

## Innovations in Survivorship Care

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Division of Hematology/Oncology  
Emory University School of Medicine



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- I have grant funding from Pfizer (not associated with topics covered today)

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## Outline

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- Overall Survivorship Statistics
- What is Survivor Care and Why is It Important?
- Innovations in Survivorship Care

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## Outline

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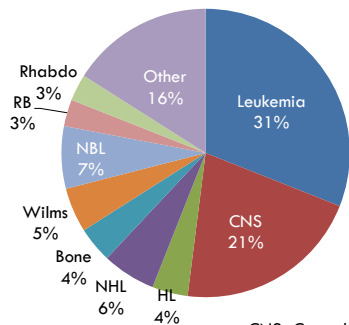
- **Overall Survivorship Statistics**
- What is Survivor Care and Why is It Important?
- Innovations in Survivorship Care

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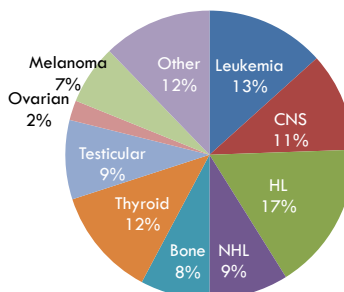
## Pediatric Cancers

1:285 children will develop cancer before age 20  
10,470 new cases/yr in children and 5,480 in adolescents

**Children <15**



**Adolescents 15-19**



CNS- Central Nervous System; HL- Hodgkin Lymphoma; NHL- non-Hodgkin Lymphoma, NBL- neuroblastoma; RB- retinoblastoma; Rhabdo- Rhabdomyosarcoma

American Cancer Society 2014 & 2022

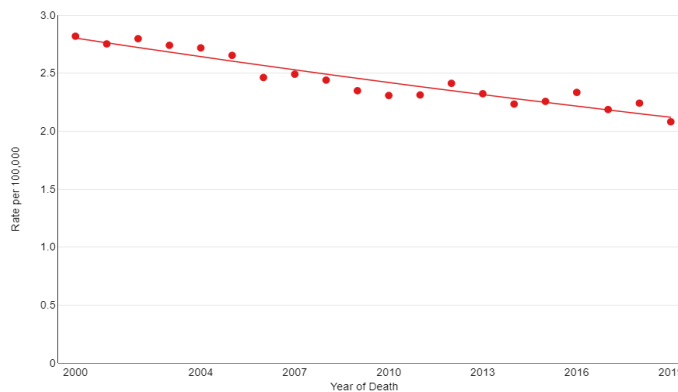
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## Childhood Cancer Mortality

- Overall mortality rate of pediatric cancer has decreased by 1.5%/yr

All Cancer Sites Combined  
Recent Trends in U.S. Age-Adjusted Mortality Rates, 2000-2019  
By Sex, All Races, Ages < 20



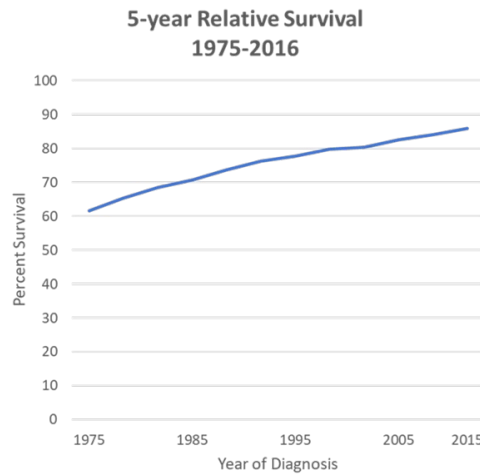
SEER 2022

Created by <https://seer.cancer.gov/statistics-network/explorer> on Mon Apr 25 2022.

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## Pediatric Oncology Survivorship



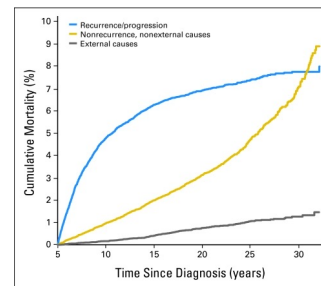
Howlader SEER 2020; Robison/Hudson Nature Reviews Cancer 2014; Hudson JAMA 2013  
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- Approximately 500,000 Americans are childhood cancer survivors.
- 1 in 750 Americans is a childhood cancer survivor
- At age 50, the cumulative incidence of a chronic health condition was 99.9% and of a serious/disabling or life-threatening condition was 96.0% compared to 96.0% and 84.9% in controls.

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## Late Effects

- Late effects are broadly defined as consequences of cancer and its treatment that manifest either during or after cancer treatment and persist beyond the end of treatment.
- As time from treatment increases, **risk of recurrence decreases** and **risk for late effects increases**.

