

## The APP Role in Survivorship Care



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

Deborah K. Mayer, PhD, RN, AOCN, FAAN  
Fox Distinguished Professor,  
University of North Carolina School of Nursing

Director of Cancer Survivorship,  
UNC Lineberger Comprehensive Cancer Center  
Chapel Hill, NC



<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 or any companies during this presentation



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## Objectives

- Identify current and future cancer trends
- Define cancer survivorship
- Describe long-term, late effects and unmet needs of survivors
- Discuss role of APP in delivering survivorship care
- List survivorship resources



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## Cancer in the US



More Than a Statistic

Experiences of a Cancer Journey

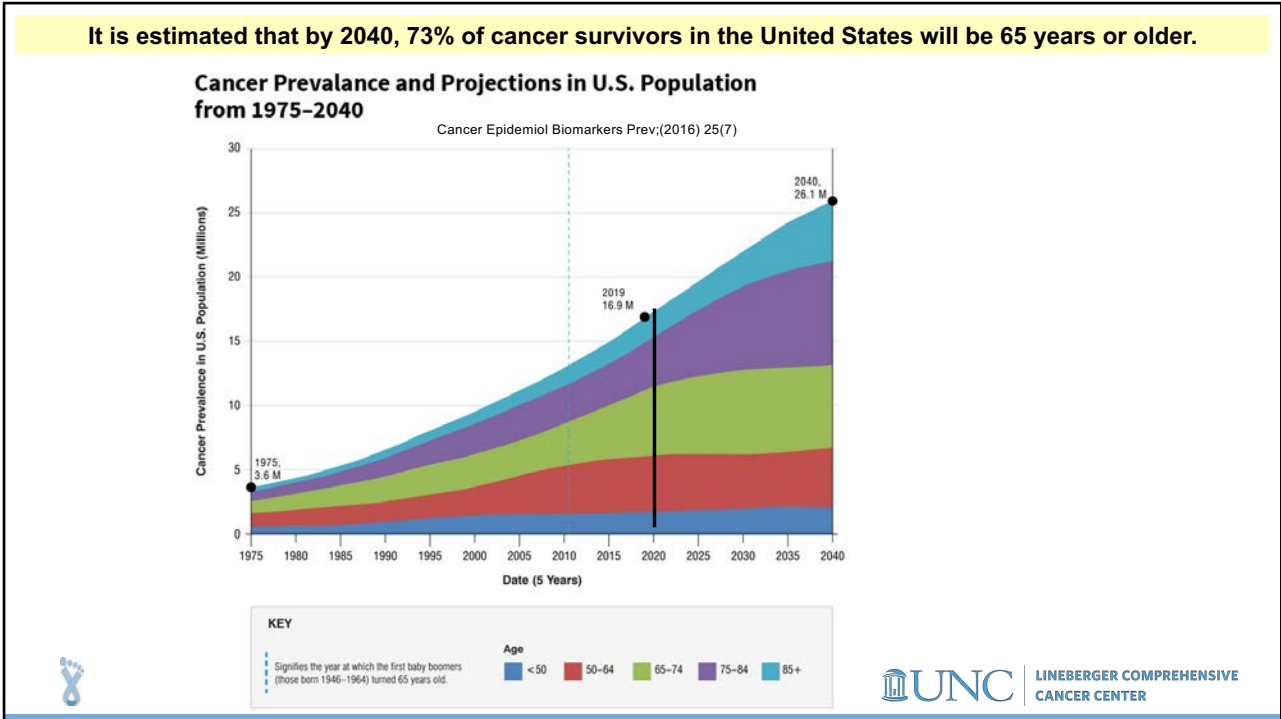
### Cancer trends

Defining survivorship  
Long-term and late effects  
and unmet needs  
Role of APP  
Resources

