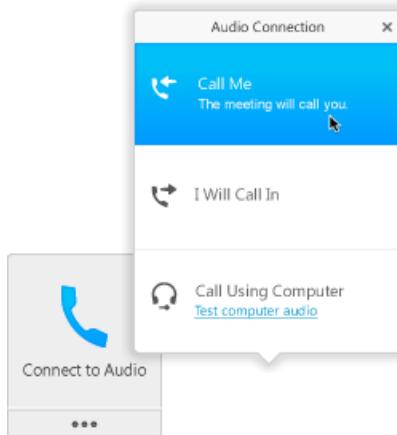


# Cancer Caregiving in the Community

Today's R2R Cyber-seminar will begin at 2 PM ET

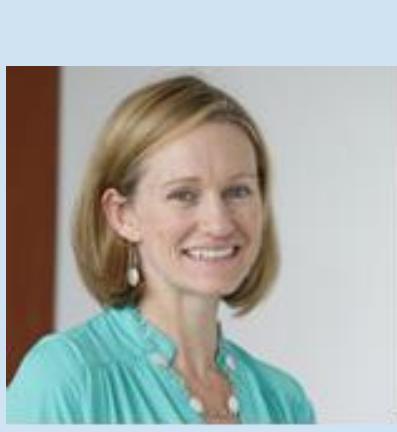
WebEx can call you at the number of your choice, or call your computer.



You can also dial in manually:

1-855-244-8681

Access code: 732 523 450

	 <b>Erin Kent</b> <i>PhD, MS</i> Epidemiologist and Program Director, Outcomes Research Branch, National Cancer Institute	 <b>Kristen Cox Santiago</b> <i>MS</i> Senior Director, Policy & Advocacy, Cancer Support Community	 <b>Allison Harvey</b> <i>MPH, CHES</i> Senior Manager, Health Care Professional Education, George Washington Cancer Institute
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# Cancer Caregiving in the Community

Research to Reality Cyber-Seminar Series November 2016

# Cancer Caregiving in the Community



**Erin Kent**  
*PhD, MS*

Epidemiologist and Program Director,  
Outcomes Research Branch,  
National Cancer Institute

**Kristen Cox Santiago**  
*MS*

Senior Director,  
Policy & Advocacy,  
Cancer Support Community

**Allison Harvey**  
*MPH, CHES*

Senior Manager,  
Health Care Professional Education,  
George Washington Cancer Institute

# Cancer Caregiving in the Community

## NCI Research to Reality Cyber-Seminar

### November 28, 2016

*Erin E. Kent, PhD, MS*

*Epidemiologist and Program Director*

*Outcomes Research Branch, Healthcare Delivery Research Program*

*Division of Cancer Control and Population Sciences*

*National Cancer Institute*

# Informal Caregivers

- Individuals that assist family members/friends by providing care which is:
  - typically uncompensated
  - usually in the home setting
  - involving significant efforts for extended time
- Caregiving can require demanding tasks, including:
  - Monitoring for side effects
  - Managing symptom burden
  - Treatment decision-making
  - Care coordination
  - Triage
  - Administering medication
  - Technical medical tasks
  - Managing patient's financial and social obligations



# Informal caregiving

- In 2015, an estimated 43.5 million U.S. adults served as a caregiver
- This care was valued at \$470 billion



# Cancer-specific caregiving

- Unique aspects of caregiving in the context of cancer
  - Rapid deterioration of health
  - High levels of emotional stress
  - Multi-modal therapies
  - More and more outpatient/home care
  - Recurrence, and fear of recurrence

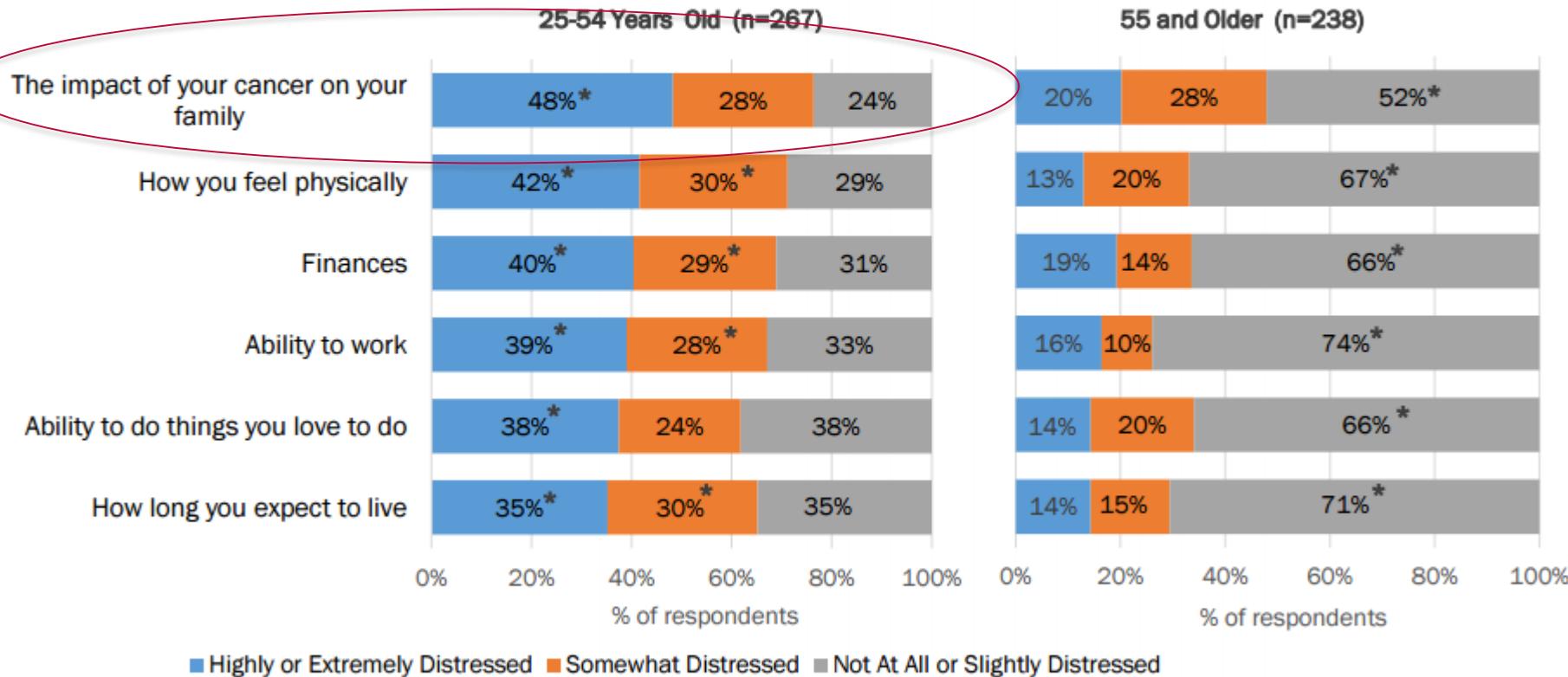


For the vast majority of respondents, being diagnosed with cancer caused distress. The impact of cancer on their family was most often reported as being extremely stressful. In all aspects of life mentioned in this survey, respondents aged 25 to 54 years were significantly more likely than those aged 55 years and older to report being highly or extremely distressed.



