NCCN Virtual Oncology Fellows Program:
New Horizons in Quality Cancer Care™

Wednesday, March 17, 2021
2:15 PM – 2:45 PM EDT

Survivorship: From Adolescents and Young Adults to Older Adults

Christine E. Hill-Kayser, MD
Abramson Cancer Center at the University of Pennsylvania

NCCN.org – For Clinicians | **NCCN.org/patients** – For Patients

Cancer Survivorship: From AYA to Older Adult

- What is cancer survivorship?
  - NCI Office of Cancer Survivorship:
    - "an individual is a cancer survivor from the moment of diagnosis through the balance of his or her life"
- Fitzhugh Mullan Seasons of Survivorship
  - **Acute survivorship:** diagnosis ➢ end of initial treatment. Focus: Cancer treatment
  - **Extended survivorship:** end of initial treatment ➢ months after. Focus: Effects of cancer and treatment
  - **Permanent survivorship**: years after the end of treatment. Focus: Long-term effects of cancer and treatment
- Survivorship care begins after cancer treatment in most cases
- May include patients with chronic cancers or long-term treatment plans
- 2005 publication "From Cancer Patient to Cancer Survivor: Lost in Transition"
  - Catalyst for the modern era of survivorship care and attention
  - Focused on "the period following first diagnosis and treatment and prior to the development of a recurrence of the initial cancer or death"

Penn Medicine
Radiation Oncology

Cancer Survivorship: From AYA to Older Adult

Trajectory of Cancer Care

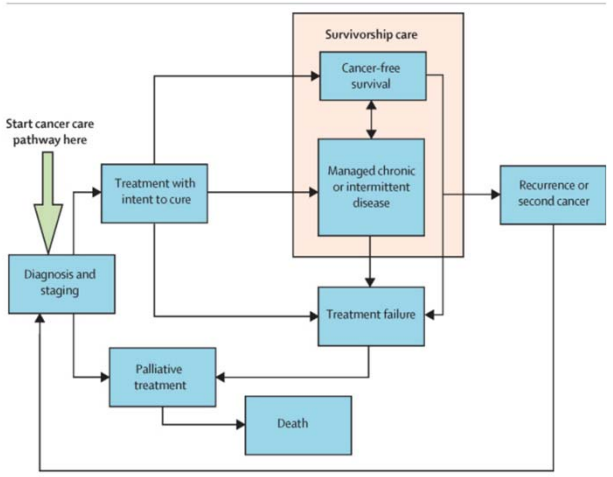
Panel 1
Cancer survivorship experiences and trajectories[8]

Living cancer free

- For the remainder of life
- For many years but experiencing one or more serious, late complications of treatment
- For many years, but dying after a late recurrence
- Living cancer free after the first cancer is treated, but developing a second cancer

Living with cancer

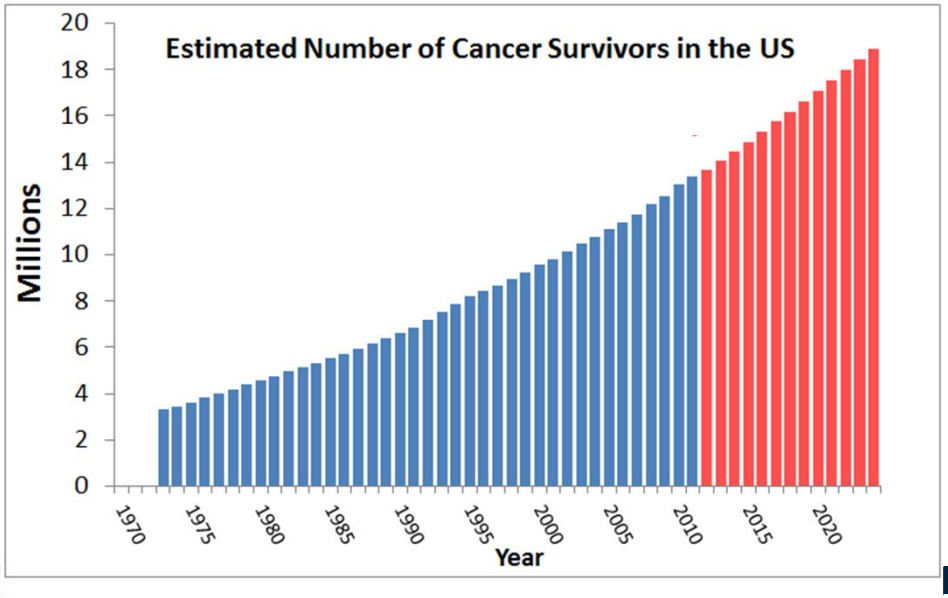
- Living with intermittent periods of active disease requiring treatment
- Living with cancer continuously without a disease-free period