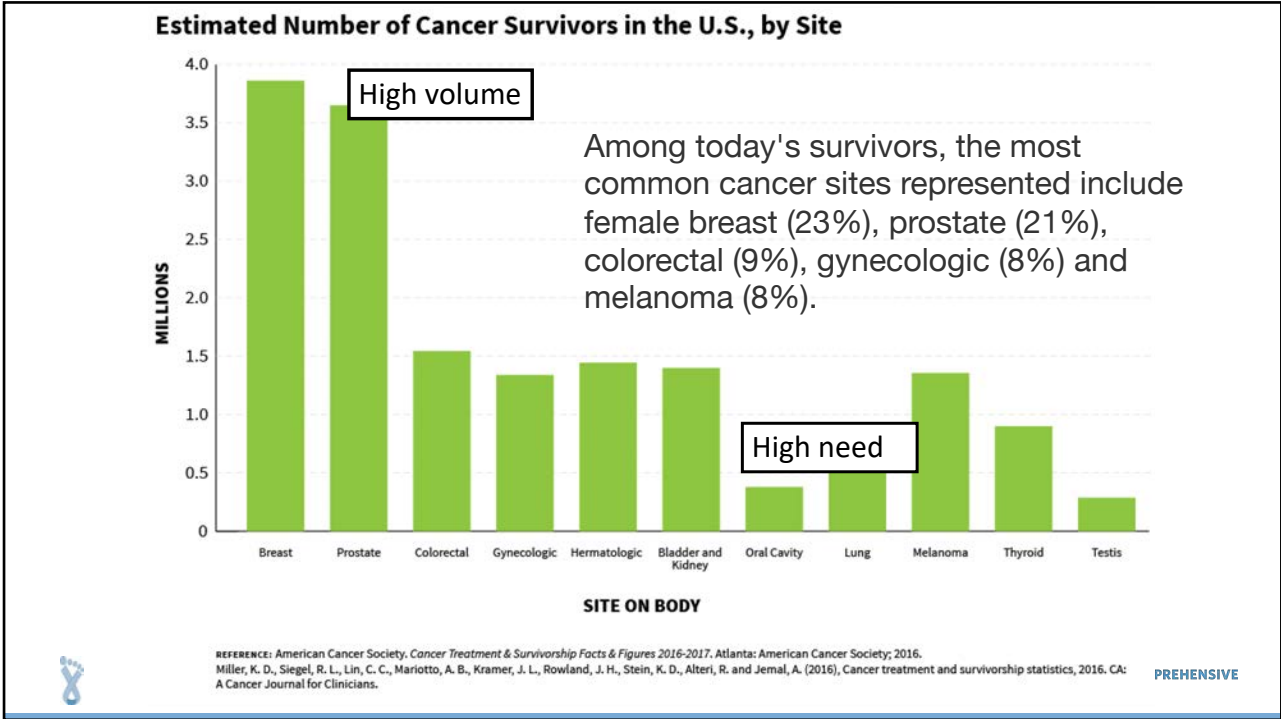


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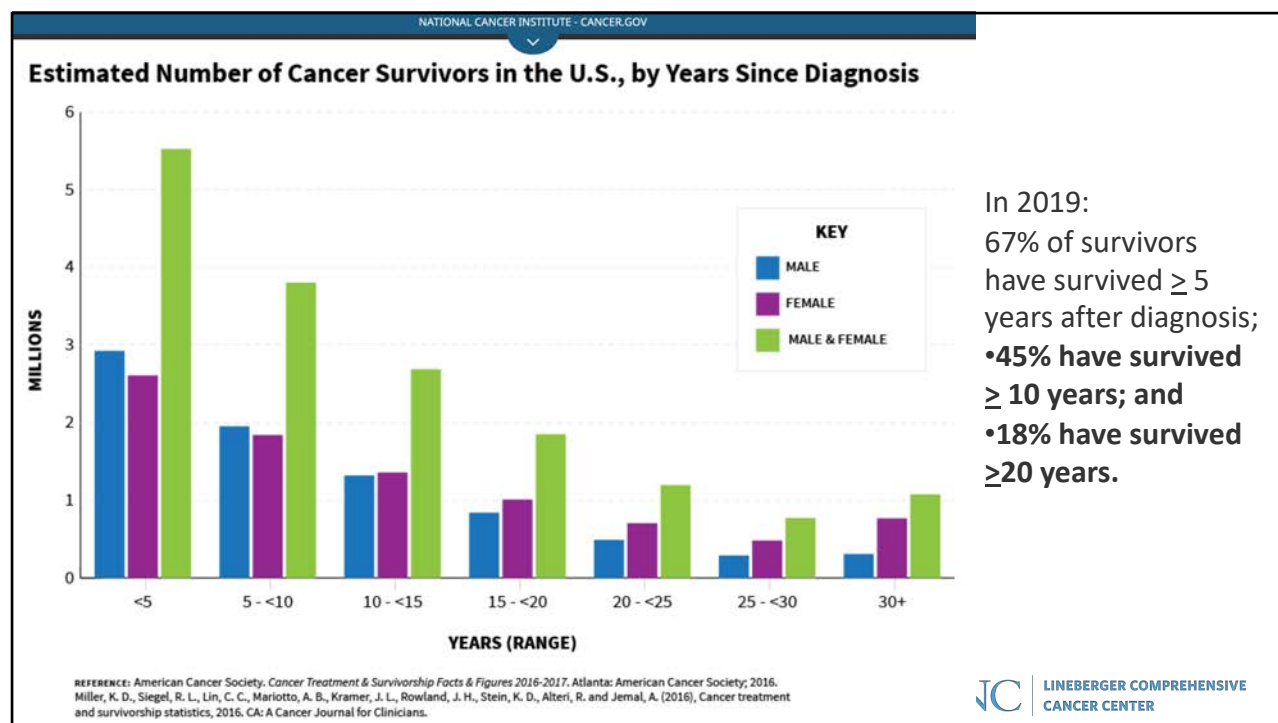
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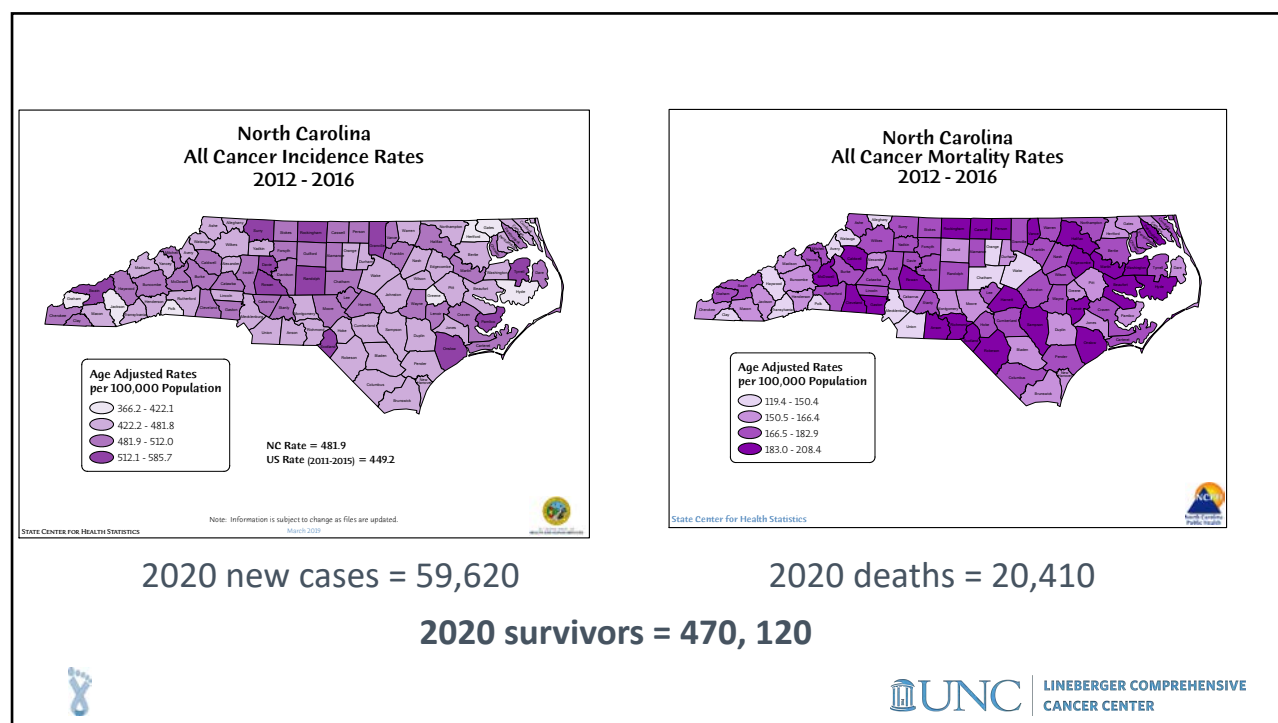
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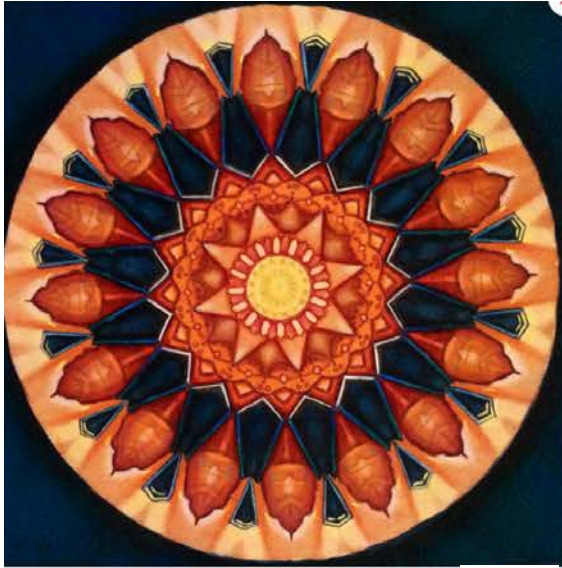
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*Revelations*

SOCIETY FOR  
CANCER ONCOLOGY  
& CANCER  
*Expressions of a Cancer Journey*

- Cancer trends
- **Defining survivorship**
- Long-term and late effects and unmet needs
- Role of APP
- Resources



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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  $\geq 1$  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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*Just because you are cancer free, it doesn't mean you are free of cancer –*  
*Julia Rowland*

- Cancer trends
- Defining survivorship
- **Long-term and late effects and unmet needs**
- Role of APP
- Resources