CANCERCARE®

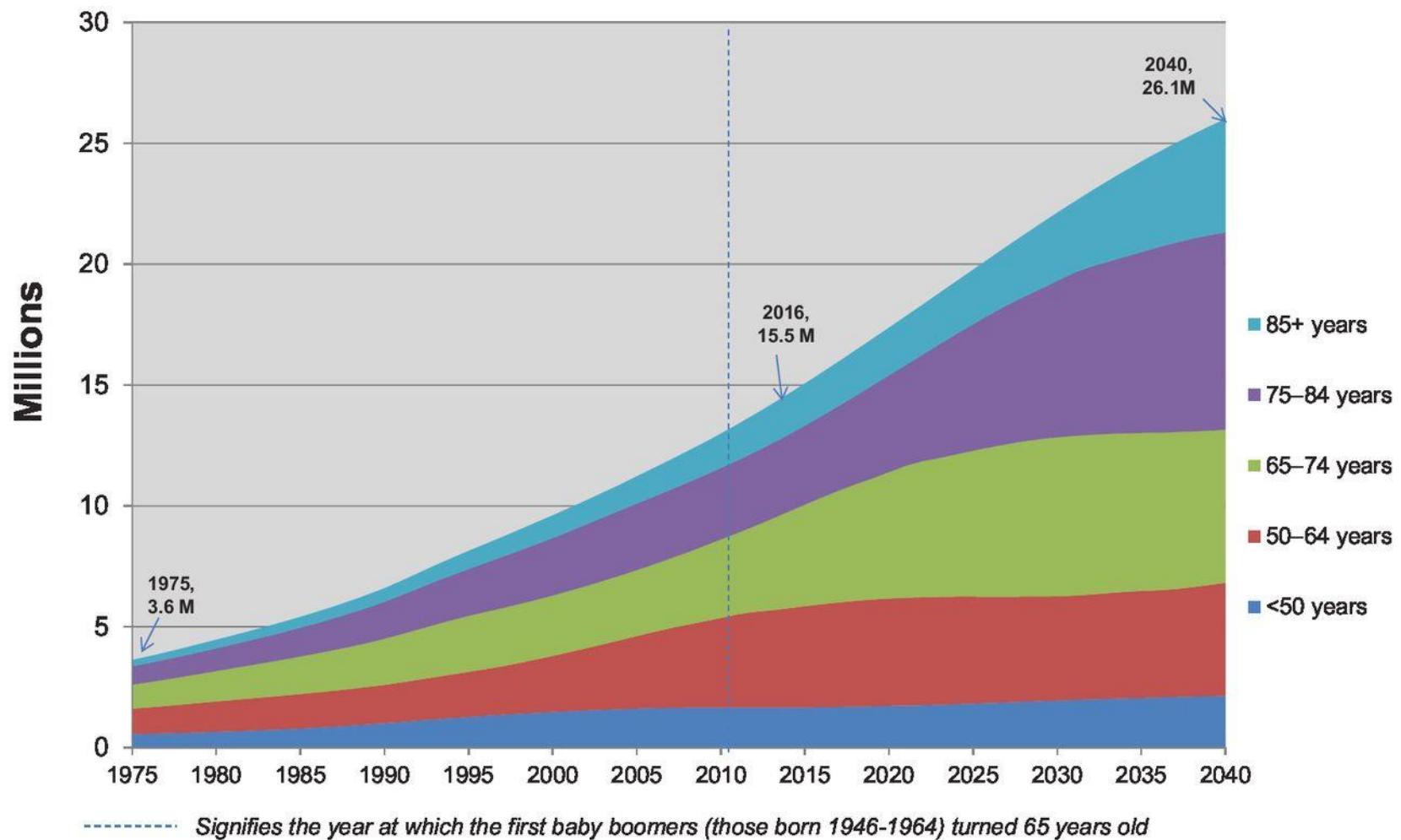
## Cancer-Related Distress



\*Indicates statistically greater at 90% confidence level

11. How distressed (anxious, extremely upset, or in emotional pain, for example) have you been due to the impact cancer has had on the following aspects of your life?

# Estimated cancer prevalence by age in the U.S. population



Shirley M. Bluethmann et al. Cancer Epidemiol Biomarkers  
Prev 2016;25:1029-1036



# CANCER CAREGIVING IN THE U.S.

*An Intense, Episodic, and Challenging Care Experience*



# Cancer Caregiving in the U.S.

- To compare individuals who report caregiving for an adult who has cancer to those who care for adults with other illnesses
  - Burden of care
  - Hours per week caregiving
  - Communication with healthcare providers
  - Making end-of-life decisions
  - Emotional stress

<http://www.caregiving.org/cancer/>



# Cancer Caregiving in the U.S.

- **Dataset:** *Caregiving in the U.S. 2015*
- **Design:** Nationally representative study of adults, age 18+, conducted in late 2014 using GfK's probability-based online KnowledgePanel®
- **Sample size:**
  - 111 caregivers identified **cancer** as the main problem or illness requiring care
  - 1,164 **non-cancer** caregivers
- **Analysis:** Bivariate comparisons using t-tests for means with equal variances and independent z-tests for proportions (unpooled) were used.

<http://www.caregiving.org/cancer/>



# Results

## ■ **Main findings:**

- Approximately 2.8 million adults serving as a caregiver to an adult with cancer in the U.S.
- 62% of cancer caregivers are in high burden situation
- Average time per week caring: 32.9 hours
- 43% report performing complex medical/nursing tasks without any prior preparation
- 50% reporting high emotional stress
- 25% reporting high levels of financial strain

<http://www.caregiving.org/cancer/>



## Results: Demographics

### ■ Cancer-caregivers:

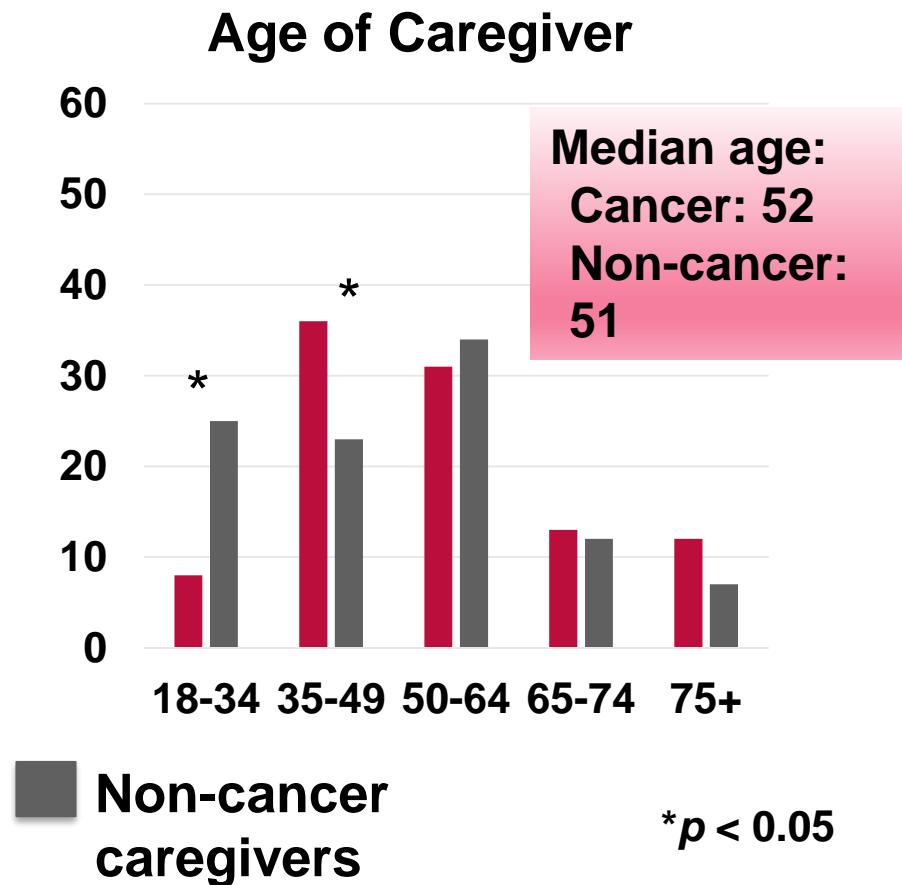
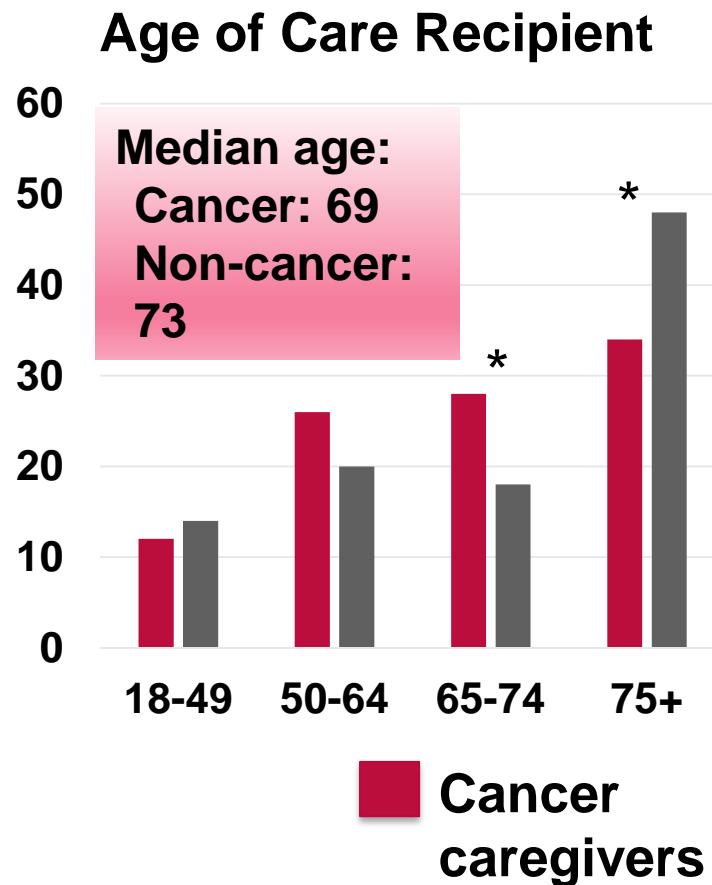
- Gender: 58% Female
- Race/ethnicity:
  - 65% White, non-Hispanic
  - 16% Hispanic
  - 11% African-American, non-Hispanic
  - 8% Asian, non-Hispanic
- Marital status: 62% married

### ■ Non-cancer caregivers:

- Gender: 60% Female
- Race/ethnicity:
  - 61% White, non-Hispanic
  - 17% Hispanic
  - 13% African-American, non-Hispanic
  - 6% Asian, non-Hispanic
  - 3% Other
- Marital status; 56% married

