

Challenges and Opportunities for Patient-Centered Care in AYA Oncology

John M. Salsman, PhD



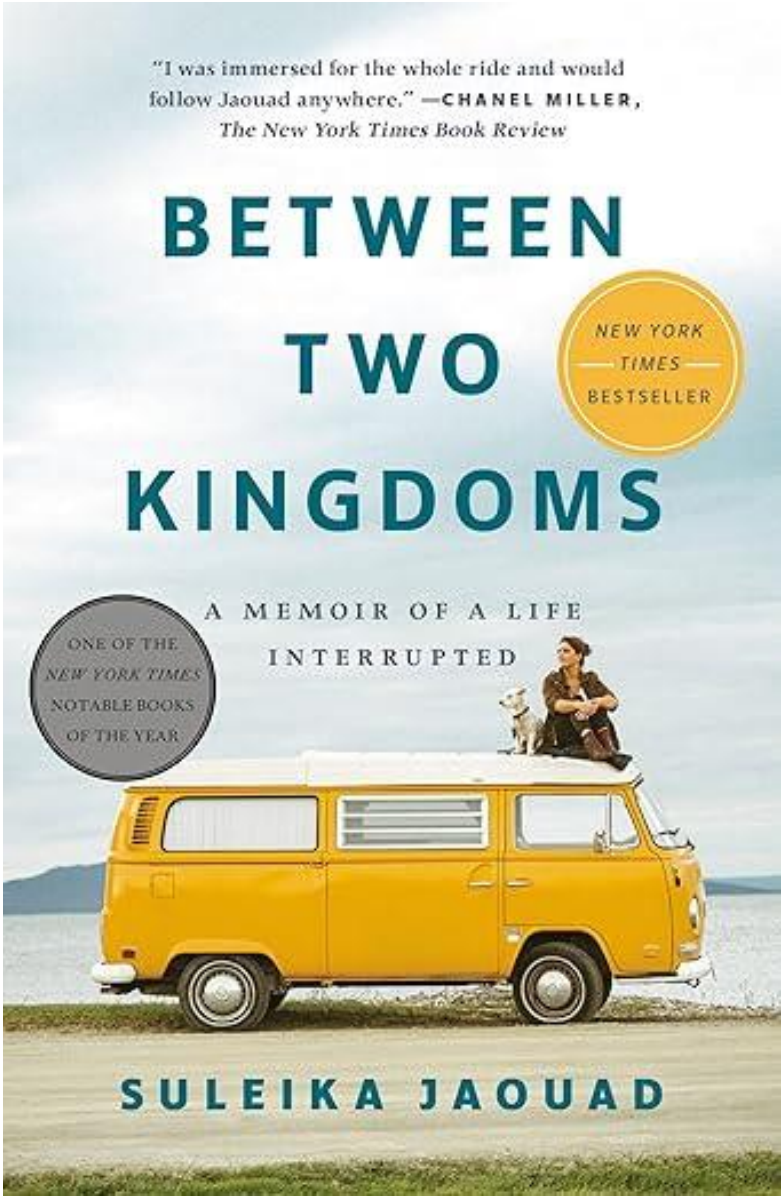
Disclosures



<https://www.teammaggiesdream.org/>



<https://www.truenorthtreks.org/>



Goals

- To better understand the special needs and challenges faced by AYAs with cancer.
- To identify current priorities for AYA-focused supportive care and care delivery.



AYA Overview

**Closing the Gap:
Research and
Care Imperatives for
Adolescents and
Young Adults with Cancer**

Report of the
Adolescent and Young Adult Oncology
Progress Review Group

U.S. DEPARTMENT OF
HEALTH AND HUMAN SERVICES
National Institutes of Health
National Cancer Institute
LIVESTRONG™ Young Adult Alliance

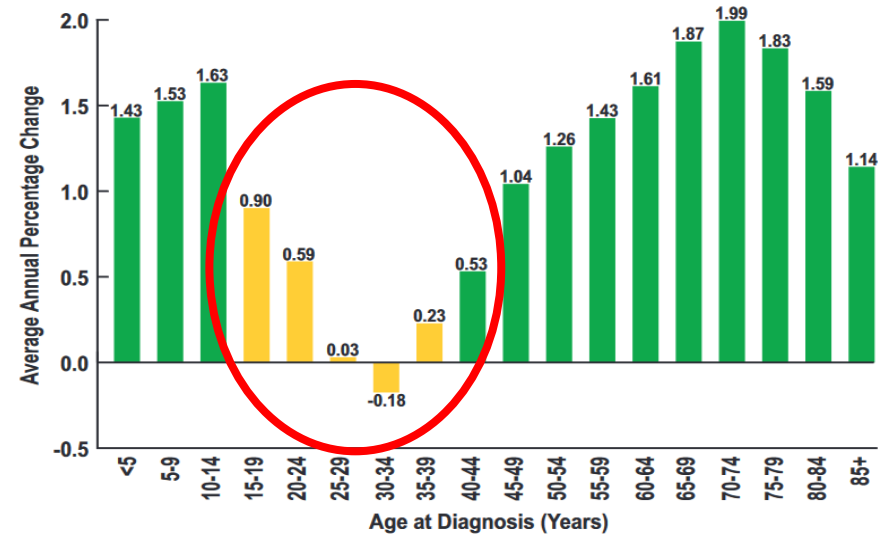


Figure 2. Improvement in 5-Year Relative Survival, Invasive Cancer, SEER 1975-1997