The Road Home

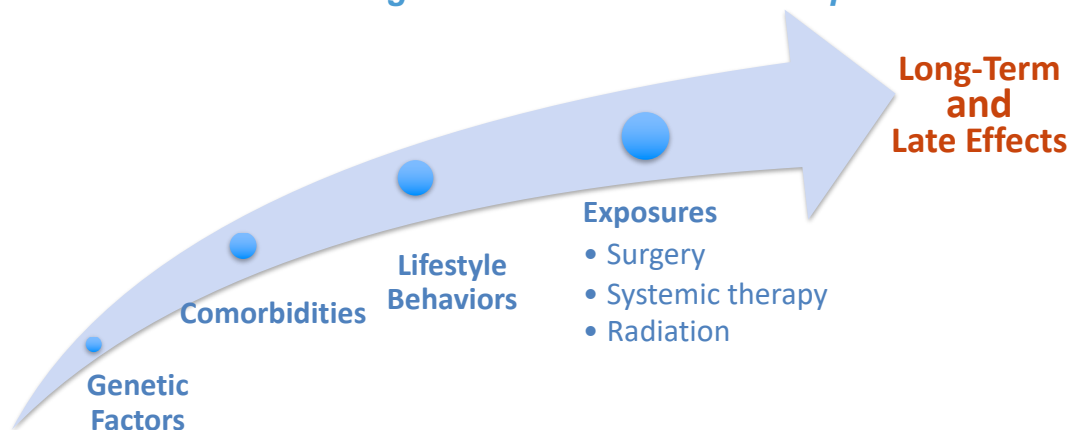


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## Cancer Survivors: Risk of Health Outcomes

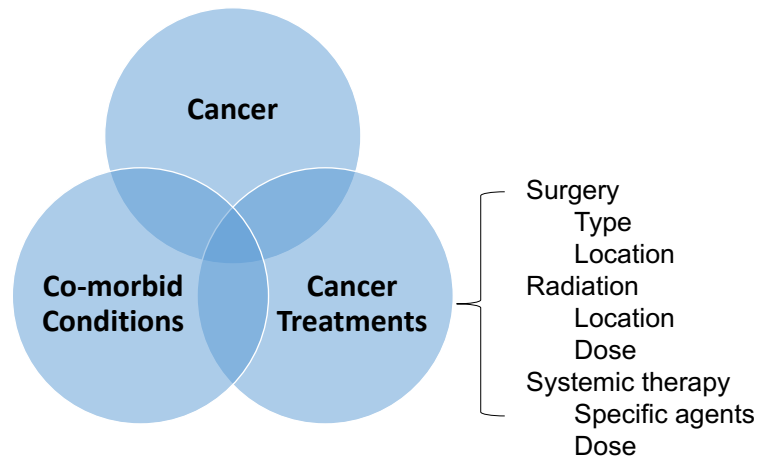
*~20% of all new cancers are diagnosed in someone with a previous cancer.*



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## Long-term and Late Effects



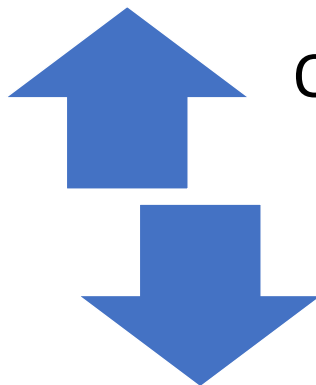
Source: From *Cancer Patient to Cancer Survivor: Lost in Transition*; page 24, Box 2-2.



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## Comorbid Conditions And Health-related Quality Of Life In Long-term Cancer Survivors



QOL

#comorbidities

N=1000 survivors 5 and 10 years after Dx

- Average 5 comorbidities
- 23% with  $\geq 7$  comorbidities
- QOL varied by type of cancer and treatment
- QOL lower than general population



Götze H, et al. (2018). *J Cancer Surviv*;12(5):712-720.



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## Meta-analysis of Quality of Life (QOL) in Long-term Survivors

- 64 articles included
  - Follow-up median 5 years (range 2-26 years)
  - Age median 60 years (range 45-80)
  - Cancer type: 31% breast, 14% CRC, H&N 13%, prostate 6%, lung 6%
  - Sample size median 220 (range 11-7369)
  - QOL measures QLQ-C30 45%, SF-36 42%, FACT 6%, QLQ+SF-36 6%
- Large negative cumulative effects sizes for worse QOL
  - Physical Health
  - Role-physical
  - Mental Health
- Not moderated by type of cancer, age, time since diagnosis



Firkins J, Hansen L, Driessnack M, Dieckmann N. (2020) *J Cancer Surviv.*;14(4):504-517.



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## Unmet Needs in Adult Cancer Survivors

N= 10717 adult cancer respondents

- Median # concerns 6 (3-10)
- Help sought for 2 concerns
- Unmet needs 4 concerns
  - Physical concerns s (86%),
  - Emotional concerns (78%),
  - Practical concerns (44%).

*Involvement of the PCP combined with the oncologist in providing care was associated with a significantly lower likelihood of reporting unmet emotional (OR, 0.78; 95% CI, 0.62-1.00; P = .05) and practical (OR, 0.72; 95% CI, 0.55-0.94; P = .01) needs.*



Shakeel S, Tung J, Rahal R, Finley C.(2020). *JAMA Netw Open*;3(3):e200506.