Mayer D, etal. Lancet Oncology, Vol18, Issue 1, 2017

Cancer Survivorship: From AYA to Older Adult

- Cancer survivors represent a huge and diverse group
  - ACS and NCI estimate 16.9 million survivors in 2019, with a prediction of increase to 22 million by 2030
  - Most (>65%) are > 65 years
  - <10% < 39 years



[1] DeSantis C, Chunchieh L, Mariotto AB, et al. (2014). Cancer Treatment and Survivorship Statistics, 2014. CA: A Cancer Journal for Clinicians. In press.

Penn Medicine
Radiation Oncology

Cancer Survivorship: From AYA to Older Adult

- Survivorship needs may be very diverse:
  - Medical needs
    - Surveillance for recurrent disease
      - May be more comprehensive with oncologic follow-up
      - Varies with disease type, often well-documented and standardized
    - Age-appropriate screening for medical illnesses
      - May be more comprehensive with follow-up from PCP
      - Standardized, but may be impacted by treatments received, specific risk factors, family history
    - Late and long-term effects
      - Incredibly diverse
      - Related to drug therapy, radiotherapy, surgery
      - May affect any organ system
      - Patient experience may differ from provider expectations
    - Wellness and healthy living: Needed by all

Penn Medicine
Radiation Oncology

Cancer Survivorship: From AYA to Older Adult

- Psychological and Psychosocial needs
  - Emotional and mental health
    - Managing fear of recurrence
    - Survivor guilt
  - Health insurance
  - Employment
  - Financial toxicity
- Many survivors are not followed by both PCP and multiple specialists
- Communication between survivors and among clinicians is challenging
  - Transitions of care, care at multiple centers, and multiple EMRs are complicated
  - Survivors frequently report being unsure of who is in charge of their care
  - Awareness of screening and management is imperative for clinicians in many specialties

Penn Medicine
Radiation Oncology

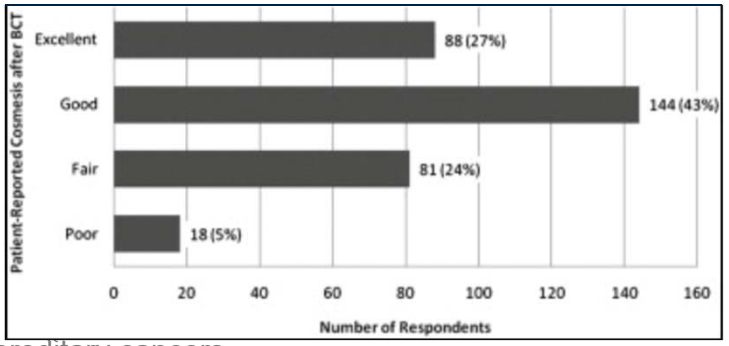
Cancer Survivorship: Late and Long-term Health Effects

- Cancer treatment-related effects may be long-term or late
  - Long-term: Occurs during therapy and persists
  - Late: Arising after completion of therapy
  - Examples: cardiotoxicity, neuropathy, chronic pain, musculoskeletal problems, fatigue, insomnia, cognitive challenges, sexual dysfunction, infertility
- Late and long-term effects are impacted by
  - Type of cancer
  - Type of treatment
  - Population
  - Co-morbidities
  - Individual experiences

Penn Medicine
Radiation Oncology

Cancer Survivorship: Breast Cancer

- Represent 41% of female cancer survivors
  - Non-breast cancer causes of death in 72% of older survivors and 48% of younger (Chapman 2008)
    - Second cancer and cardiovascular disease most common causes of non-BC death
    - Association of obesity and breast cancer risk; survivors at risk for other health issues associated with obesity
    - Healthy lifestyle and wellness of particular importance
- Late/long-term effects include:
  - Fatigue & cognitive changes
  - Neuropathy & arthralgias
  - Cardiopulmonary dysfunction
  - Lymphedema
  - Cosmesis and emotional impact – patient vs. provider
- Survivorship issues vary widely with age:
  - Younger: Premature menopause/reproductive issues, risk of hereditary cancers
  - Older: fatigue and cognitive changes confounded by aging process
  - Significant disparities between socioeconomic and ethnic/racial groups



