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A Comprehensive Cancer Center Designated by the National Cancer Institute

Cancer Survivorship: A Personalized Precision Approach

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Disclosures

I am a stockholder and advisor to Carevive Systems

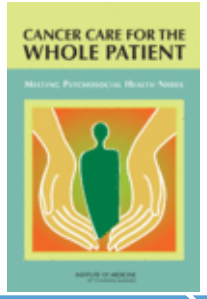
I will not discuss any drugs during this presentation

Objectives:

- Analyze cancer survivorship trends
- Define cancer survivorship
- Identify the components of survivorship care
- Describe major challenges facing cancer survivors
- Evaluate current and evolving models of survivorship care
- Discuss challenges in addressing survivorship issues in the US

Survivorship Over Time

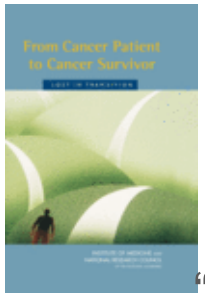
"War" → "Competition" → "Journey"



1950 5-yr survival = 30% → 1975 5-yr survival = 48% → 1986 → 1996 → 2005 → 2007 → 2019 5-yr survival = 68%

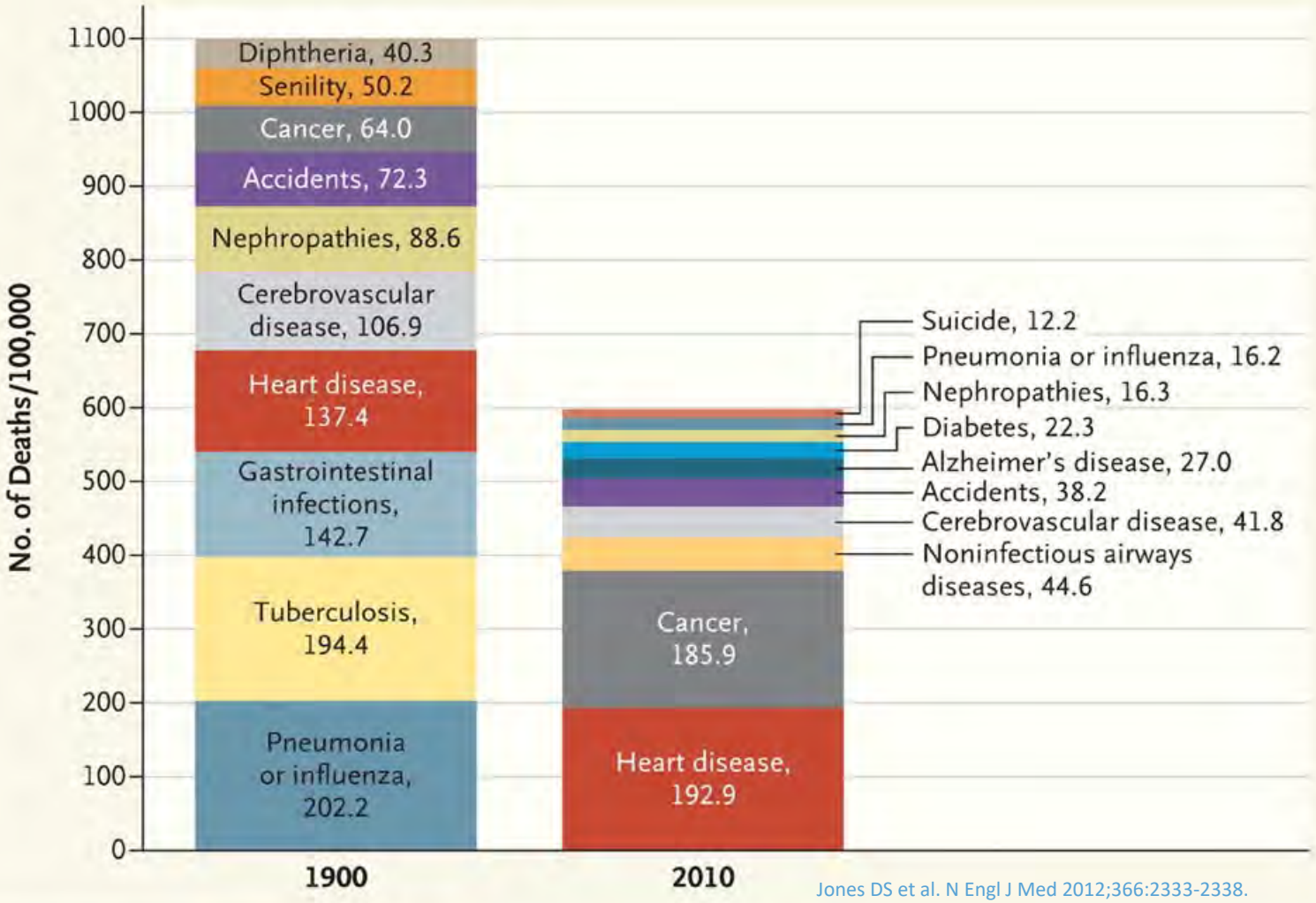
3m

16.9 m



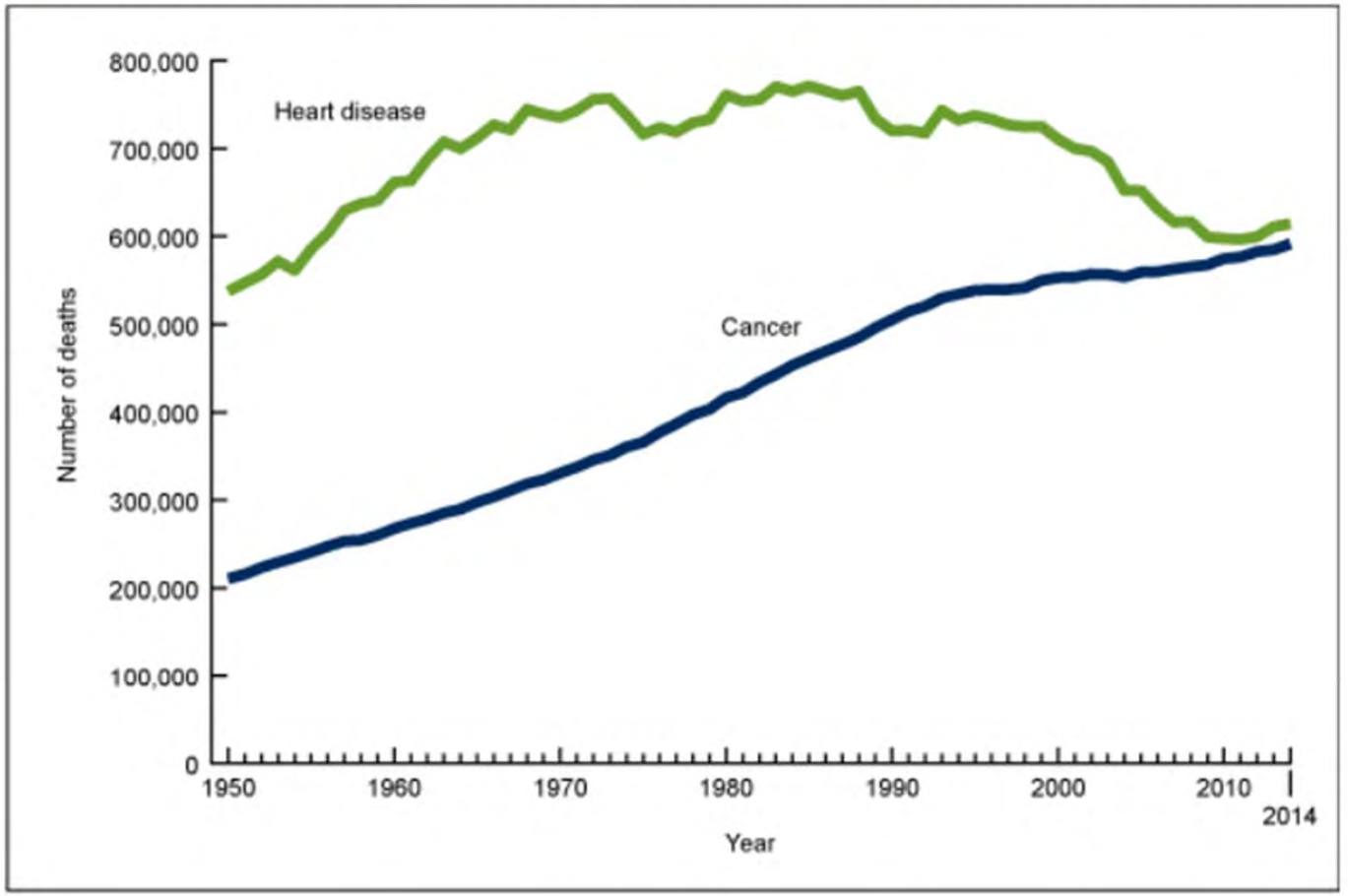
"Good Patient" / "Victims" → "Empowered Patient" / "Survivors"

Top 10 Causes of Death: 1900 vs. 2010



Jones DS et al. N Engl J Med 2012;366:2333-2338.

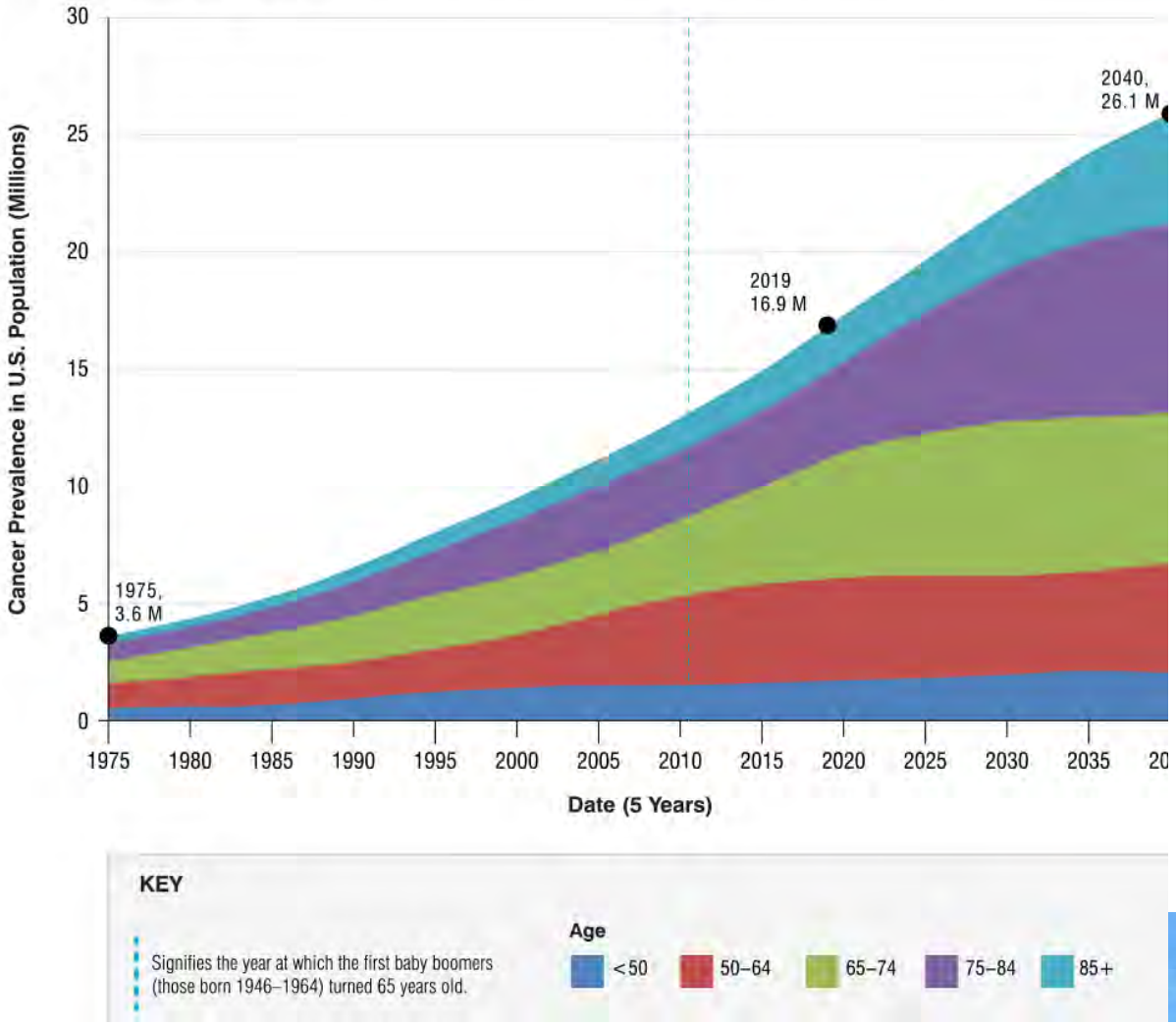
Figure 1. Number of deaths due to heart disease and cancer: United States, 1950–2014