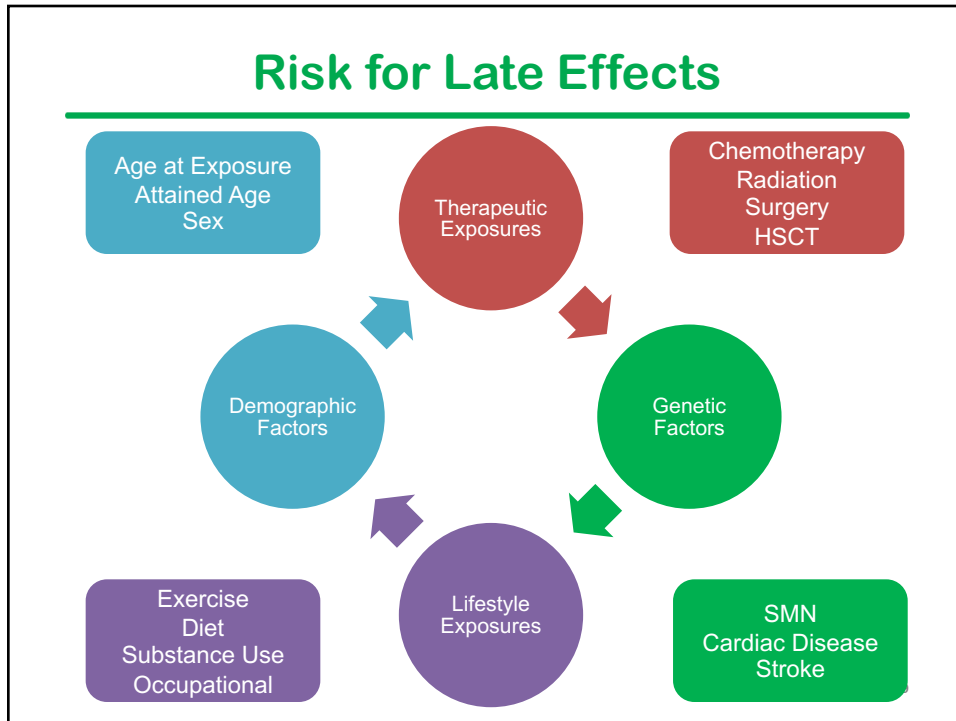


Armstrong JCO 2009

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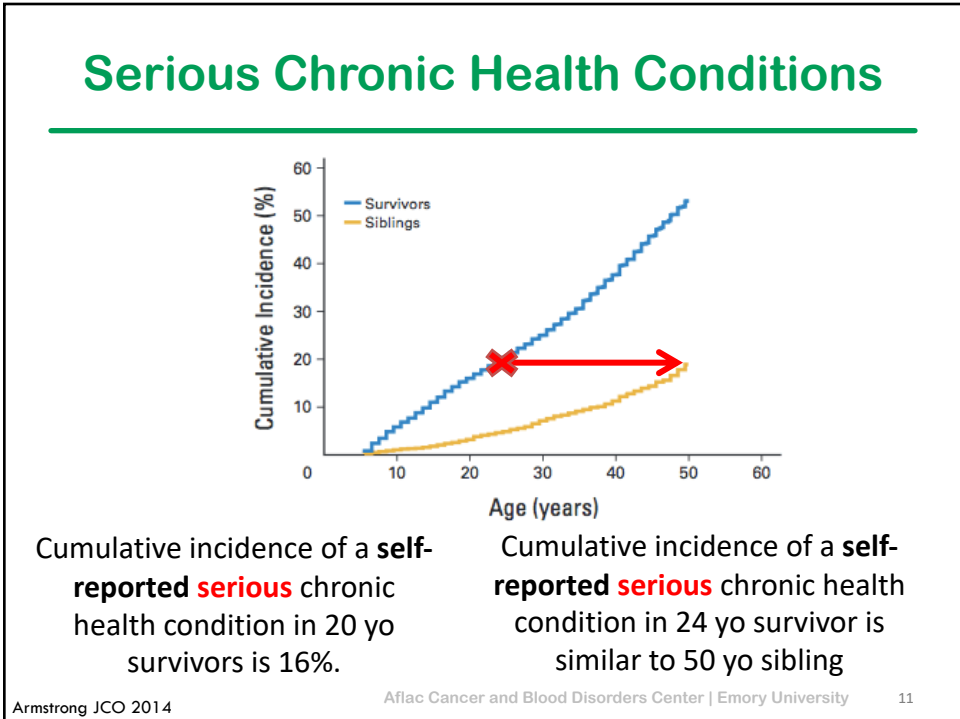
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### Common Late Effects

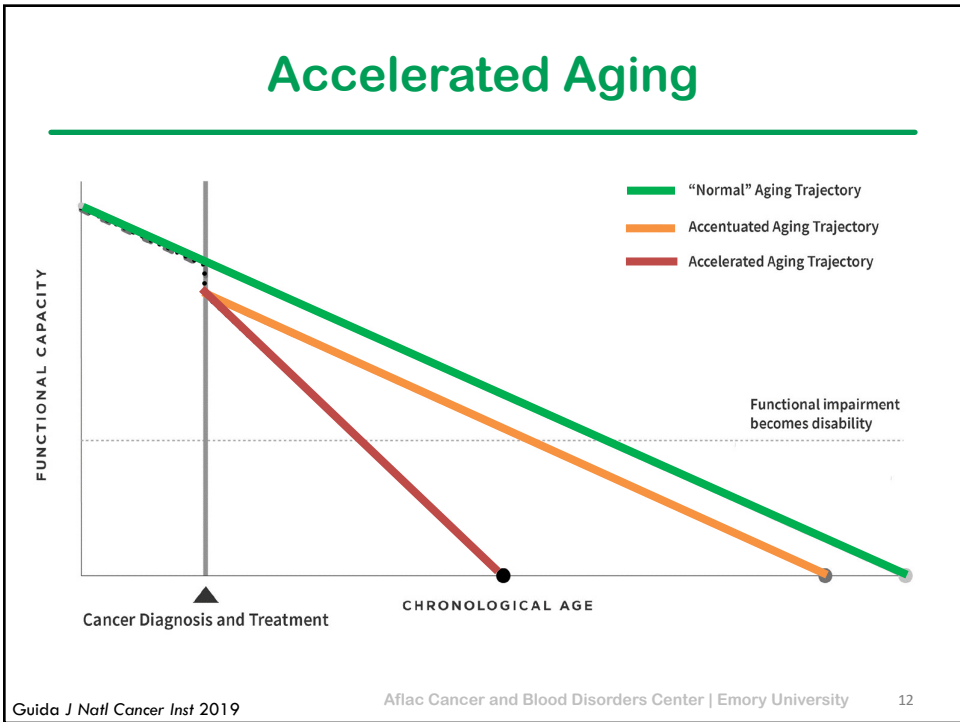
<ul style="list-style-type: none"> <li>Cataracts</li> <li>Hearing loss</li> <li>Dental anomalies</li> <li>Thyroid dysfunction</li> <li>Cardiovascular Disorders</li> <li>Pulmonary fibrosis</li> <li>Bowel obstruction</li> <li>Kidney dysfunction</li> <li>Hemorrhagic cystitis</li> </ul>		<ul style="list-style-type: none"> <li>Psychosocial effects</li> <li>Educational effects</li> <li>Short stature</li> <li>Hypopituitarism</li> <li>Osteopenia</li> <li>Infertility</li> <li>Dyslipidemia</li> <li>Metabolic syndrome</li> <li>Secondary malignancies (leukemia, solid tumors)</li> </ul>
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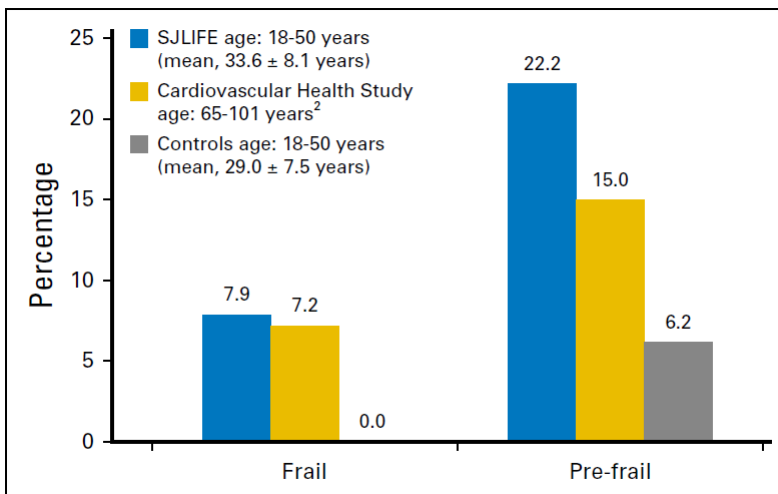