Hill-Kayser, IJROBP, 2010

Penn Medicine
Radiation Oncology

Cancer Survivorship: Lung Cancer

- Lung cancer survivors represent about 3% of the overall survivor population
- Most survivors will have had thoracic surgery +/- chemotherapy, radiotherapy

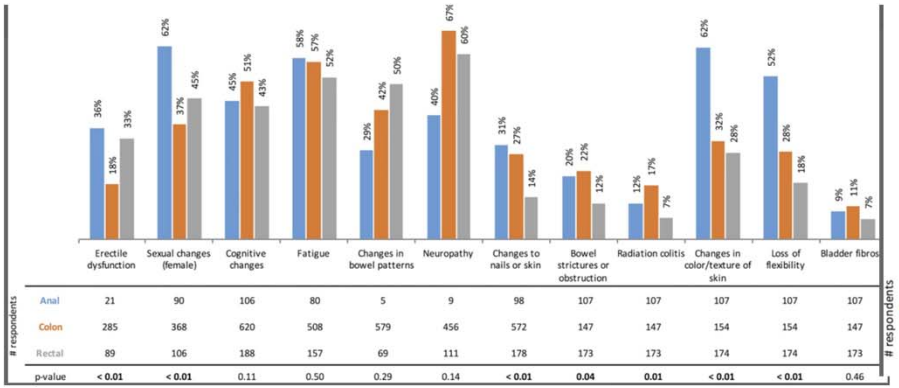
- QOL in survivorship impacted by (Li 2002; Ozturk 2009):
  - Post-thoracotomy pain, reduced lung capacity, fatigue, cough, dyspnea, depression, neuropathy
  - 90% of survivors report persistent fatigue
  - Up to 50% report cognitive changes (Berman 2016)
    - May relate to intersection with normal aging process
  - Stigma associated with lung cancer and “fault” related to smoking

- Behavioral health/ modifiable risk counseling of high importance
  - Tobacco cessation

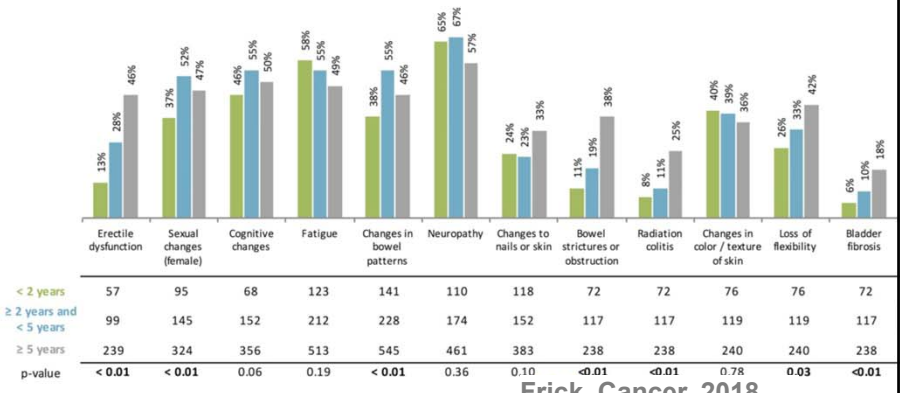
Penn Medicine
Radiation Oncology

Cancer Survivorship: Colorectal Cancer

- Dramatic increase in survival over the past decade, largely due to screening
- Treatment is generally surgical +/- chemotherapy, radiotherapy
- Common late and long-term effects (Frick, 2018):
  - Fatigue, cognitive changes in >50%
  - Neuropathy
  - Diarrhea/stool changes
  - Sexual dysfunction
    - Higher in men with rectal and anal cancer compared to colon ca (>30% vs 18%)
    - Higher in women with anal cancer vs colon or rectum (62% vs <50%)



# respondents	Erectile dysfunction	Sexual changes (female)	Cognitive changes	Fatigue	Changes in bowel patterns	Neuropathy	Changes to nails or skin	Bowel strictures or obstruction	Radiation colitis	Changes in color/texture of skin	Loss of flexibility	Bladder fibrosis
Anal	21	90	106	80	5	9	98	107	107	107	107	107
Colon	285	368	620	508	579	456	572	147	147	154	154	147
Rectal	89	106	188	157	69	111	178	173	173	174	174	173
p-value	< 0.01	< 0.01	0.11	0.50	0.29	0.14	< 0.01	0.04	0.01	< 0.01	< 0.01	0.46