NOTES: Leading cause is based on number of deaths. Access data table for Figure 1.

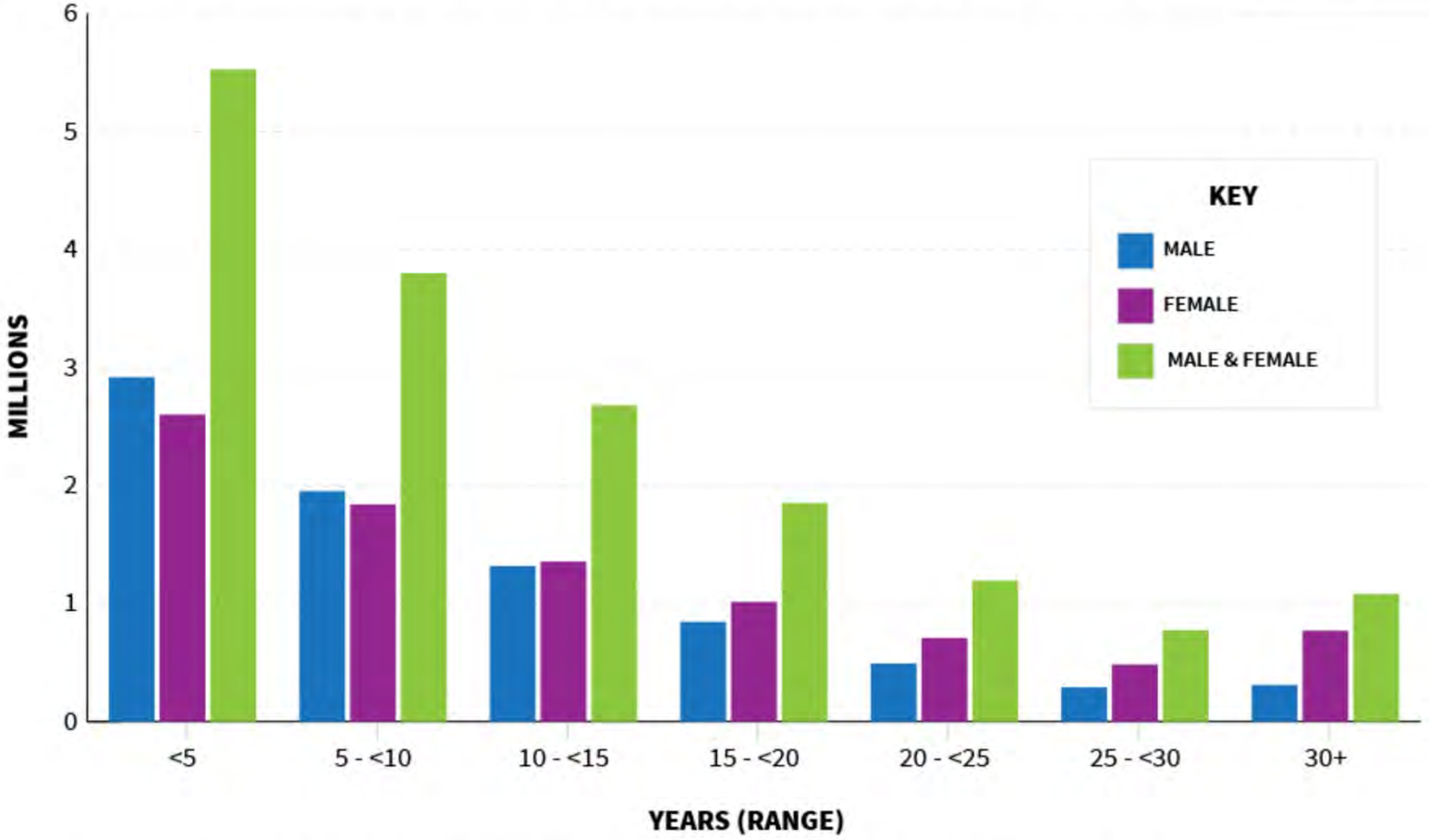
SOURCE: NCHS, National Vital Statistics System, Mortality.

Cancer Prevalance and Projections in U.S. Population from 1975–2040



NATIONAL CANCER INSTITUTE - CANCER.GOV

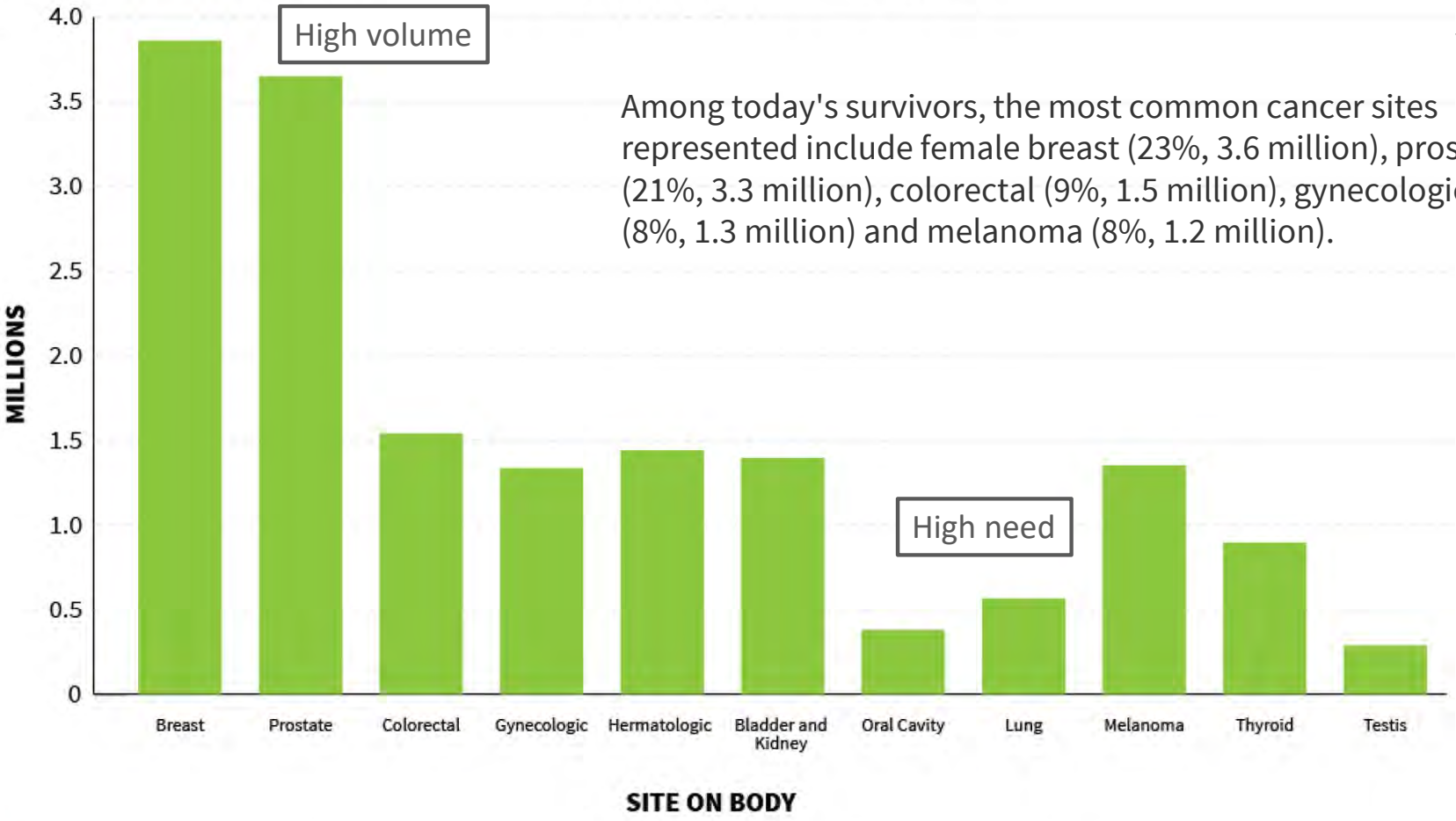
Estimated Number of Cancer Survivors in the U.S., by Years Since Diagnosis



REFERENCE: American Cancer Society. *Cancer Treatment & Survivorship Facts & Figures 2016-2017*. Atlanta: American Cancer Society; 2016. Miller, K. D., Siegel, R. L., Lin, C. C., Mariotto, A. B., Kramer, J. L., Rowland, J. H., Stein, K. D., Alteri, R. and Jemal, A. (2016), Cancer treatment and survivorship statistics, 2016. CA: A Cancer Journal for Clinicians.

- In 2019, 67% of survivors (10.3 million) have survived 5 or more years after diagnosis;
- 45% have survived 10 or more years; and
- **18% have survived 20 or more years.**

Estimated Number of Cancer Survivors in the U.S., by Site



Among today's survivors, the most common cancer sites represented include female breast (23%, 3.6 million), prostate (21%, 3.3 million), colorectal (9%, 1.5 million), gynecologic (8%, 1.3 million) and melanoma (8%, 1.2 million).

REFERENCE: American Cancer Society. *Cancer Treatment & Survivorship Facts & Figures 2016-2017*. Atlanta: American Cancer Society; 2016.
Miller, K. D., Siegel, R. L., Lin, C. C., Mariotto, A. B., Kramer, J. L., Rowland, J. H., Stein, K. D., Alteri, R. and Jemal, A. (2016), Cancer treatment and survivorship statistics, 2016. CA: A Cancer Journal for Clinicians.