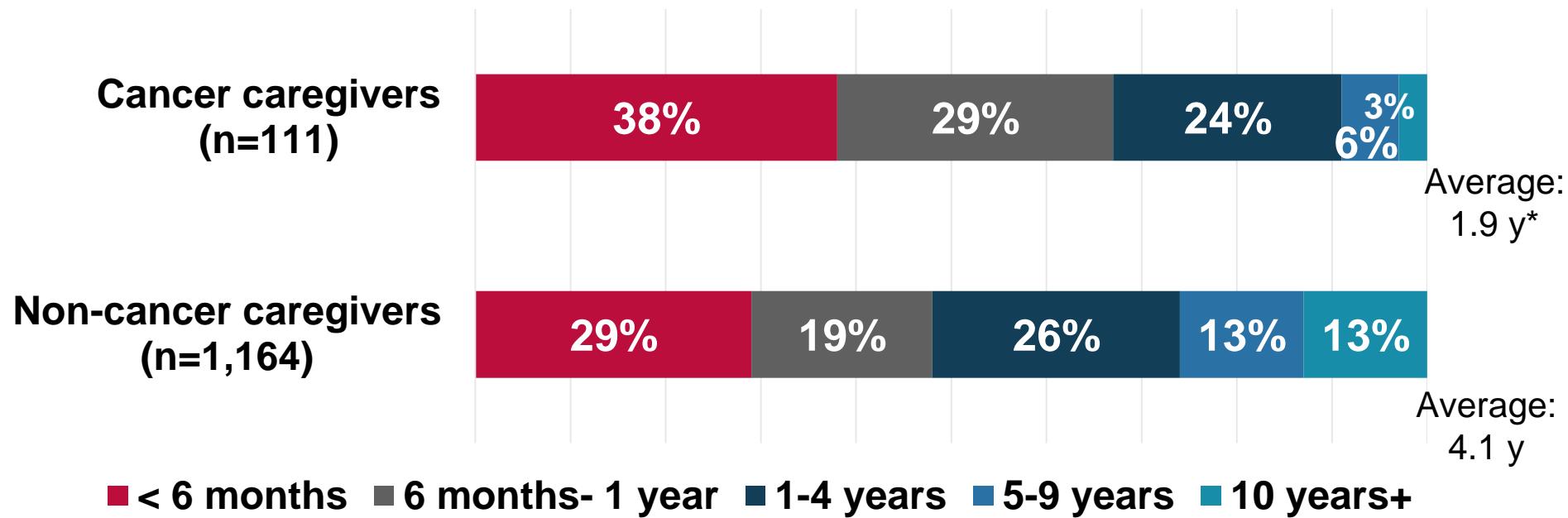


# Results: Age Distribution





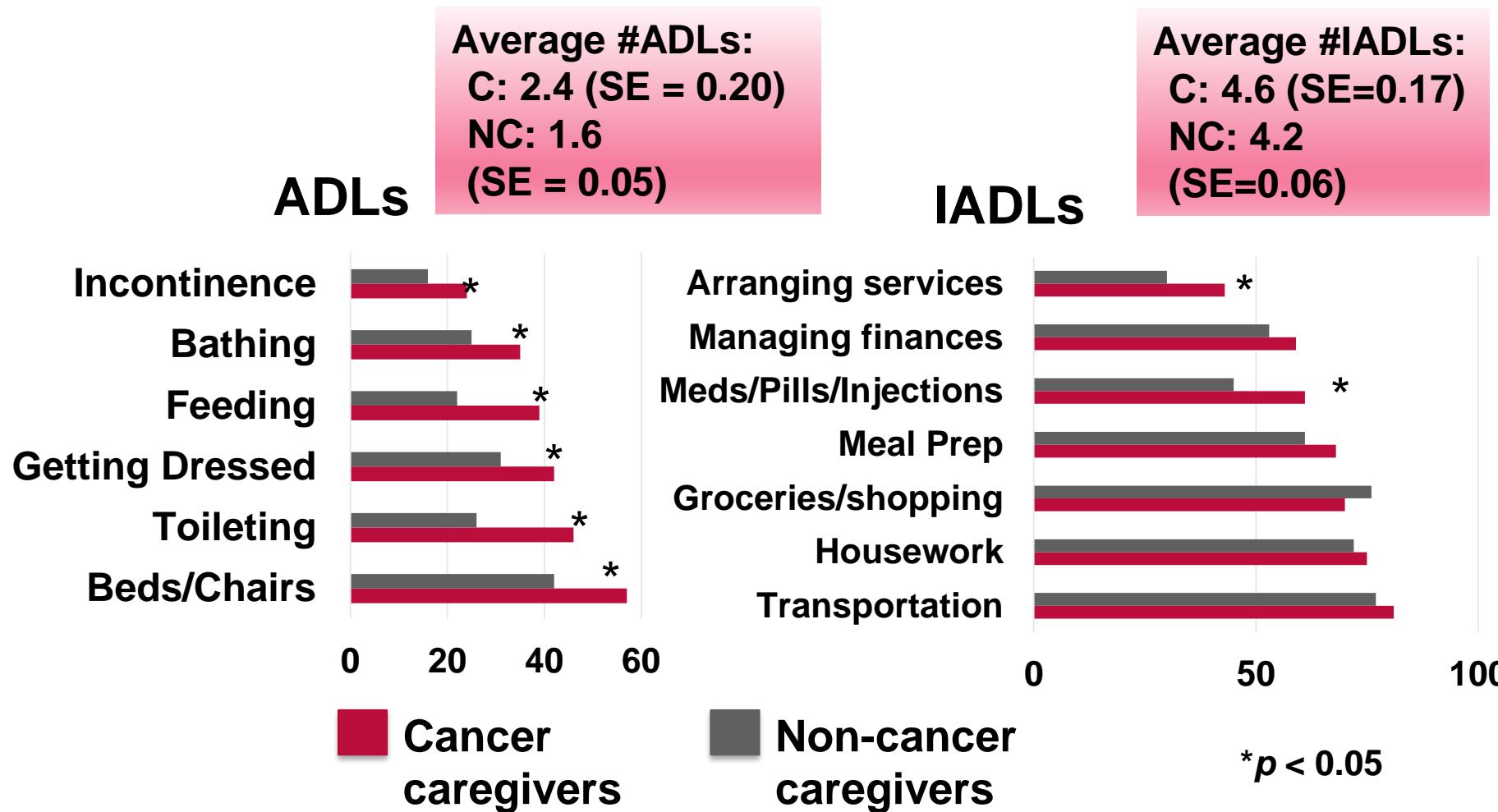
## Results: Duration of Care



\* $p < 0.05$

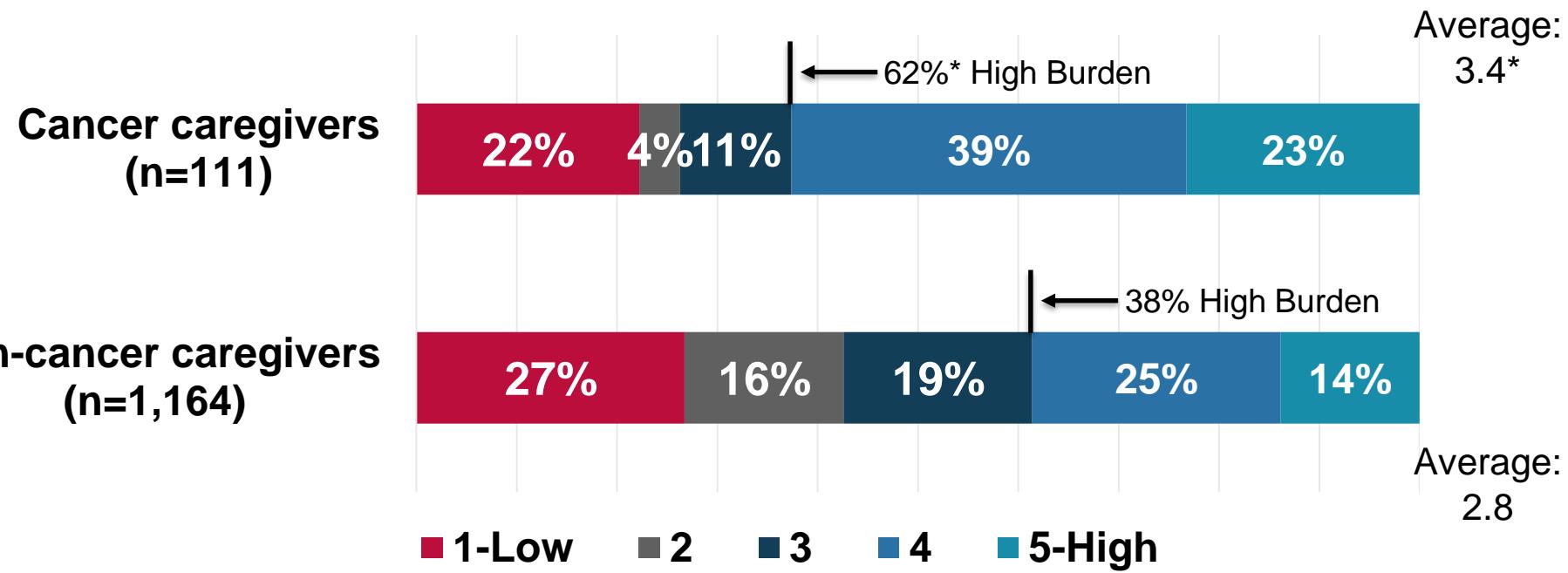


## Results: % Assisting with ADLs and IADLs





## Results: Burden of Care



\* $p < 0.05$



# Results: Tasks and Preparation

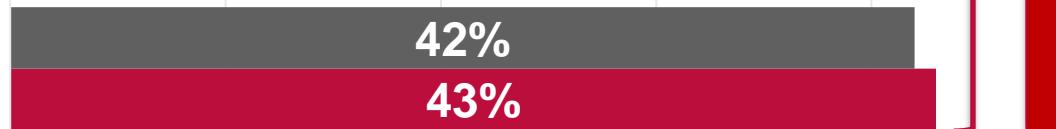
**Does tasks & was well prepared**



\*

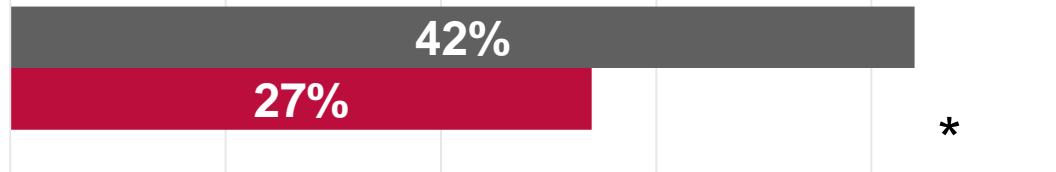
55% of non-cancer caregivers do medical/nursing tasks

**Does tasks, not prepared**



71%\* of cancer caregivers do medical/nursing tasks

**Does not do tasks**



\*

■ Non-cancer caregivers (n=1,164) ■ Cancer caregivers (n=111)

\* $p < 0.05$



## Results: Help with key activities

	Cancer Caregiver (n=111)	Non-Cancer Caregiver (n=1,164)
Communicating with healthcare professionals (doctors, nurses, social workers) about his/her care	<b>82%*</b>	62%
Monitoring severity of recipient's condition to adjust care accordingly	<b>76%*</b>	66%
Advocating for him/her with health care providers, community services, government agencies	<b>62%*</b>	49%

\* $p < 0.05$



## Results: Help with key activities

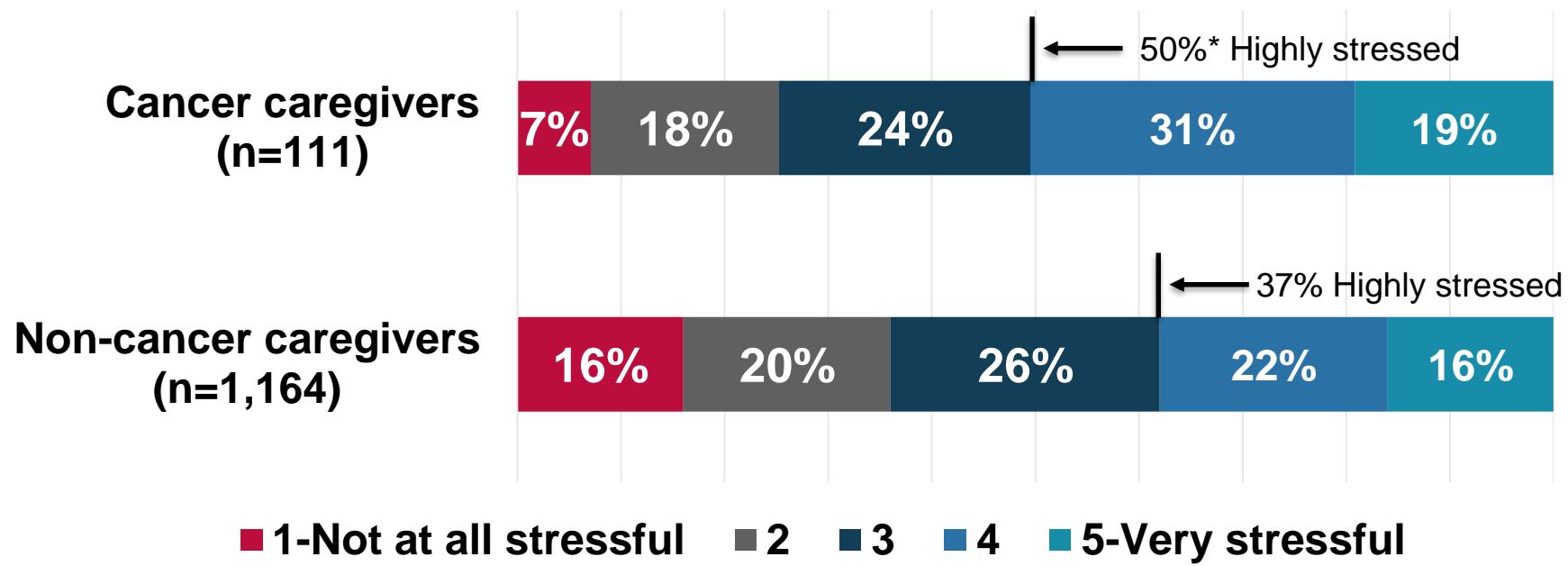
As a caregiver, on which of the following do you feel you need more help or information...	Cancer Caregiver (n=111)	Non-Cancer Caregiver (n=1,164)
Managing your emotional and physical stress	<b>43%</b>	42%
Making end-of-life decisions	<b>40%*</b>	21%
Keeping care recipient safe at home	<b>33%</b>	42%
Managing his/her incontinence or toileting problems	<b>15%</b>	11%
Managing his/her challenging behaviors, such as wandering	<b>10%</b>	13%
Finding non-English language educational materials	<b>5%</b>	5%



\* $p < 0.05$



# Results: Emotional Stress of Caregiving



\* $p < 0.05$