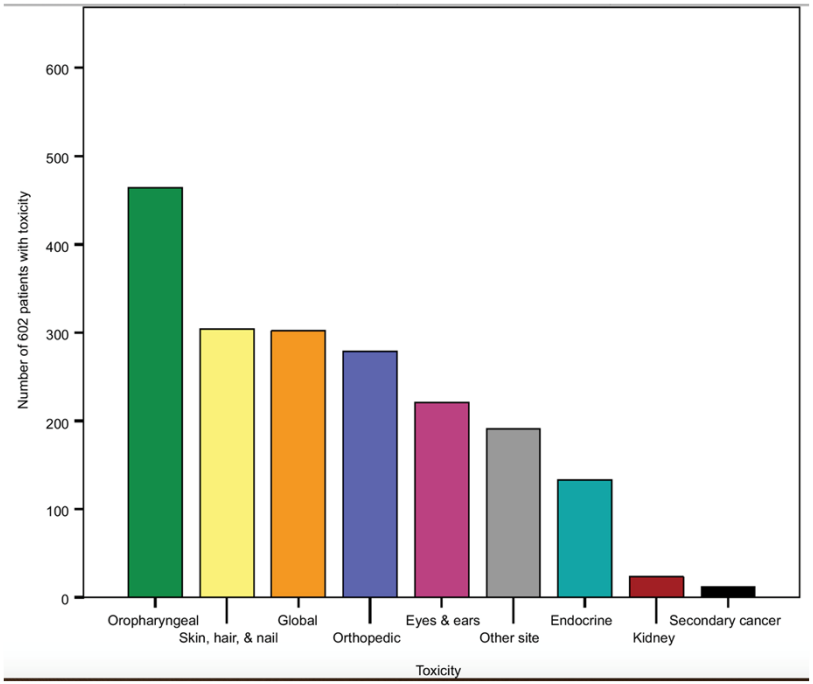


# respondents	Erectile dysfunction	Sexual changes (female)	Cognitive changes	Fatigue	Changes in bowel patterns	Neuropathy	Changes to nails or skin	Bowel strictures or obstruction	Radiation colitis	Changes in color / texture of skin	Loss of flexibility	Bladder fibrosis
< 2 years	57	95	68	123	141	110	118	72	72	76	76	72
≥ 2 years and < 5 years	99	145	152	212	228	174	152	117	117	119	119	117
≥ 5 years	239	324	356	513	545	461	383	238	238	240	240	238
p-value	< 0.01	< 0.01	0.06	0.19	< 0.01	0.36	0.10	<0.01	<0.01	0.78	0.03	<0.01

Frick, Cancer, 2018

Cancer Survivorship: Head & Neck Cancer

- Represent 3% of survivor population
- Population growing, with younger age due to HPV-associated HNC (Song, 2020)
- Unmet needs identified in 60-70%
  - Directly correlate with QOL (Giuliana 2016)
- Specific needs:
  - Speech/swallowing difficulties
    - Feeding tubes
  - Dental needs/edentulism
  - Significant impact on self esteem, depression, anxiety
  - Cognitive changes
  - Fatigue
  - Neuropathy



Peach, PRO,2017

Penn Medicine
Radiation Oncology

Cancer Survivorship: Chronic Cancer

- Chronic cancer – cannot be cured, but can be controlled for months to years
- Goal of treatment – for survivors to live as well as possible, for as long as possible

- Chronic cancers: chronic leukemia, recurrent/metastatic cancer of another nature
  - Likely expanding population as advances in treatment and supportive care continue
  - May include curable cancer with extended treatment (e.g., hormone therapy for breast cancer)
- Chronic cancer survivors may be more likely to report significant multisystem late/long term effects
  - Fatigue, cognitive changes, dyspnea, neuropathy, sexual dysfunction, kidney/liver disease (Frick 2017)
- May be more likely to be managed by oncologist alone vs co-management by PCP and oncologist (Frick 2017)