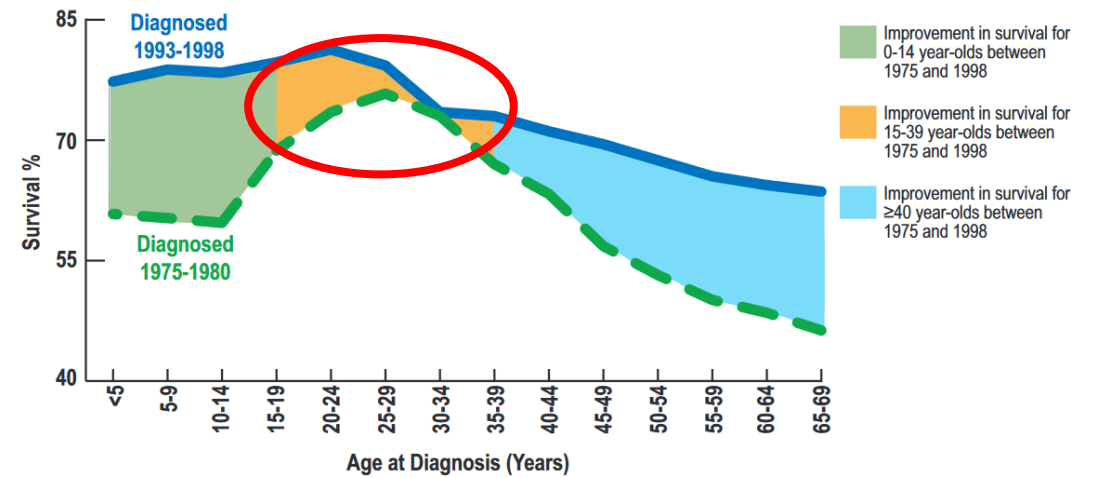
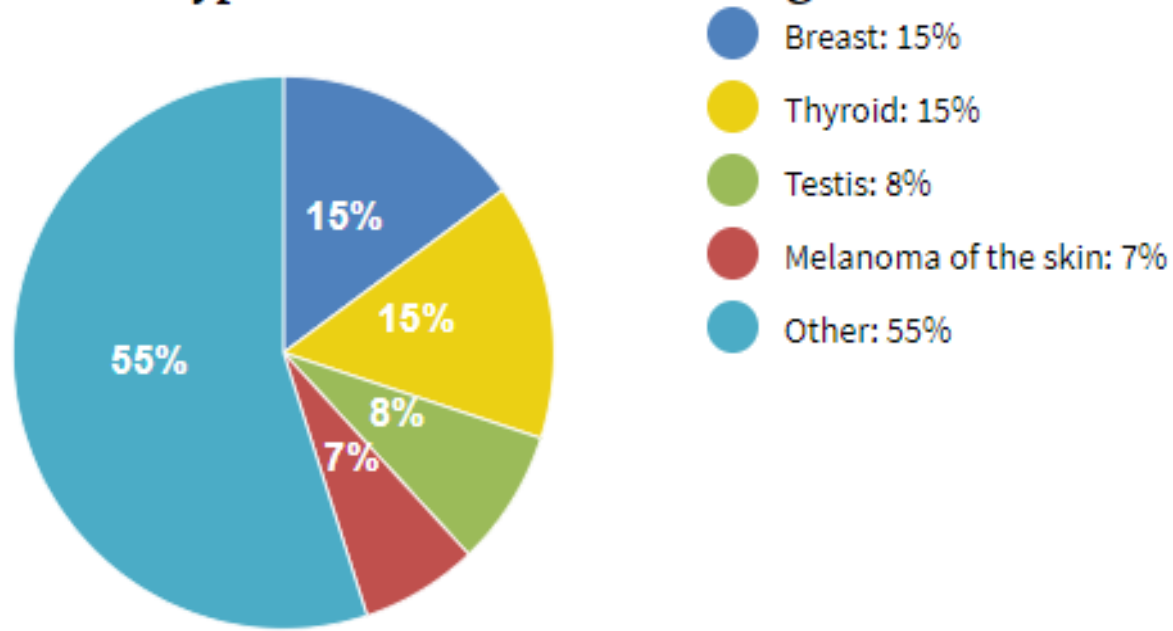


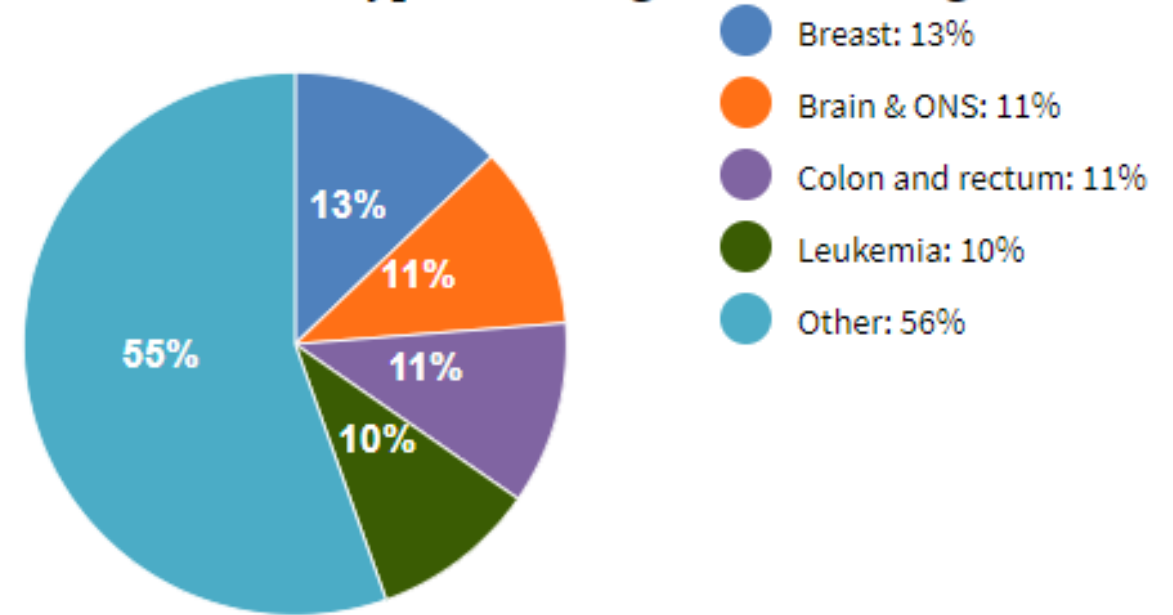
Figure 3. 5-Year Survival of Patients with Cancer by Era, SEER, 1975-1998

Common Types of New Cancers Among AYAs



Distribution based on age-adjusted rates of new cases.
SEER 22, 2017-2021.