Additional resources  
on cancer caregiving  
research

# Intervening with cancer caregivers to improve patient & caregiver health outcomes and optimize healthcare utilization: PAR-16-317 (R01), PAR-16-318 (R21)

- Fund interventions that support the success of informal cancer caregivers for adult cancer patients, as measured by the following outcomes:

## **1. Improved patient health:**

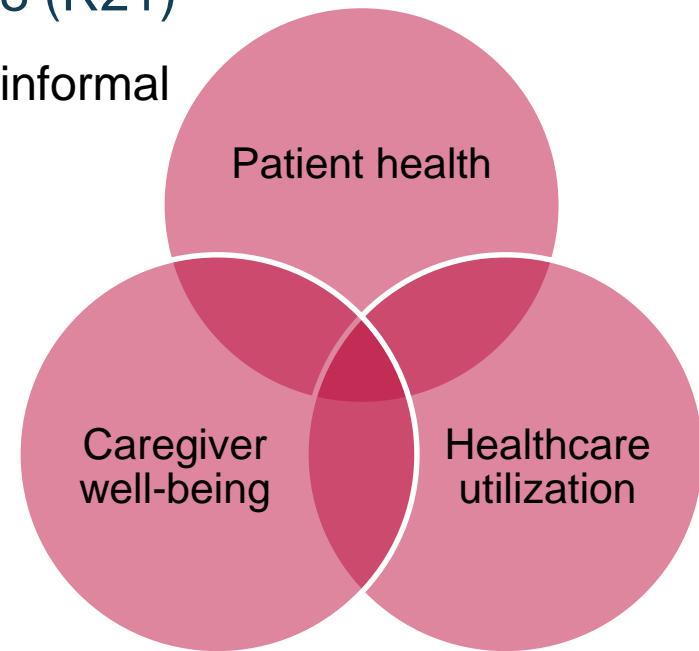
Physical and psychosocial outcomes, quality of life

## **2. Improved caregiver well-being:**

Lower burden, higher capacity and quality of life

## **3. Optimized healthcare utilization:**

Improved oral medication adherence; reduced emergency room visits, hospitalization and hospital readmissions; lower rates of infection; timely medication refills; better adherence; use of supportive/palliative care service; primary care visits



Next due date:  
April 11,  
2017

# Palliative Care Needs of Individuals with Rare Advanced Diseases and Their Family Caregivers: PAR-17-018 (R01), PAR-17-018 (R21), NINR/NCI FOA

- Expand knowledge and increase the evidence base for palliative care in advanced rare diseases, including rare cancers, and to improve well-being and quality of life among seriously ill individuals and their family caregivers.
- Qualitative, mixed methods, observational, quasi-experimental, and experimental designs with focus on individual- and family-centered outcomes encouraged
- Goal: Examine unique physical and psychosocial issues related to end-of-life and palliative care that may present among adults with advanced rare cancers\* and their family/informal caregivers, including but not limited to:
  - Psychological distress
  - Prognostic uncertainty,
  - Social isolation
  - Decisional regret
  - Decision-making in an emotional and ambiguous context.