Penn Medicine
Radiation Oncology

Cancer Survivorship: Models for Care

- Very limited evidence regarding services to improve outcomes for cancer survivors
- Essential elements of survivorship care model:
  - Surveillance for recurrence, screening for second cancers, assessment and intervention of long-term/late effects, counseling for healthy living, and communication/coordination with primary care
- Evolution regarding who provides survivorship care, and for how long
  - Prior focus on oncologist has shifted
- Models for survivorship care:
  - Nurse-led survivorship care models
    - Survivor may transition from oncologist to NP; alternativey, NP provides finite survivorship visits while oncologist continues care
  - PCP partner – risk-based approach to shared care or transition to PCP
  - Rehabilitation care model – psychosocial care, exercise, PT; more common in Europe
  - Self-management model – methods of patient empowerment allow individuals to optimize health; elementary phases, may not be an independent model

Penn Medicine
Radiation Oncology

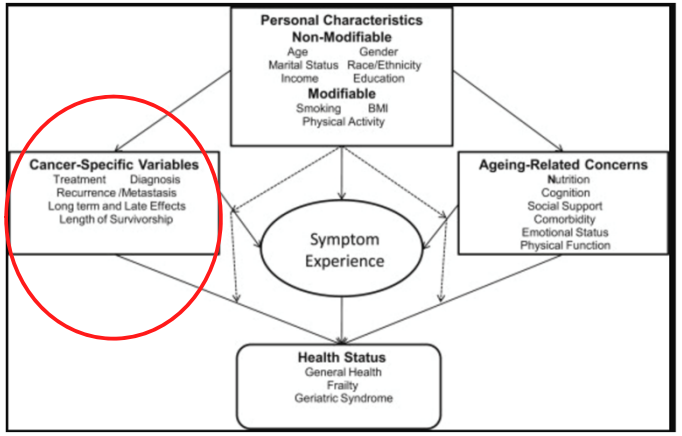
Cancer Survivorship: Models for Care

- Nurse-led survivorship care models (Halpern 2016)
  - Transition from oncologist to NP
    - Radiation oncologist treats prostate cancer, transfers care to survivorship NP at FUV 1 or 2
    - NP provides routine surveillance FU care; patient transitions back to oncologist only if recurrence
    - PCP remains involved
    - May be most appropriate for diseases unlikely to recur with standardized follow-up guidelines
  - Dedicated NP survivorship visit
    - Oncologist treats patient with colon cancer
    - At end of therapy, patient has survivorship consultation with NP
    - Survivorship issues outside of disease surveillance discussed with NP; oncologist continues disease surveillance
    - May be most appropriate for patients with diseases more likely to recur or more rare
- PCP Partner Risk-Adapted Model
  - A group of lung cancer survivors are evaluated
  - Those at lower risk for recurrence/late effects (RT only) transitioned to PCP for all care
  - Those at higher risk for recurrence/late effects continue seeing oncologist and PCP

Penn Medicine
Radiation Oncology

Cancer Survivorship: Older Adults

- The vast majority of survivors living in the US are older adults (> 65 years)
  - Health effects of cancer treatments compounded by effects of aging
    - Osteoporosis
    - Sexual dysfunction
    - Cognitive decline
    - Decreased immunity
  - Older cancer survivors frequently have poorer health and functional status than those without a cancer diagnosis
  - Proposed models for care and research endorse a gero-oncology survivorship paradigm
  - Often requires care by multiple specialists



Bellury,Eur J Onc Nurs, 2011

Penn Medicine
Radiation Oncology

Cancer Survivorship: Adolescents & Young Adults

- Opposite end of health spectrum: May have late or long-term effects in setting of otherwise healthy body
- Very diverse group based on diagnosis as child vs. adult
  - Survivors of pediatric cancer may have access to dedicated survivorship clinic
  - Transition from pediatric to adult center often challenging
  - Coincides with other transitions:
    - Parents' care to self-care
    - Relocation
    - Desire for "normal life"
- Health needs may be very complex and involve multiple organ systems
- Psychosocial needs are very different
  - Employment
  - Fertility
  - Lack of knowledge
  - Some individuals well-positioned for self-management

Penn Medicine
Radiation Oncology

Cancer Survivorship: Adolescents & Young Adults

- Long-term and late effect reporting varies based on diagnosis as well as age
  - Neurocognitive and sexual complaints may be less common, fatigue may be more common
- Communication strategies may differ
  - AYA survivors may be more willing to engage in digital or app interventions
  - AYA-STEPS trial
    - 85% retention with digital intervention
    - 88% uptake of digital survivorship information (King-Dowling 2021)
      - Engagement increased in summer (Pshigios 2021)