Defining Survivors and Survivorship

The Face of Cancer

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

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

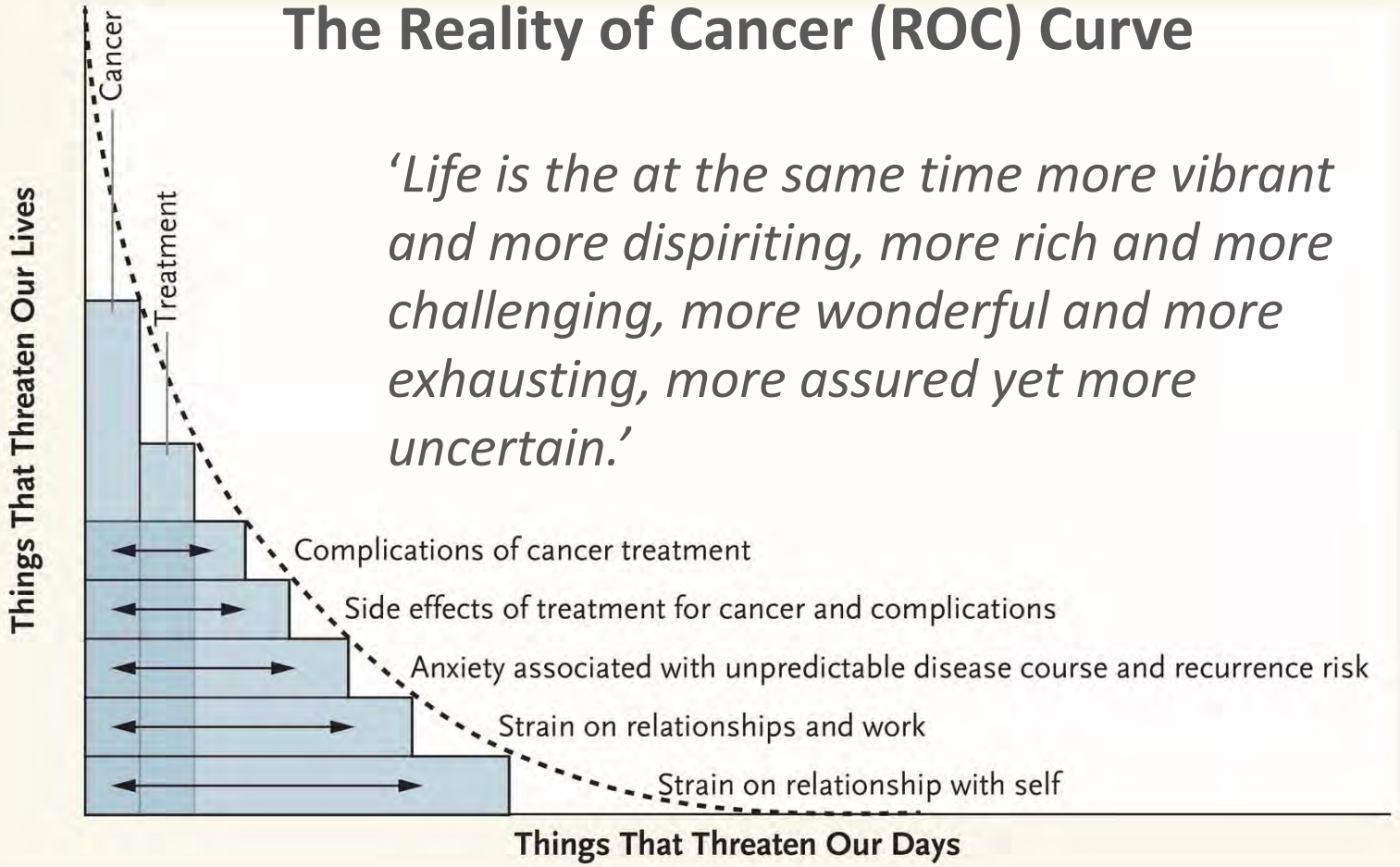
Survivorship Definition and Attributes

- 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.*

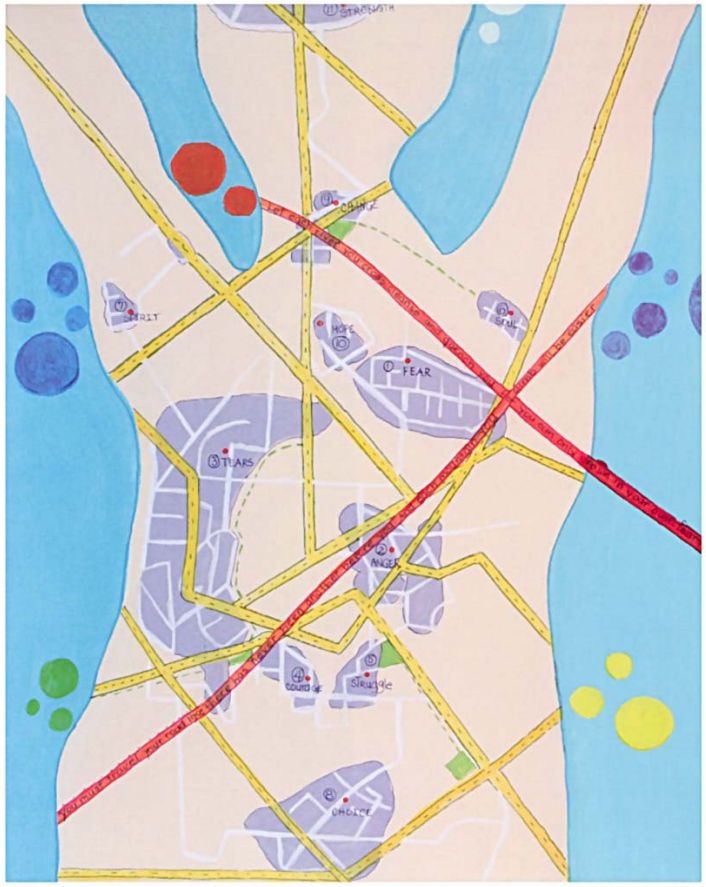
The Reality of Cancer (ROC) Curve

'Life is the at the same time more vibrant and more dispiriting, more rich and more challenging, more wonderful and more exhausting, more assured yet more uncertain.'



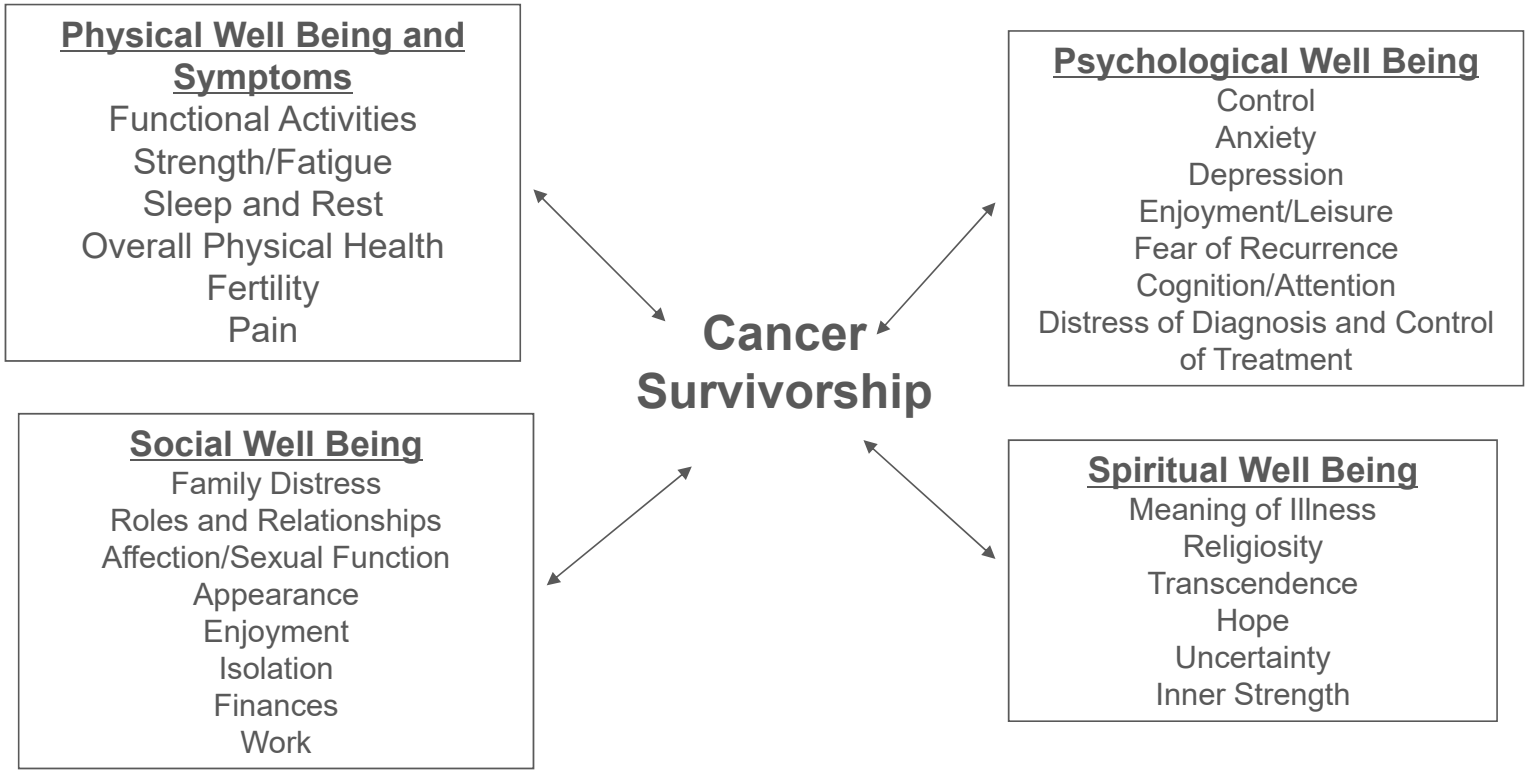
Walker, S. Receiver Operator Curve Redefined-Optimizing Sensitivity (and Specificity) to the Lived Reality of Cancer. *N Engl J Med* 2019; 380:1594-1595

