



**Survivorship Care Planning –
Beyond Standard 3.3**





*When Life Is Sewn
Back Together,
It Has Changed*





Commission on Cancer

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Poll: What is Standard 3.3?

1. A requirement from the American College of Surgeons Commission on Cancer
2. A requirement from the Joint Commission
3. A requirement for NCI clinical trials

**Poll: Have you developed
or delivered a survivorship
care plan?**

1. Yes
2. No

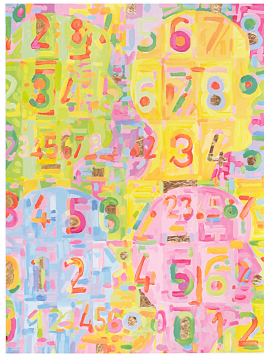



Objectives

- Describe cancer survivorship trends over time
- Define who is a cancer survivor
- Identify survivors needs across the cancer continuum
- Discuss survivorship care planning to address unmet needs



Cancer in the US



More Than a Statistic



Demographic Trends

Aging population (70%)

By 2050 20.2% US population will be >65

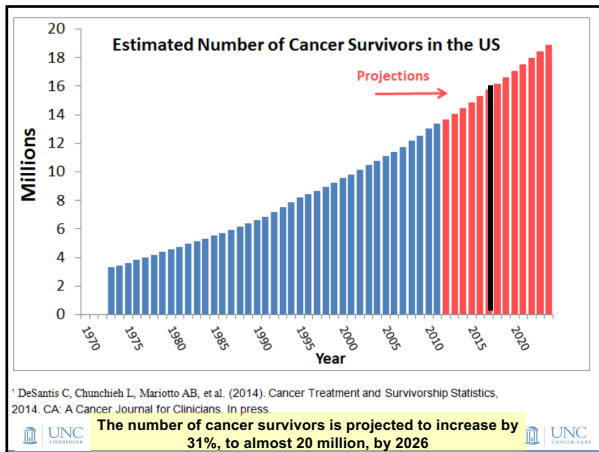
Minority populations (28%)

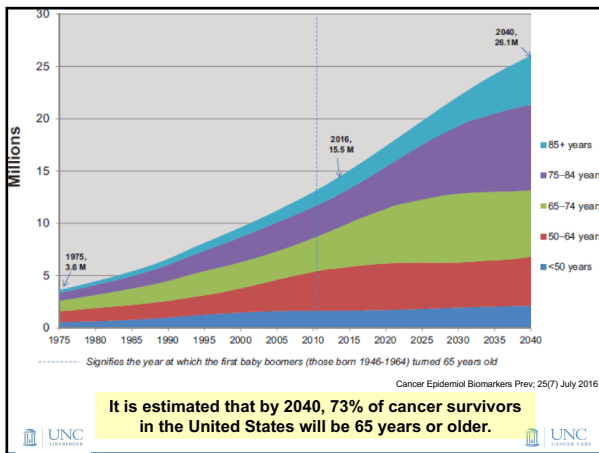
By 2050 US population will be 35% Hispanic and 25% combined AA, Native American and Asian.

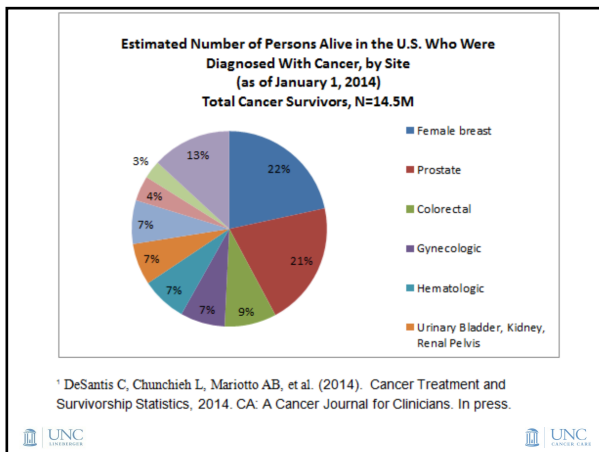
Overall increase in volume

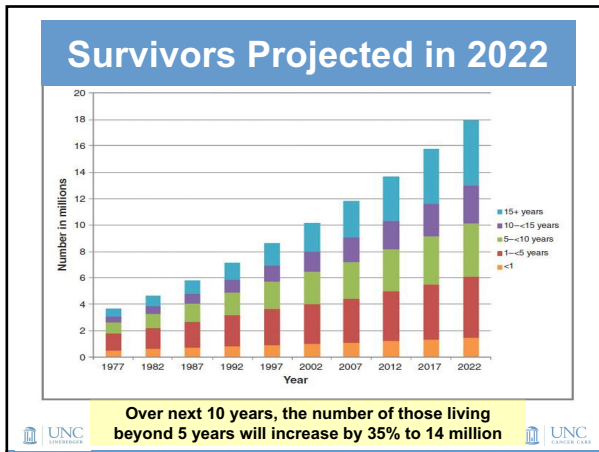
1.7→2.3 million cancer diagnosis/year → ↑ survivors











Poll: How many cancer survivors are there today?