Patient-reported late effect	*YAS*	*AS*	p
Fatigue	156/277 (56)	443/769 (58)	0.719
Neurocognitive	243/485 (50)	776/1226 (63)	<0.001
Cardiovascular	4/402 (1)	106/1209 (1.4)	0.50
Pulmonary	65/200 (33)	78/167 (47)	0.005
Second cancer	16/454 (4)	36/233 (3)	0.501
Female sexual	178/377 (47)	714/1237 (58)	<0.001
Male sexual	19/143 (13)	36/233 (15)	0.564

	YAS of breast cancer	*AS of breast cancer*	
Fatigue	84/92 (91)	262/478 (54)	<0.001
Neurocognitive	99/165 (60)	457/680 (67)	0.080
Cardiovascular	0/167 (0)	3/779 (0.4)	0.503
Pulmonary	11/15 (73)	34/51 (66)	0.962
Second cancer	0/114 (0)	16/814 (2)	0.131
Female sexual	68/124 (54.8)	531/859 (61.8)	0.137

	YAS of lymphoma	*AS of lymphoma*	
Fatigue	21/49 (42)	31/52 (60)	0.092
Neurocognitive	21/49 (42)	40/76 (53)	0.402
Cardiovascular	0/44 (0)	5/64 (8)	0.012
Pulmonary	8/19 (42)	5/13 (38)	0.266
Second cancer	0/44 (0)	0/67 (0)	n/a
Female sexual	8/35 (23)	29/59 (49)	0.012
Male sexual	2/14 (14)	4/27 (15)	0.964

Szalda, JAYA Onc, 2016

Penn Medicine
Radiation Oncology

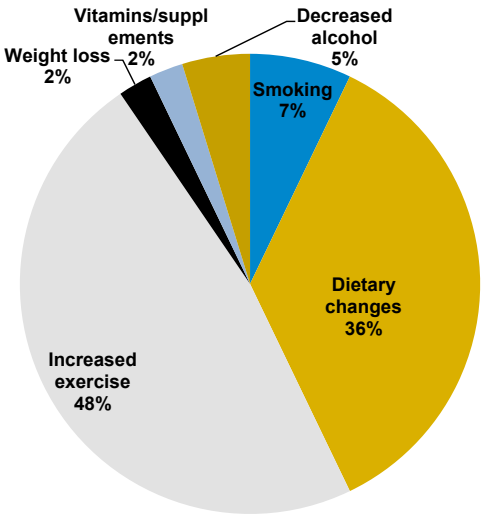
Cancer Survivorship: Tools to Support Care

- IOM recommends that all survivors receive a treatment summary and survivorship care plan
- Support self management model as well as facilitate communication between survivors and providers/among providers (both NP and PCP models)
- Treatment summary:
  - Provided by oncology team, summarizes all oncology care received
  - Most centers do not clearly delineate responsibility
- Survivorship care plan:
  - Comprehensive document customized to patient demographics, diagnosis, treatment and providing information on surveillance, screening, late/long term effects, psychosocial concerns, healthy living
  - May be provided by center or via template (Journey Forward, Oncolink)
  - Difficult to provide; may be a key part of NP survivorship consultation
  - Optimal timing may differ based on disease, treatment, and population

Penn Medicine
Radiation Oncology

Cancer Survivorship: Tools to Support Care

- Are survivorship care plans helpful?
- Remains controversial, largely because of barriers to completion
  - No immediate benefit, not efficient, no compensation
  - Attempt at requirement by COC was rescinded largely due to barriers
- May serve as sole comprehensive information source
- Can be completed by survivors themselves
  - Large volume of information
  - Largest barrier to sharing with healthcare team is fear that they will not care (Benci 2017)
- Positive impact on health behaviors (Hill-Kayser, 2013)
  - 63%: Care plan changed health care participation
  - 80% shared/planned to share with their health care team
    - 80% reported that it improved communication with their health care providers
  - 54% made or planned to make a lifestyle change in response to the plan, most commonly dietary modification and increased exercise