Management of Long Term and Late Sequelae



The Road Home

Quality of Life

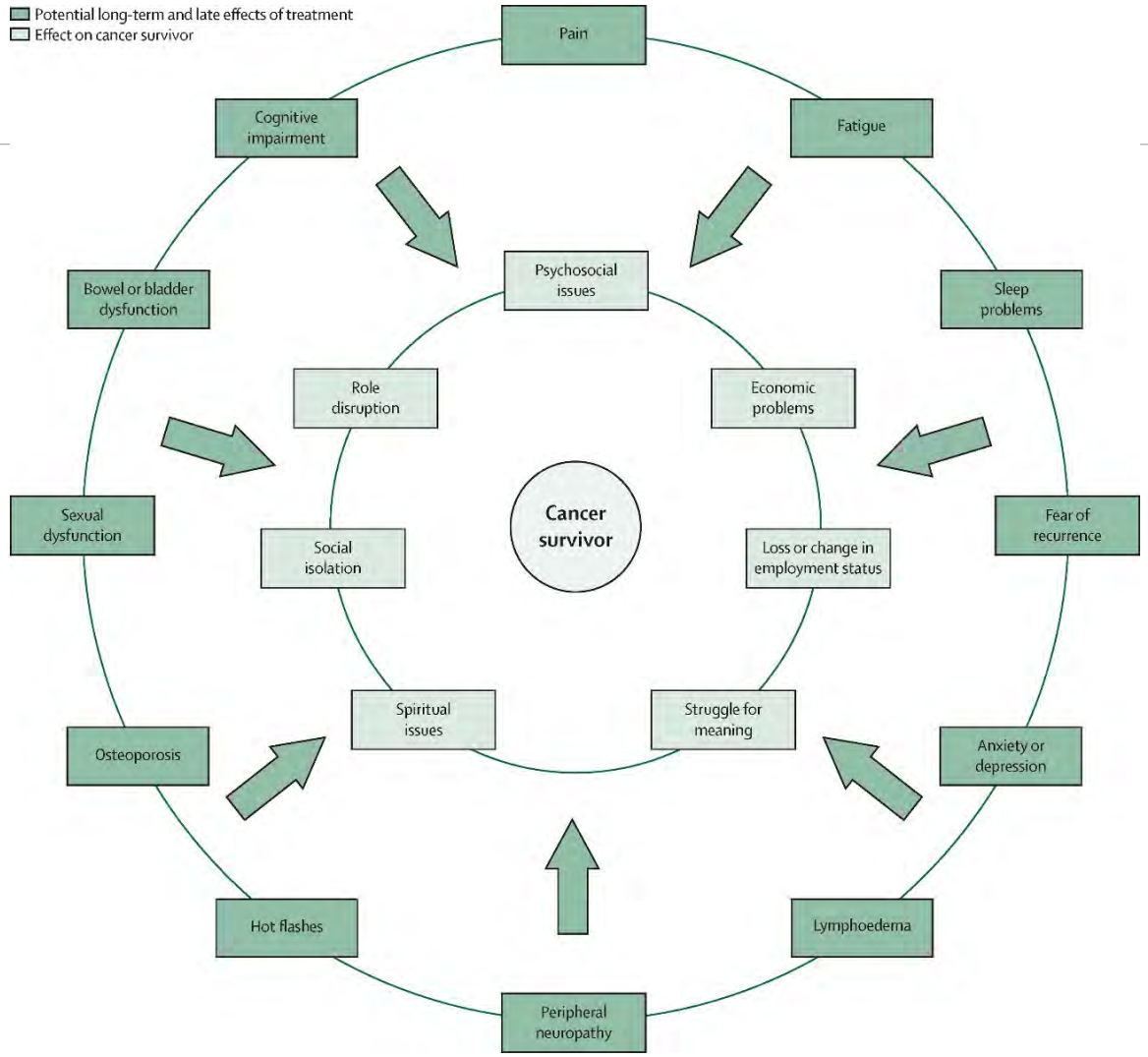


Ferrell, BR and Grant, M. City of Hope Beckman Research Institute (2004)

Long Term and Late Effects

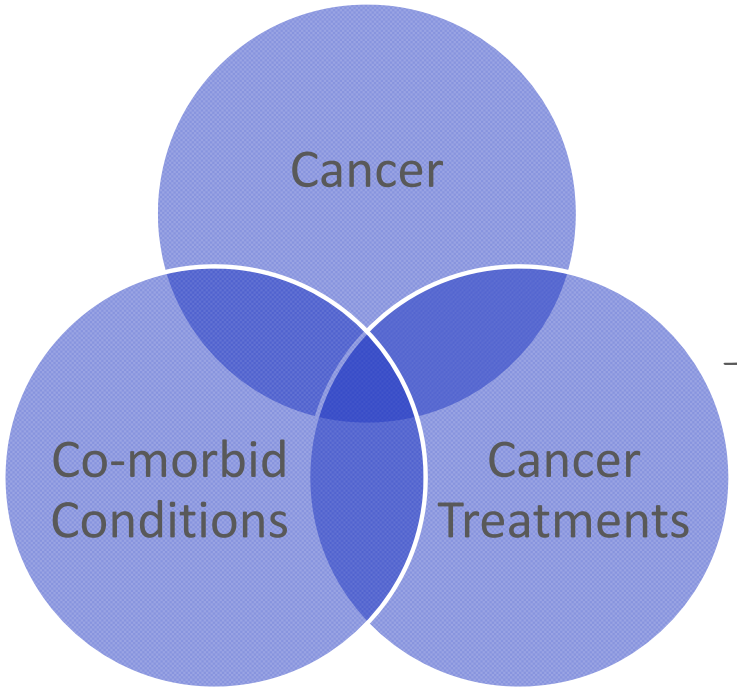
Late effects: unrecognized toxicities that are absent or subclinical at the end of treatment and manifest months or years later

Long term effects: any side effect or complication for which the survivor must compensate


Potential long-term and late effects of treatment
Effect on cancer survivor
Pain
Fatigue
Sleep problems
Fear of recurrence
Anxiety or depression
Lymphoedema
Peripheral neuropathy
Hot flashes
Osteoporosis
Sexual dysfunction
Bowel or bladder dysfunction
Cognitive impairment
Psychosocial issues
Economic problems
Loss or change in employment status
Struggle for meaning
Spiritual issues
Social isolation
Role disruption
Cancer survivor

Long-term and Late Effects

Obesity
Diabetes
Depression
Cognitive changes
Age related changes
Dyslipidemia
Hypertension
Osteoporosis
Osteopenia
Hypothyroidism



Surgery
- Type
- Location

Radiation
- Location
- Dose

Systemic therapy
- Specific agents
- Dose

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

Common Long-Term Sequelae

Cardiovascular
- Cardiomyopathy
- Valvular heart disease
- Electrical/conductive
- Coronary artery disease

Pulmonary
- Pulmonary fibrosis
- Interstitial lung disease
- Strictures/obstructions

Gastrointestinal
- Malabsorbtion
- Strictures/Obstruction

Renal

Musculoskeletal
- Osteopoenia/osteoporosis
- Osteonecrosis
- Lymphedema

Endocrine
- Hypothyroidism
- Fertility
- Metabolic syndrome

Neurologic
- Cognitive changes
- Neuropathies

Psychological
- Depression
- Anxiety
- PTSD

Long-term Cancer Survivors Comorbid Conditions

- 1527 breast, prostate, CRC, gyn cancer survivors
  - **Average of 5 comorbid conditions--**1.9 *after* diagnosis
  - Higher burden with older age, breast ca, living alone, BMI >25, physically inactive

Leach (2015). *J Cancer Surviv*, 9: 239-251.

Cardiovascular Late Effects

>1 in 3 Americans have ≥ 1 types of cardiovascular disease

Death rate for noncancer causes RR 1.37 compared to general population with most ½ due to CVD

Survival was significantly worse among cancer survivors who developed CVD (60%) when compared with cancer survivors without CVD (81%; $P < .01$).

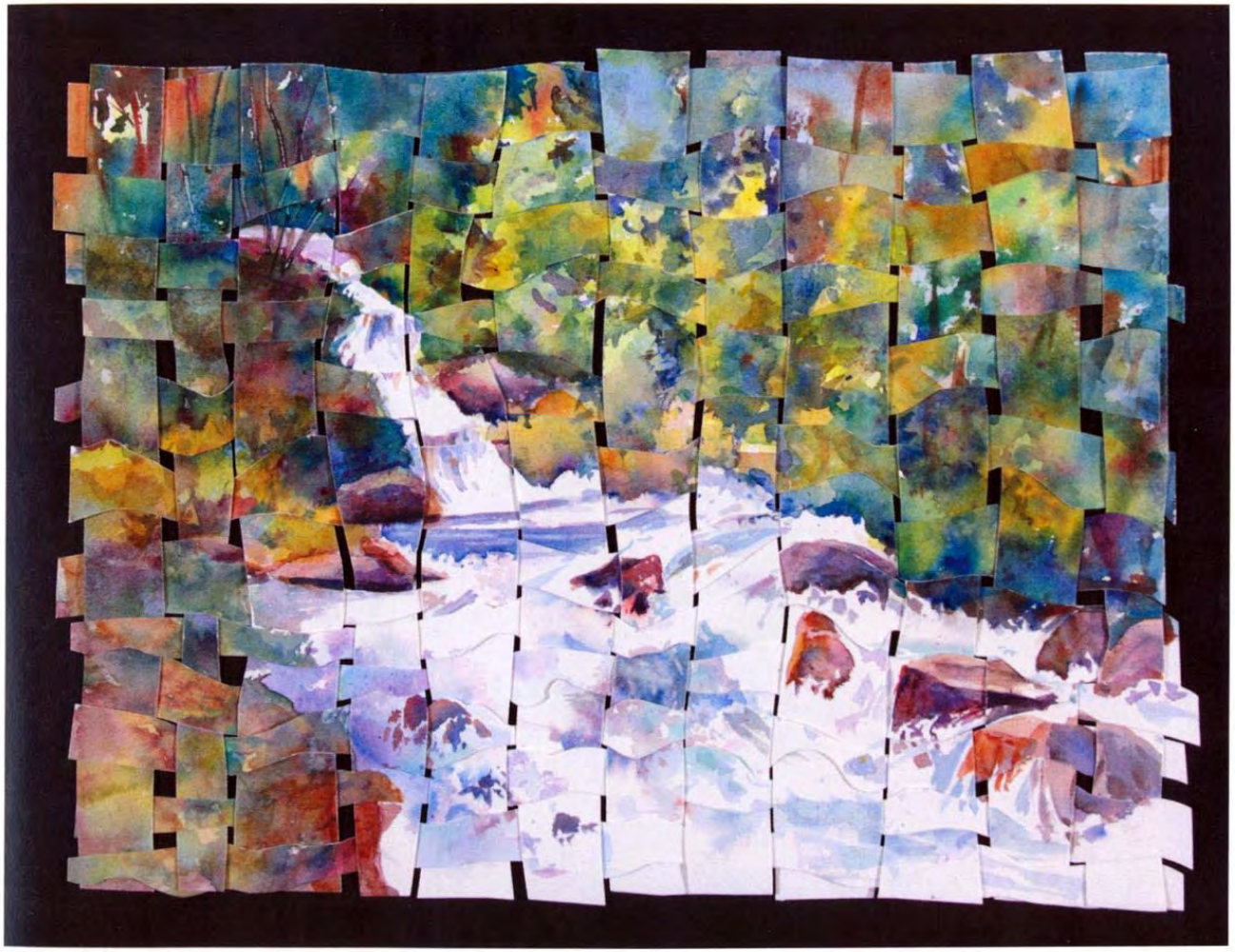
Cancer survivors with two or more CVRFs (hypertension, diabetes, dyslipidemia) had the highest risk of CVD

Cardiovascular disease is leading cause of death in cancer survivors when looking at all cause mortality

Naaktgeboren WR, et al (2017). Maturitas;105:37-45; Giza DE, et al. (2017) Curr Oncol Rep;19(6):39; Armenian SH, et al. (2016). J Clin Oncol;34(10):1122-30.