1. Over 13.5 million
2. Over 15.5 million
3. Over 20 million
4. Over 26 million

Survivorship Defined



An individual is considered a cancer survivor from the time of diagnosis, through the balance of his or her life.

Family members, friends, and caregivers are also impacted by the survivorship experience and are therefore included in this definition.

NCI-Adapted from the National Coalition for Cancer Survivorship



Survivorship Defined

- Living cancer free
 - For remainder of life
 - Experiences ≥ 1 treatment complication
 - But dying after a late recurrence
 - But develops another cancer
- Living with cancer
 - Intermittent periods of active disease on/off treatment
 - Continuously without disease free period





Survivorship Attributes

- Defined as those who have lived through a potentially deadly or life altering event.
- It is a dynamic process
- It involves uncertainty
- It is a life changing experience
- It has duality of positive and negative aspects
- It is an individual experience with universality
 - Doyle, N. (2008) Cancer survivorship: evolutionary concept analysis. *J Adv Nursing*, 62(4): 499-509.
 - Peck (2008) Survivorship: A concept analysis. *Nsg. Forum*, 43(2), 91-102.





From Cancer Patient to Cancer Survivor: Lost in Transition




Essential Components of Survivorship Care:

- **Prevention** of recurrent and new cancers and other late effects
- **Surveillance** for cancer spread, recurrence or second cancers and assessment of medical and psychosocial late effects
- **Interventions** for consequences of cancer and it's treatment
- **Coordination** between specialists and primary care providers to ensure that all of the survivors health needs are met



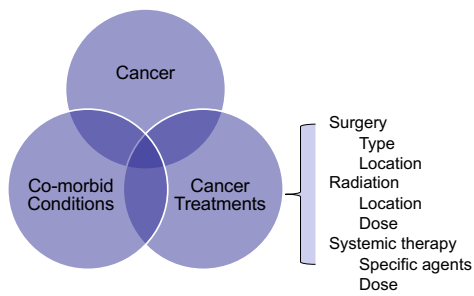

Management of Long Term and Late Sequelae



The Road Home

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Long-term and Late Effects



Source: From *Cancer Patient to Cancer Survivor: Lost in Transition*, page 24, Box 2-2.

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Comorbid Conditions in Long-term Cancer Survivors

- 1527 breast, prostate, CRC, gyn cancer survivors
- Average of 5 conditions (95% CI 4.8, 5.1) with 1.9 (95% CI, 1.8, 2.0) after diagnosis
- Hypertension 54%, Eye/ear 48.2%, Arthritis 46.3%, Heart 35.3%, Lung 30.6%, GI 25.5%, Kidney 26.6%, Diabetes 21%, Thyroid 16.5%, Bone 19.7%
- Higher burden with older age, breast ca, living alone, BMI >25, physically inactive
 - » Leach (2015). *J Cancer Surviv*, 9: 239-251.

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Unmet Needs of Cancer Survivors (ACS Cohort)

- N=1514, 2, 5 and 10 year survivors
- Not associated with time since diagnosis but there were gender and age differences
- Unmet needs included:
 - Physical (38.2%)
 - Financial (20.3%)
 - Information (19.5%)
 - » Burg (2015) Cancer



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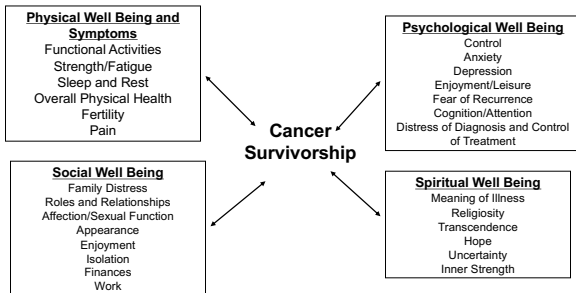