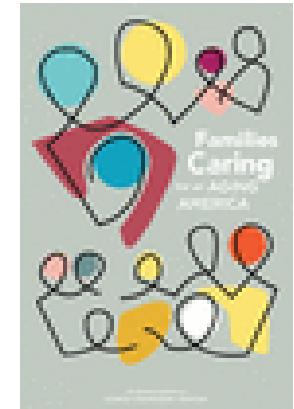
First due date:  
January 16,  
2017

\*(those with an incidence of fewer than 150 per million per year or approximately 40,000 cases or fewer) (Greenlee, 2014)

# National Academies of Medicine Study of Caregiving in Older Adults (September), 2016

## *Selected Recommendations:*

1. (1) Establishment of a National Family Caregiver Strategy
2. (1-f): Expansion of data collection infrastructure across HHS on the experiences of family caregivers
3. (1-g): Multi-agency research program to evaluate caregiving interventions in community and real-world settings



# Additional Areas for Future Research/Development

- Population-based studies

-  Cancer Care Outcomes Research and Surveillance Consortium
- Items on national surveys:



- HINTS V items
-  BRFSS™
  - 24 states fielded 8-item caregiving module in 2015

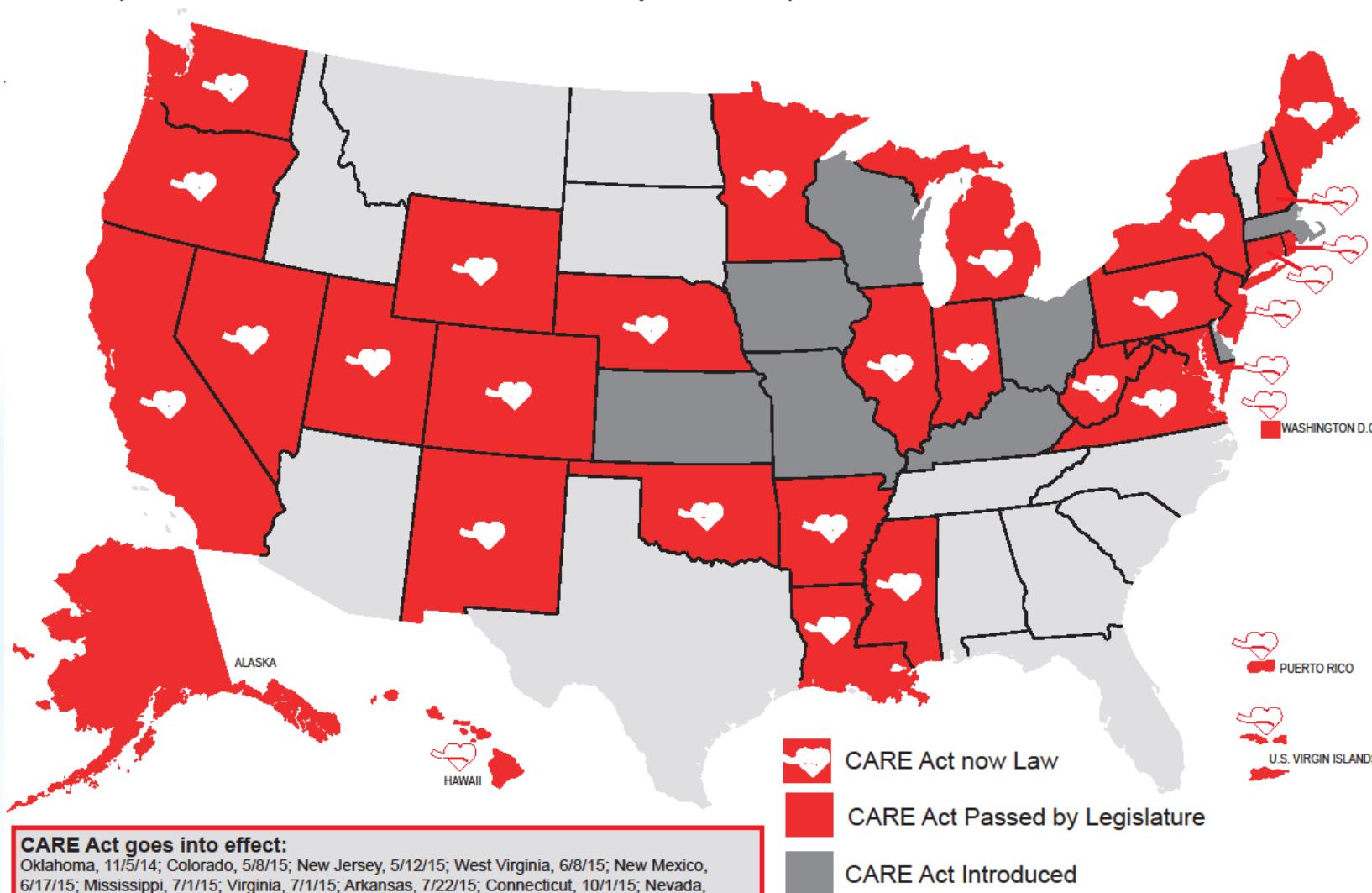
- Longitudinal studies
- Dyadic analysis
- More needed research in underserved groups

# Caregiving legislation in action

- Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act (S. 1719/ H.R. 3099):
  - Require Secretary of HHS to create a national strategy to support family caregivers
- Caregiver Advise, Record, Enable (CARE) Act:
  - *Record* identity of caregiver upon hospital admission
  - *Advise* caregiver prior to discharge
  - *Enable* caregivers by involving and instructing them in discharge planning

# The Caregiver Advise, Record, Enable (CARE) Act

The CARE Act is a commonsense solution that supports family caregivers when their loved ones go into the hospital, and provides for instruction on the medical tasks they will need to perform when their loved one returns home.



## CARE Act goes into effect:

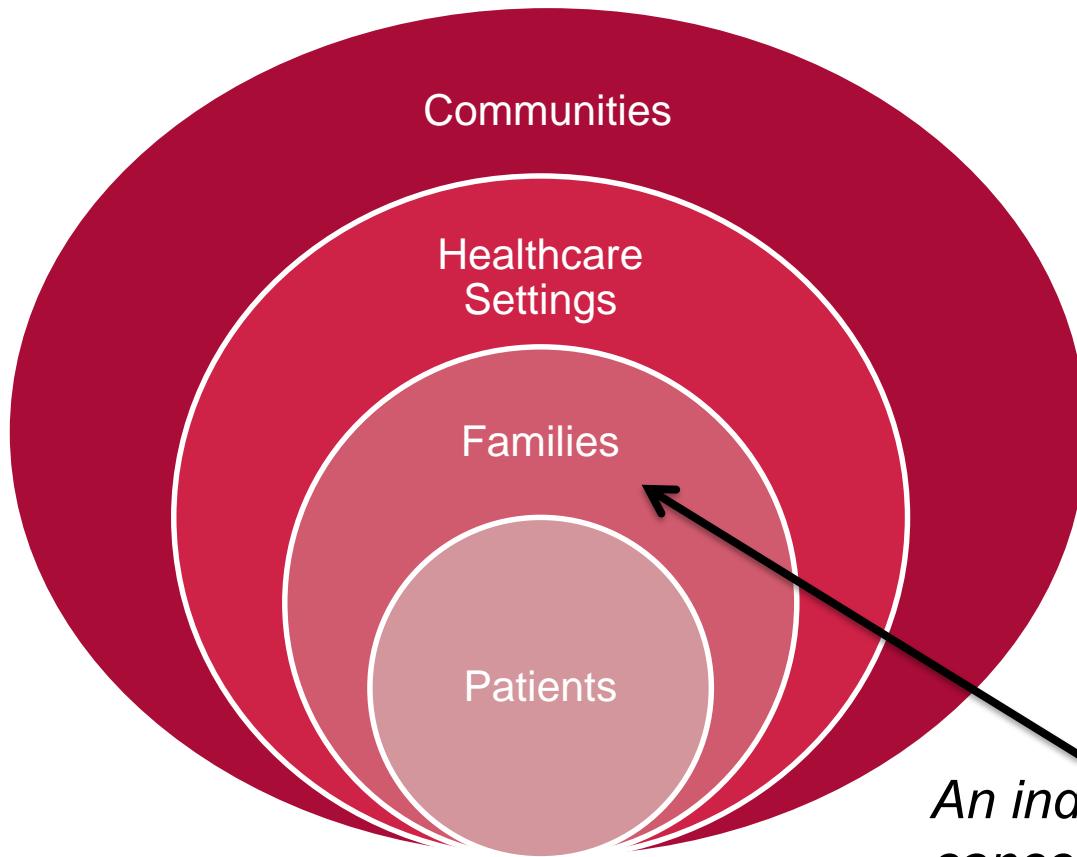
Oklahoma, 11/5/14; Colorado, 5/8/15; New Jersey, 5/12/15; West Virginia, 6/8/15; New Mexico, 6/17/15; Mississippi, 7/1/15; Virginia, 7/1/15; Arkansas, 7/22/15; Connecticut, 10/1/15; Nevada, 10/1/15; Maine, 10/15/15; Puerto Rico, 12/31/15; California, 1/1/16; Indiana, 1/1/16; New Hampshire, 1/1/16; Oregon, 1/1/16; Illinois, 1/27/2016; Utah, 2/10/16; Rhode Island, 3/1/16; Nebraska, 3/30/16; New York, 4/23/16; Washington, 6/9/16; Wyoming, 7/1/16; Michigan, 7/12/15; Louisiana, 8/1/16; Maryland, 10/1/16; Minnesota, 1/1/17; Hawaii, 7/1/17; Virgin Islands, TBD; Washington D.C.: TBD