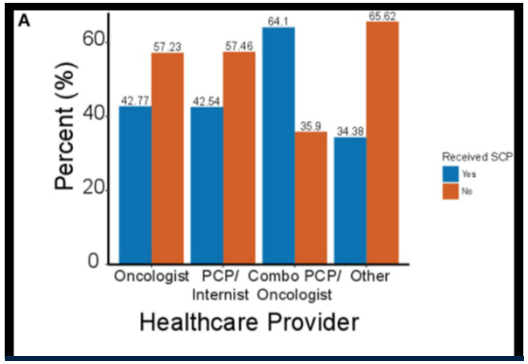


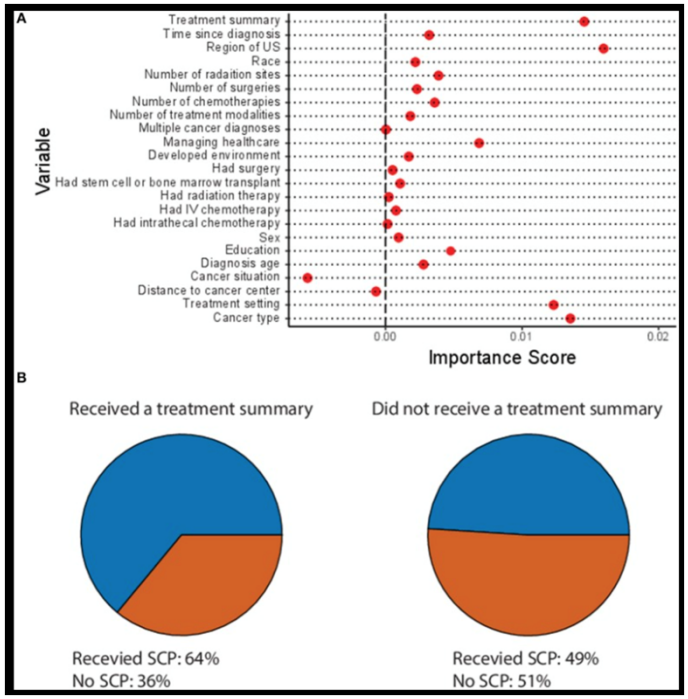
Hill-Kayser, Cancer, 2013

Penn Medicine
Radiation Oncology

Cancer Survivorship: Tools to Support Care

- Survivorship care plan delivery is variable
- Plans are not provided to most survivors
- Volume of information required and provided remains controversial





Benci, Front Oncol, 2021

Penn Medicine
Radiation Oncology

NCCN Guidelines Version 1.2021
Survivorship

*The 2021 update for this algorithm is in progress.

DEFINITION OF SURVIVORSHIP

- An individual is considered a cancer survivor from the time of diagnosis, during and immediately after treatment, and through the balance of his or her life. Family members, friends, and caregivers are also affected by cancer.[a]
- These guidelines focus on the vast and persistent impact both the diagnosis and treatment of cancer have on the adult survivor. This includes the potential impact on health, physical and mental states, health behaviors, professional and personal identity, sexuality, and financial standing.
- These guidelines are applicable to survivors across the continuum of care, including those on endocrine therapy, with chronic cancers (eg, metastatic disease), and long-term survivors.

STANDARDS FOR SURVIVORSHIP CARE[b]

Care of the cancer survivor should include:

1. Prevention of new and recurrent cancers and other late effects
2. Surveillance for cancer spread or recurrence, and screening for subsequent primary cancers (SURV-3)[c]
3. Assessment of late psychosocial, physical, and immunologic effects
4. Intervention for consequences of cancer and treatment
   (eg, medical problems, symptoms, psychologic distress, financial and social concerns)
5. Coordination of care between primary care providers and specialists to ensure that all of the survivor's health needs are met
6. Planning for ongoing survivorship care:[d]
   - ◊ Information on treatment received including all surgeries, radiation therapy, and systemic therapies
   - ◊ Information regarding follow-up care, surveillance, and screening recommendations
   - ◊ Information on post-treatment needs, including information regarding acute, late, and long-term treatment-related side effects and health risks when possible (See NCCN Guidelines for Treatment of Cancer by Site)
   - ◊ Delineation regarding roles of oncologists, primary care physicians (PCPs), and subspecialty care physicians in long-term care and the timing of transfer of care if appropriate
   - ◊ Healthy behavior recommendations (See HL-1)
   - ◊ Periodic assessment of ongoing needs and identification of appropriate resources