Implications

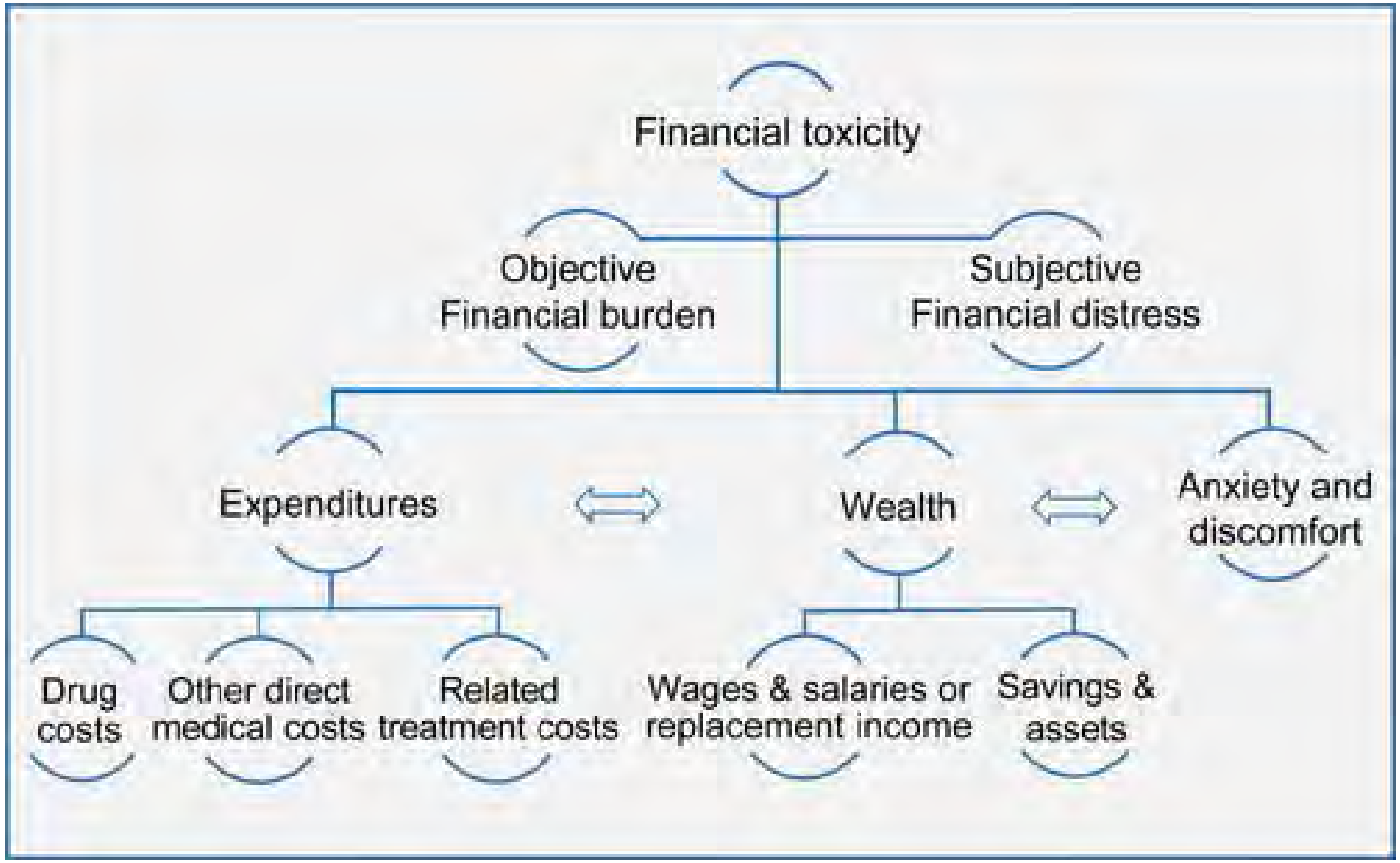
- People with cancer have many physical and psychosocial unmet needs.
- Better knowledge of these early and late cardiac effects in cancer patients will enable adoption of both primary and secondary prevention measures of long-term treatment complications in cancer survivors.
- These needs may be highest in the first year of diagnosis but continue across the life of the survivor.



Financial Toxicity

WILD WATER

THE FINANCIAL BURDEN AND DISTRESS OF PATIENTS WITH CANCER: UNDERSTANDING AND STEPPING-UP ACTION ON THE FINANCIAL TOXICITY OF CANCER TREATMENT



CA: A Cancer Journal for Clinicians, Volume: 68, Issue: 2, Pages: 153-165, First published: 16 January 2018, DOI: (10.3322/caac.21443)

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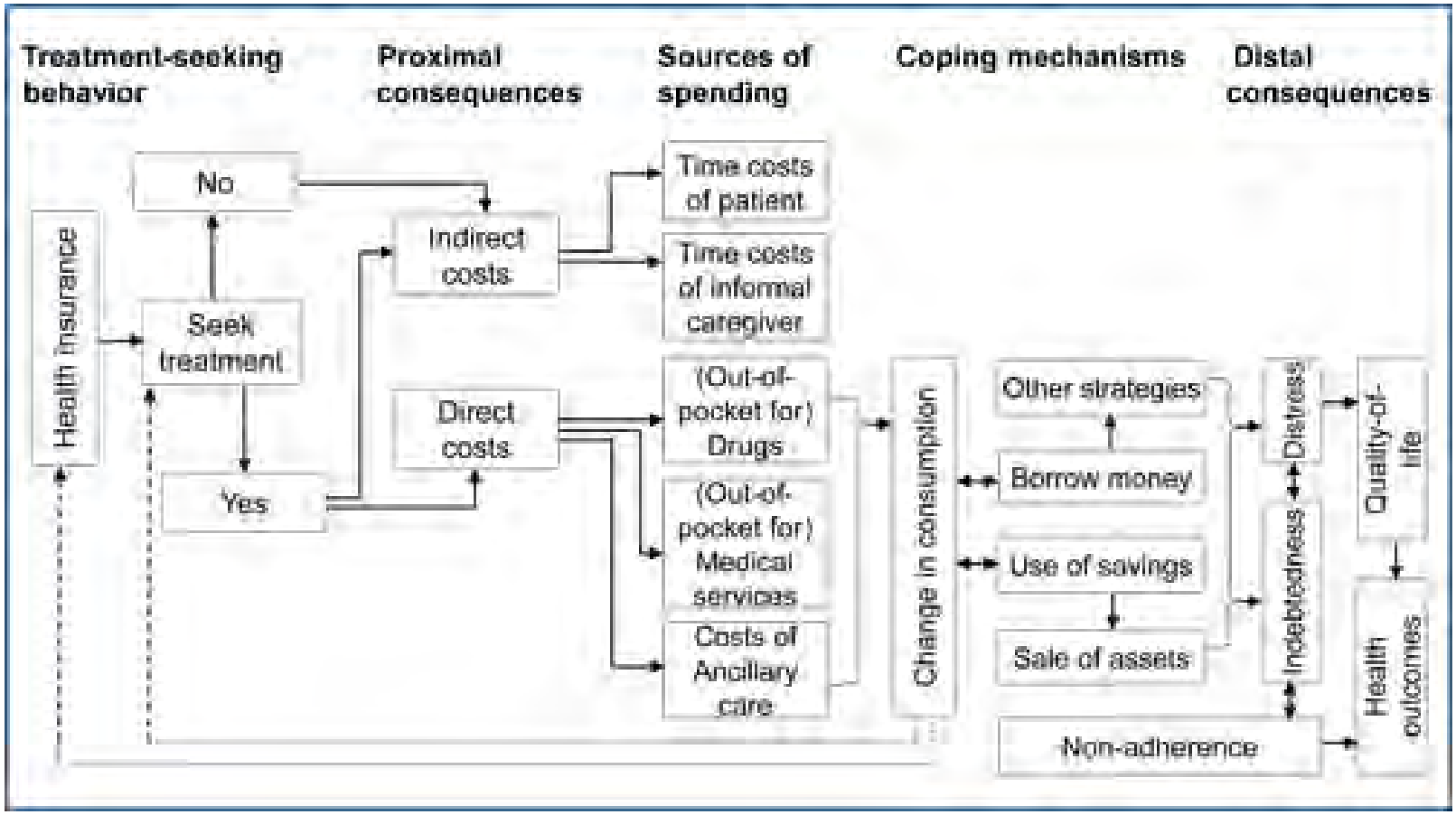

CA: A Cancer Journal for Clinicians, Volume: 68, Issue: 2, Pages: 153-165, First published: 16 January 2018, DOI: (10.3322/caac.21443)

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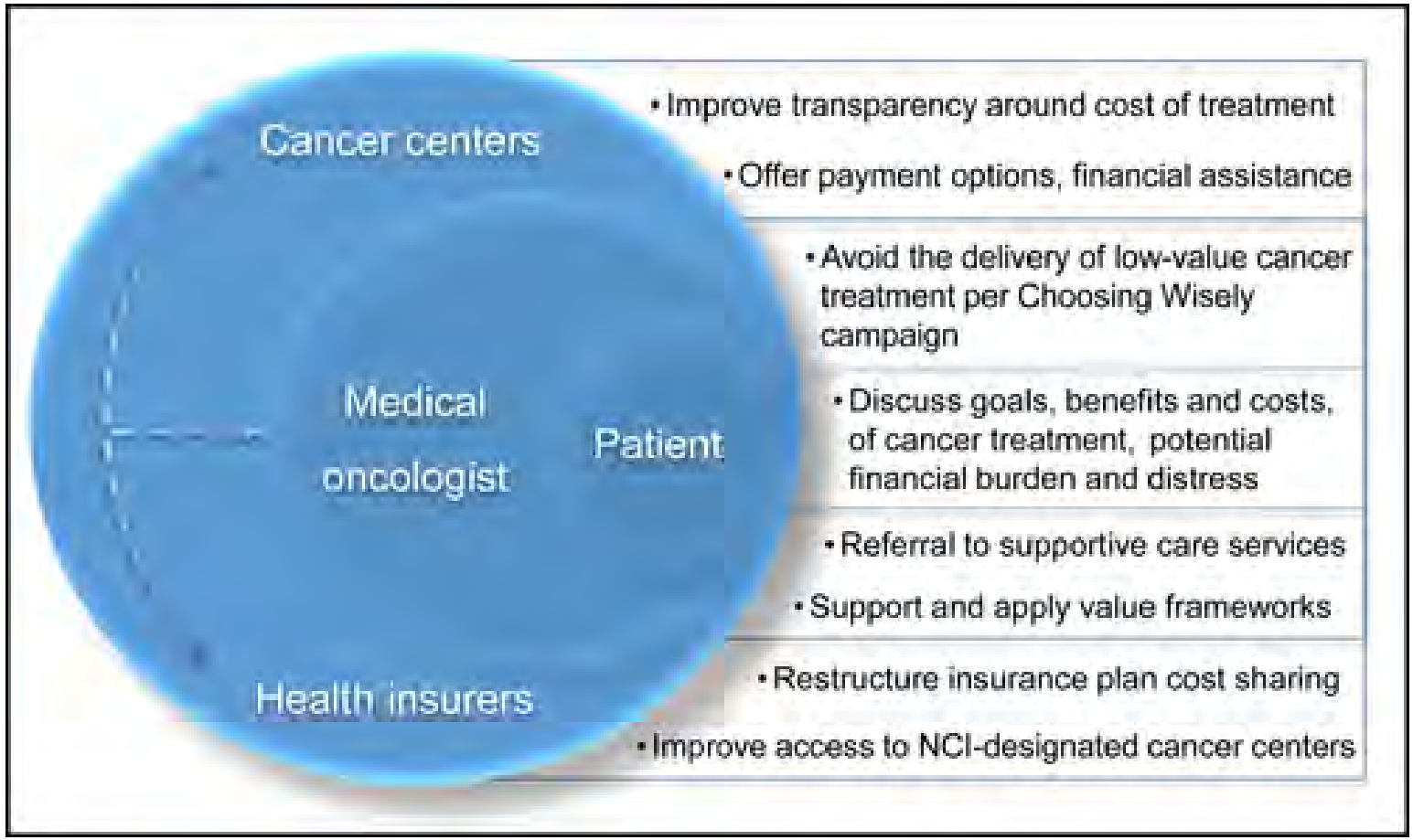