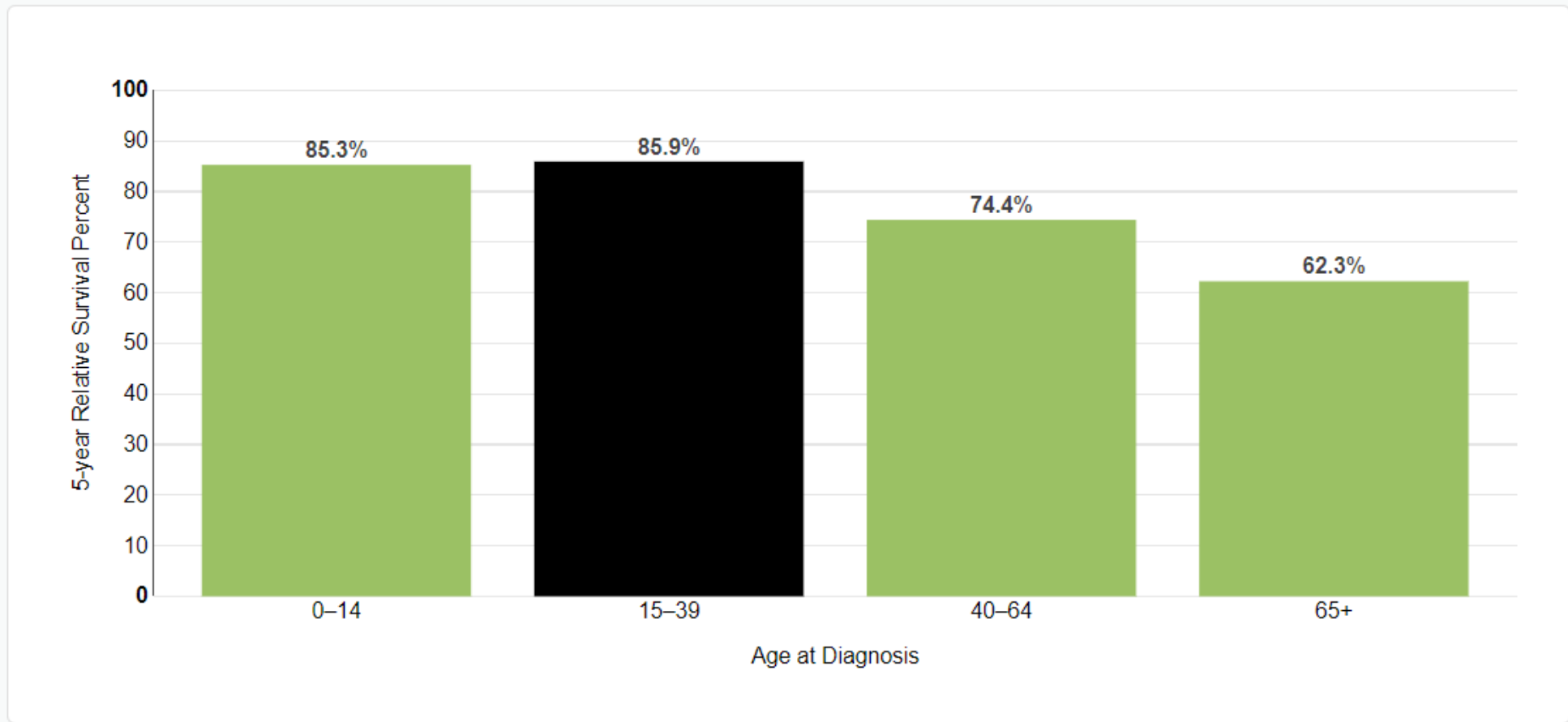
Common Cancer Types Causing Death Among AYAs



Distribution based on age-adjusted death rates.
U.S. Mortality, 2018-2022.

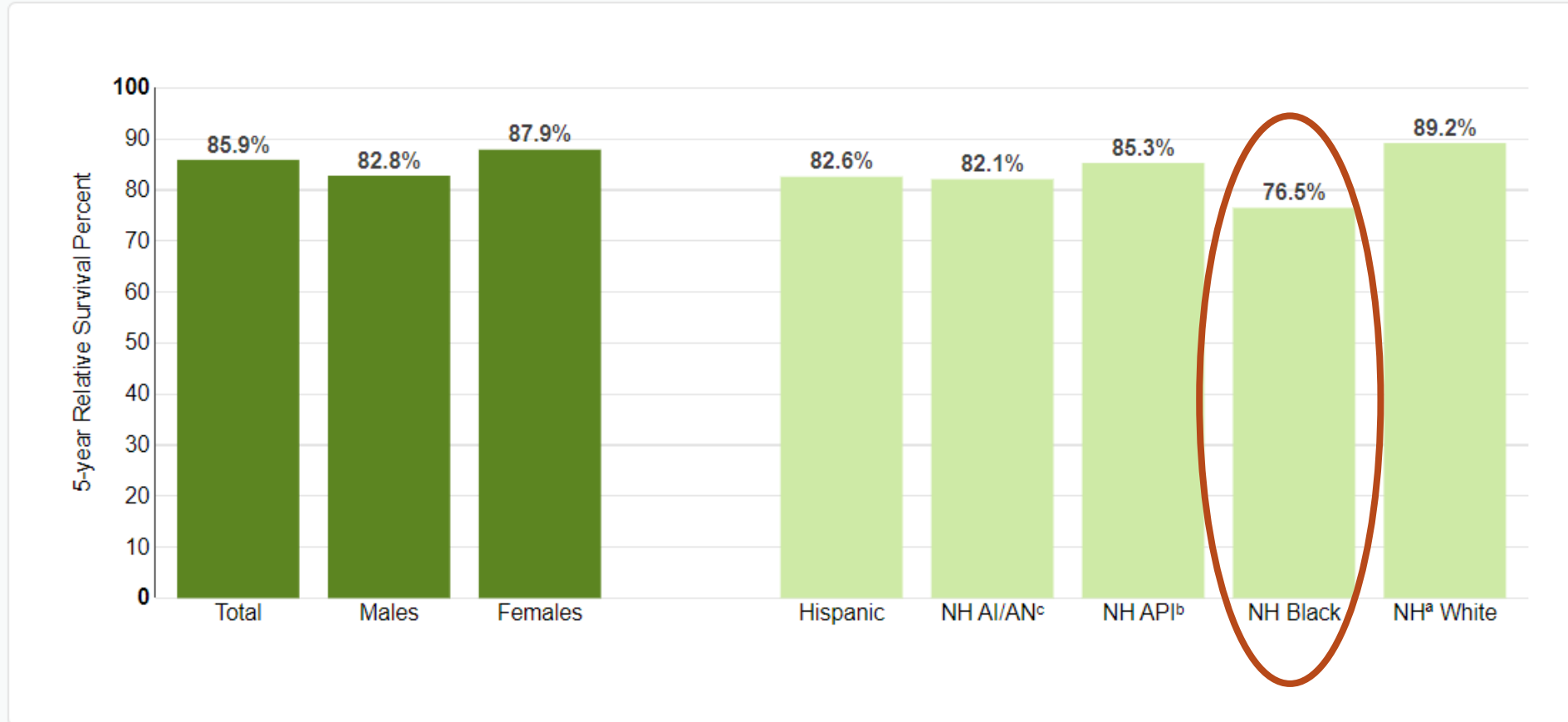


How Does Cancer Survival Among AYAs Compare to Cancer Survival at Other Ages?