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## Frailty



Definition of Frailty: 3+ low lean muscle mass, reduced strength, slow walking speed, low energy expenditure, fatigue

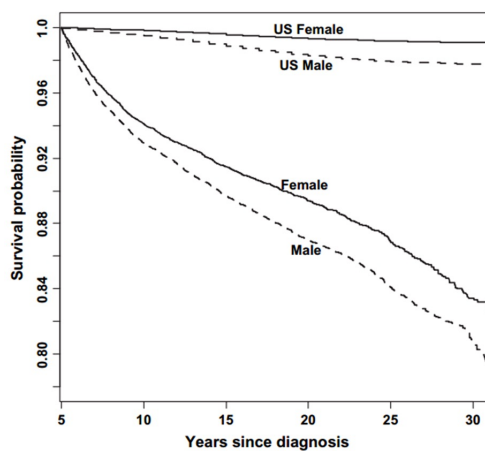
Ness JCO 2018

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## Early Mortality



**18% of 5-year survivors had died by 30 years after their diagnosis**

Mertens J Natl Cancer Inst 2008

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## Outline

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- Overall Survivorship Statistics
- **What is Survivor Care and Why is It Important?**
- Innovations in Survivorship Care

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## Goal Survivorship Care

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- Coordinated interdisciplinary care based on risk
  - Focus on surveillance, prevention, and early detection
- Education (for survivors, families, and providers)

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## Important Pieces of Survivor Care

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- Good relationship with primary care doctor
- Survivor visits
- Dental visits every 6 months
- Eye doctor visits annually (if needed)
- Dermatology visits (if needed)
- **Healthy lifestyle**
- **Mental Health Support**

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## Survivorship Clinics in US

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- 97% of COG institutions provided late effects care
- 75% provided care in a late effects program
- 41% have to transfer young adult survivors at a specific age
- 26% transfer young adult survivors when ready

Effinger *J Cancer Surviv* 2022  
Marchak *J Cancer Surviv* 2023

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# Surveillance Guidelines

[www-survivorshipguidelines.org](http://www-survivorshipguidelines.org)



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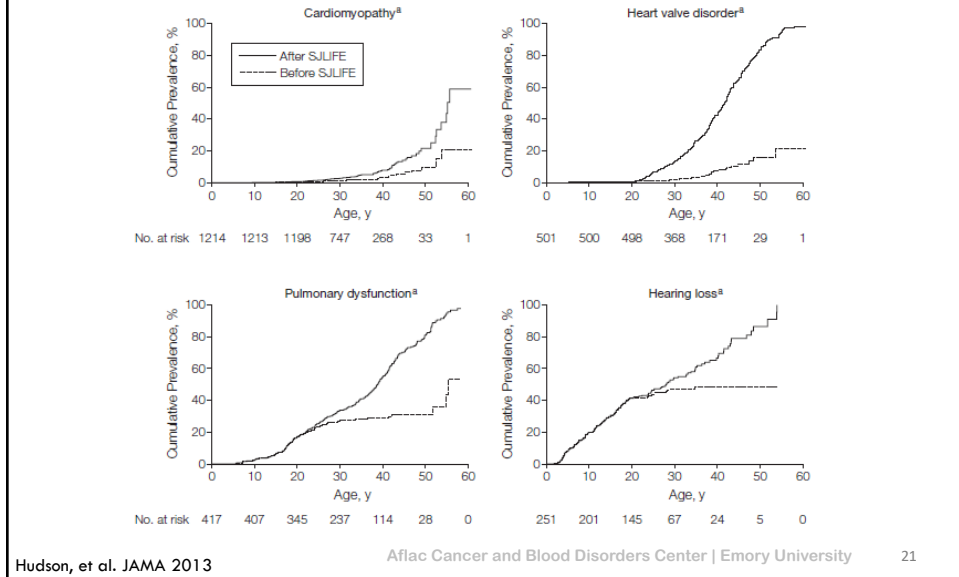
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# Long Term Follow-Up Guidelines

CHEMOTHERAPY		ANTHRACYCLINE ANTIBIOTICS (CONT)	
Sec #	Therapeutic Exposure	Potential Late Effects	Periodic Evaluation
	<b>Therapeutic Exposure</b> Anthracycline Antibiotics Daunorubicin Doxorubicin Epirubicin Idarubicin Mitoxantrone	<b>Potential Late Effects</b> Cardiac toxicity Cardiomyopathy Subclinical left ventricular dysfunction	<b>Periodic Evaluation</b> HISTORY PHYSICAL SCREENING
	<b>HEALTH LINKS</b> Heart Health Cardiovascular Risk Factors Diet and Physical Activity <b>COUNSELING</b> POTENTIAL CONSIDERATIONS FOR FURTHER TESTING AND INTERVENTION		<b>TESTING AND INTERVENTION</b> (Detailed text regarding testing and intervention for cardiac toxicity)
		EKG (include evaluation of QTc interval) Baseline at entry into long-term follow-up, repeat as clinically indicated	SYSTEM = Cardiovascular SCORE = 1
<b>Additional Information</b> Although Mitoxantrone technically belongs to the anthracenedione class of anti-tumor antibiotics, it is related to the anthracycline family and is included in this section because of its cardiotoxic potential.			