CA: A Cancer Journal for Clinicians, Volume: 68, Issue: 2, Pages: 153-165, First published: 16 January 2018, DOI: (10.3322/caac.21443)

Impact of Financial Strain

- 309 women with breast cancer
  - 37.5% of women experienced financial strain (varying by SES)
  - 26.1% reported treatment-specific financial toxicity

- Financial strain was significantly associated with more severe symptoms of depression ($P < 0.001$) and anxiety ($P < 0.001$) and worse physical symptom burden ($P < 0.001$) and perceived health ($P < 0.001$).

- On average, cancer survivors had significantly higher annual out-of-pocket medical expenditures than did persons without a cancer history.

- Overall, 25% of survivors reported problems paying medical bills, and 33% reported worry about medical bills. Financial hardship was more common among the uninsured than among those with insurance coverage.

- The most commonly reported financial sacrifices included cutbacks on household budgets, challenges with health care insurance and costs, career/self-advancement constraints, reduction/depletion of assets, and inability to pay bills.

- Survivors who incurred $10,000 or more in debt were significantly more likely to report social and economic impacts, including housing concerns and strained relationships.

Perry LM, et al (2019). J Pain Symptom Manage;58(3):454-459.
Ekwueme, DU, et al. (2019) MMWR ;68:494–499.
Benegas. MP, et al. (2019). J Cancer Surviv; 13(3): 406-417.

Work Accommodations for Survivors

Approximately 2/3 of working cancer survivors *ever* discussed employment with a healthcare provider.

4 recommendations:

(1) graduated return to work plans and flexible scheduling,
(2) modification of work duties and performance expectations,
(3) retraining and supports at the workplace, and
(4) modification of the physical work environment and/or the provision of adaptive aids/technologies.

Processes to ensure effective accommodations included:

(1) developing knowledge about accommodations,
(2) employer's ability to accommodate,
(3) negotiating reasonable accommodations,
(4) customizing accommodations, and
(5) implementing and monitoring accommodation plans.

Challenges included:

(1) survivors' fears requesting accommodations,
(2) developing clear and specific accommodations,
(3) difficult to accommodate jobs, and
(4) workplace challenges, including strained pre-cancer workplace relationships, insufficient/inflexible workplace policies, employer concerns regarding productivity and precedent setting, and limited modified duties.

Stergiou-Kita M, et al. (2016) *J Cancer Surviv*;10(3):489-504.
de Moor JS, et al (2018). *J Cancer Surviv*;12(6):813-820.

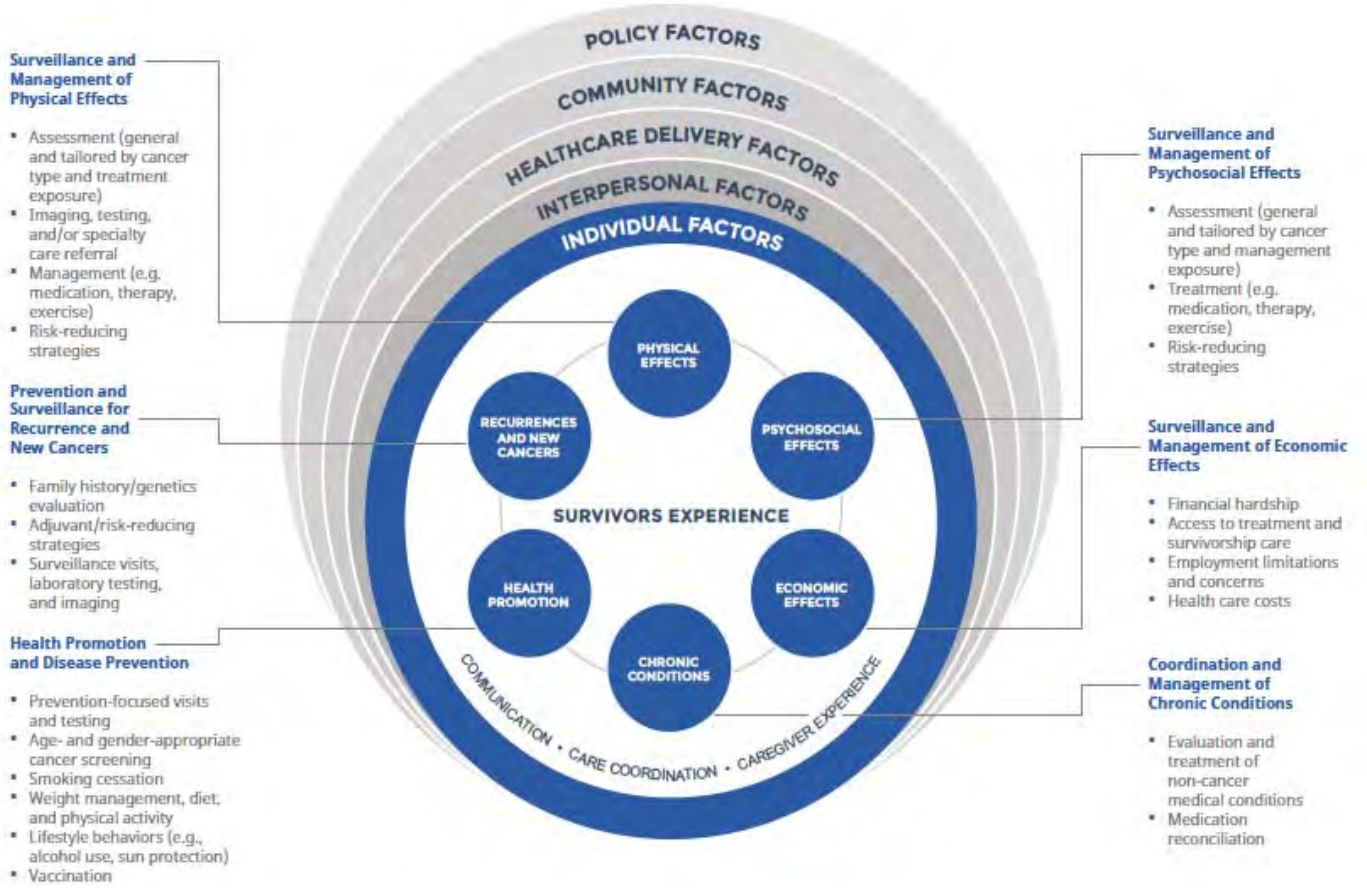
Models of Survivorship Care

Uncharted

Essential Components of Survivorship Care

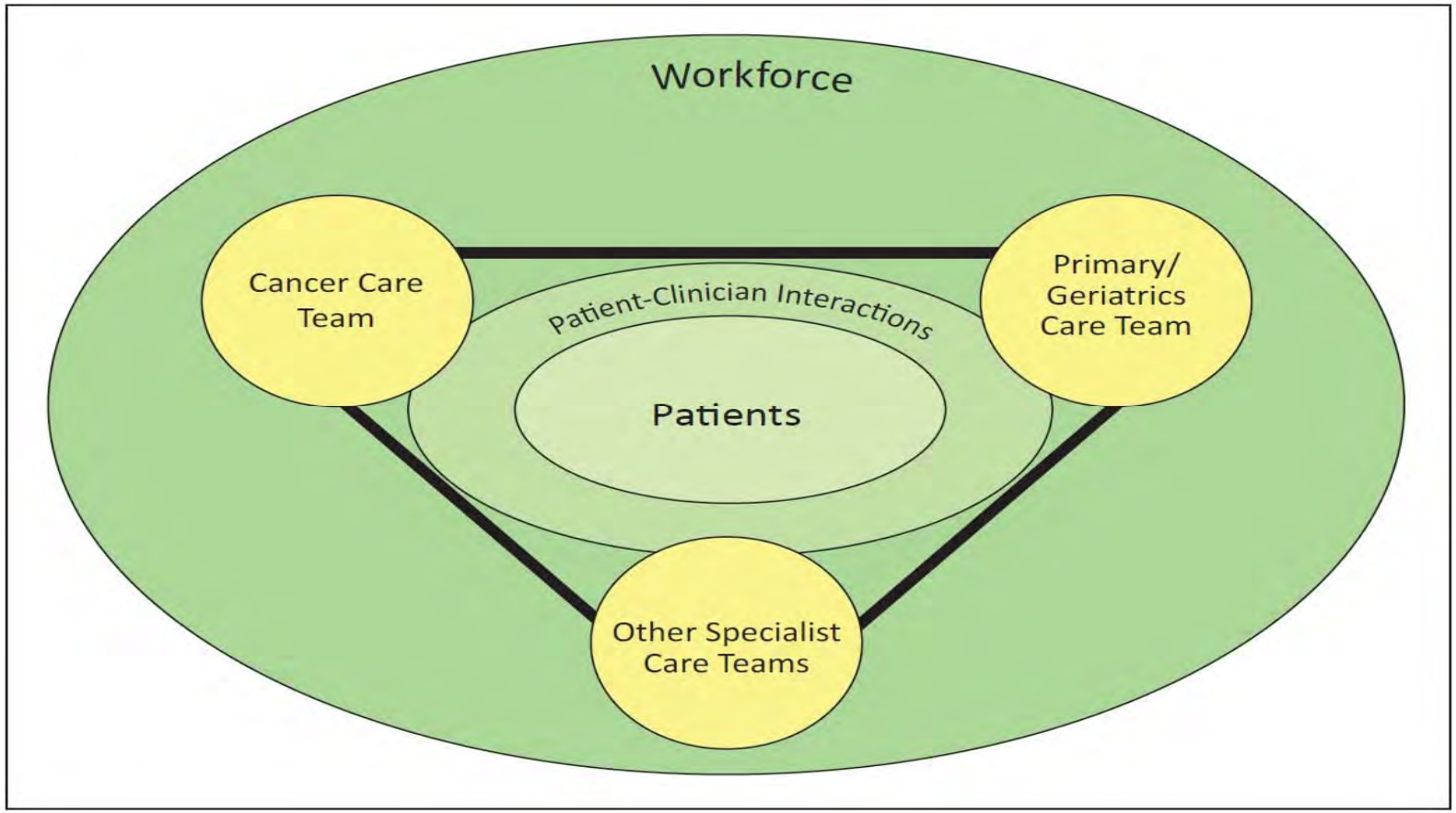
- *Prevention* of recurrent and new cancers and other late effects
- *Surveillance* for cancer spread, recurrence or new cancers and assessment and mitigation of physical and psychosocial late effects
- Health Promotion
- Coordination between specialists and primary care providers to ensure that the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

Cancer Survivorship Research



Adapted from Nekhlyudov, L, Mollica, M., Jacobsen, P., Mayer, DK, Shulman, LN, Geiger, AM. (2019). Developing a Quality of Cancer Survivorship Care Framework: Implications for Clinical Care, Research and Policy. *JNCI*, epub ahead of print

Care Coordination



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.