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## Unmet Needs in Adult Cancer Survivors (n=10,717)

### • Physical Concerns

- Change in concentration/memory (75%)
- Fatigue (65%)
- Change in sexual activity (64%)
- Nervous system problems (55%)
- Hormonal menopause (53%)
- Bladder incontinence (44%)
- Chronic pain (43%)
- GI tract problems (40%)
- Swelling (40%)

### • Emotional Concerns

- Anxiety (68%)
- Depression (67%)

### • Practical Concerns

- Difficulty getting health/life insurance (73%)
- Returning to work or school (69%)
- Taking care of family (69%)
- Paying health care bills (65%)
- Transportation (55%)



Shakeel S, Tung J, Rahal R, Finley C. (2020). *JAMA Netw Open*;3(3):e200506.



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## Unmet Needs of Cancer Survivors After Treatment Ends (N=26 studies)

### • Physical domain

- Dealing with feeling tired
- Not being able to do things you used to do

### • Psychological domain had greatest unmet needs

- Fear of recurrence

### • Information domain

- Being informed about the things you can do to help yourself get well

### • 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.



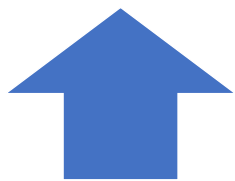
Lisy (2019). Asia-Pac J Clin Oncol 115:e68-e78.



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### Perceived Stress Is Associated With A Higher Symptom Burden In Cancer Survivors



Perceived  
Stress



Symptom  
burden

N=623 adult cancer survivors  
Mean # symptoms = 9.1 +/-5.2



Mazor M, et al (2019) Cancer;125(24):4509-4515.



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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  
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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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## Fear of Recurrence (FoR)

- Elevated FoR: ( 1 ) preoccupation with thoughts that the cancer may recur or progress; ( 2 ) the adoption of coping strategies that are unhelpful; ( 3 ) impaired daily functioning; ( 4 ) distress that is clinically significant; and ( 5 ) a limited ability to plan for the future.
- In 1002 survivors, FoR was found in 17%.
- Higher rates in women, younger age, receiving hormonal therapy, low social and emotional functioning, and high anxiety levels. FoR was slightly lower at 10 vs 5 years.
- Concerns about future of the family and being nervous prior to clinical visits.
- Mindfulness-based Interventions, CBT demonstrated effectiveness in reducing distress related to FoR



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***Involvement of the PCP combined with the oncologist in providing care was associated with a significantly lower likelihood of reporting unmet emotional and practical needs.***



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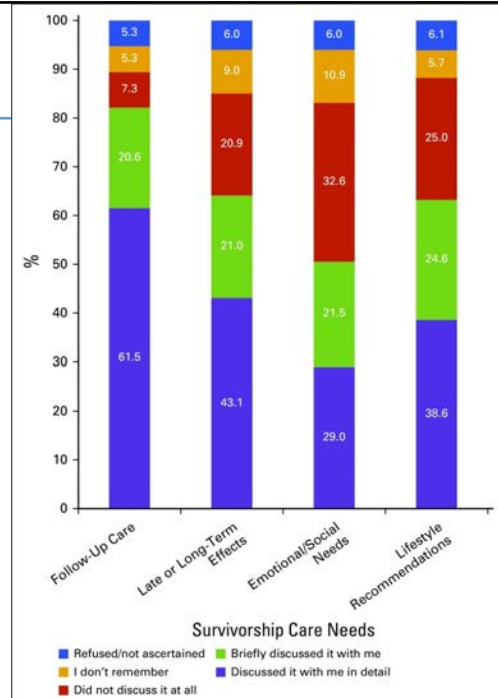
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## Patient-Provider Communication (n=1202 MEPS)

**Only 24% reported high-quality communication for all elements**

Chawla N, et al. (2016). *J Oncol Pract.*;12(12):e964-e973.



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- Cancer trends
- Defining survivorship
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*My Healing Begins*

**ONCOLOGY**  
*a Cancer*  
*Experiences of a Cancer Journey*

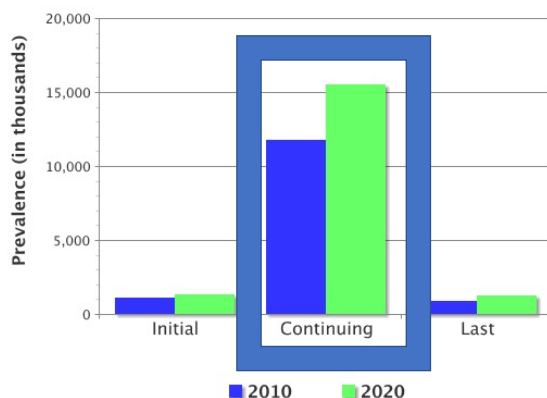


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## Continuing Care for Cancer Survivors

Prevalence by Phase of Care, All Sites, All Ages, Male and Female, in 2010 Dollars