\*\*Updated on 6/21/2016

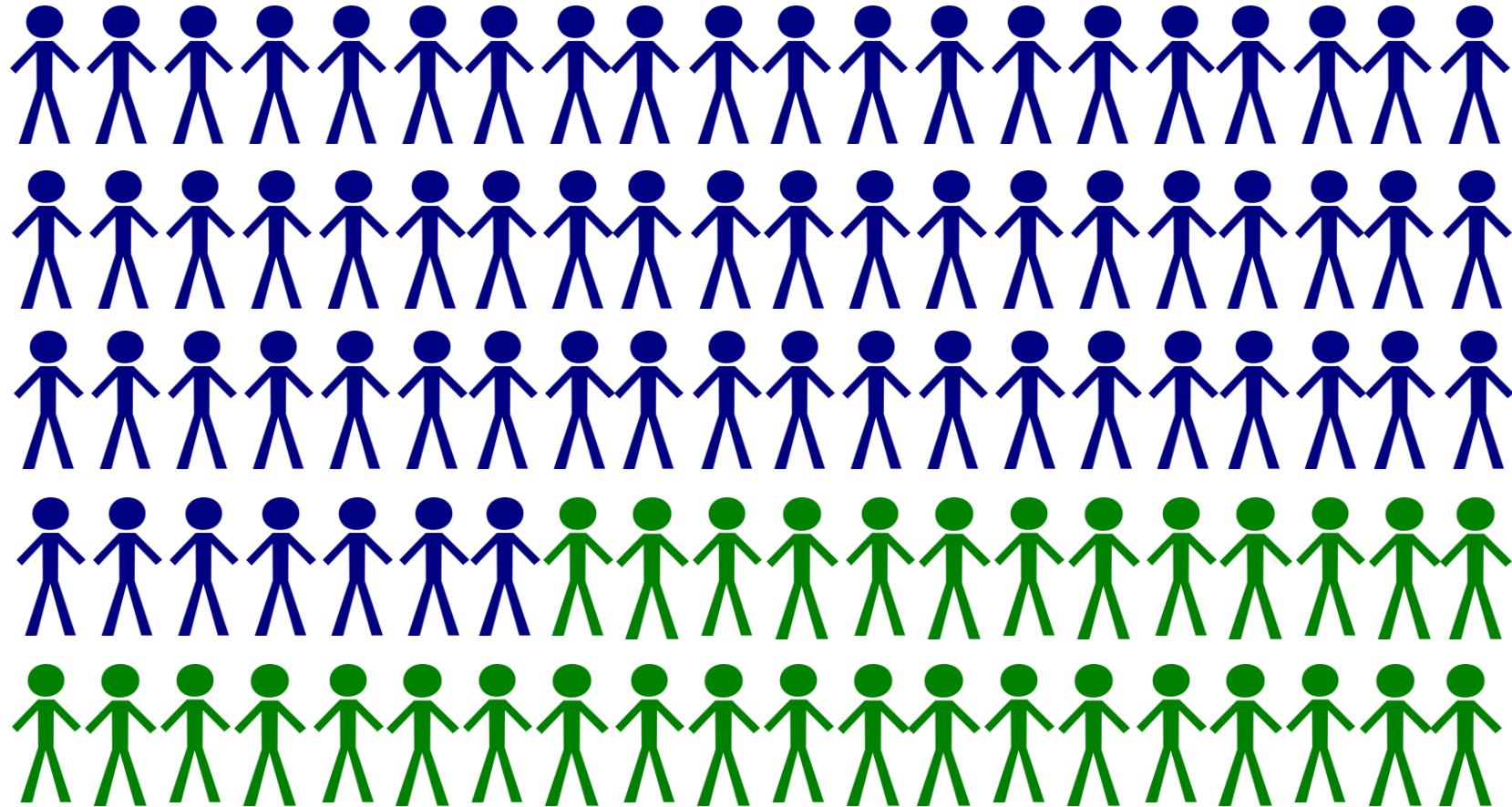


aarp.org/iheartcaregivers

# Caregiving: puts the focus on families



*An individual doesn't get cancer;  
a family does.  
-T. T. Williams*



*1 out of 3 cancer patients in active treatment  
reported having no caregiver*

CancerCare Patient Access and Engagement Report, 2016



# CANCER SUPPORT COMMUNITY

*A Global Network of Education and Hope*

R2R Cancer Caregiving in the Community  
November 29, 2016  
Kristen Cox Santiago

# Cancer Support Community (CSC)

## OUR MISSION:

To ensure  
that all people  
impacted by  
cancer are  
empowered  
by knowledge,  
strengthened  
by action, and  
sustained by  
community.



# Cancer Support Community



# Service Delivery

- 46 centers, 120 satellite locations
- Cancer Support Helpline®
- CancerSupportSource®
- Open to Options®
- Frankly Speaking About Cancer®
- Online Support: The Living Room®



*"It is just the greatest place; I have found support, friends and new ways to meet the challenge of having cancer."*

“The emotional support I got from the Cancer Support Community allowed me to draw positive energy from people who were going through what I was going through.”

Kelly, Cancer Experience Registry

“The way they listened to me patiently without judgment, consoling my ocean of tears, gently offering a supportive ear and tender advice, and understanding the enormous stressors on caregivers, is a service that is **priceless**. The *Cancer Support Helpline* was truly a **LIFELINE** for me.”

Malaya Cooks, Caregiver & Helpline Caller

# Frankly Speaking About Cancer

FRANKLY  
SPEAKING  
ABOUT CANCER

Support from  
a Distance

People who are addressing cancer with  
become  
wellness  
turing th  
cancer e  
with can

FRANKLY  
SPEAKING  
ABOUT CANCER

De Cuidador a Cuidador  
Compartiendo nuestras experiencias durante  
el cuidado a mujeres con cáncer de seno

CANCER SUPPORT  
COMMUNITY

FRANKLY  
SPEAKING  
ABOUT CANCER

Caregivers

Caring for a Loved One

Family members, spouses, partners and friends who take on a caregiving role have a unique relationship to cancer. Caregivers see and experience firsthand how deep and wide cancer's emotional impact can be. They learn how quickly life can become complicated and constrained by a cancer diagnosis. They become attuned to a new reality of making appointments, managing treatments and deciphering insurance forms and medical fees.

It, all too often, others don't "see" how much you, the caregiver, are doing. Your loved one is at the center of the orbit of cancer care, and friends and family members may not recognize the toll it is to provide the care your loved one needs. Taking care of someone with cancer can be a challenging experience. As a caregiver, you are likely to experience a wide range of feelings, fluctuating between sadness or from camaraderie to loneliness all in one day. On the following pages, you will find information that will help you succeed in your role as a caregiver, manage your distress, get support and, importantly, address your own needs.



FRANKLY  
SPEAKING  
ABOUT CANCER

When a Woman You Care About  
has Breast Cancer

People who are about someone with cancer can be active participants in enhancing health and wellness for themselves and their loved ones, and nurture their relationships through and beyond the cancer experience. People who care about someone with cancer can be active participants in enhancing health and well-being for everyone involved.

THE CANCER SUPPORT COMMUNITY

# Research and Training Institute

## Experts in the Cancer Patient Experience



- The first and only *Institute* in the U.S. dedicated to psychosocial, behavioral and survivorship research and training
- Led by a PhD behavioral psychologist and staffed by a multidisciplinary team of clinical and research professionals

# Cancer Experience Registry®

- First cancer Registry in the world designed to:
  - Understand the full impact of the patient and caregiver experience with cancer
  - Positively influence each individual's cancer experience
  - Develop programs to help the nation's health care systems be more responsive to the needs of cancer survivors and caregivers
  - Accelerate and enhance the productivity of research and treatment to improve the lives of those living with cancer
- Currently 10,800 participants (and growing!)