Risk Stratified Model National Cancer Survivorship Initiative

Supported self-management (patients at low risk for developing long-term and late effects of treatment):
- Patients are given the knowledge and skills to self-manage their care

Shared care (patients at moderate risk for developing long-term and late effects of treatment):
- Patients have regular contact with health-care professionals

Complex case management (patients at high risk for developing long-term and late effects of treatment):
- Patients need intensive support from health-care services to meet their needs

Patients at low risk of developing long-term and late effects of treatment
All of the following:
- Surgery only
- Non-alkylating chemotherapy
- No radiotherapy
- Low risk of recurrence
- Mild or no persistent toxicity of therapy

Patients at moderate risk of developing long-term and late effects of treatment
Any of the following:
- Low or moderate-dose alkylating agent
- Low or moderate-dose radiotherapy
- Autologous stem-cell transplantation
- Moderate risk of recurrence
- Moderate persistent toxicity of treatment

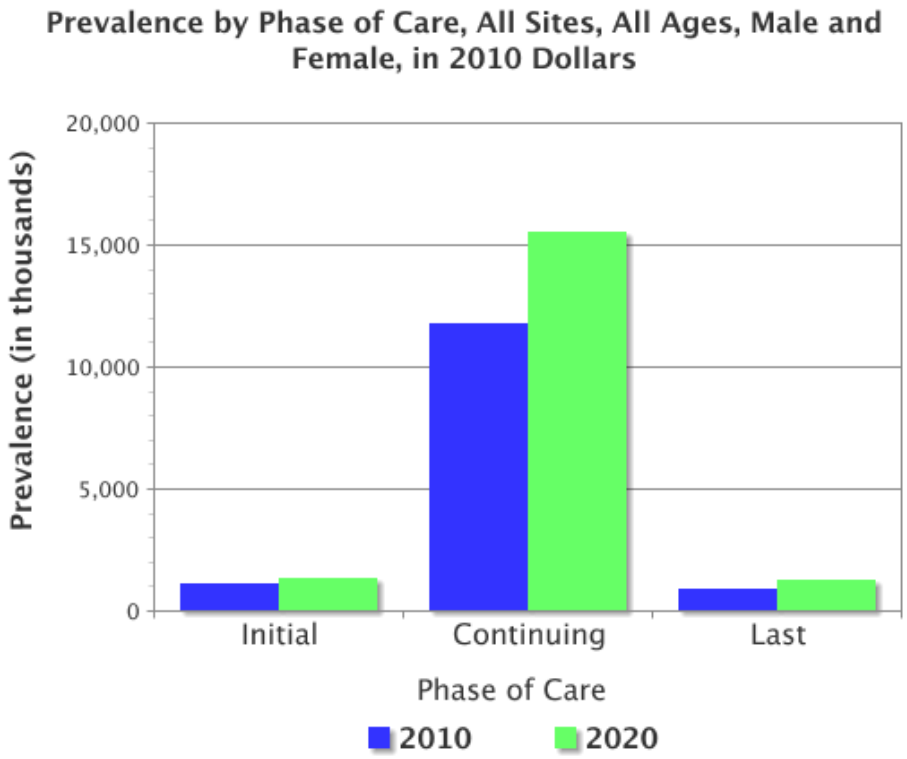
Patients at high risk of developing long-term and late effects of treatment
Any of the following:
- High-dose alkylating agent
- High-dose radiotherapy
- Allogeneic stem-cell transplantation
- High risk of recurrence
- Multi-organ persistent toxicity of therapy

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

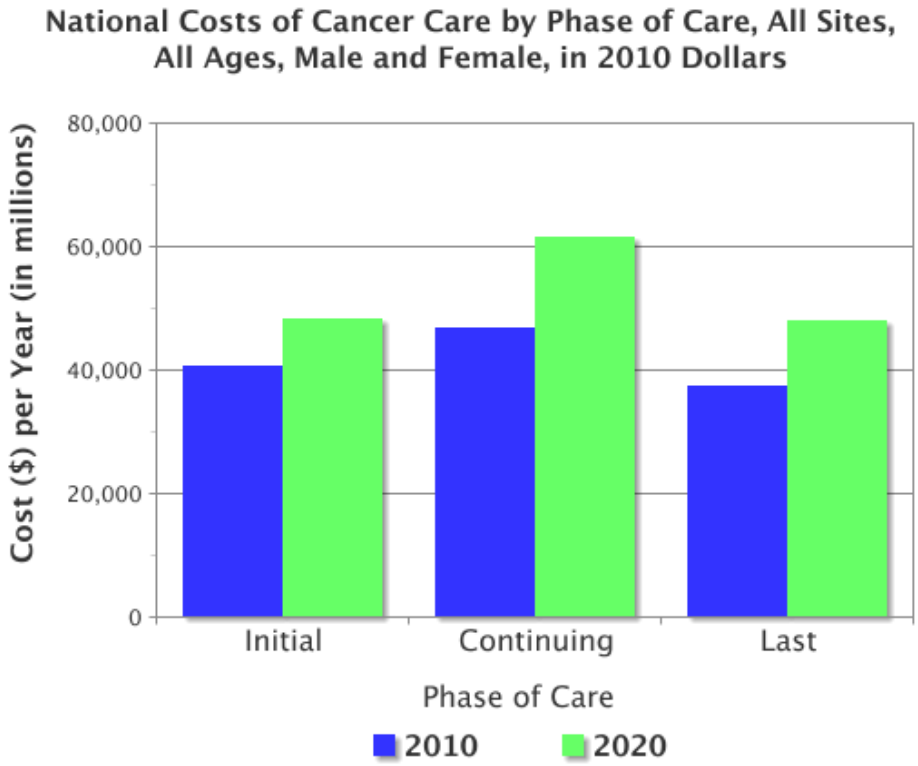
Principles of Personalized Follow-up Care Pathways

- 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.

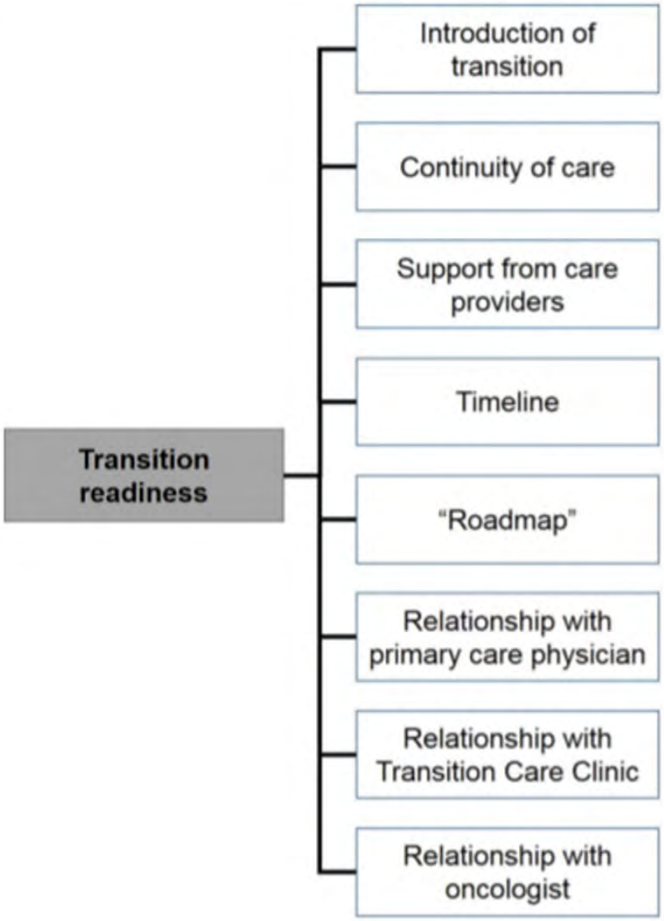
Continuing Care for Cancer Survivors



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



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



CURRENT ONCOLOGY
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ORIGINAL ARTICLE

The experiences of cancer survivors while transitioning from tertiary to primary care

B.B. Franco,* L. Dharmakulaseelan,* A. McAndrew BA RAP,* S. Bae MPH,* M.C. Cheung MD MSc,*,a and S. Singh MD MPH*,a

ABSTRACT

Purpose In current fiscally constrained health care systems, the transition of cancer survivors to primary care from tertiary care settings is becoming more common and necessary. The purpose of our study was to explore the experiences of survivors who are transitioning from tertiary to primary care.

Methods One focus group and ten individual telephone interviews were conducted. Data saturation was reached with 13 participants. All sessions were audio-recorded, transcribed verbatim, and analyzed using a qualitative descriptive approach.

Results Eight categories relating to the main content category of transition readiness were identified in the analysis. 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, and desire for a "roadmap." Although all participants spoke about the effect of their relationships with health care providers (tertiary, transition, and primary care), their relationship with the primary care provider had the most influence on their transition readiness.

Conclusions Our study provided insights into survivor experiences during the transition to primary care. Transition readiness of survivors is affected by many factors, with their relationship with the primary care provider being particularly influential. Understanding transition readiness from the survivor perspective could prove useful in ensuring patient-centred care as transitions from tertiary to primary care become commonplace.

Key Words Primary care, transitions in care, patient-centred care, qualitative research, survivors

Curr Oncol. 2016 Dec;23(6):378-385 www.current-oncology.com

Actions *Oncology Clinicians* Can Pursue Now

- Clearly communicate to patients from the time of diagnosis that they will be expected to continue to be followed by their primary care provider and likely will transition back to predominately primary care after treatments ends.
- Examine current patient rosters, clinic utilization patterns, and new patient visit slots →consider how shifting care of low-risk/low-need survivors to primary care or advanced practice practitioners would affect these factors.

Alfano, C. et al. *CA Cancer J Clin*. 2019;69(3):234-247

Actions *Oncology Clinicians* Can Pursue Now

- Reinforce expectations about follow-up by ongoing communication throughout cancer treatment.
- Shift follow-up appointments for patients off treatment so they are clustered.
- Support patients who are doing well in self-managing their health.
- Build bridges with primary care.