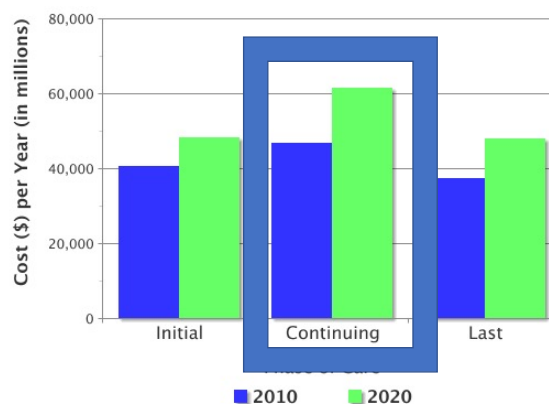


Assumptions:  
Incidence - Constant (2003 - 05 average rate)  
Survival - Constant (2005 rate)  
Source: <https://costprojections.cancer.gov>



<https://costprojections.cancer.gov/>

National Costs of Cancer Care by Phase of Care, All Sites, All Ages, Male and Female, in 2010 Dollars



Assumptions:  
Incidence - Constant (2003 - 05 average rate)  
Survival - Constant (2005 rate)  
Cost Increase - 0% per year  
Source: <https://costprojections.cancer.gov>

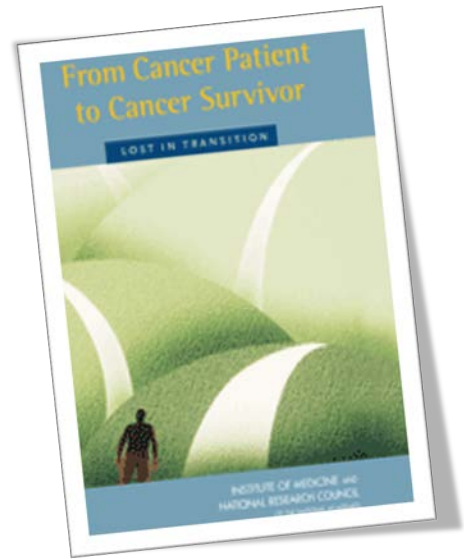


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## Components of Survivorship Care

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



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## Patients' Priorities For Quality Survivorship

### Survivors Principles:

- **Principle 1. Underscoring the chronic nature of survivorship to prepare survivors**
- **Principle 2. Creating an integrated, holistic system to better manage ongoing issues in survivorship**

### Practice priorities at the individual survivor level:

- Priority 1. Understanding expectations of survivorship care and how to "live with cancer"
- Priority 2. Having peer networks for emotional and social support
- Priority 3. Getting information and resources to help manage care
- Priority 4. Getting mental health support

### Practice priorities at the interpersonal level:

- Priority 5. Having supportive and responsive providers
- Priority 6. Being an empowered and engaged patient
- Priority 7. Engaging in meaningful communication and shared-decision making between providers and survivors

### Practice priorities at the organizational level:

- Priority 8. Seamless care coordination and transitions across providers
- Priority 9. Offering practical life support
- Priority 10. Creating infrastructure/processes to increase access and facilitate continuous care



Priority 11. Providing a full spectrum of care without access barriers

Mead, K.H., et al. (2020). *J Cancer Surviv* 14, 939–958.



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Mead, K.H., Raskin, S., Willis, A. *et al.* (2020). *J Cancer Surviv* 14, 939–958.



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## Patient Centered Follow-Up Care (n=239)

Question	Endorsed
Who to contact if you have any questions or concerns	95%
Who to contact if signs or symptoms occur	91%
What to expect in follow-up care	90%
The role of your GP now that treatment has finished	79%
What symptoms or signs might suggest cancer has returned	74%
Written care plan	71%



Hobden, B. et al. (2020) *J Psychosocial Oncology*.



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## Patient Expectations About Follow-up Care N= 12 studies

849 survivors (age range 28-90)

- Detect recurrence
- Extensive testing to get reassurance
- Relevant information/advice about different aspects of illness
- Psychosocial support
- Consistency of care
- Continuity of care
- Prefer long and intensive follow-up (fear of recurrence/uncertainty)



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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.



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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.



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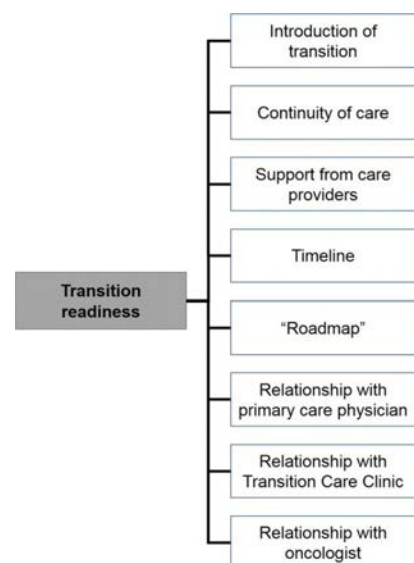
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## The Experiences Of Cancer Survivors While Transitioning From Tertiary To Primary Care.