SEER 22 (Excluding IL/MA) 2014-2020

5-year Relative Survival by Sex and Race



SEER 22 (Excluding IL/MA) 2014–2020, Ages 15–39

^a Non-Hispanic, ^b Asian/Pacific Islander, ^c American Indian / Alaska Native

Challenges

Developmental Characteristics

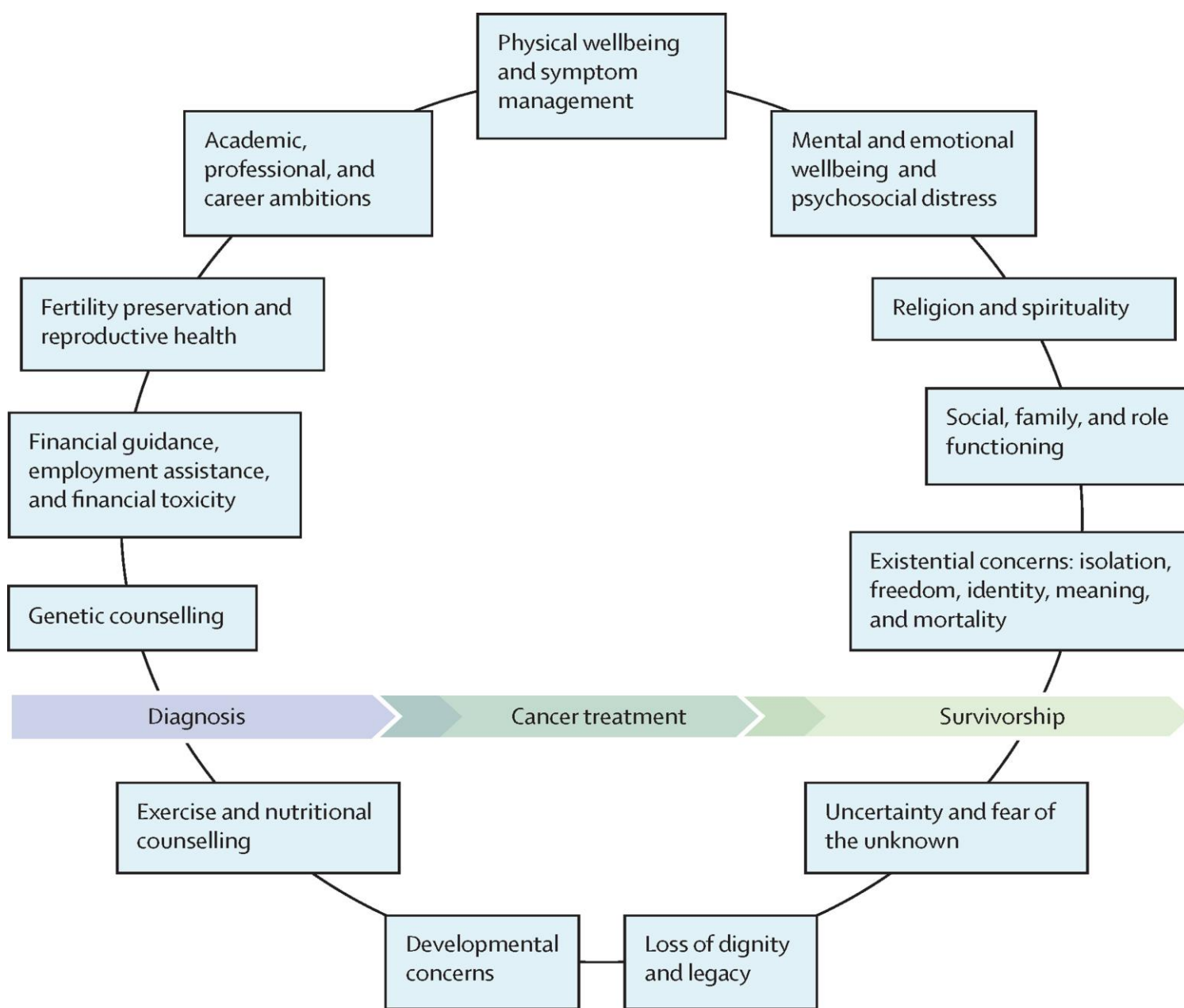
- **Adolescents** – completing high school, driver's license, dating
- **Emerging adults** – completing college, living on own, establishing financial independence, seeking employment, gaining voting privileges, forming intimate relationships
- **Young adults** – forming long-term relationships, establishing their careers, family building financially independent



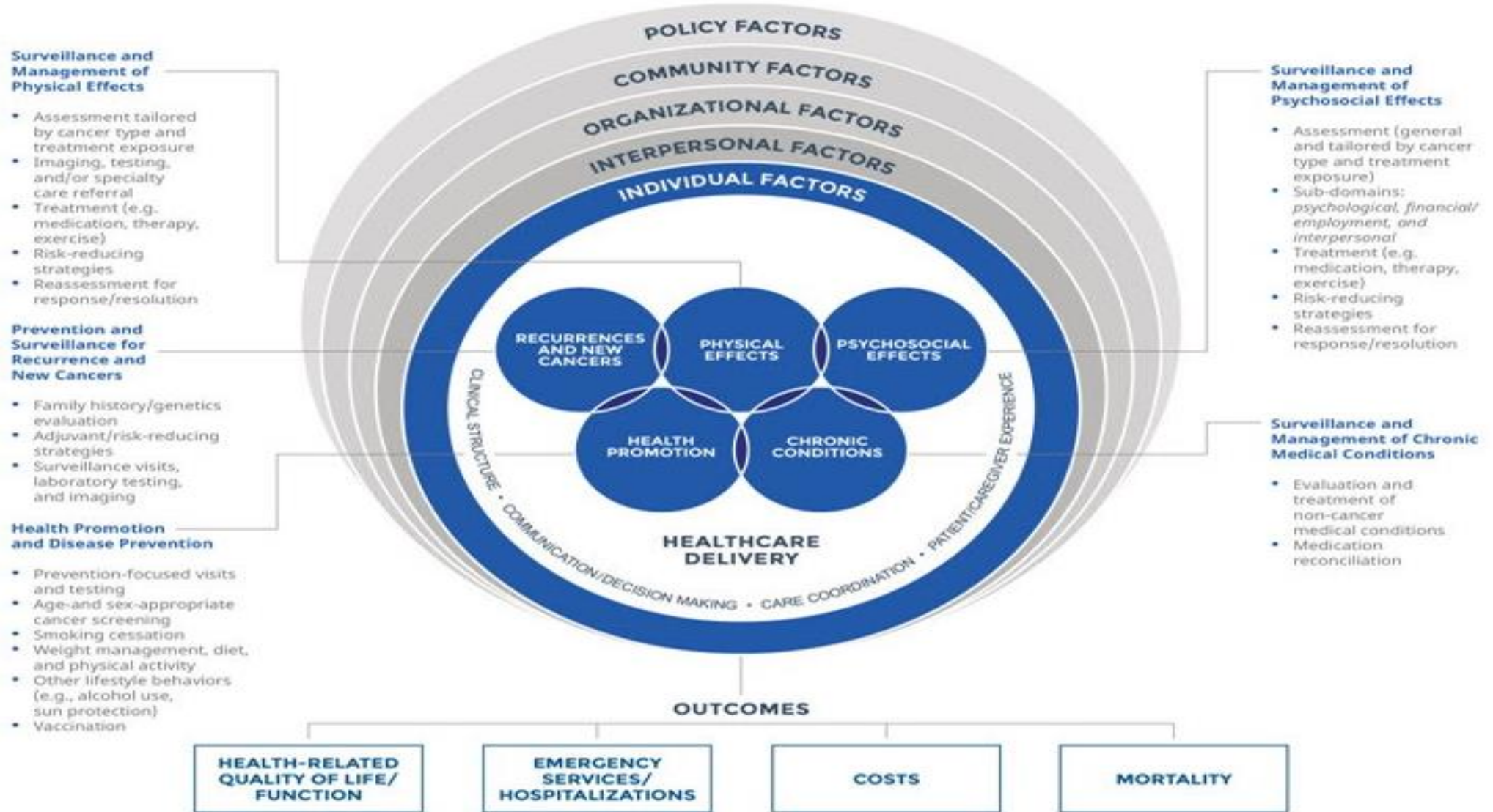


When AYAs are diagnosed with cancer, they have a range of concerns and challenges that older or younger patients may not face - on top of navigating cancer treatment.