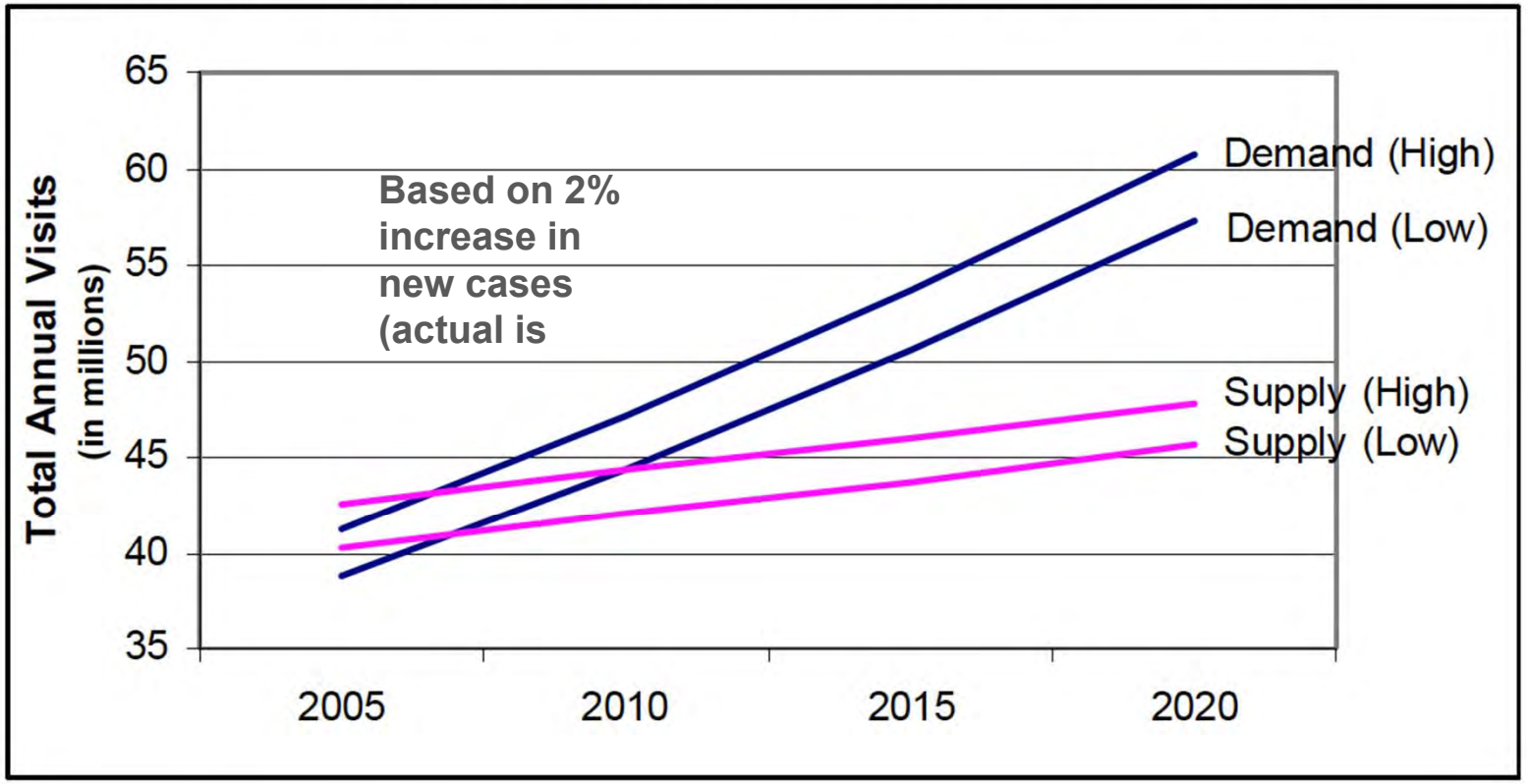
Alfano, C. et al. *CA Cancer J Clin*. 2019;69(3):234-247

Oncology Workforce Issues

Healing Hands of Hope

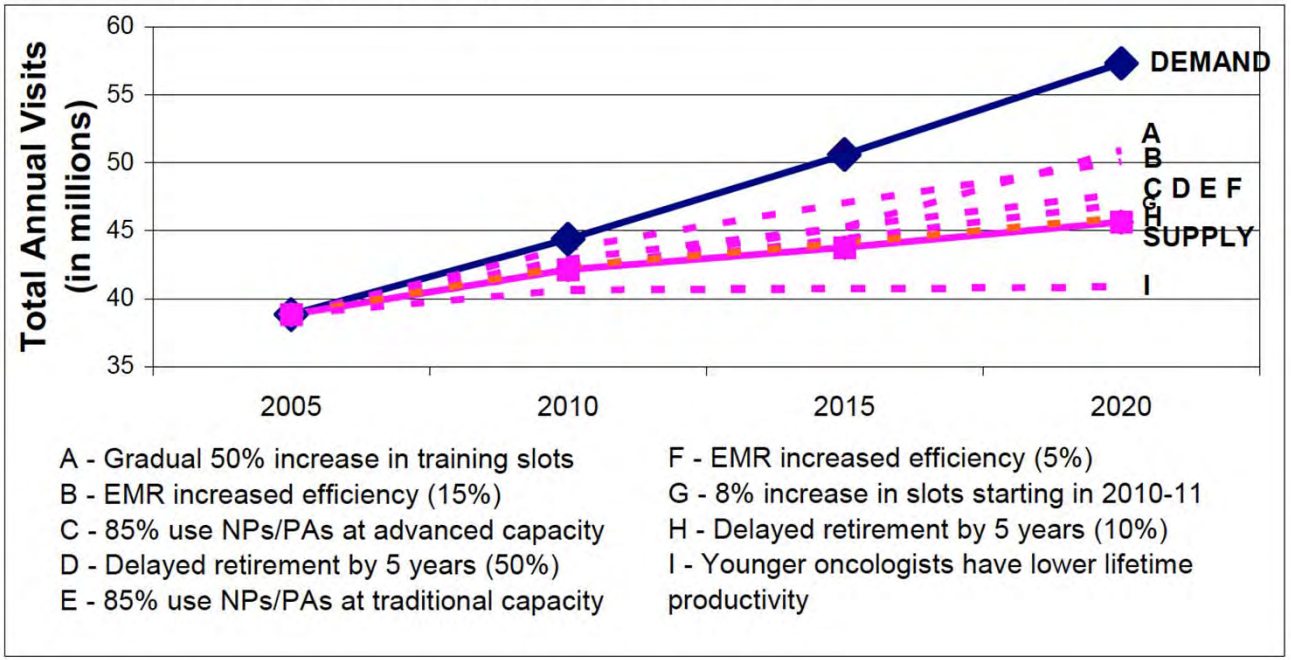
Forecasting Supply And Demand For Oncologists (ASCO, 2007)

Figure 1: Projected supply (visit capacity) and demand for visits, 2005-2020



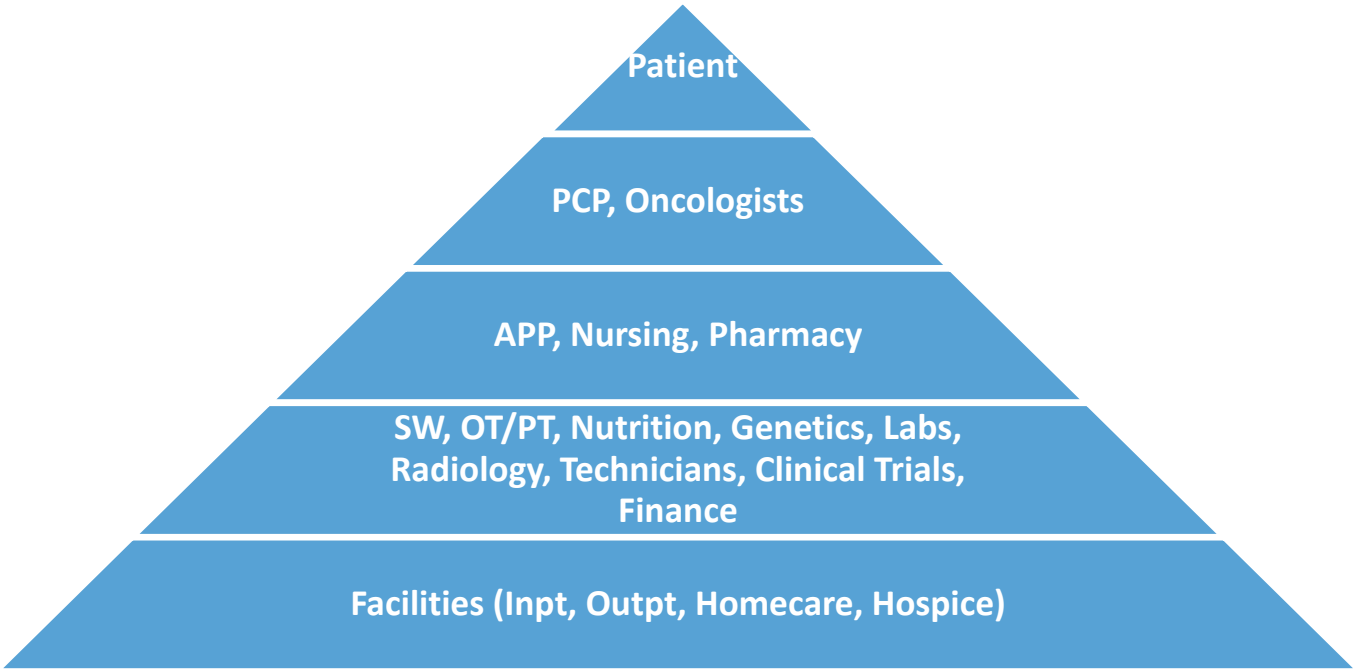
Forecasting Supply And Demand For Oncologists (ASCO, 2007)

Figure 55: Alternate supply scenario projections, 2005-2020



Cancer Services and Programs

How do we calculate workforce and other needs based on numbers of patients?



Health Care Without Walls

Care at point of need not just point of care: a system that came to people, meeting them where they are, in their homes, workplaces or elsewhere → more distributed virtual care.

Health care workers need to use technology to more equitably distribute care.

Current Shift from Fee-for-Service to Value-based care.

Regulatory changes at state and federal level are also needed.

Need to address social determinants of health-food insecurity, housing, transportation

Implications

- Our success in treating cancer, coupled with the wave of baby boomers, is creating a tsunami of survivors.
- The greatest volume of survivors will have breast, prostate and colorectal cancers but the greatest need may be in smaller volume cancers such as lung and head and neck cancers (80 *and* 20 rule).
- We must pay attention and address work and financial issues.
- This information can be used when developing screening and management programs.

Conclusions

- **Current cancer are can not be sustained**
- More survivorship research to help prevent or mitigate long term and late effects
- There is no one solution to address this issue but all require culture change in cancer care delivery.
- Projections for staff and facilities must go beyond # new cases and beyond the next 1-2 years.
- ***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, and supported self-management.***
- Multiple strategies need to be tested.
- 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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When Life Is Sewn Back Together, It Has Changed