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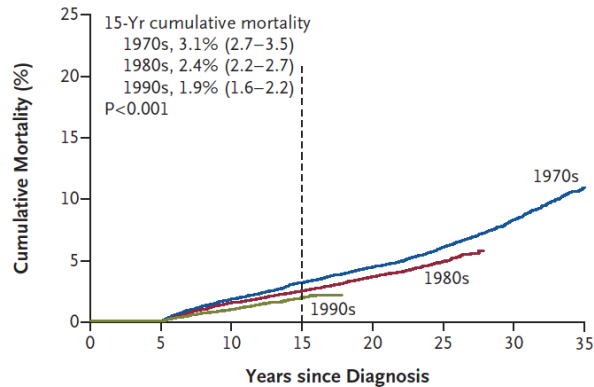
## Why is Screening Important?



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## Improvement over Time

### Death from Health-Related Cause



#### No. at Risk

1970s	9,416	8,722	8,406	8,182	7,942	5,556	1,506
1980s	13,181	13,443	13,105	10,389	3,583		
1990s	11,436	11,411	3,924				

Armstrong NEJM 2016

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## Providers' Knowledge

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- 74% providers lacked knowledge/training in cancer survivorship
- Only 25-37% of providers were comfortable caring for childhood cancer survivors
- Only 9-15% of providers correctly identified screening recommendations

Iyer, Support Care Cancer 2017  
Suh, Ann Intern Med 2014

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## Survivors' Knowledge

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- 72% knew their diagnosis (e.g. Leukemia)
- 94% knew they had chemotherapy
- 89% knew they had radiation
  - Of those 70% could recall the site

Kadan- Lottick JAMA 2002

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## Outline

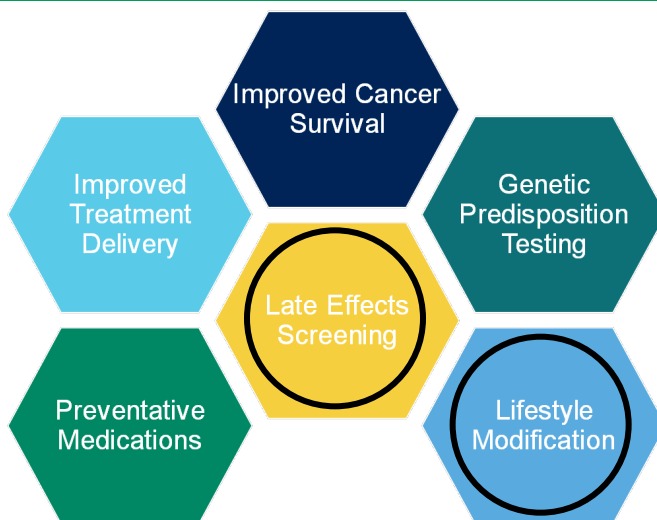
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- Overall Survivorship Statistics
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## Decreasing Mortality in Survivors

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## Barriers to Appropriate Screening

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- Transition to/Engagement in Survivor Care
- Transition of Young Adults to Adult Care
- Lack of Survivor Care Plan Utilization

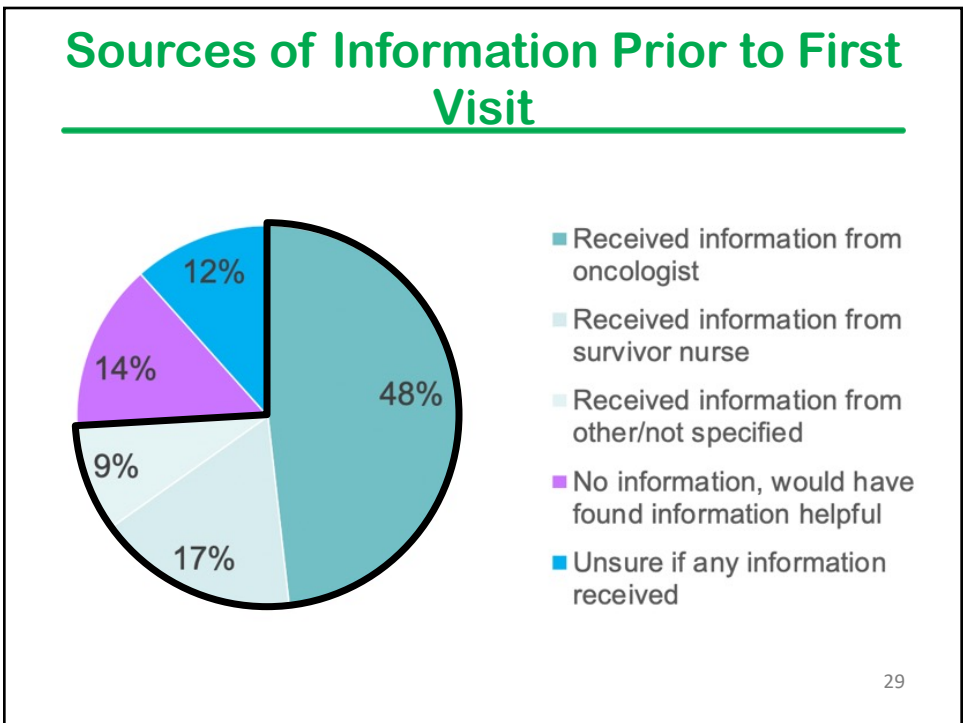
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## Engagement in Survivor Clinic

