

Delivering Survivorship Care in NC



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

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<https://www.lillyoncology.com/lilly-oncology-on-canvas>



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Disclosures

- I am a stockholder and advisor to Carevive Systems
- I will not discuss any drugs during this presentation



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Objectives:

- Analyze cancer survivorship trends and define cancer survivorship
- Describe unmet needs of cancer survivors and identify the components of survivorship
- Discuss current and evolving models of survivorship care



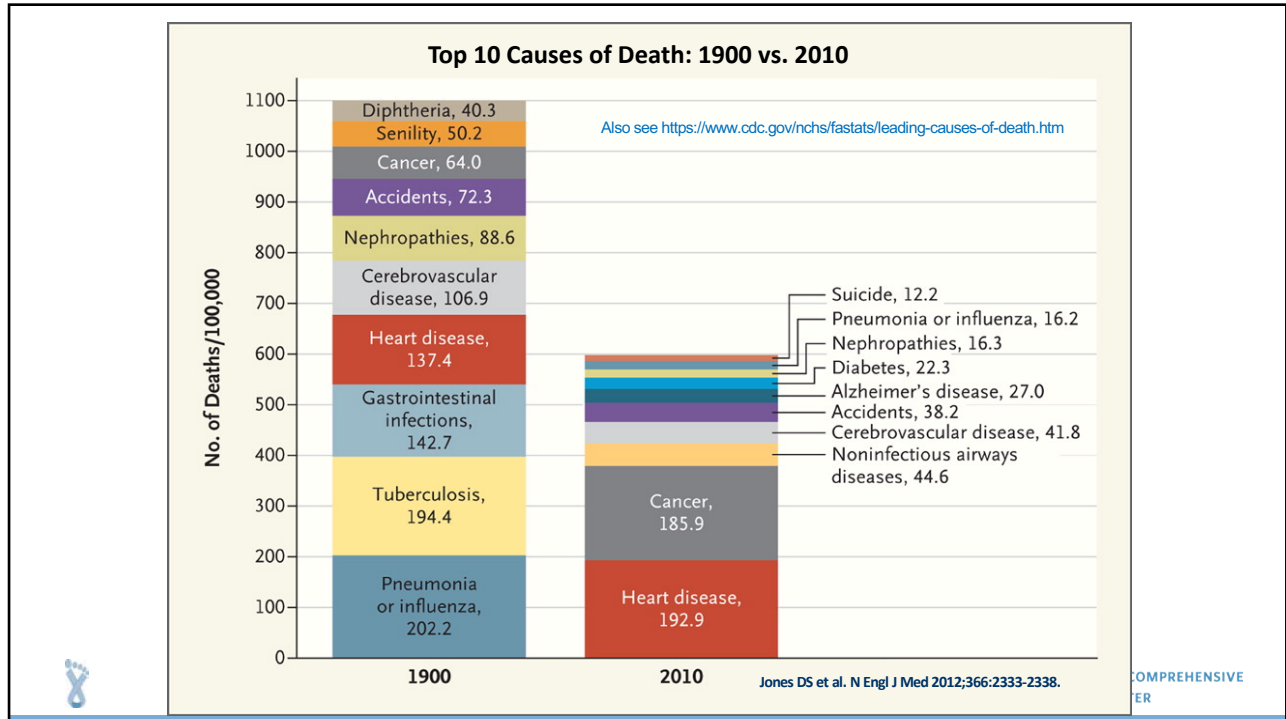
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Content

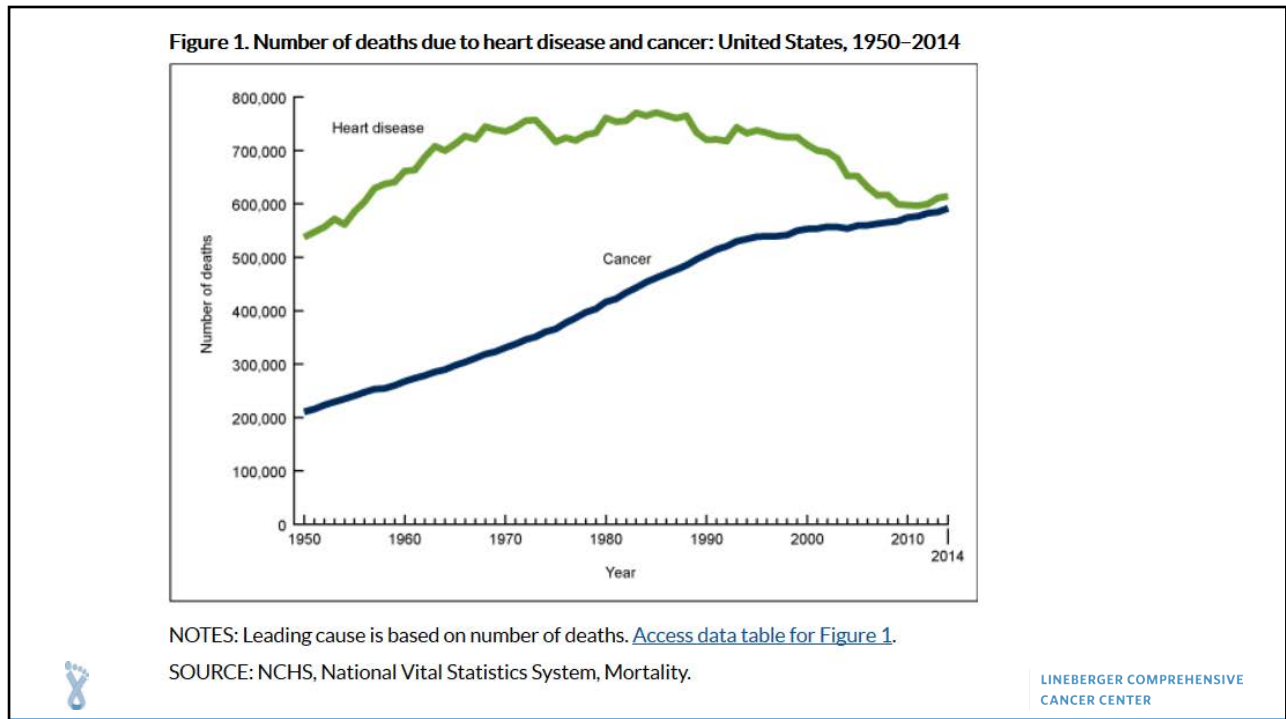
- **Cancer trends**
- Defining survivorship
- Unmet needs
- Health promotion
- Care Models



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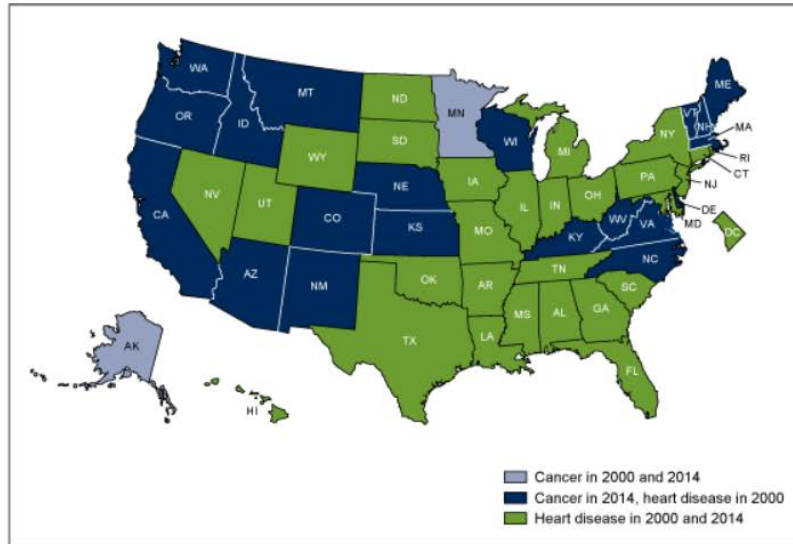


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Figure 2. Leading cause of death for each state: United States, 2000 and 2014



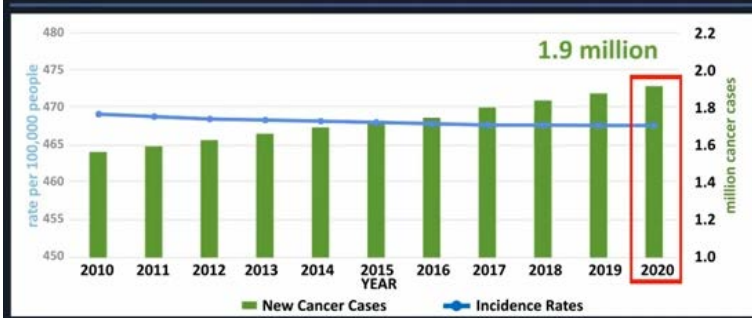
NOTE: Leading cause is based on number of deaths.
 SOURCE: NCHS, National Vital Statistics System, Mortality.