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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## Self-management

- Prepare survivors for active involvement in care
- Shift care culture to support survivors as partners in clinical practices and pathways
- Prepare workforce with knowledge and skills to help survivors' self-manage
- Establish and implement PRO measuring effects of self-management support
- Advance evidence and research on self-management
- Expand reach and access to self-management support programs



Howell, D., et al. (2020). *JNCI*: 113(5): djaa083



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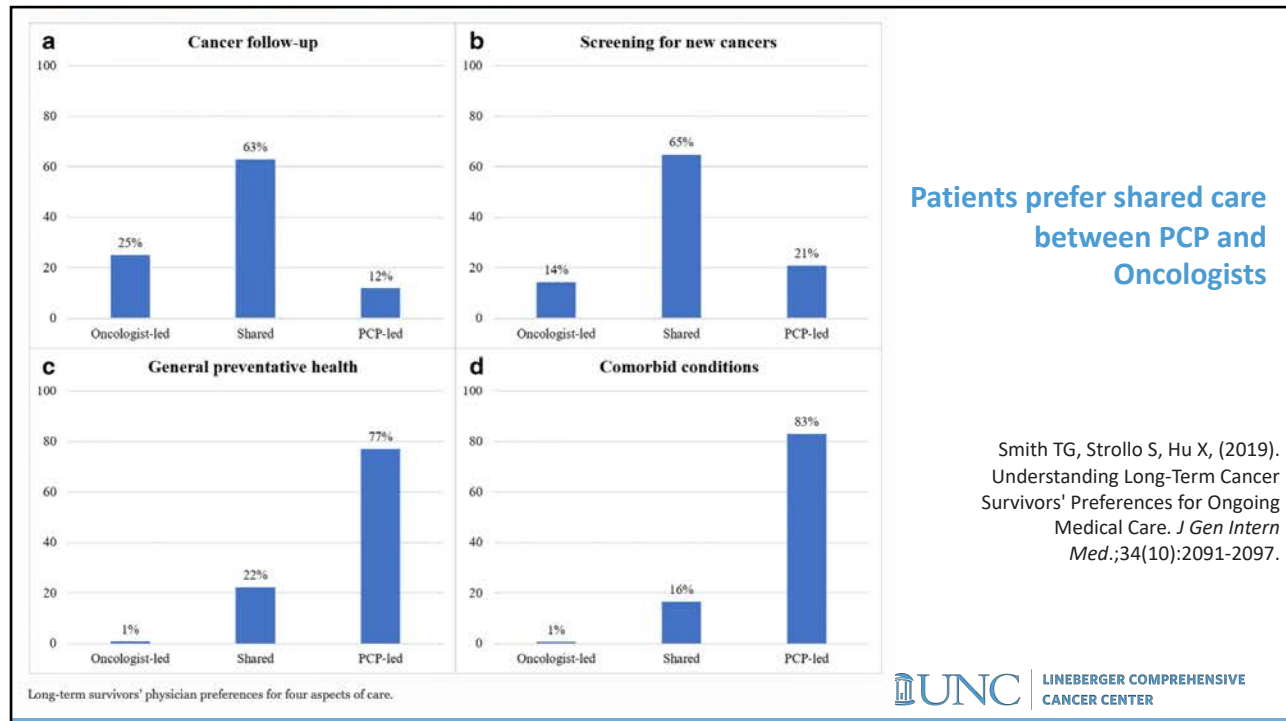
## Barriers to Survivorship Care

- **Fragmented Delivery System**
  - Hampers coordinated care
  - Little HCP education/training on topic
  - Little evidence-based standards of care/guidelines
  - EHR documentation/sharing/tracking
  - Capacity and sites of care
  - Reimbursement issues
- **Communication**
  - HCP to HCP
  - HCP and Survivor
- **Research**
  - Use of existing data/ more research on long term and late effects
  - Evaluate models of care
  - Conduct more longitudinal studies of adults



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## Summary

- Follow-up care = survivorship care
- Many survivors have a range of physical, psychological and supportive care needs.
- Survivors are not routinely screened for these needs.
- Unmet needs continue to exist many years after diagnosis
- Survivors do better with shared care between oncologist and PCP
- We need to address barriers to quality survivorship care



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- Cancer trends
- Defining survivorship
- Long-term and late effects and unmet needs
- Role of APP
- **Resources**



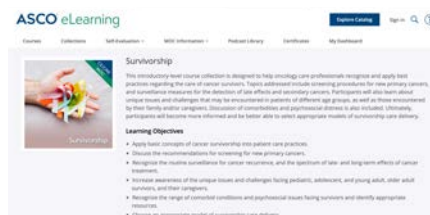
SEARCHING: THE ANSWER IS OUT THERE



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## Survivorship Resources for Clinicians