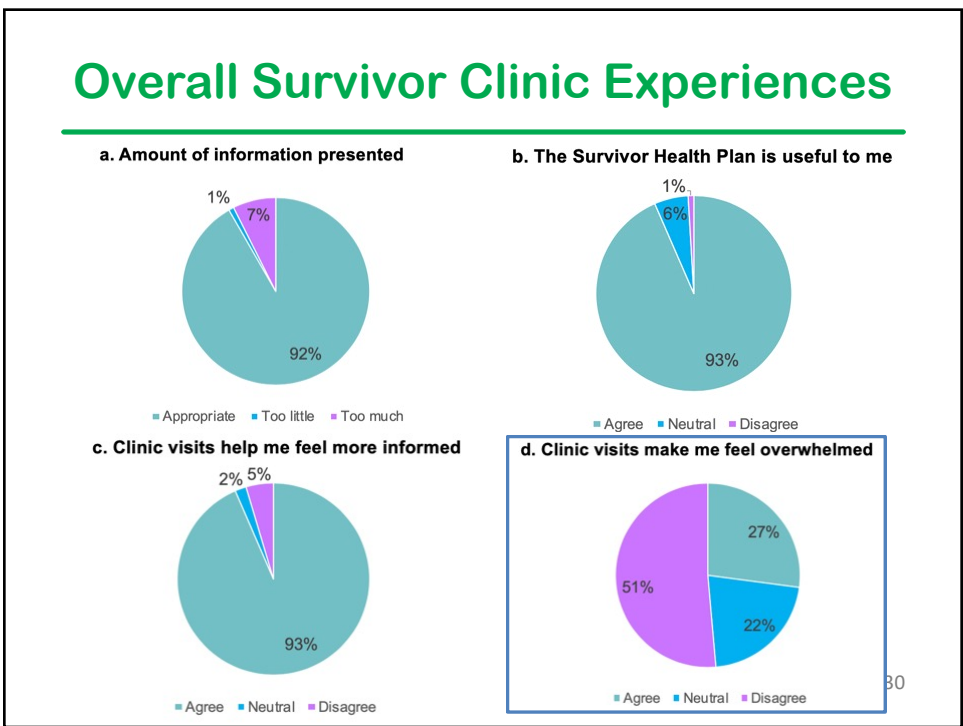
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- Anonymous survey of survivors seen in survivorship clinic from December 2022-May 2023
- Survivors >1 year off-therapy, <22 years of age
- Through March 2023: 110 participants

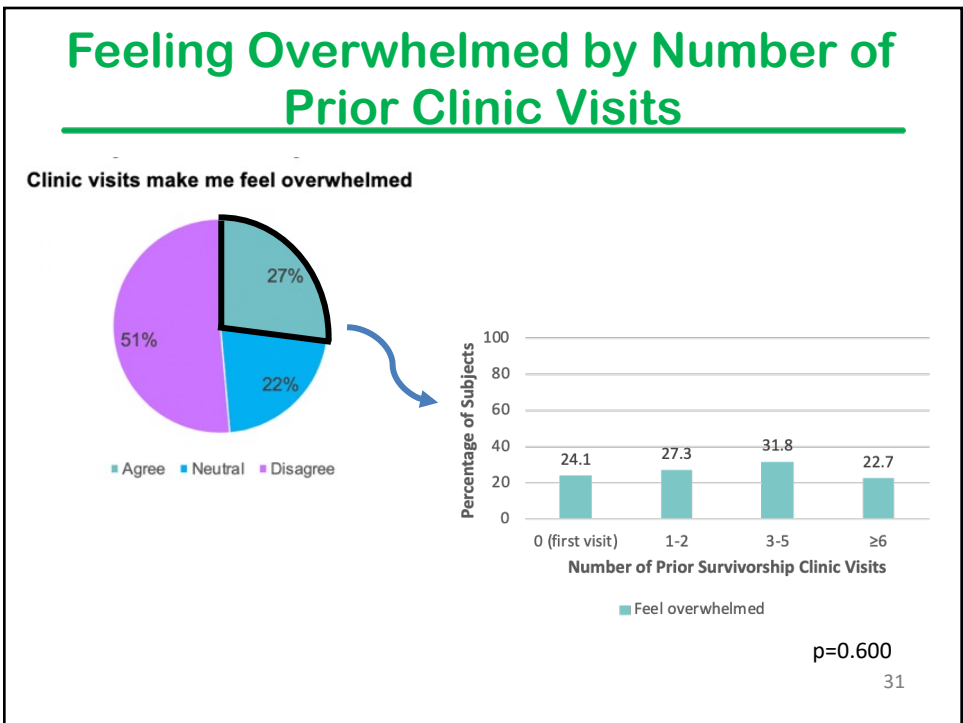
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## Transition of Young Adult Survivors

- Improving Support for Survivors Engaged in Transition (IS-SET) sponsored by NCI P30
- **GOAL:** Reduce long-term inequities in care for adult survivors of pediatric cancer through **understanding** and **improving** formal **healthcare transition practices**

PIs: Jordan Marchak, PhD  
Karen Effinger, MD

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## IS-SET

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- **AIM 1:** Evaluate **organizational programming** needed to promote **continuation of risk-based care** among young adult aged survivors of pediatric cancer
- **AIM 2:** Identify **organizational barriers & facilitators** to **implementing** the **Six Core Elements of Transition** in the context of survivor care

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## Need for eHealth Options to Improve SCPs

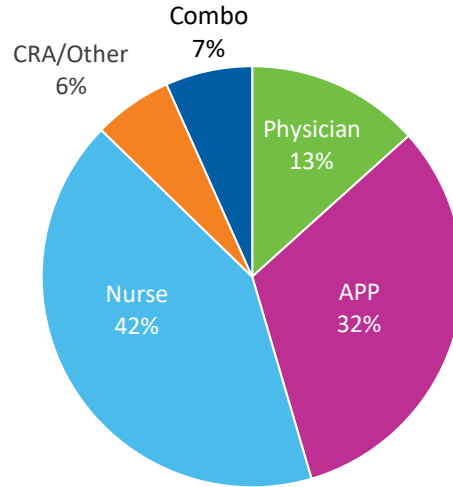
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- Improvement of SCP development/delivery
- Options for survivor SCP access and education