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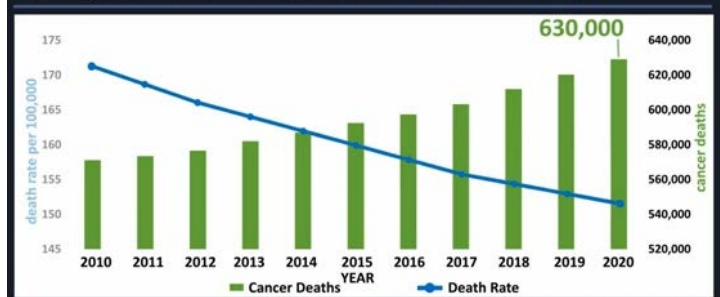
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Projected **new cancer cases**



Projected New Cancer Cases and Deaths, 2010 Through 2020

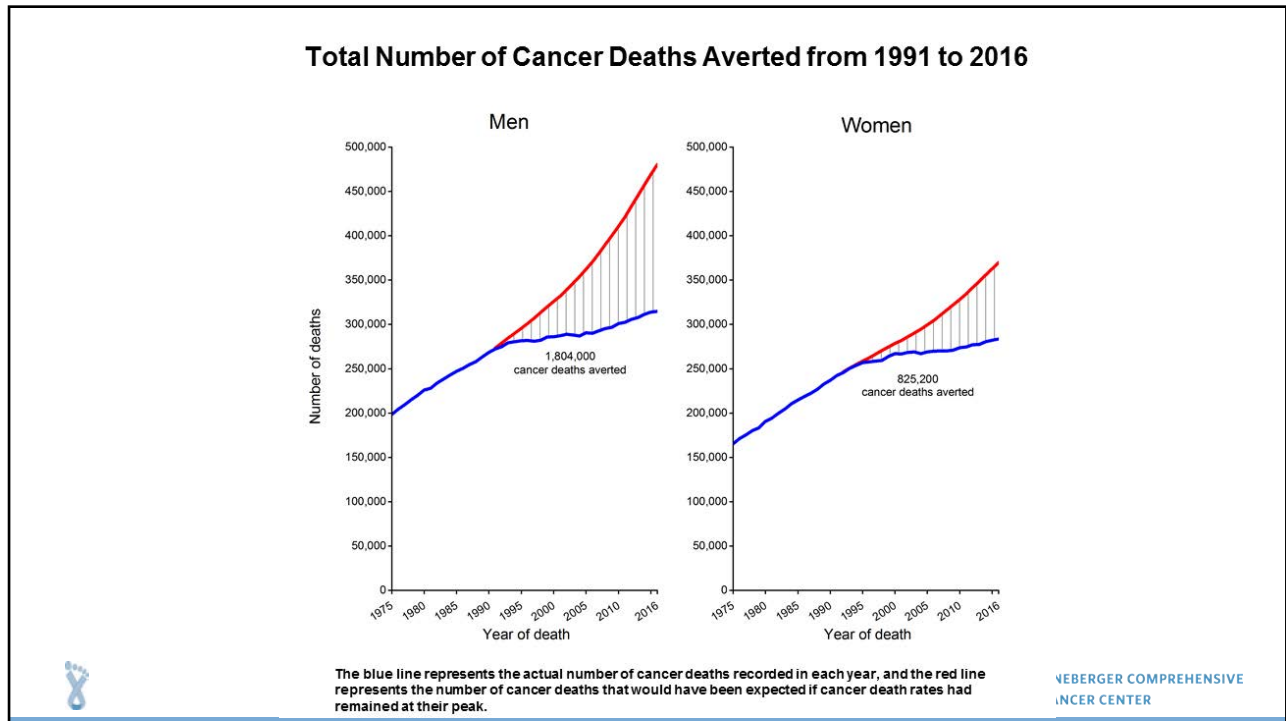
Projected number of **cancer deaths**



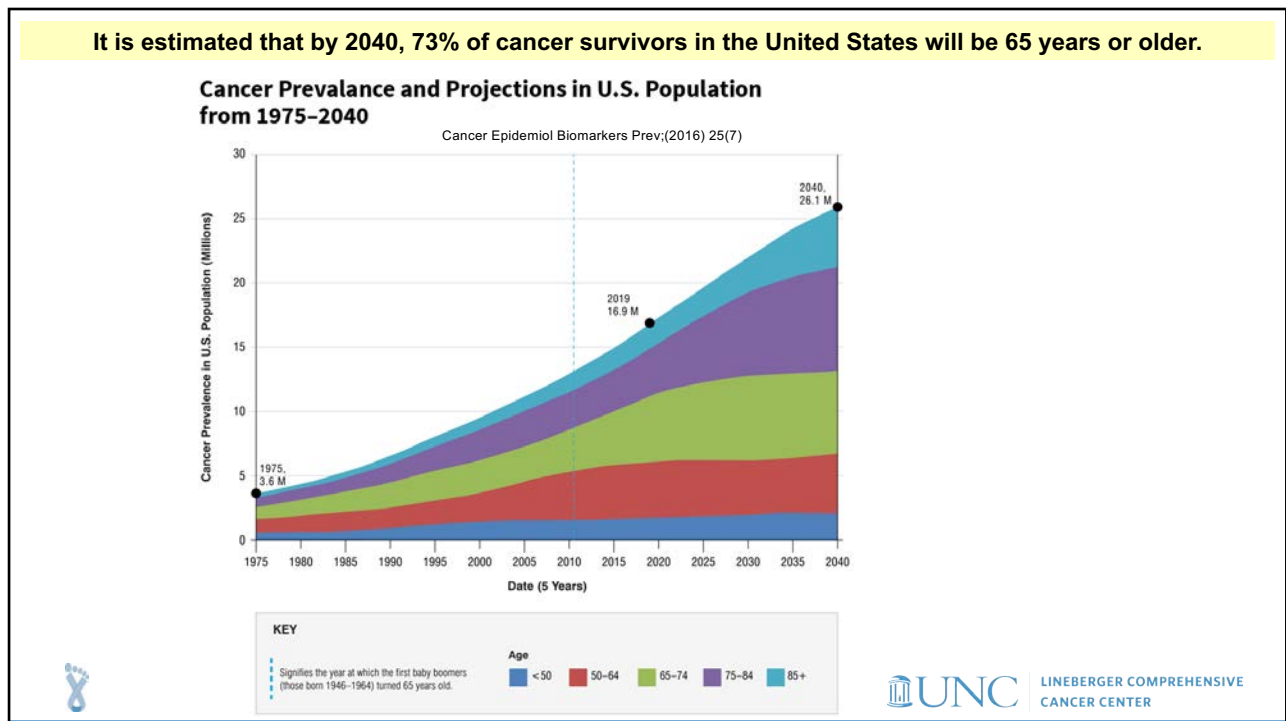
https://www.cdc.gov/cancer/dpcp/research/articles/cancer_2020.htm