SURV-1

Essential aspects of survivorship care

- Surveillance for disease recurrence
- Age-appropriate cancer screening
- Assessment of insurance coverage/financial health
- Psychosocial and rehabilitation resources
- Healthy living
  - Weight management
  - Nutritious diet
  - Smoking cessation
  - Sun safety
  - Alcohol avoidance
  - Importance of routine immunizations
- Communication and care models are not one-size fits all
- Should and will vary based on disease and population being served
- Centers benefit from dedicated team with multidisciplinary representation

Penn Medicine
Radiation Oncology

Cancer Survivorship: Conclusions

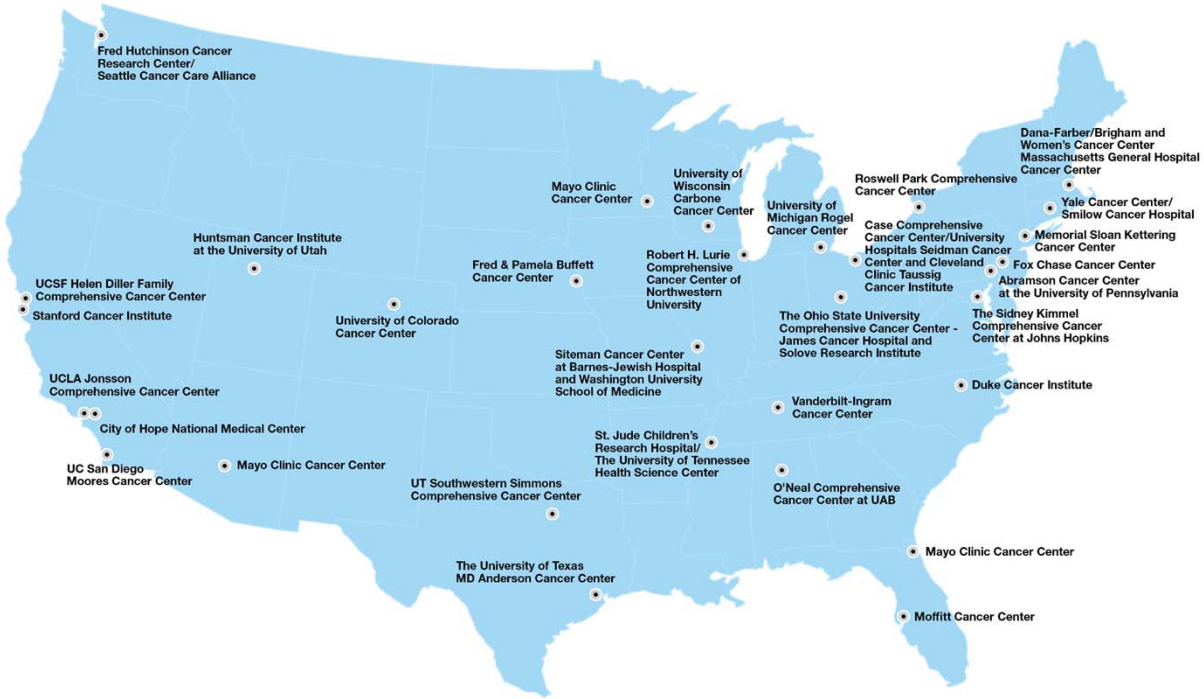
- Definition of *survivor* varies – survivorship care generally refers to the time following diagnosis and initial treatment, but may include patients with chronic cancer and those receiving extended treatment
- Survivors and their care needs are extremely diverse
  - Surveillance for recurrence, screening for medical illness, management of late/long-term effects, wellness, psychological and psychosocial needs
- Survivorship care models in the US involve collaboration between oncologist, NP and PCP
  - Care may be transferred to NP and/or PCP
  - Often, prolonged multidisciplinary care is required
  - Self-management may be used in conjunction with other models, particularly in AYA population
- Many groups recommend use of treatment summaries and survivorship care plans to promote self management and multidisciplinary communication

Penn Medicine
Radiation Oncology

National Comprehensive Cancer Network®

NCCN Member Institutions

- **Who We Are**
  An alliance of leading cancer centers devoted to patient care, research, and education
- **Our Mission**
  To improve and facilitate quality, effective, efficient, and accessible cancer care so patients can live better lives
- **Our Vision**
  To define and advance high-quality, high-value, patient-centered cancer care globally



NCCN.org – For Clinicians | **NCCN.org/patients** – For Patients