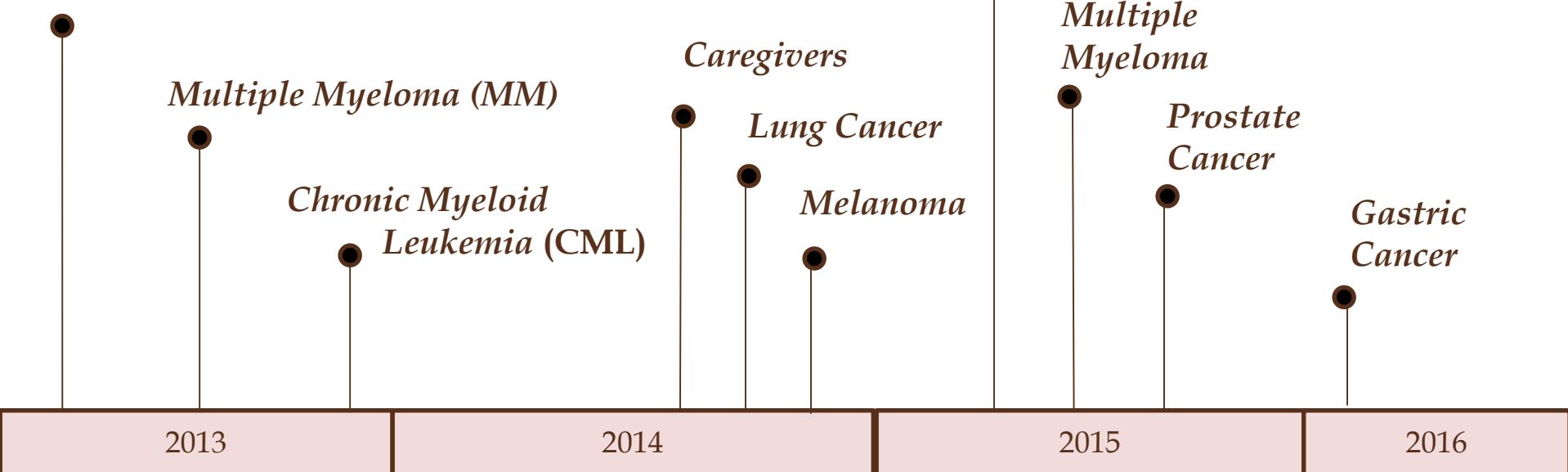


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# The Evolution of the Registry: Specialty Registries

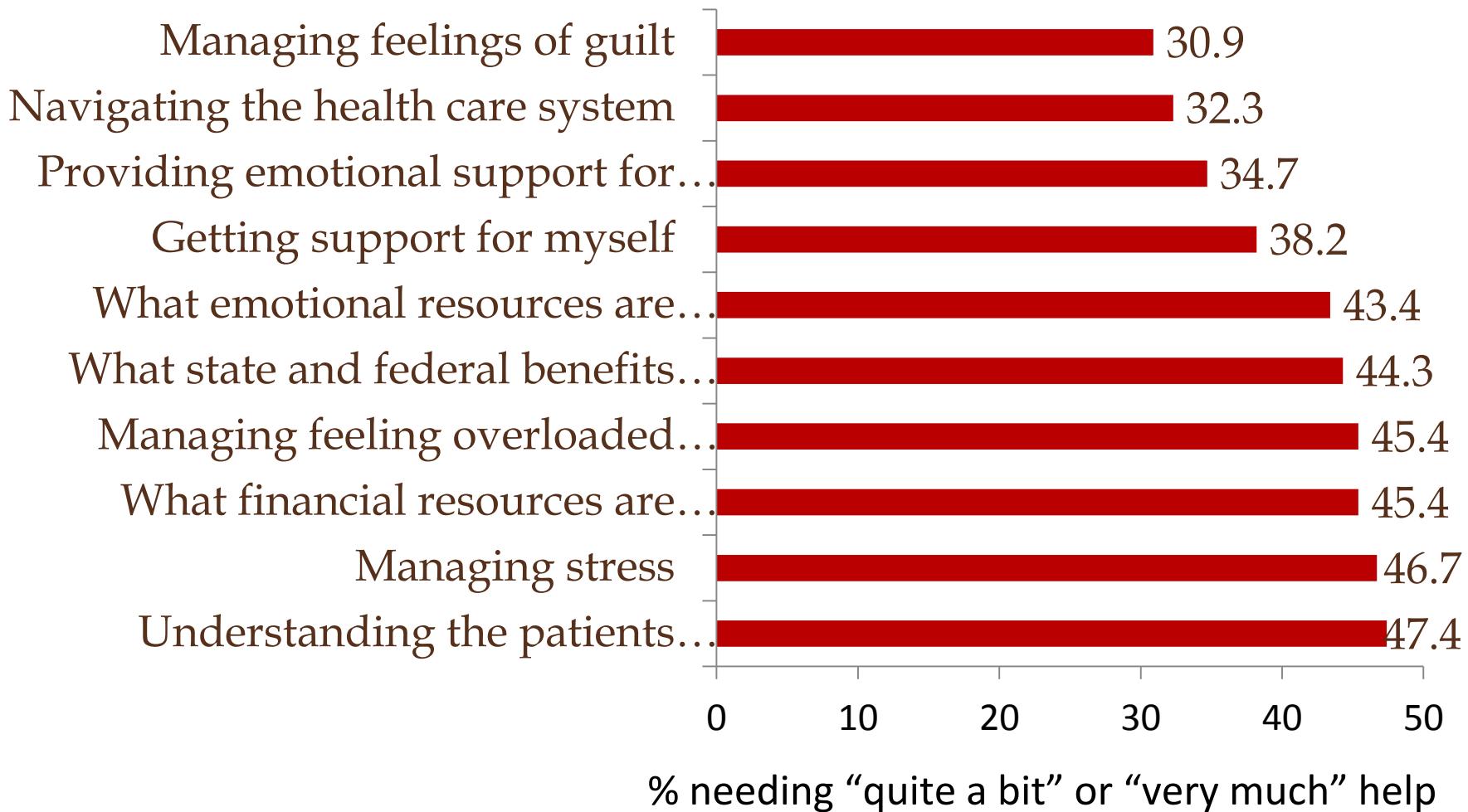
*The General Cancer Experience Registry  
Metastatic Breast Cancer (MBC)  
Breast Cancer*