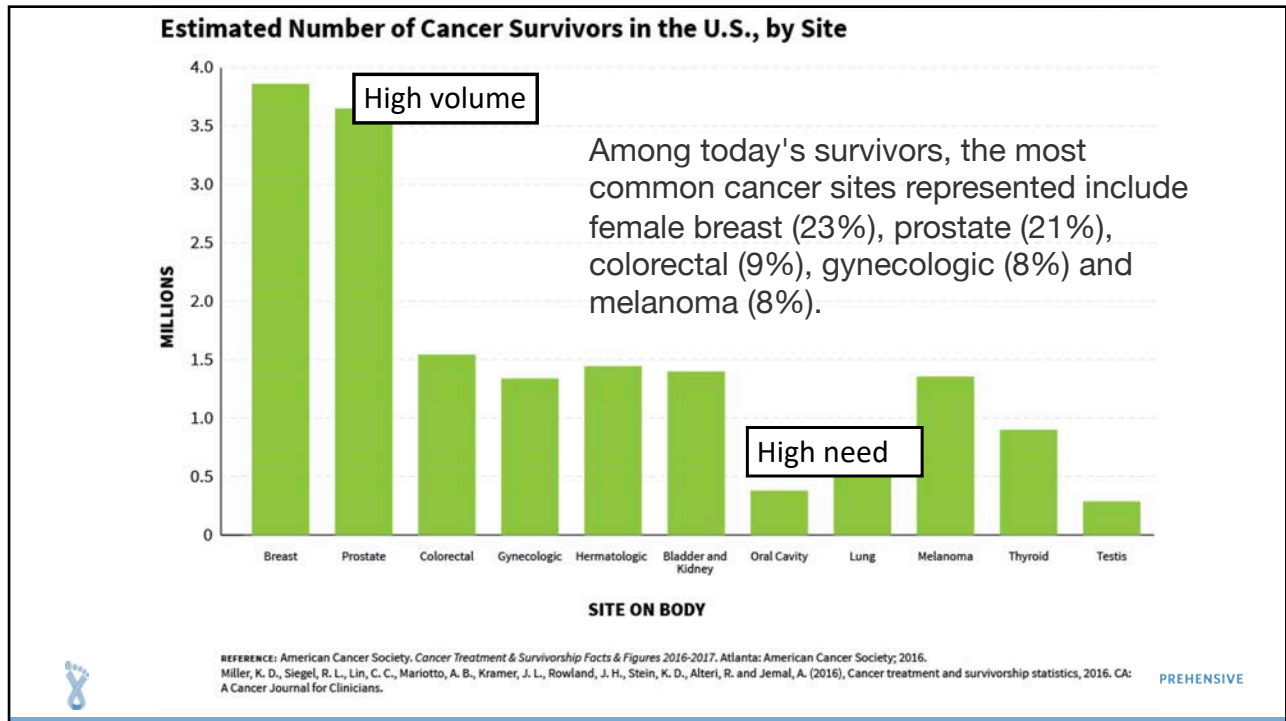
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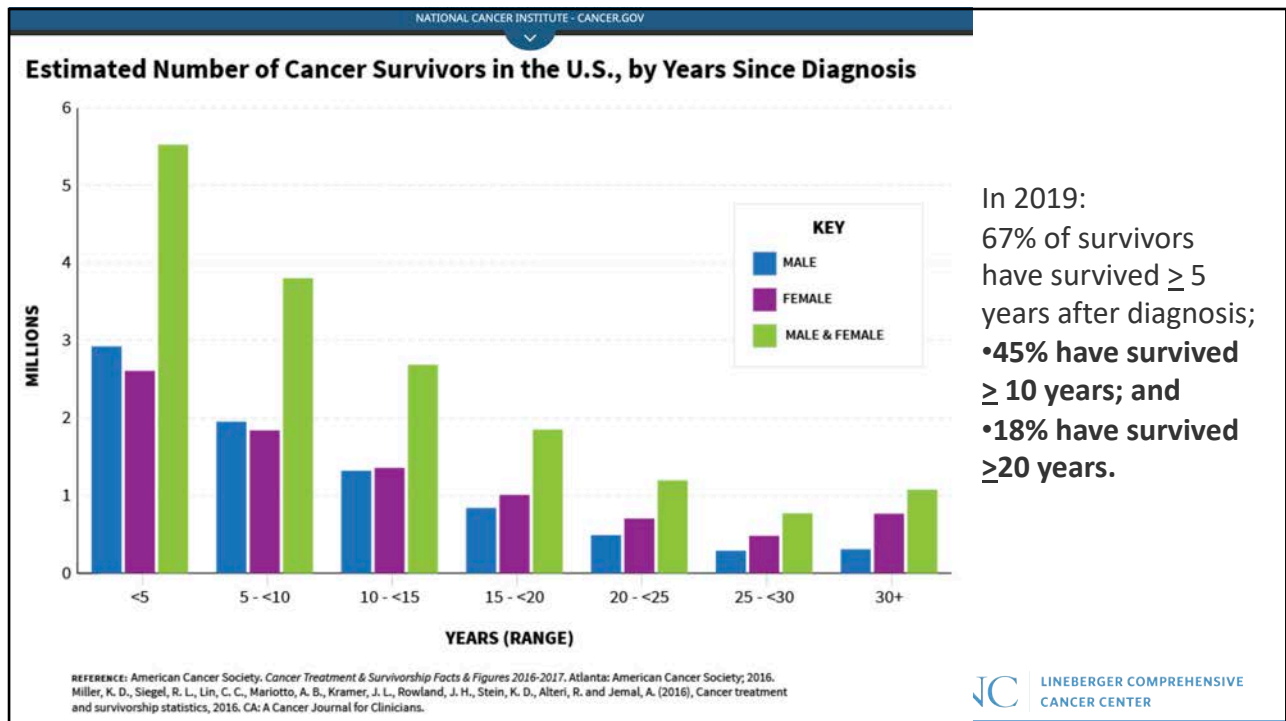
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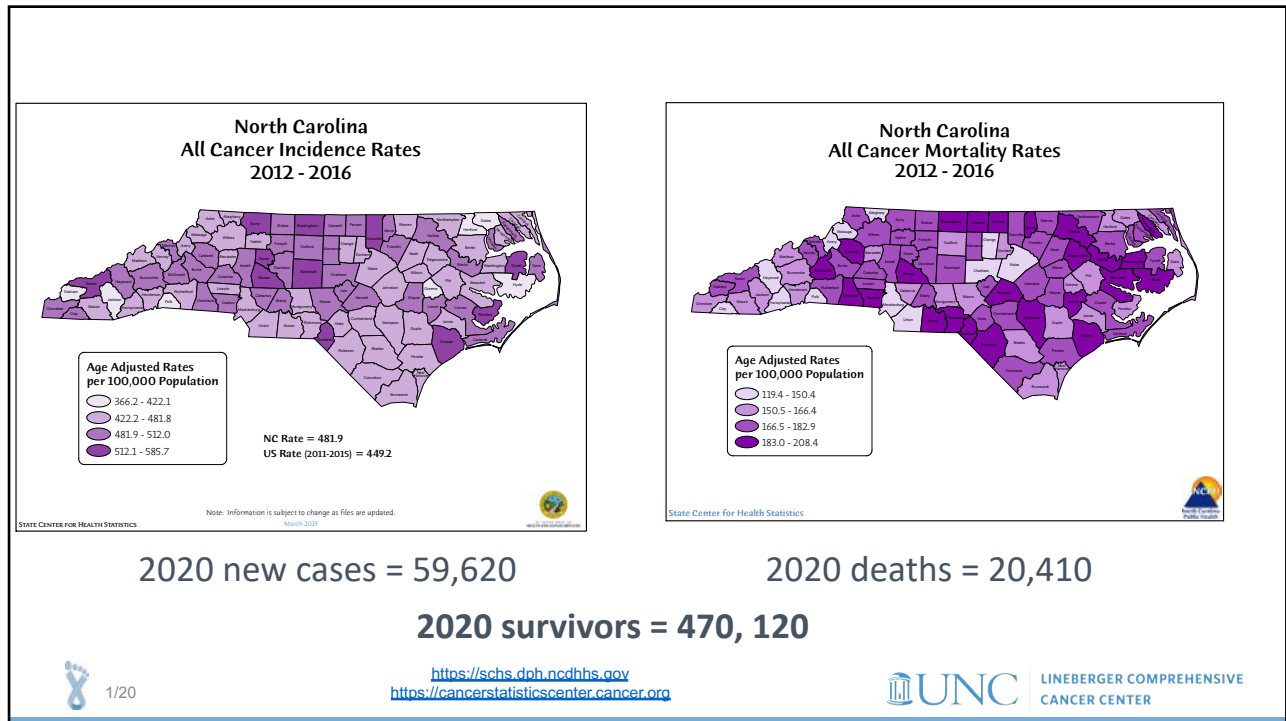
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- Cancer trends
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The Face of Cancer

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Updated NCI Survivor and Survivorship Definitions

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

There are many types of survivors, including those living with cancer and those free of cancer.

This term is meant to capture a population of those with a history of cancer rather than to provide a label that may or may not resonate with individuals.