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## Utilizing EHR for Survivor Care Plans

- 88% delivered a cancer treatment summary



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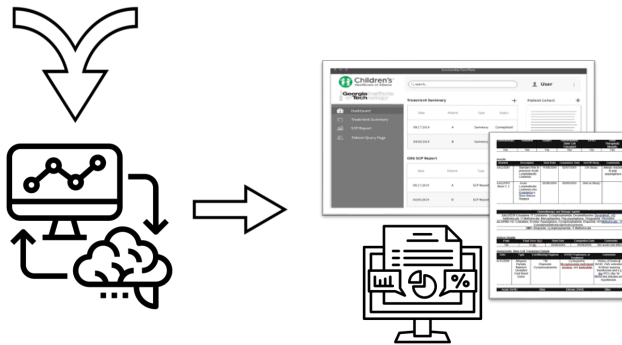
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## Imlay Innovation Award



PIs: May Wang, PhD  
Karen Effinger, MD

Co-Is: Wayne Liang, MD  
Ann Mertens, PhD



Icons: thenounproject.com

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## Cancer SurvivorLink™

SurvivorLink was developed to **educate** & **empower** survivors to engage in care needed to stay healthy after childhood cancer



Slide courtesy of Dr. Jordan Marchak | Aflac Cancer and Blood Disorders Center | Emory University

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## What is Cancer SurvivorLink?

Web-based tool to support survivors of childhood cancer

- LEARN**  
Educational resources
- STORE**  
Patient-controlled ePHR
- SHARE**  
Patient-Provider file sharing



Slide courtesy of Dr. Jordan Marchak | Aflac Cancer and Blood Disorders Center | Emory University

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# SurvivorLink: Metrics

<https://cancersurvivorlink.org/>

Visitors from **50** states & **116** countries

Used in **13** clinics across the US

More than **2,100** registered users

865 parents of survivors <18 years

865 young adult patients

361 healthcare providers

Patients stored nearly **1,700** health documents

Supportive Care in Cancer  
<https://doi.org/10.1007/s00520-019-05199-w>

**ORIGINAL ARTICLE**

User-centered design and enhancement of an electronic personal health record to support survivors of pediatric cancers


Jordan Gilleland Marchak<sup>1,2</sup>  · Brooke Cherven<sup>1,3</sup> · Rebecca Williamson Lewis<sup>1</sup> · Paula Edwards<sup>1</sup> · Lillian R. Meacham<sup>1,4</sup> · Michael Palgon<sup>1</sup> · Cam Escoffery<sup>2</sup> · Ann C. Mertens<sup>1,5</sup>

Received: 22 August 2019 / Accepted: 20 November 2019  
 © Springer Verlag GmbH Germany, part of Springer Nature 2019

J Cancer Surviv  
 DOI 10.1007/s11764-019-0486-6

**Predictors of successful use of a web-based healthcare document storage and sharing system for pediatric cancer survivors: Cancer SurvivorLink<sup>TM</sup>**

Rebecca Williamson · Lillian Meacham · Brooke Cherven · Leann Haven-Schilling · Paula Edwards · Michael Palgon · Sofia Espinosa · Ann Mertens

Research Article  Applied Clinical Informatics 250

**Meaningful Use of an Electronic Personal Health Record (ePHR) among Pediatric Cancer Survivors**

Rebecca S. Williamson<sup>1</sup>, Brooke O. Cherven<sup>1</sup>, Jordan Gilleland Marchak<sup>1,2</sup>, Paula Edwards<sup>1</sup>, Michael Palgon<sup>1</sup>, Cam Escoffery<sup>1</sup>, Lillian R. Meacham<sup>1,3</sup>, Ann C. Mertens<sup>1</sup>

<sup>1</sup>Atlas Cancer and Blood Disorders Center, Children's Healthcare of Atlanta, Atlanta, GA, USA;  
<sup>2</sup>Department of Pediatrics, Emory University, Atlanta, GA, USA;  
<sup>3</sup>IBM Watson, LLC, Atlanta, GA, USA;  
<sup>4</sup>Rollins School of Public Health, Emory University, Atlanta, GA, USA

J Cancer Surviv (2019) 6:276–277  
 DOI 10.1007/s11764-019-0424-z

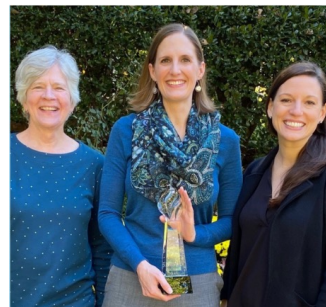
**Primary care providers as partners in long-term follow-up of pediatric cancer survivors**

Lillian R. Meacham · Paula J. Edwards · Brooke O. Cherven · Michael Palgon · Sofia Espinosa · Leann Haven-Schilling · Ann C. Mertens

Slide courtesy of Dr. Jordan Marchak | Aflac Cancer and Blood Disorders Center | Emory University

# SurvivorLink<sup>TM</sup> Mobile App

- Qualitative interviews with low-users and high-users to determine desires for mobile app
- Support from Children's Cancer Cause Survivorship Champion's Prize