Symptom Burden and QOL in Survivors

- ~1/3 of survivors experience symptoms after treatment equivalent to during treatment
- Most common:
 - Fatigue
 - Depression or mood disturbance
 - Sleep disruption
 - Pain
 - Cognitive limitations
- Greater symptoms and poorer QOL with younger age, lower SES, increased co-morbidities
 - » Wu & Harden, *Cancer Nurs* 5/14/14 epub ahead of print
 - » Harrington et al (2010) *Int J Psychiatry Med*, 40: 163



Quality of Life



Ferrell, BR and Grant, M. City of Hope Beckman Research Institute (2004)



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<http://www.nejm.org/doi/full/10.1056/NEJMp1406033>

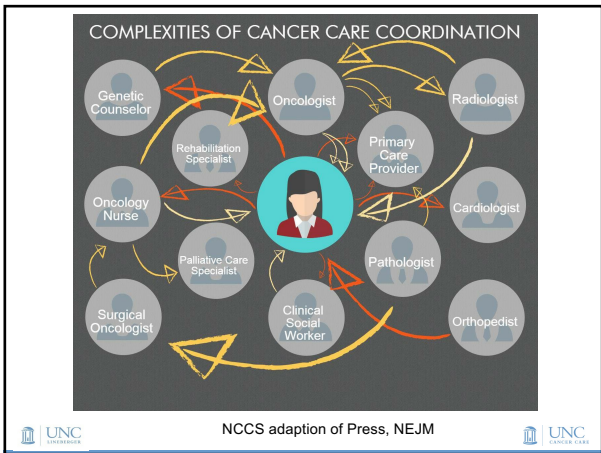
Ambulatory Care Coordination for One Patient.

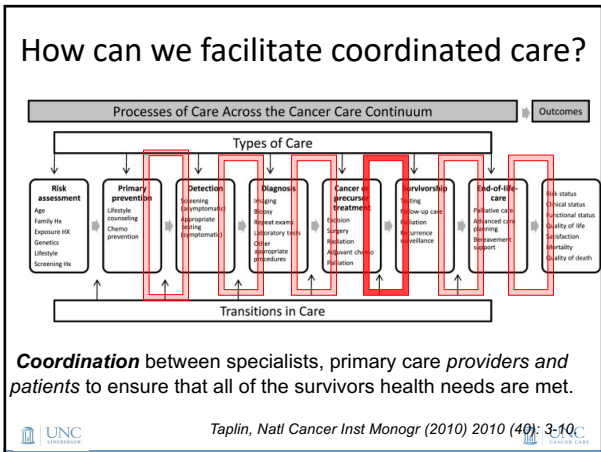
Over an 80-day period:

- 12 clinicians were involved in the care of the patient;
- Primary care physician (PCP) communicated with the other clinicians 40 times (32 e-mails and 8 phone calls) and with the patient (or his wife) 12 times;
- Patient underwent 5 procedures and had 11 office visits (none of them with his PCP).

Press MJ. (2014) Instant replay—a quarterback's view of care coordination. *N Engl J Med.*;371(6):489-91







Poll: All newly diagnosed adults with cancer should receive a SCP

- 1. True
- 2. False

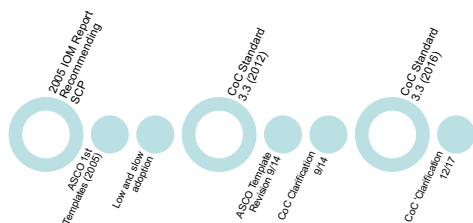


Background

- Survivorship Care Plans (SCP) consist of a treatment summary and follow-up plan for cancer survivors.
- This is intended to be delivered to the patient and primary care provider **when curative treatment ends (not stage IV).**
- The American College of Surgeons Commission on Cancer Standard 3.3 requires SCP
- Previous research has demonstrated that it is time consuming to develop and has low and sporadic uptake.



SCP Timeline



Mayer, DK, Neckiyudov, L, Snyder, C., Merrill, J., Wollins, D., Shulman, L. (2014). ASCO Clinical Expert Statement on Cancer Survivorship Care Planning. *J Onc Practice*, 10(6):345-51.

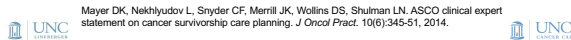


Survivorship Care Plans (SCP)

ASCO Clinical Expert Statement on Survivorship Care Planning:

- Discusses the importance of developing SCPs in delivering this information to both the patient and primary care provider
- Summarizes the *minimum data elements* needed in the SCP
- Identifies and provides solutions to barriers to implementation (especially time to complete)

Mayer DK, Nekhyudov L, Snyder CF, Merrill JK, Wolins DS, Shulman LN. ASCO clinical expert statement on cancer survivorship care planning. *J Oncol Pract.* 10(6):345-51, 2014.