-Adapted from the National Coalition for Cancer Survivorship



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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



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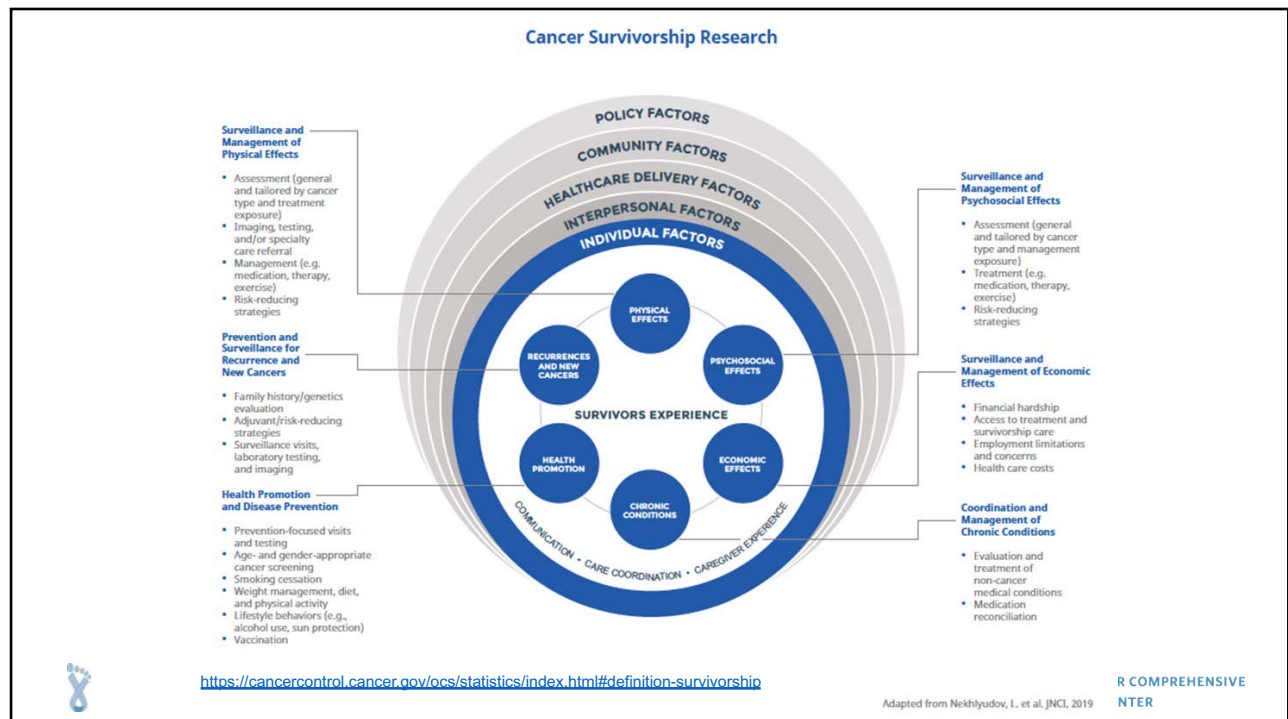
Survivorship Definition and Attributes

- 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

- Berry, LL., Davis, S., Flynn AG, et al. (2019). Is it time to reconsider the term 'cancer survivor'. *J Psychosocial Oncology*; 37(4):413-426.
- Doyle, N. (2008) Cancer survivorship: evolutionary concept analysis. *J Adv Nursing*, 62(4): 499-509.
- Hebdon, M. (2015). Survivor in the cancer context: a concept analysis. *J Adv Nursing*, 71(8): 1774-1786.
- Marzorati, C., Riva, S., Pravettoni, G. (2017). Who is a cancer survivor? *J Cancer Education*; 32:228-237.
- Peck (2008) Survivorship: A concept analysis. *Nsg. Forum*, 43(2), 91-102.



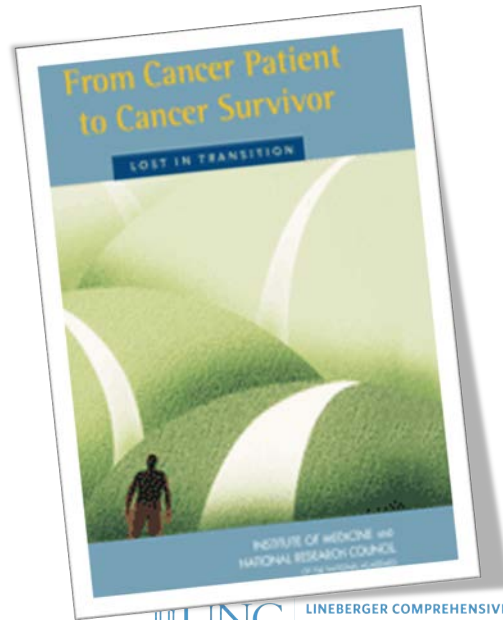
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Components of Survivorship Care

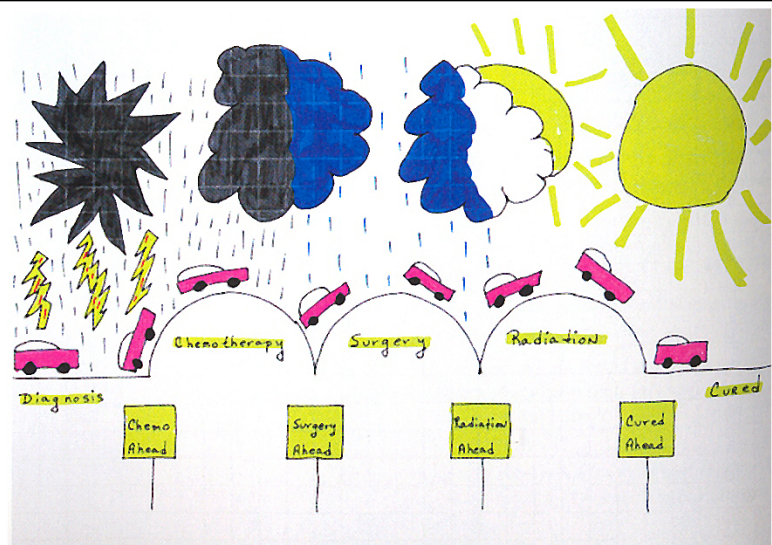
- Prevention and Surveillance for Recurrences and New Cancers
- Management of Long-Term and Late Effects: Physical
- Management of Long-Term and Late Effects: Psychosocial
- Health Promotion
- Care Coordination
- Economic Effects



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Bumps on the Road of Life



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Unmet Needs of Cancer Survivors After Treatment Ends

Systematic review of 26 studies:

- Psychological domain had greatest unmet needs
 - Fear of recurrence
- Information domain
 - Being informed about the things you can do to help yourself get well
- Physical domain
 - Dealing with feeling tired
 - Not being able to do things you used to do
- Greater unmet needs in survivors were associated with those who were younger (<65), had anxiety, poorer QOL, had comorbidities and ongoing symptoms.



Mirosevic, S. et al. (2019). *Eur J Cancer Care*; 28:e13060



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Top Unmet Needs of Cancer Survivors (n=17 studies)

Domain	Need	Prevalence Range
Physical	Not being able to do usual things	13-27%
Psychosocial	Fear of recurrence/progression	14-42%
	Help to reduce stress	12-34%
	Feeling uncertain about the future	12-26%
	Worry about partners/family/friends	12-26%
Supportive Care	Information about support services	11-33%
	Access to CAM	17-31%
	Know that clinicians communicate to coordinate care	15-31%
	Needing to talk to other people who have had cancer	13-26%
	Affordable hospital car parking	12-26%

How do we identify these people?

Greater unmet needs were significantly higher in survivors with anxiety, depression, lower QOL, younger age and more advanced cancer.



Lisy (2019). *Asia-Pac J Clin Oncol* 115:e68-e78.





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WEIGHTED % OF RESPONDENTS (n=2115) ANSWERING 'STRONGLY AGREE' OR 'AGREE' TO THE SYMPTOM ITEMS AT 1, 3 AND 5 YEARS POST-DIAGNOSIS				
Symptom item	Tumour group	1 year	3 years	5 years
I have fears about my cancer coming back	Breast	61.7	51.8	56.6
	Colorectal	53.2	33.6	33.7
	Prostate	23.7	29.9	29.0
I have trouble sleeping	Breast	59.2	49.6	52.4
	Colorectal	38.3	37.8	40.9
	Prostate	35.2	27.9	35.0
I have trouble concentrating	Breast	42.1	35.2	26.7
	Colorectal	24.9	24.9	27.8
	Prostate	21.8	21.5	21.2
I always feel tired	Breast	51.0	45.2	41.7
	Colorectal	38.2	28.6	39.1
	Prostate	29.6	27.6	31.3

How do we identify these people?

Compared to the general public, survivors had greater difficulties with usual activities (mobility, personal care, pain) 28% vs 15%), anxiety or depression (35% vs 22%). Jefford, et al. *Support Care Cancer* (2017) 25: 3171-3179.