## Options for Collaboration

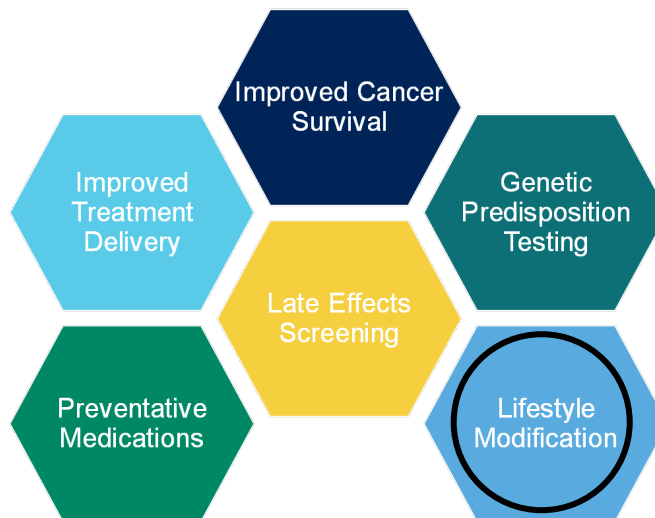
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## Decreasing Mortality in Survivors

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## Barriers to Sleep & Physical Activity

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- **Survivors** aged 13-17.9 years, >1 year from completion of therapy & **Caregivers**
- Online self-report survey of physical activity, sleep, perceived cancer-related barriers, home physical activity and sleep environment
- 72 survivor families (**66 CCS** & **70 Caregivers**)
- Funded by Emory Synergy Award

PIs: Jordan Marchak, PhD  
 Karen Effinger, MD  
 Michelle Kegler, PhD

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## Health Behaviors

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- Physical Activity
  - 23% of survivors meet recommendations
  - 54% of caregivers meet recommendations
- Sleep
  - 50% of survivors meet recommendations
  - 52% of caregivers meet recommendations
- 39% of CCS and 27% of caregivers fail to meet guidelines for both

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## Cancer Specific Barriers

- 71.2% of CCS reported a wellness barrier
  - 53.8% barrier to physical activity
  - 65.2% barrier to sleep
- 68.6% of caregivers reported a wellness barrier
  - 55.7% barrier to physical activity
  - 52.2% barrier to sleep

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## Barriers to Physical Activity

	Survivors N (%)	Caregivers N (%)
<b>Cancer-related barriers to physical activity</b>		
Low motivation for exercise	14 (21.5%)	14 (20.0%)
Too much screen time	12 (18.5%)	11 (15.7%)
Pain	10 (15.4%)	NA
Fatigue	7 (10.8%)	18 (25.7%)
Depression related to the cancer experience	7 (10.8%)	14 (20.0%)
Out of regular exercise or sport routine	8 (12.3%)	10 (14.3%)
Exercise limitations due to physical changes	7 (10.8%)	NA
Social challenges that impact comfort in PA	6 (9.2%)	NA
Fears related to injury	8 (12.3%)	NA
Weight gain during treatment led to trouble	6 (9.2%)	14 (20.0%)
Financial strain impacting family budget	NA	8 (11.4%)

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## Barriers to Sleep

	Survivors N (%)	Caregivers N (%)
<b>Cancer-related barriers to physical activity</b>		
Anxiety/Depression/PTSS symptoms related to cancer experience	20 (30.8%)	18 (25.7%)
Spending time in bed doing things other than sleeping	20 (30.8%)	16 (22.9%)
Lack of a bedtime routine	17 (26.2%)	11 (15.7%)
Going to bed late and getting up late	16 (24.6%)	15 (21.4%)
Daytime napping	14 (21.5%)	14 (20.0%)
Bed sharing or co-sleeping	4 (6.2%)	1 (1.4%)
Pain	12 (18.5%)	NA

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## Next Steps

- Randomized controlled trial of a dyadic intervention to address wellness barriers in survivors and their families

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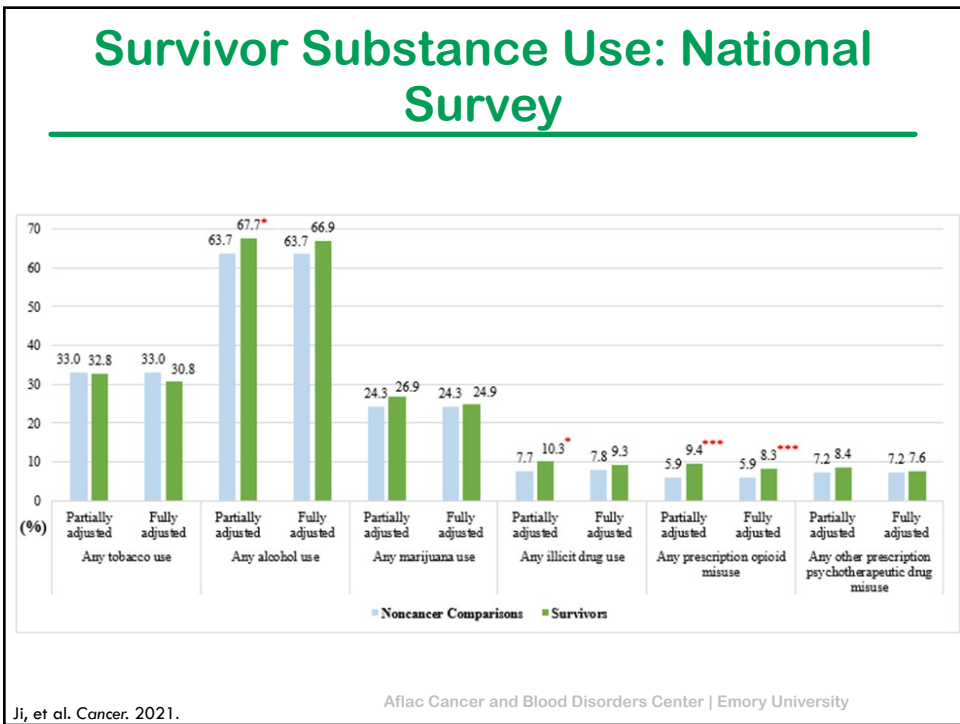
## Substance Use in Survivors