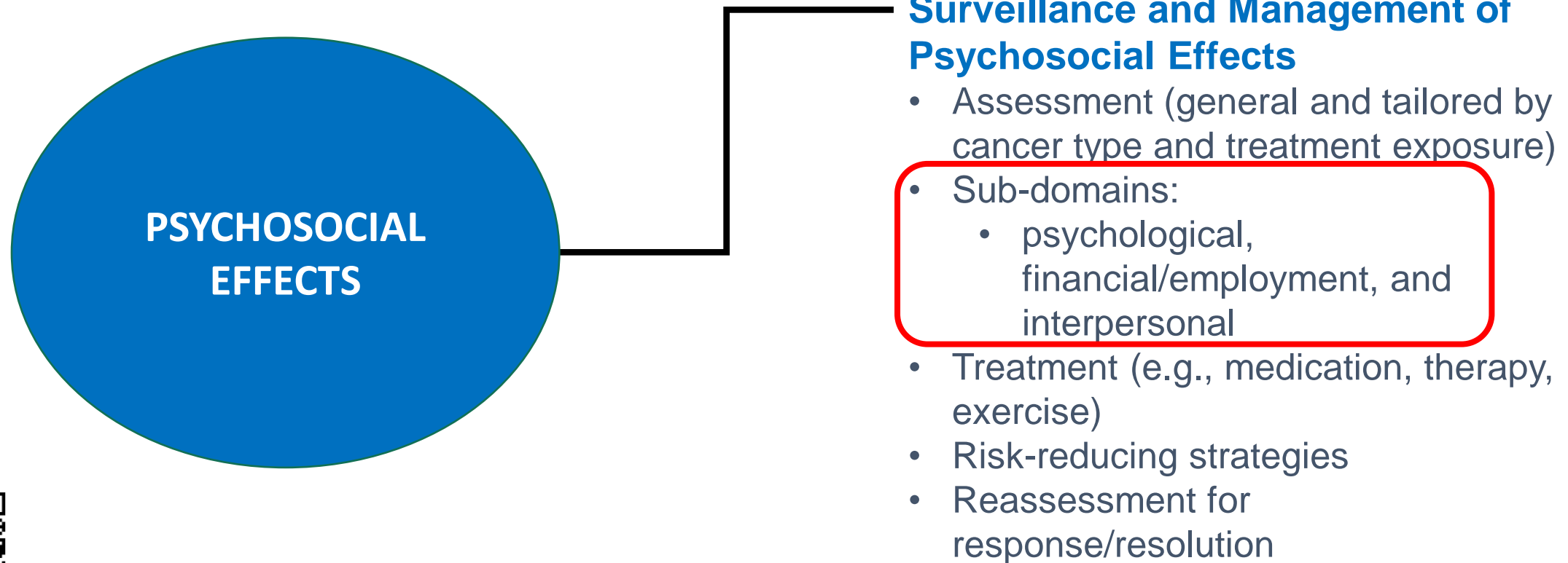




Framework for Measuring Quality of Cancer Survivorship Care



Framework for measuring quality of cancer survivorship care



Psychological

AYA cancer survivors report:

- greater cancer-specific distress
- high prevalence of fear of recurrence (31%-85%) with higher levels in AYAs
- higher rates of depression (13-25%) compared to AYAs without cancer
- clinical symptoms of anxiety (15-20%) that persist years beyond treatment completion



Financial

Finally, AYA cancer survivors experience:

- More financial hardship than the general population
- Increased spending on out-of-pocket medical costs
- Higher uninsured rates compared with other age groups
- Higher rates of bankruptcy and more frequently forgo needed medical care because of cost compared with older survivors

Being uninsured or having public health insurance → significant delays in diagnosis → poorer outcomes and more extensive treatment.



Interpersonal

“Our epidemic of loneliness and isolation has been an underappreciated public health crisis that has harmed individual and societal health. Our relationships are a source of healing and well-being hiding in plain sight – one that can help us live healthier, more fulfilled, and more productive lives,”