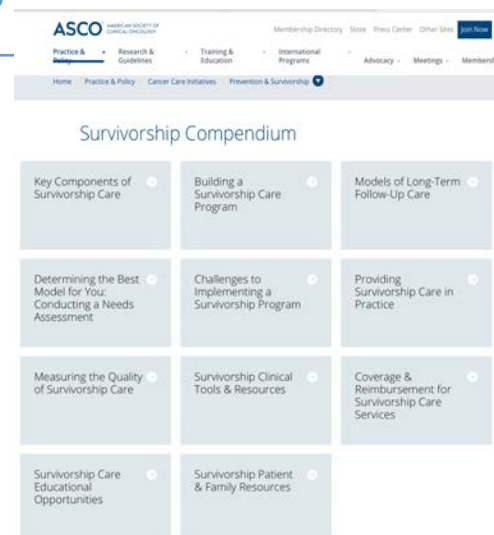
- **Oncology Focused**
  - ASCO University
  - Survivorship Compendium
  - PDQ summaries (NCI)



<https://elearning.asco.org/coursecollection/survivorship>

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

<https://www.cancer.gov/publications/pdq/information-summaries/supportive-care>



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## Survivorship Resources for Clinicians

### • Primary Care

- George Washington

### • Both

- Cancer survivorship care tools and resources
- for providers, organizations and communities (ACS).
- PDQ summaries (NCI)

<http://gwcehp.learnercommunity.com/elearning-series>

<https://www.cancer.org/health-care-professionals/national-cancer-survivorship-resource-center/tools-for-health-care-professionals.html>

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### NCCN Guidelines Version 2.2020 Survivorship

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[NCCN Survivorship Panel Members](#)  
[NCCN Survivorship Sub-Committee Members](#)  
[Summary of the Guidelines Updates](#)

**General Survivorship Principles**

- [Definition of Survivorship & Standards for Survivorship Care \(SURV-1\)](#)
- [General Principles of the Survivorship Guidelines \(SURV-2\)](#)
- [Screening for Subsequent New Primary Cancers \(SURV-3\)](#)
- [Assessment By Health Care Provider at Regular Intervals \(SURV-4\)](#)
- [Survivorship Assessment \(SURV-A\)](#)
- [Survivorship Resources For Health Care Professionals And Patients \(SURV-B\)](#)

**Preventive Health**

- [Healthy Lifestyles \(HL-1\)](#)
  - ▶ [Physical Activity \(SPA-1\)](#)
  - ▶ [Nutrition and Weight Management \(SNWM-1\)](#)
  - ▶ [Supplement Use \(SSUP-1\)](#)
- [Immunizations and Infections \(SIMIN-1\)](#)

**Late Effects/Long-Term Psychosocial and Physical Problems**

- [Cardiovascular Disease Risk Assessment \(SCVD-1\)](#)
- [Anthracycline-Induced Cardiac Toxicity \(SCARDIO-1\)](#)
- [Anxiety, Depression, Trauma, and Distress \(SANXDE-1\)](#)
- [Cognitive Function \(SCF-1\)](#)
- [Fatigue \(SFAT-1\)](#)
- [Lymphedema \(SLYMPH-1\)](#)
- [Hormone-Related Symptoms \(SMP-1\)](#)
- [Pain \(SPAIN-1\)](#)
- [Sexual Function \(SSF-1\)](#)
  - ▶ [Female Treatment Options \(SSF-2\)](#)
  - ▶ [Male Treatment Options \(SSF-3\)](#)
- [Sleep Disorders \(SSD-1\)](#)

**Clinical Trials:** NCCN believes that the best management for any patient with cancer is in a clinical trial. Participation in clinical trials is especially encouraged.

To find clinical trials online at NCCN Member Institutions, [click here: nccn.org/clinical\\_trials/member\\_institutions.aspx](http://nccn.org/clinical_trials/member_institutions.aspx).

**NCCN Categories of Evidence and Consensus:** All recommendations are category 2A unless otherwise indicated.

See [NCCN Categories of Evidence and Consensus](#).

The NCCN Guidelines® are a statement of evidence and consensus of the authors regarding their views of currently accepted approaches to treatment. Any clinician seeking to apply or consult the NCCN Guidelines is expected to use independent medical judgment in the context of individual clinical circumstances to determine any patient's care or treatment. The National Comprehensive Cancer Network® (NCCN®) makes no representations

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## National Resources

- National Coalition for Cancer Survivorship  
[www.canceradvocacy.org](http://www.canceradvocacy.org)
- American Society of Clinical Oncology  
<http://www.asco.org>
- American Cancer Society  
[www.cancer.org](http://www.cancer.org)
- National Cancer Institute-OCS  
[www-survivorship.cancer.gov](http://www-survivorship.cancer.gov)
- National Comprehensive Cancer Network  
[www.nccn.org](http://www.nccn.org)
- Lance Armstrong Foundation (LIVESTRONG)  
[www.livestrong.org](http://www.livestrong.org)



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## Patients' Priorities For Quality Survivorship

*"These principles and practice priorities challenge the field to organize a more patient-centered survivorship care system that empowers and respects patients and provides a holistic approach to survivors' chronic and long-term needs."*

Mead, K.H., Raskin, S., Willis, A. *et al.* (2020) Identifying patients' priorities for quality survivorship: conceptualizing a patient-centered approach to survivorship care. *J Cancer Surviv* **14**, 939–958.



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