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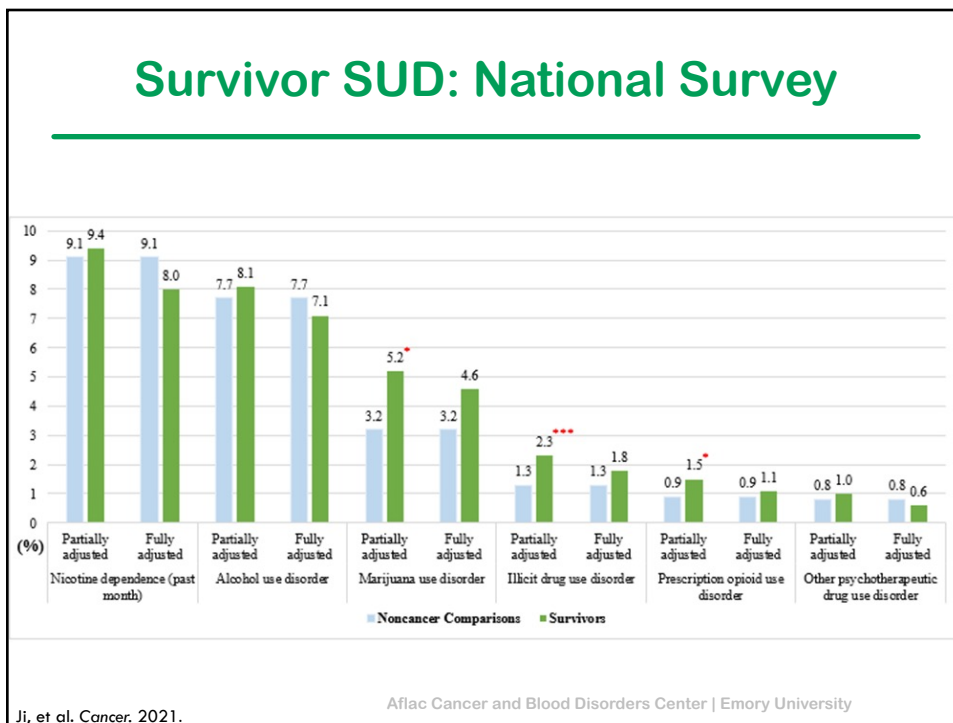
- 2015-2018 National Survey of Drug Use and Abuse
- 12-34y
- Past year use
- 832 survivors, 140,826 non-survivors

PI: Xu Ji, PhD
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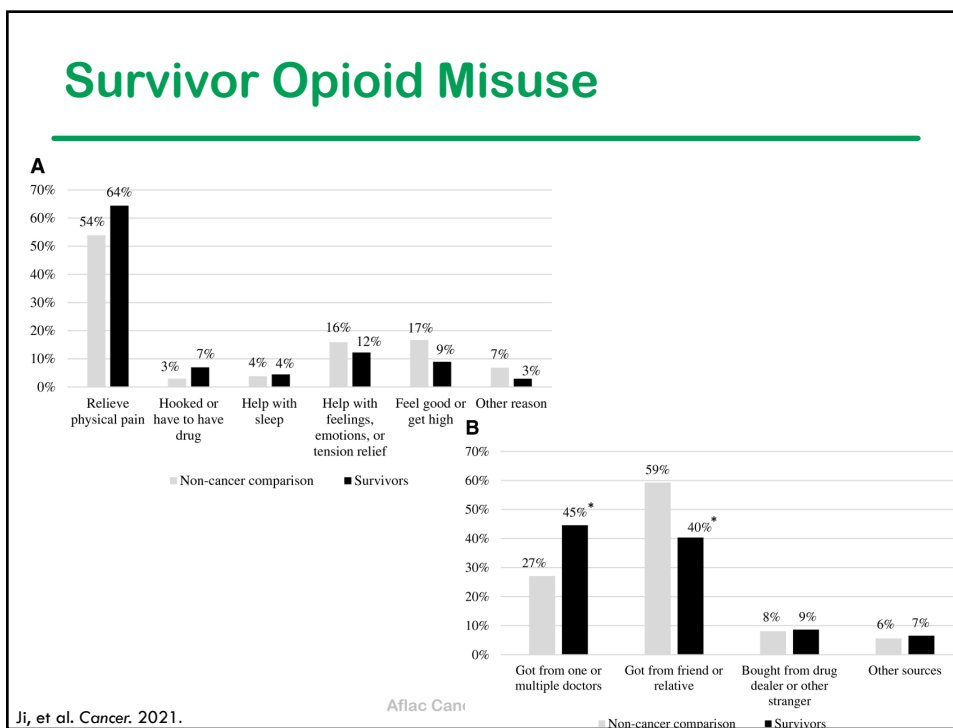
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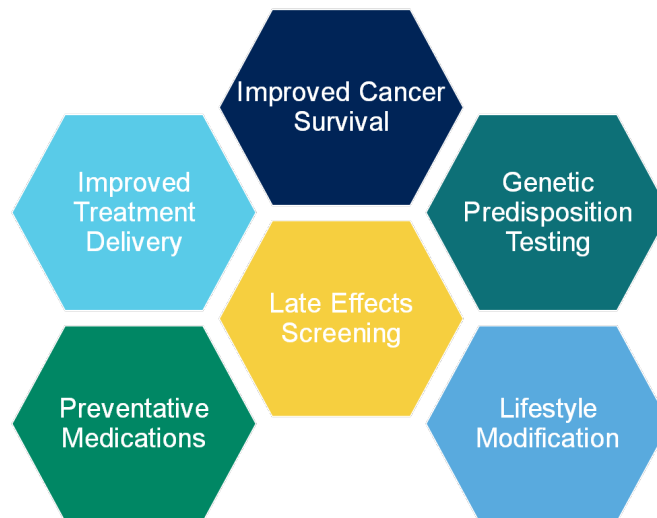
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## Next Steps

- Study evaluating pain management in AYA survivors of childhood cancer funded by an Aflac Pilot Grant (PI: Ji, Emory)
- R61/33: ADAPTED Culturally adapted mobile treatment of chronic pain in adolescent survivors of pediatric bone sarcoma (PI: Brinkman, St. Jude)

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## Decreasing Mortality in Survivors



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# CURE IS NOT ENOUGH



Guilio D'Angio,  
Cancer, March 1975

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# Thank you!

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@DrEffinger

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