U.S. Surgeon General Dr. Vivek Murthy

Our Epidemic of Loneliness and Isolation

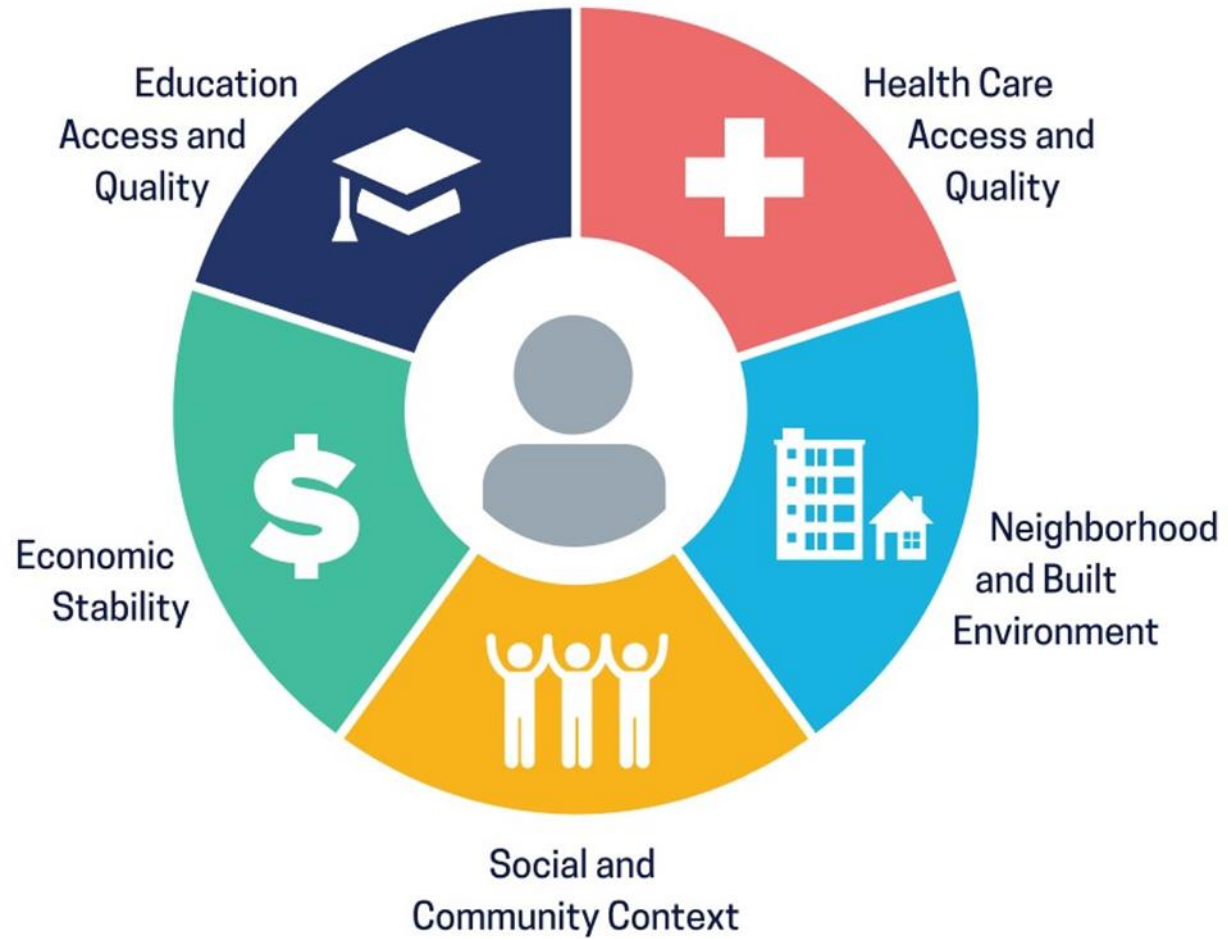


2023

The U.S. Surgeon General's Advisory on the Healing Effects of Social Connection and Community



Social Determinants of Health



Social Determinants of Health
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 Healthy People 2030





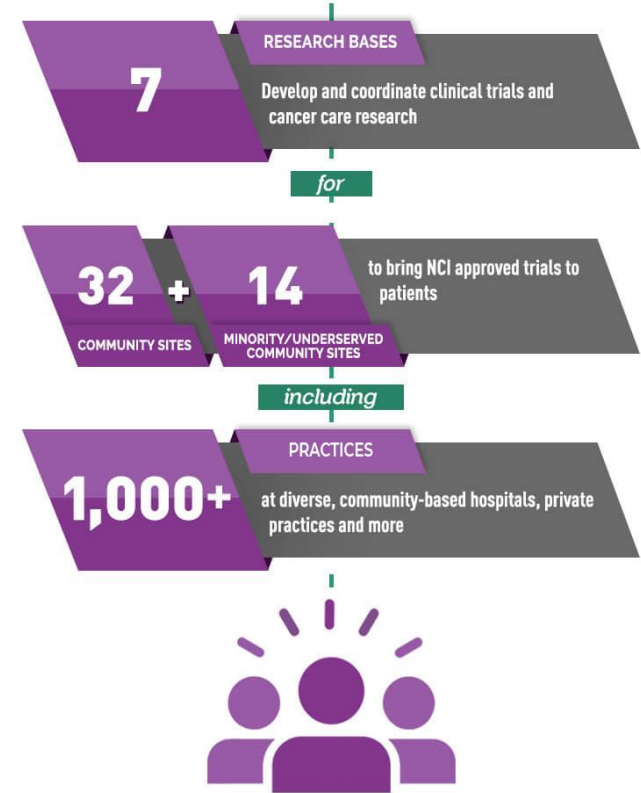
NIH NATIONAL CANCER INSTITUTE

Cancer Clinical Trials in Your Community

NCI Clinical Oncology Research Program (NCORP)

NATIONAL CANCER INSTITUTE

The **NCI Community Oncology Research Program (NCORP)** brings cancer research studies and results to patients in a variety of community settings across the United States.



[NCORP.cancer.gov](https://ncorp.cancer.gov)

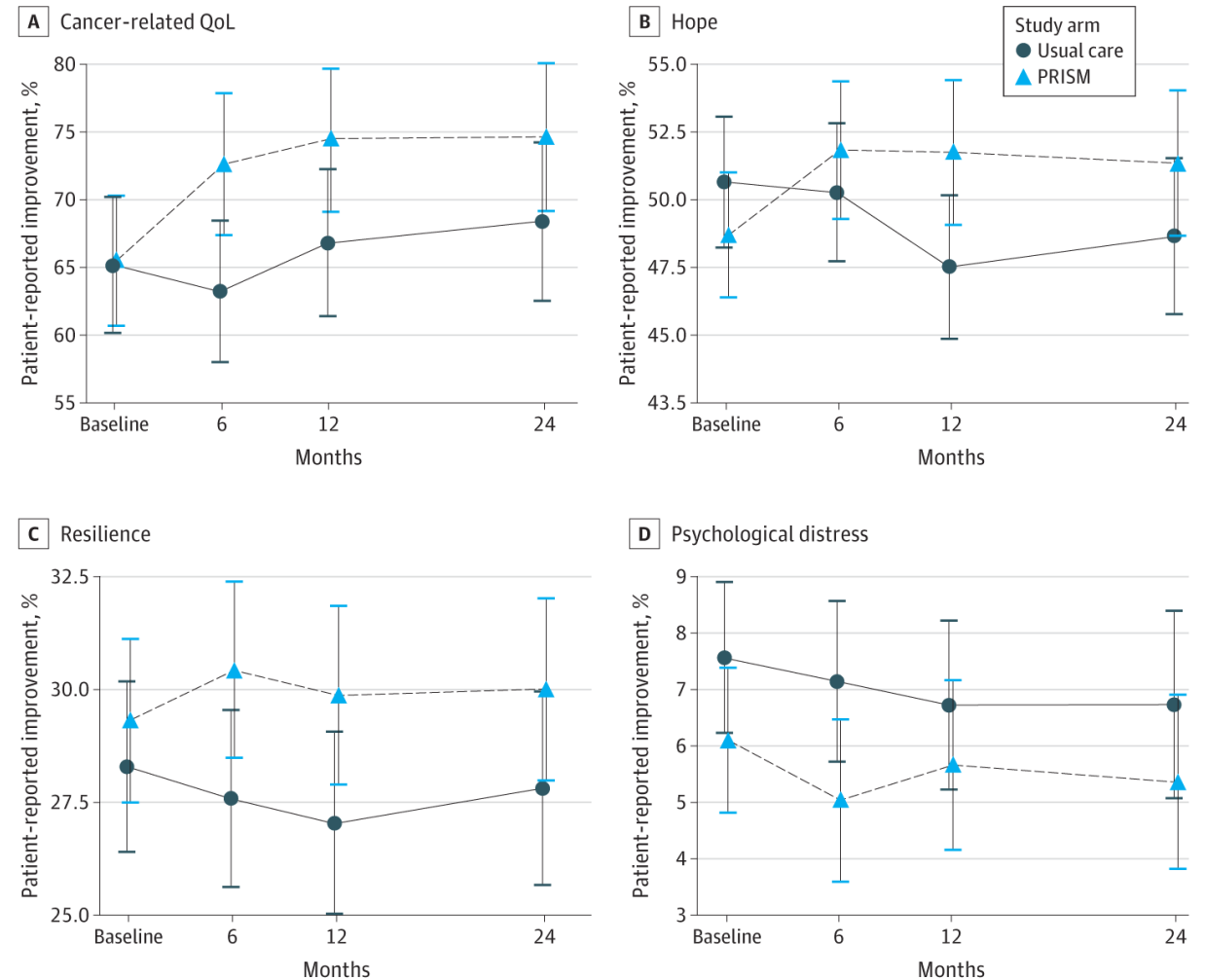


Opportunities

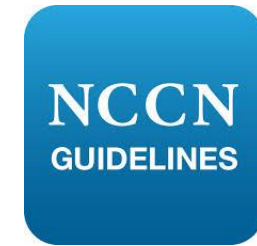
Psychological Interventions for AYAs

PRISM is a brief, skills-based coaching program targeting 4 resilience resources (stress management, goal setting, cognitive reframing, and meaning making).