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Depression and Anxiety in Longer-term Survivors (n=1002; 5 and 10 years)

- 17% Moderate to severe depression (PHQ-9)
- 9% Moderate to severe anxiety (GAD-7)
- Higher in women, lower in older (>60) survivors
- Those with financial problems, poorer global QOL and cognitive function strongest association

How do we identify these people?

Götze H, Friedrich M, Taubenheim S, Dietz A, Lordick F, Mehnert A. (2020) Depression and anxiety in long-term survivors 5 and 10 years after cancer diagnosis. *Support Care Cancer*.;28(1):211-220.

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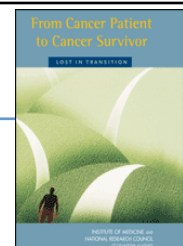
PATIENT-PROVIDER COMMUNICATION



CANCER CHAOS

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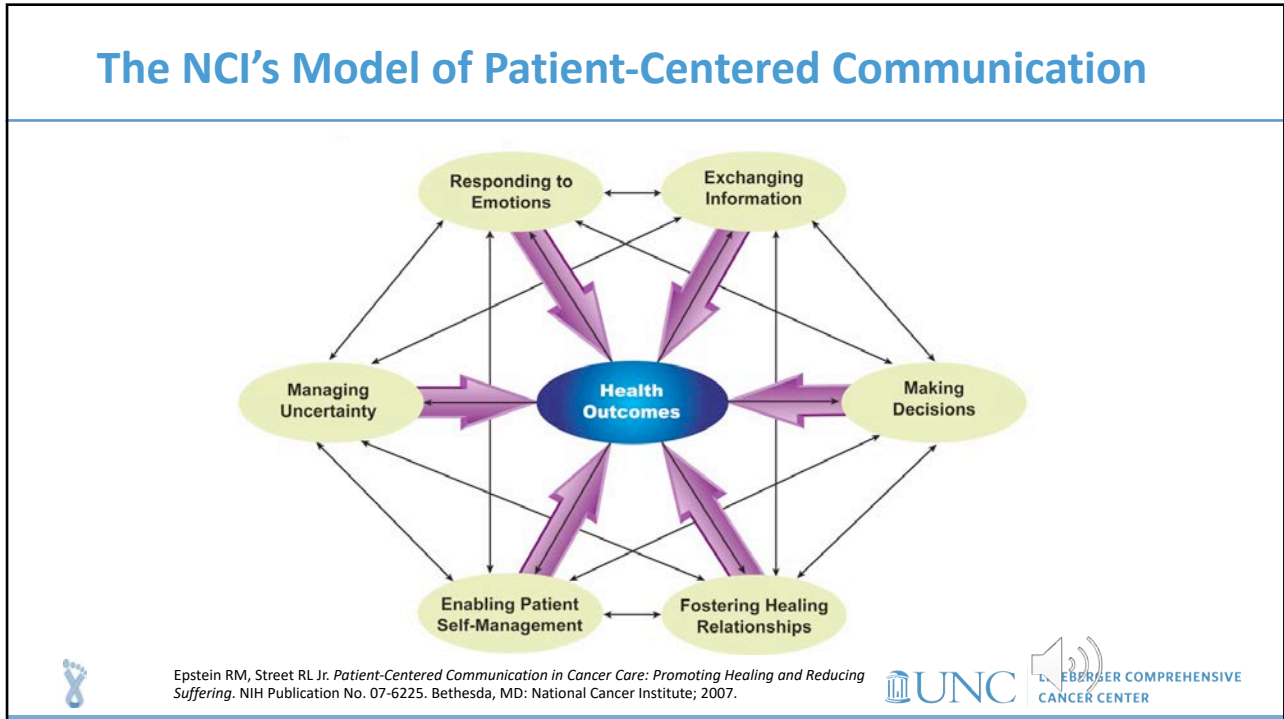
Essential Components of Survivorship Care



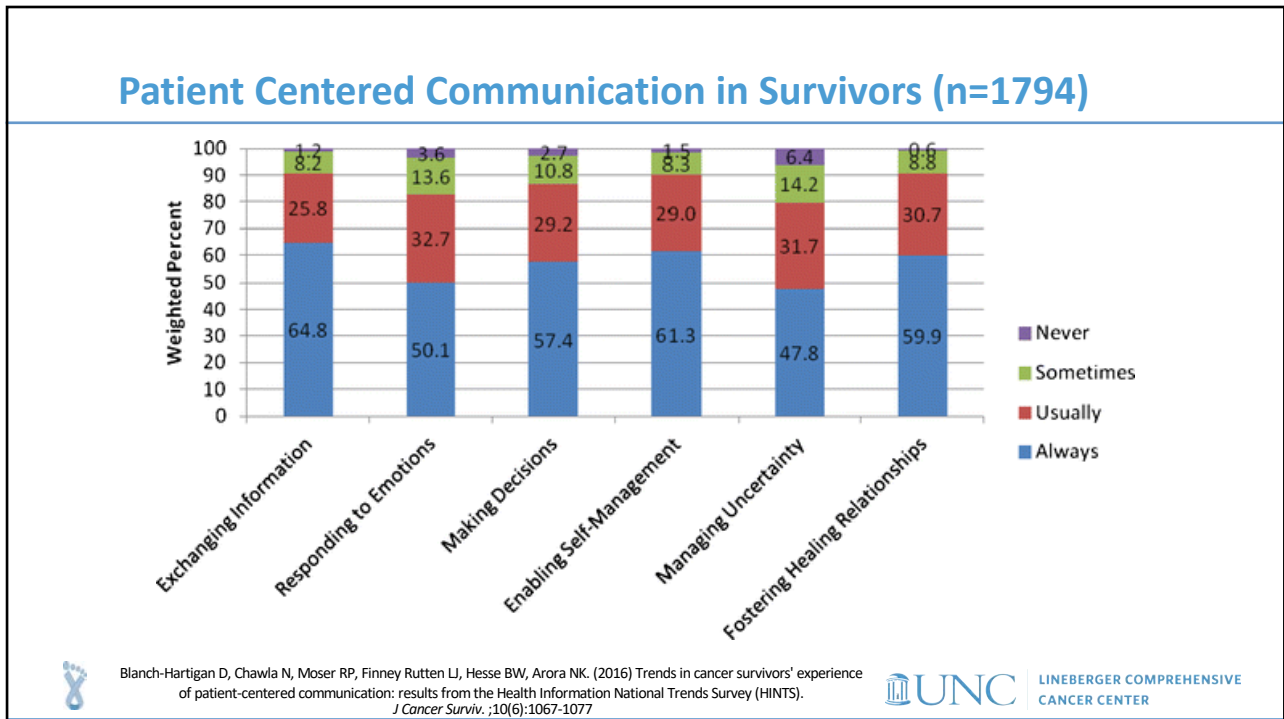
- *Prevention* of recurrent and new cancers and other late effects
- *Surveillance* for cancer spread, recurrence or new cancers and assessment and mitigation of physical and psychosocial late effects
- Health Promotion
- Coordination between specialists and primary care providers to ensure that the survivors health needs are met