ASCO SURVIVORSHIP CARE PLAN ASSUMPTIONS

- The SCP has two-parts, a treatment summary and care plan.
- It is intended to facilitate *communication and coordination* of care between the patient, oncology providers, primary care providers and other providers.
- It does not replace discussions but rather is *an adjunct* to those discussions.
- The SCP should be as simple, clear and understandable as possible to meet the needs of the intended users; if actions are identified, the SCP should include who is primarily responsible.
- The SCP is not intended to be or to replace the medical record; detailed original source documentation may be needed by providers for clinical care.
- It is intended for patients treated with curative intent for adult cancers regardless of tumor type.
- Future development of SCPs intended for other patients (e.g. survivors with advanced cancer, survivors with ongoing treatment) is needed.
- It may not always be developed and/or presented in an electronic format but its documentation should be included in the survivor's medical record along with a copy sent to the primary care provider.



Disease-Specific SCP Templates

- ASCO had five existing disease-specific templates
 - Breast
 - Colorectal Cancer
 - Non-Small Cell and Small Cell Lung cancer
 - Diffuse Large B-Cell Lymphoma
- Engaged disease-site experts to develop new templates based on the minimum essential elements
- Available at ASCO Survivorship Compendium
 - downloaded ~7000 times over first 12 months with ~3000 times in the first 3 months

<http://www.asco.org/practice-research/survivorship-care-clinical-tools-and-resources>



CoC 'Clarifications'

Survivorship Care Plan Standard 3.3. Report


Commission on Cancer updated the scope and timing of its standard based on ASCO work:

- Jan. 1, 2015: Implement a pilot survivorship care plan process involving 10% of eligible patients
- Jan. 1, 2016: Provide survivorship care plans to $\geq 25\%$ of eligible patients
- Jan. 1, 2017: Provide survivorship care plans to $\geq 50\%$ of eligible patients
- Jan. 1, 2018: Provide survivorship care plans to $\geq 75\%$ of eligible patients

During the implementation period, cancer programs should initially concentrate on their most common disease sites, such as breast, colorectal, prostate, early-stage bronchogenic, and lymphoma.



- Cancer Programs that have fully implemented the Standard by the time of their on-site visit during the 2015, 2016, 2017 survey cycle, will receive special recognition in their Performance Reports at the time of their next survey.

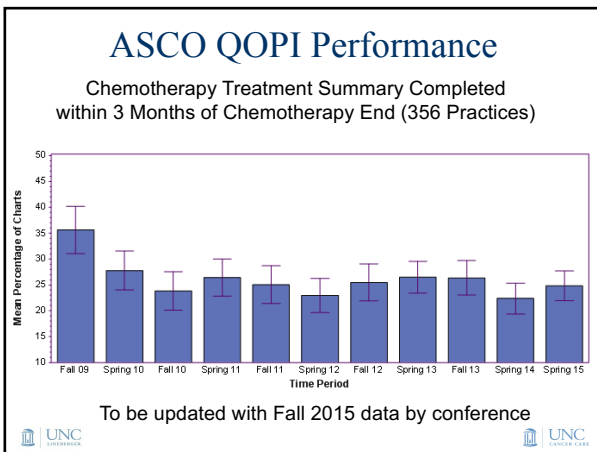
<https://www.facs.org/publications/newsletters/coc-source/special-source/standard33>

CoC Clarifications

- The [Commission on Cancer](#) (CoC) announced that effective December 11, 2017, the percentage of delivered survivorship care plans to eligible patients required for CoC-compliance with Standard 3.3 has been lowered to 50% for 2018. All CoC-accredited programs will be expected to meet or exceed the delivery of survivorship care plans to 50% of eligible patients by the end of 2018.



Team Questions

- Who completes and enters Dx/Staging into EPIC?
- Who will estimate projected approx. treatment end date and track when SCP due?
- Who should receive the alert that SCP is due?
- What happens with the alert once received?
- How does the first follow-up visit get scheduled?
- Who will develop the SCP?
- Who delivers/shares/documents the SCP?



UNC Process for SCP Development

Each tumor group given SCP draft template to adapt to reflect groups' standards for each cancer and to decide process for identifying, tracking and delivering SCP to eligible patients.

SCP Template submitted for Epic creation → validated by tumor group and validation of the diagnosis groupers so the right template attaches to the correct dx.

Approved SCP template put in production in Epic → piloted by group for 2-4 weeks for any changes needed.

SCP presented to entire tumor group during a tumor board.

Group begins SCP implementation.

Create reporting tools to identify eligible patients and track delivery.