PRISM was associated with improved QoL, hope, resilience, and distress between baseline and 6 months, and these associations were sustained for QoL over 12 months and hope throughout the study period (12 and 24 months).



NCCN Recommendations to Address Psychological Needs



- Child life specialists or appropriate psychosocial support specialists (if available) should meet with the patient soon after diagnosis **to address any potential concerns regarding treatment or procedures and assist with coping mechanisms to reduce any potential anxiety.**
- Consider a referral to a social worker, mental health provider, and community-based resources serving AYA patients **to screen for any symptoms of depression, anxiety, suicidal ideation/behaviors, and self-injurious behavior.**
- For lesbian, gay, bisexual, transgender, queer (or questioning), intersex, asexual, 2-spirit (LGBTQIA2S+) AYA patients, **consider offering psychosocial support and referrals surrounding stressors, stigma, or rejection** related to their sexuality or gender identity.



Financial Interventions



Health Insurance Literacy Improvements Among Recently Diagnosed Adolescents and Young Adults With Cancer: Results From a Pilot Randomized Controlled Trial

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DOI: <https://doi.org/10.1200/JCO.2023.00171>

ABSTRACT

PURPOSE Adolescents and young adults (AYAs; age 18–39 years) with cancer report needing support with health insurance. We conducted a pilot randomized controlled trial to assess the feasibility and acceptability of a virtual health insurance navigation intervention (HIAYA CHAT) to improve health insurance literacy (HIL), awareness of Affordable Care Act (ACA) protections, financial toxicity, and stress.

MATERIALS AND METHODS HIAYA CHAT is a four-session navigator delivered program; it includes psychoeducation on insurance, navigating one's plan, insurance-related laws, and managing costs. Participants were eligible if they could access an internet-capable device, were <1 year from diagnosis, and received treatment from University of Utah Healthcare or Intermountain Health systems. We assessed the feasibility, acceptability, and preliminary efficacy of HIAYA CHAT compared with usual navigation care, including HIL (nine items), insurance knowledge (13 items), ACA protections (eight items), Comprehensive Score for financial Toxicity (COST; 11 items), and Perceived Stress Scale (PSS; four items), using *t* tests and Cohen's *d*.

RESULTS From November 2020 to December 2021, *N* = 86 AYAs enrolled (44.6% participation) and 89.3% completed the 5-month follow-up survey; 68.6% were female, 72.1% were White, 23.3% were Hispanic, 65.1% were age 26–39 years, and 87.2% were privately insured. Of intervention participants (*n* = 45), 67.4% completed all four sessions; among an exit interview subset (*n* = 10), all endorsed the program (100%). At follow-up, compared with usual navigation care, intervention participants had greater improvements in HIL, insurance and ACA protections knowledge, and PSS; effect sizes ranged from moderate to large (0.42–0.77). COST did not differ.

CONCLUSION The results support the feasibility and acceptability of HIAYA CHAT with related improvements in HIL.

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INTRODUCTION

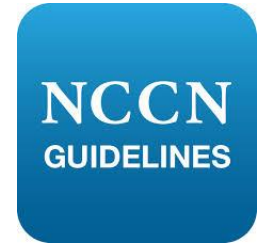
Health insurance literacy (HIL)—the knowledge and application of health insurance concepts—is critical for patients with cancer to navigate care after cancer treatment. Adolescent and young adult (AYA) patients with cancer (age 18–39 years at diagnosis)⁶ often have little experience navigating health care and insurance,^{2,3} which can lead to significant access to care and cost consequences.⁴ AYA cancer patients commonly experience substantial financial toxicity because of vocational gaps, inconsistent employment, and lost wages during treatment.^{4,5} Lapses in health

insurance coverage are common, often at age 26 years when dependent coverage ends, meaning that young adults age 26–39 years have the highest rate of being uninsured and underinsured among adults.^{6,7} These financial and insurance issues, coupled with psychosocial concerns and resource limitations,^{8,9} can mean that many AYA patients face access to care barriers.

HIL is a necessary skill to help AYA patients with cancer manage health care costs and care during treatment.^{10,11} Choosing a health insurance plan can be daunting,¹² especially for patients who have experienced unexpected health



NCCN Recommendations to Address Socioeconomic Issues



- **Assess AYA patients' health insurance status and provide information on potential sources of coverage** (eg, Medicaid, Health Insurance Marketplace, parent's insurance) and other key elements associated with insurance coverage.
- **Refer patients for career counseling and/or education support** as indicated. Encourage discussion with guidance counselors and educators about the impact of cancer care on education.
- **Direct AYA patients to legal resources and/or advocates** for assistance with understanding health insurance coverage.
- **Provide information about recommended and reliable online resources and financial support programs** to access information related to their cancer.



Interventions



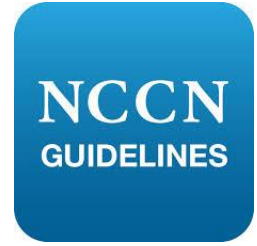
IMERMAN
ANGELS



CACTUS
CANCER SOCIETY



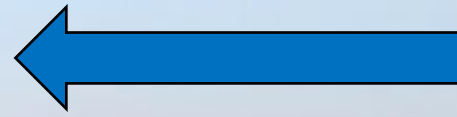
NCCN Recommendations to Address Social Needs