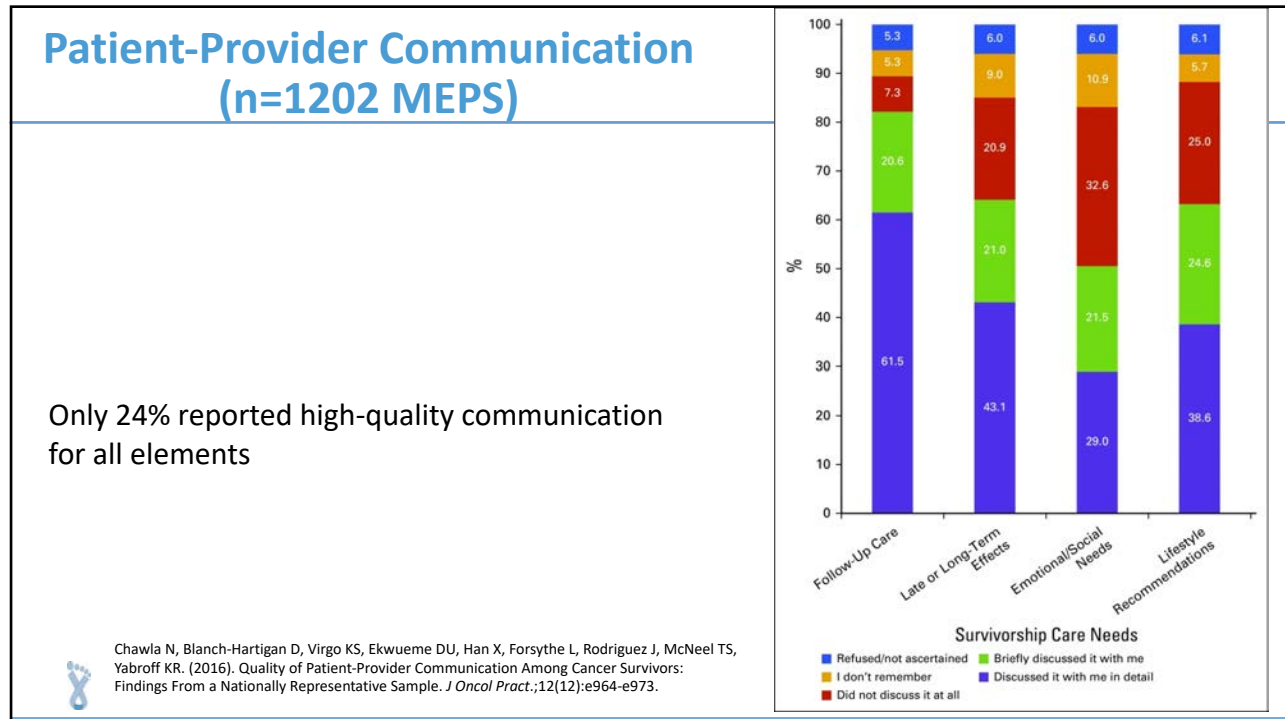
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Survivors Reported Discussions about Follow-up Care

- 615 survivors of breast, CRC, prostate, lung and melanoma across 3 health systems receiving detailed or brief discussions about:
 - 92% surveillance
 - 75% late and long-term effects
 - 69% lifestyle and health behaviors
 - 53% emotional and social needs
 - 47% treatment summaries
- No significant differences by cancer type

Reed SC, Walker R, Ziebell R, Rabin B, Nutt S, Chubak J, Nekhlyudov L. (2018) Cancer Survivors' Reported Discussions with Health Care Providers About Follow-Up Care and Receipt of Written Care Plans. *J Cancer Educ.*;33(6):1181-1188.



LINEBERGER COMPREHENSIVE CANCER CENTER

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Would have been helpful to have advice/information on these topics:

- Diet and lifestyle
- Physical activity and exercise
- Financial help or benefits
- Cost of prescriptions
- Returning to or staying in work
- Pain management and control
- Information about support groups
- Physical aspects of living with and after cancer
- Psychological or emotional aspects of living with and after cancer

About half of survivors felt they had all the advice and information needed 5 years after diagnosis (worse for survivors with co-morbid conditions, cancer not responding to treatment, not being certain about plan of care, and being female).

Jefford, et al. *Support Care Cancer* (2017) 25: 3171-3179.



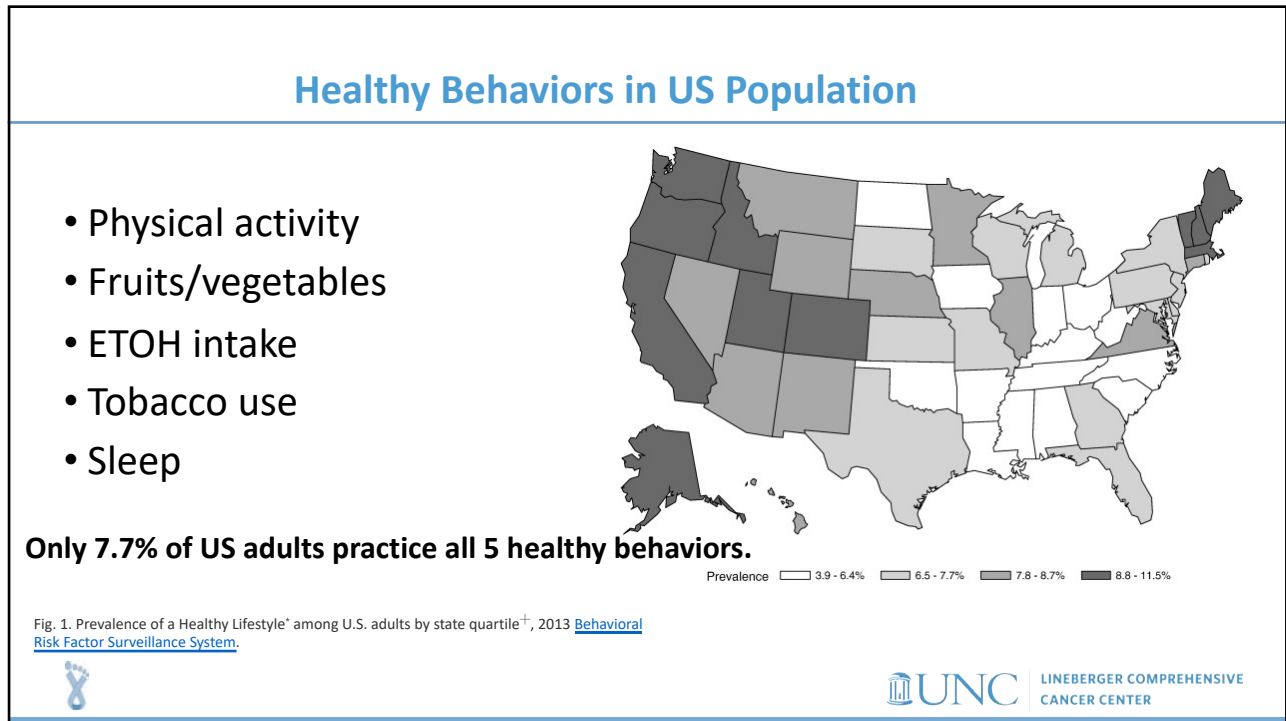
Health Promotion

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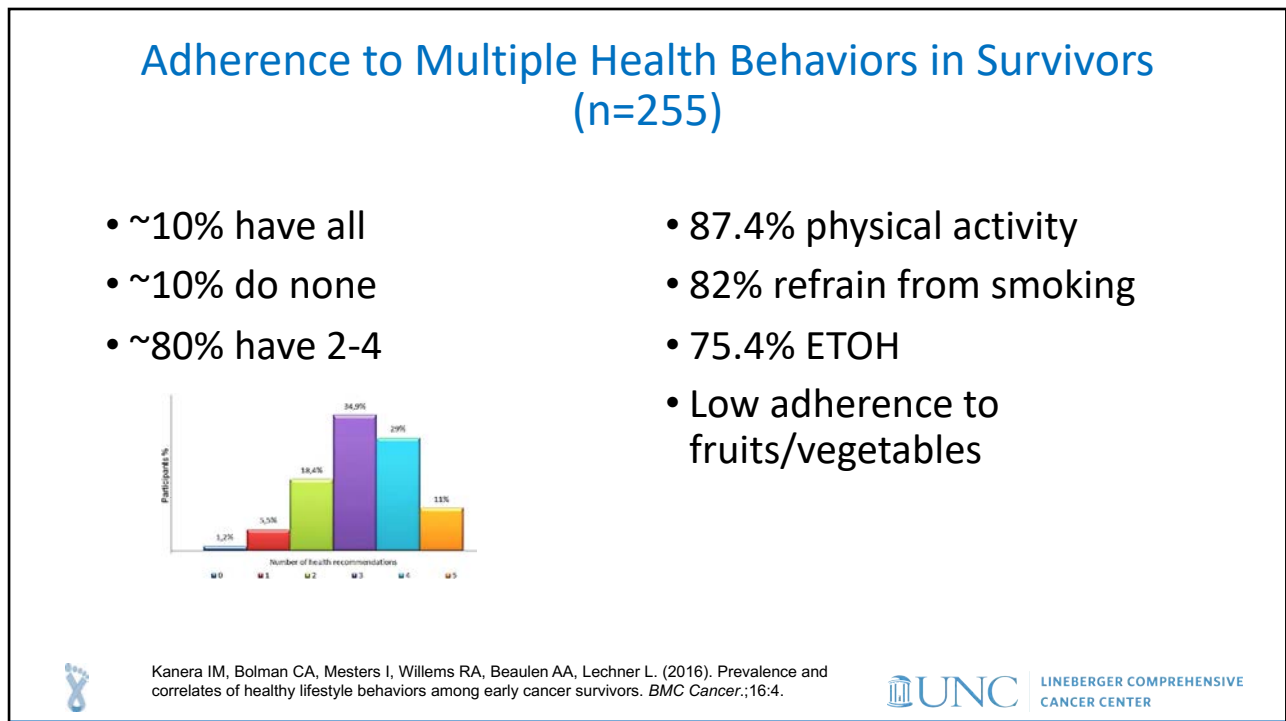