Epic Tip Sheet Instructions Reflected SCP Refinements

Beginning:
5 pages → 9 steps,
>20min.

After Beacon updates:
2 pages → 4 steps,
<5min.

Currently working on
automatically importing
diagnosis and staging and
develop reporting tools



What have we learned and where are we now?

Lessons:

- Start small → narrowed scope to bladder cancer but look for higher incidence of events
- Have inclusive team (then ask who else should be included)
- Keep key people informed of progress
- Ask for feedback
- Prepare for glitches along the way; Beacon upgrade created delays but simplified processes



Survivorship: Where are we headed?

- Many transitions throughout cancer care requiring *written* plans-move upstream and repeat
- SCP alone may be inadequate to meet the survivorship needs of patients and PCP
- One size will not fit all
- Future development of SCPs intended for other patients (e.g. survivors with advanced cancer) is needed.
- Careful attention is needed for consistent implementation
- It is a **slow** process



**Survivorship:
Where are we headed?**

- Survivorship care plans → include Treatment Plan
- More organized survivorship care programs
- Increased training for all HCPs
- NP models of survivorship care
- Risk based triage
- Better communication and coordination of care between providers (enhanced with EHR)
- Tools for measuring needs of survivors and outcomes of care
- More attention is needed in addressing health care disparities



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Survivorship Compendium

As an accompaniment to the educational opportunities and clinical guidance ASCO offers on survivorship care, the Survivorship Care Compendium has been developed to serve as a repository of tools and resources to enable oncology providers to implement or improve survivorship care within their practices. Although ASCO endorses the National Coalition for Cancer Survivorship definition of a cancer survivor as starting at the point of diagnosis, the focus of the information and resources offered throughout this compendium is on those individuals who have completed curative treatment or who have transitioned to maintenance or prophylactic therapy.

Key Components of Survivorship Care Building a Survivorship Care Program Models of Long-Term Follow-Up Care

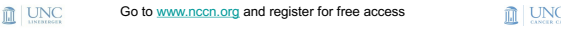
<http://www.asco.org/practice-guidelines/cancer-care-initiatives/prevention-survivorship/survivorship/survivorship-compendium>



Survivorship Guidelines (NCCN)

- Assessment By Health Care Provider at Regular Intervals (SURV-4)
- Survivorship Baseline Assessment (SURV-A)
- Anxiety and Depression (SANXDE-1)
- Cognitive Function (CF-1)
- Fatigue (SFAT-1)
- Female sexual functioning (SSFF-1)
- Male sexual functioning (SSFM-1)
- Definition of Survivorship & Standards For Survivorship Care (SURV-1)
- General Principles of the Survivorship Guidelines (SURV-2)
- Screening for Second Cancers (SURV-3)
- Survivorship Resources For Healthcare Professionals And Patients (SURV-B)
- Pain (SPAIN-1)
- Sexual Function
- Sleep Disorders (SSD-1)
- Healthy Lifestyles (HL-1)
- Immunizations and Infections (SIMIN-1)
- General Survivorship Principles
- Late Effects/Long-Term Psychosocial and Physical Problems
- Preventive Health
- Physical Activity (SPA-1)
- Nutrition and Weight Management
- Immunizations

Go to www.nccn.org and register for free access



National Resources

Cancer Survivorship E-Learning Series for Primary Care Providers

<https://smhs.gwu.edu/gwci/survivorship/hcsrc/elearning>

- Module 1: The Current State of Survivorship Care and the Role of Primary Care Providers
- Module 2: Late Effects of Cancer and its Treatments: Managing Comorbidities and Coordinating with Specialty Providers
- Module 3: Late Effects of Cancer and its Treatments: Meeting the Psychosocial Health Care Needs of Survivors
- Module 4: The Importance of Prevention in Cancer Survivorship: Empowering Survivors to Live Well
- Module 5: A Team Approach: Survivorship Care Coordination
- Module 6: Cancer Recovery and Rehabilitation
- Module 7: Spotlight on Prostate Cancer Survivorship: Clinical Follow-Up Care Guideline for Primary Care Providers
- Module 8: Spotlight on Colorectal Cancer Survivorship: Clinical Follow-Up Care Guideline for Primary Care Providers
- Module 9: Spotlight on Breast Cancer Survivorship: Clinical Follow-Up Care Guideline for Primary Care Providers
- Module 10: Spotlight on Head and Neck Cancer Survivorship: Clinical Follow-Up Care Guideline for Primary Care Providers

Cancer Survivorship in Primary Care

www.cancersurvivorshipprimarycare.org