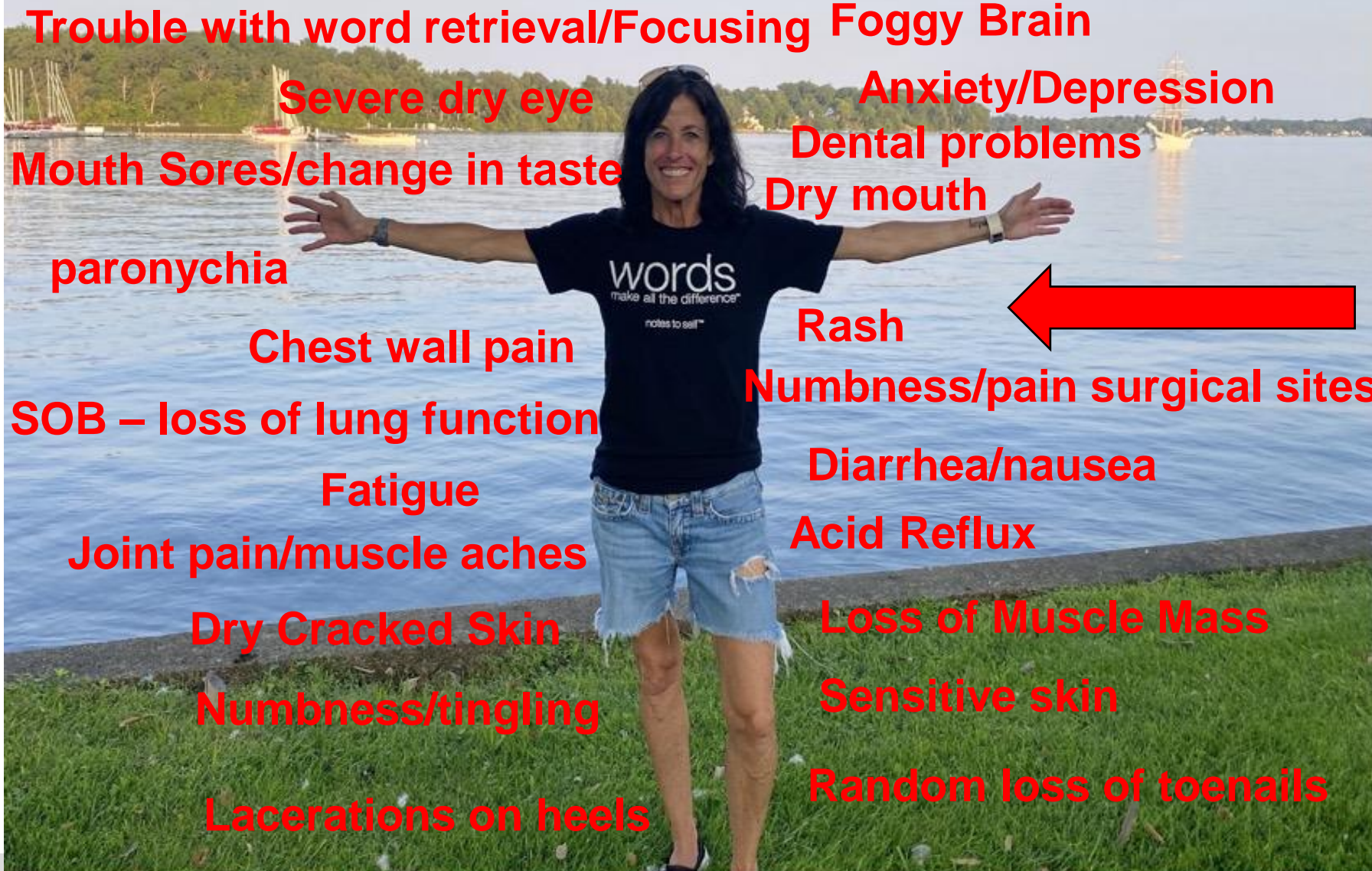
- **Promote collaborative communication** between AYA patients and parents, caregivers, children, spouse/partners, other family members, siblings, friends, and/or social networks.
- **Provide AYA-specific activities and/or support groups** (in person and/or virtually), especially for inpatients, to provide psychosocial support and reduce boredom, anxiety, and depression. Such interventions include AYA support groups, social and recreational programs, and psychoeducational programs.
- **Provide information about peer support and social networking opportunities** and create flexible visiting hours and an environment that will **encourage peers to visit AYA patients.**



She looks GREAT!



How my care team and others perceive I feel



Trouble with word retrieval/Focusing Foggy Brain

Severe dry eye

Anxiety/Depression

Mouth Sores/change in taste

Dental problems

Dry mouth

paronychia



How I actually feel

Chest wall pain

Rash

SOB – loss of lung function

Numbness/pain surgical sites

Fatigue

Diarrhea/nausea

Joint pain/muscle aches

Acid Reflux

Dry Cracked Skin

Loss of Muscle Mass

Numbness/tingling

Sensitive skin

Lacerations on heels

Random loss of toenails

**Patient
Important
Outcomes**

***Administer:**

1. Study entry
2. Interim disease eval
3. End of treatment
4. 1,2,3 years post tx

*administer annually, at minimum

**PROMIS AYA
Health Status
Profile**

†4-item:
 Depression
 Anxiety
 Physical function
 Fatigue
 Pain interference
 Emotional support
 Cognitive function

1 item:
 Pain intensity

†can substitute other PROMIS short forms

Administer:

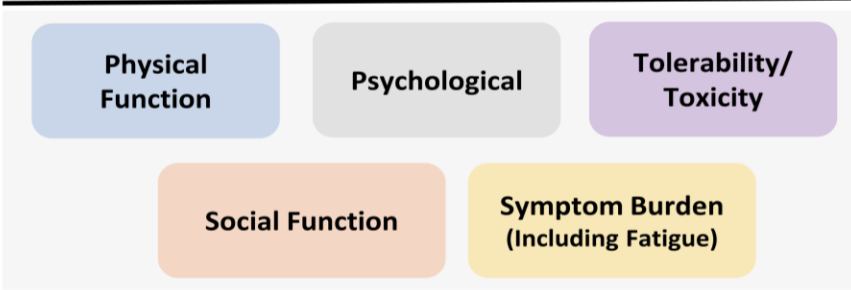
1. Baseline assessment
2. Frequency based on anticipated timing of toxicity
3. Tailored into survivorship

**PRO-CTCAE/
Ped-PRO-CTCAE**
 (4-8 core symptomatic AEs + 4 study specific symptomatic AEs)

and/or

**Study Specific
Symptom
Inventory**

Domains



of Items

**PROMIS Tools (8 HRQoL domains) + PRO-CTCAE
(8 core + 4 study specific AEs) = ~41-60 Items**

**Completion
Time**

8-12 Minutes



Summary



1. Center and normalize the patient experience
2. Ask the “right” questions, follow-up and refer
3. Leverage medical team and community strengths
4. Prioritize AYAs’ chosen family
5. Partner with researchers to advance supportive care

Finding a New Life Purpose

“The life I envisioned before cancer is very different from the life I’m now living, but it’s a small price to pay for being alive. I was sure by now I would be married and have several children, and a career in forensic science. Cancer has given me a new perspective on life. It has made me realize how precious and fragile life is. Rather than lament what I don’t have, I’m grateful for everything I do have: a wonderful family and friends, a career with the American Cancer Society as Director of Project ECHO, good health, and a new life purpose to help bridge the gap between the health-care system and the communities it serves.”



Alison Rosen, MS





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