Hurdles of Hope

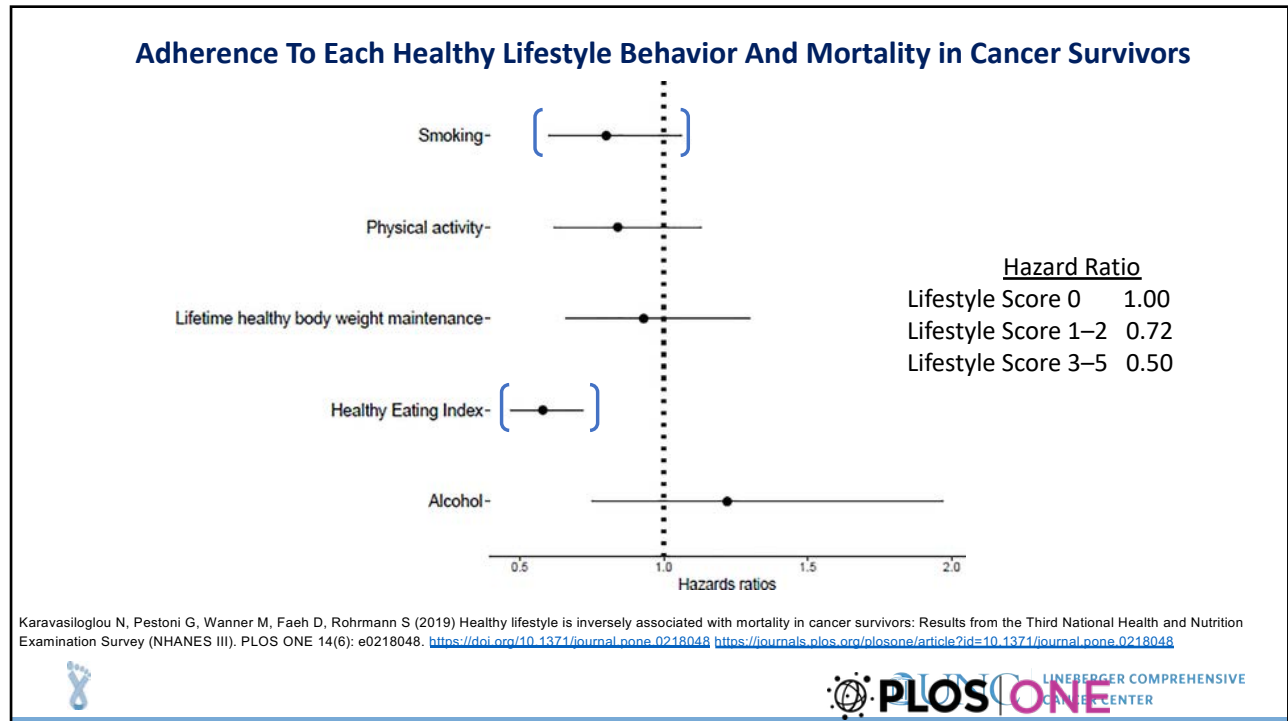




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PHYSICAL ACTIVITY

SUMMARY OF EVIDENCE THAT PHYSICAL ACTIVITY PREVENTS CANCER AND IMPROVES CANCER-SPECIFIC SURVIVAL ⁶				
LEVEL OF EVIDENCE	PHYSICAL ACTIVITY AND LOWER RISK OF DEVELOPING CANCER ^a	SEDENTARY TIME AND HIGHER RISK OF DEVELOPING CANCER ^a	PREDIAGNOSIS PHYSICAL ACTIVITY AND LOWER RISK OF CANCER-SPECIFIC SURVIVAL ^b	POSTDIAGNOSIS PHYSICAL ACTIVITY AND LOWER RISK OF CANCER-SPECIFIC SURVIVAL ^b
Strong	Colon, breast, endometrial, kidney, ^c bladder, ^c esophageal, ^d stomach (cardia) ^c Lung ^c · Myeloma and hematologic, ^c head and neck, ^c pancreas, ^c ovary, ^c prostate ^c	Endometrial, ^d colon, ^c lung ^c Liver ^e	Breast, colon	Breast, colon, prostate
Moderate				
Limited				

LEVEL OF EVIDENCE FOR THE BENEFIT OF EXERCISE ON CANCER-RELATED HEALTH OUTCOMES		
STRONG EVIDENCE ^a	MODERATE EVIDENCE	INSUFFICIENT EVIDENCE
Reduced anxiety	Sleep	Cardiotoxicity
Fewer depressive symptoms	Bone health (for osteoporosis prevention, not bone metastases)	Chemotherapy-induced peripheral neuropathy
Less fatigue		Cognitive function
Better QOL		Falls
Improved perceived physical function		Nausea
No risk of exacerbating upper extremity lymphedema		Pain
		Sexual function
		Treatment tolerance

CA Cancer J Clin 2019;69:468-484

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Healthy Lifestyle Discussions

874 lung and CRC survivors >5 years from diagnosis

- 59% physical activity (how much and what kind)
- 44% diet (how much and what kind)
- 24% no discussion

1460 >65 years old >1 year from diagnosis

- 49% physical activity
- 53% diet
- 28% vegetable
- 33% weight loss in overweight/obese survivors
- 85% smoking cessation in smokers

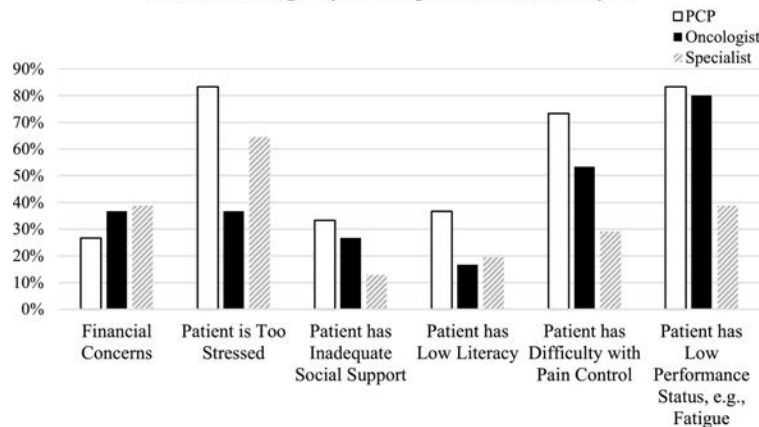
• Kenzik K, Pisu M, Fouad MN, Martin MY. (2016). Are long-term cancer survivors and physicians discussing health promotion and healthy behaviors? *J Cancer Surviv.*;10(2):271-9.
 • Halilova KI, Pisu M, Azuero A, Williams CP, Kenzik KM, Williams GR, Rocque GB, Martin MY, Kvale EA, Demark-Wahnefried W. (2019) Healthy lifestyle discussions between healthcare providers and older cancer survivors: Data from 12 cancer centers in the Southeastern United States. *Cancer Med.*;8(16):7123-7132.



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Physicians' Perspectives On Medication Adherence And Health Promotion Among Cancer Survivors

What barriers for cancer patients in remission would keep you from discussing ways to adopt a healthier lifestyle?



Oncologists barriers: Cancer focus, time pressure, lack of expertise in behavior change training, care coordination, concerns about adherence



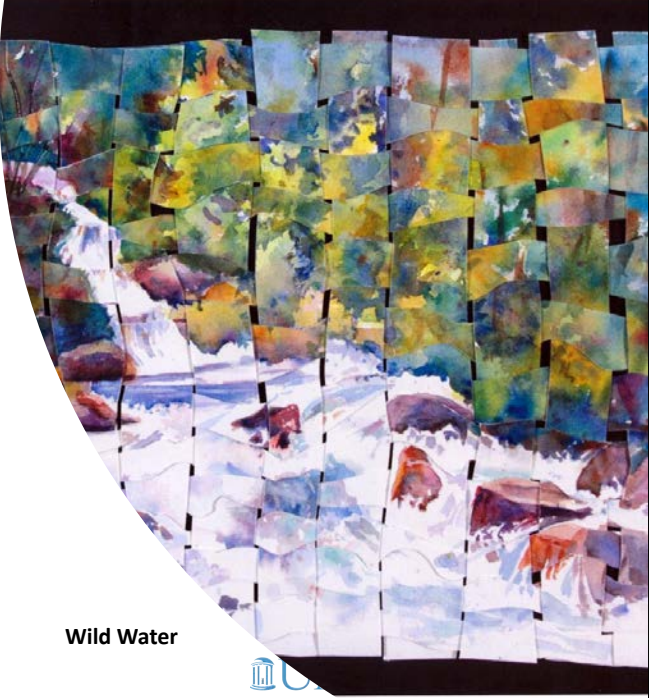
Stump TK, Robinson JK, Yanez B, Penedo F, Ezeofor A, Kircher S, Spring B. (2019). Physicians' perspectives on medication adherence and health promotion among cancer survivors. *Cancer.*;125(23):4319-4328.



