport

• Hospital based services
• Community partners
• Talk to patients
• What do treatment team members wish they had?
Ideal “Bow Tie Model” Palliative Care Service

- Services available early in course of illness
- Services 'dip' in and out when need arises
- Open door accessibility, preferably 24/7
- Co-location with disease-specific services for patient-centred care provision
- Clear role definitions
- Multidisciplinary team functioning, with team meetings and excellent communication
- Close links with community hospice (or palliative care) services and rehabilitation services

From: The Bow Tie Model and Survivorship NOSM April 2022

Pippa Hawley FRCPC
Clinical Professor, Dept. of Medicine, UBC
Medical Director: BC Cancer Pain & Symptom Management/Palliative Care Program
Thank you Dr Hawley

• For patients and their families living with serious illness
• Designed to be used from time of diagnosis
References