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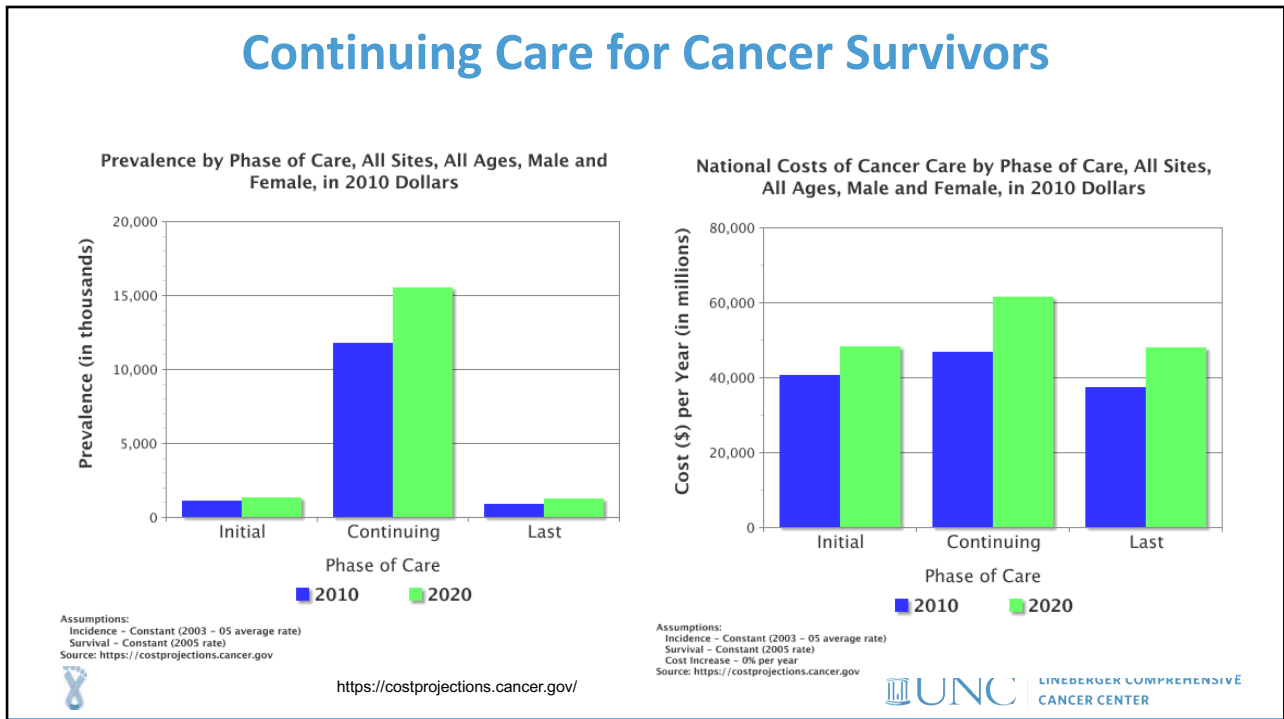
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Wild Water

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Adult Follow-up Care Models

- Multidisciplinary
- Disease specific
- Consultative service
- Integrated care model
- Risk-stratified and shared care

Jacobs & Shulman (2017) *Lancet Oncol*; 18: e19-29.



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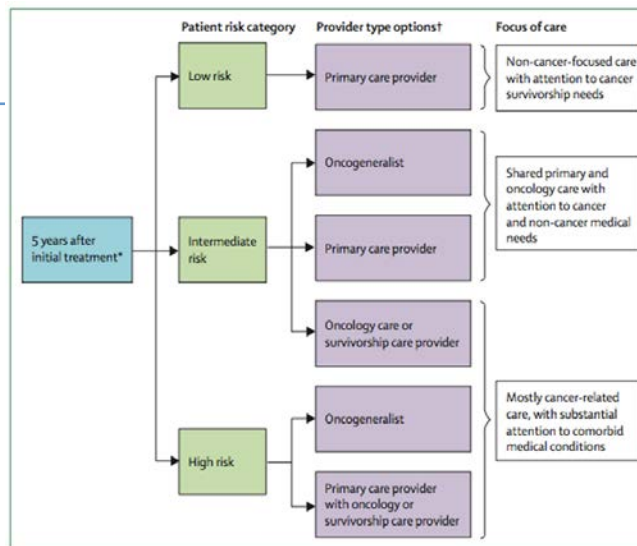


Figure 2: Survivorship care strategies
 *5 years is based on general recommendations in the cancer community; transition of care might vary. †Any of these models might be appropriate for nurse practitioner or physician assistant involvement.



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The Experiences Of Cancer Survivors While Transitioning From Tertiary To Primary Care.

Several factors affected participant transition readiness:

- How the transition was introduced, perceived continuity of care
- Support from health care providers
- Clarity of the timeline throughout the transition
- Desire for a "roadmap."
- **Their relationship with the primary care provider had the most influence on their transition readiness.**

Franco BB, Dharmakulaseelan L, McAndrew A, Bae S, Cheung MC, Singh S. (2016) *Curr Oncol.*;23(6):378-385.

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Principles of Personalized Follow-up Care Pathways

- Triage into care pathways is influenced by more than risk of recurrence, subsequent cancers or late effects.
- **Patient-identified issues should guide the delivery of care.**
- Remote monitoring should be used to imbed a survivor in a surveillance system to monitor them for the exacerbation of ongoing cancer-related symptoms or functional limitations, and for early recurrence, new cancer, or late effects detection.
- Shifting patients to supported self-management and reducing face-to-face clinic visits is critical for improving clinic utilization and cost outcomes.
- Coordination and information exchange among oncology, primary care, specialists and patients is essential.
- Engaging all stakeholders, securing their buy-in, and using change management and continuous improvement principles are critical for successful follow-up care transformation.

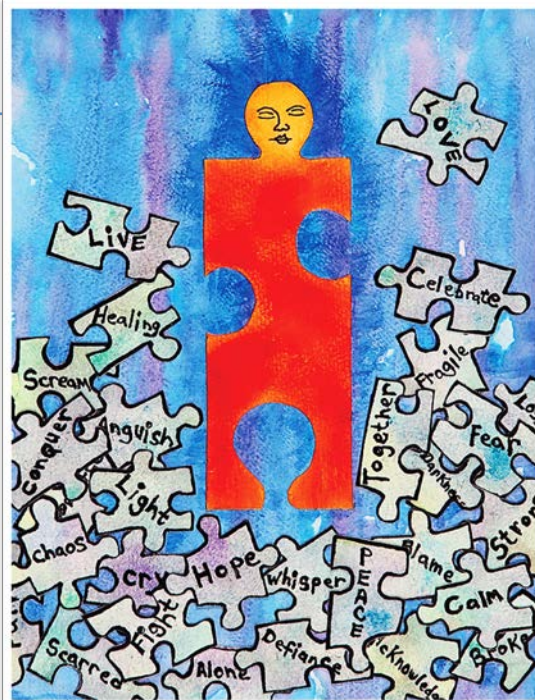
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Conclusions

- Subgroups of survivors have greater unmet needs
- Health promotion is not well integrated into cancer care
- Current cancer care cannot be sustained
- More survivorship research is needed to help prevent or mitigate long term and late effects and explore different models of care
- *Shifting model for follow-up survivorship care is part of the solution but needs to be based on risk stratification, collaboration between PCP and Oncologists, team-based care with APPs, ? New roles (health coaches?) and supported self-management.*
- We need to develop *and implement* a range of evidence-based programs that do not require 1:1 face-to-face interventions.



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Picking Up My Pieces



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