*Chronic  
Lymphocytic  
Leukemia (CLL)*

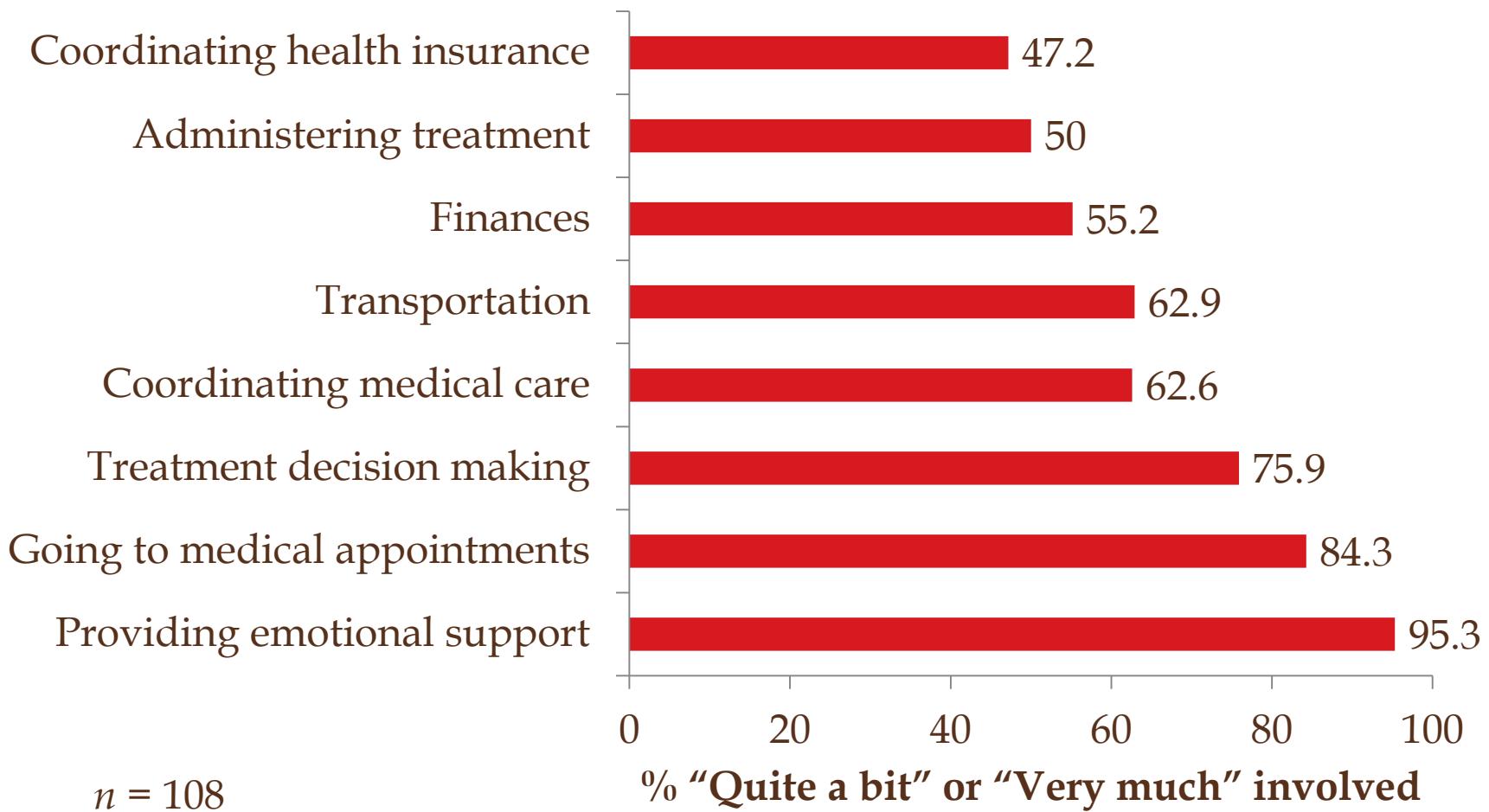


# Top Areas Needing Help as a Caregiver

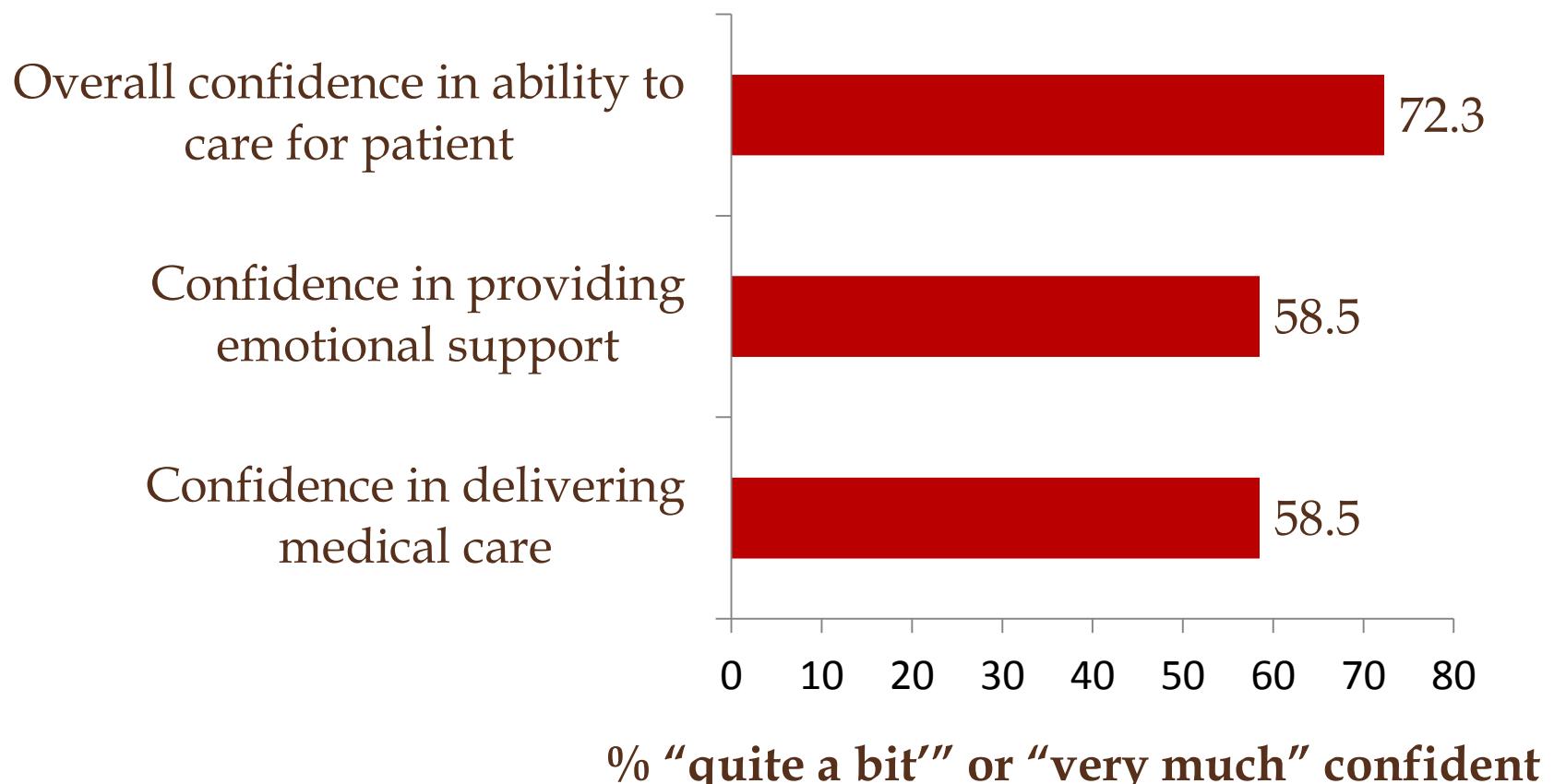
Please tell us how much help you need /needed... (n=97)



# Caregivers are Highly Involved in Medical Care and Health Interactions



# Caregiving Self-Efficacy



n=94; Remaining % “not at all,” “a little bit,” or “somewhat” confident

“...Place the oxygen mask on yourself first before helping small children or others who may need your assistance.”



# CancerSupportSource® Caregiver

## Four Themes and Sample Items

### Emotional Concerns\*

Feeling sad or depressed  
Worrying about the future

### Caregiving Tasks

Managing household/family activities  
Getting info about patient care

### Self-Care

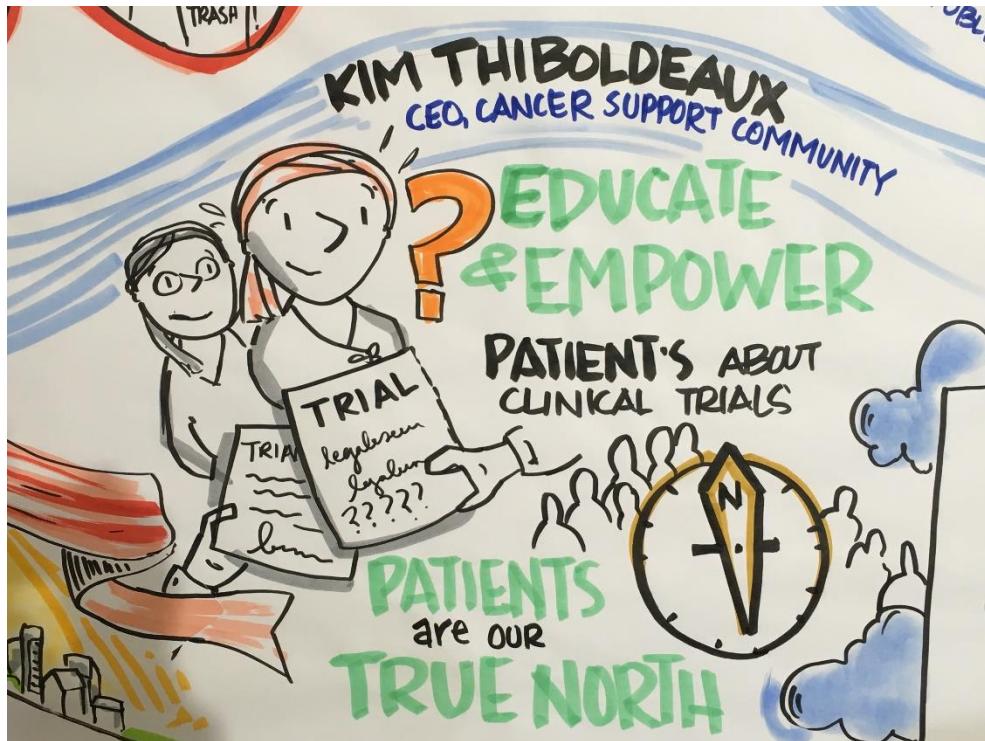
Exercise/being physically active  
Eating and nutrition

### Patient Well-Being

Patient's pain/physical discomfort  
Changes in patient's mood/behavior

\*Includes 4-item subscale to assess risk for clinical level of depression

# CSC & The Cancer Moonshot



# CSC Local Cancer Moonshot Summits

## June 29, 2016

CSC Redondo Beach

CSC Santa Monica

CSC Delaware

CSC Greater Miami

UF Health Cancer Center-  
Orlando Health

GC South Florida

CSC Atlanta

OSF Saint Francis Medical Center

CSC Central Indiana

GC Evansville

GC Quad Cities

GC Metro Detroit

CSC Greater Ann Arbor

GC Twin Cities

CSC Greater St. Louis

GC Kansas City

CSC Montana

CSC Central New Jersey

CSC Greater Cincinnati-Northern  
Kentucky

CSC Central Ohio

CSC Greater Lehigh Valley

CSC Greater Philadelphia

Greenville Health System

GC Nashville

Whitman-Walker Health Clinic

GC Madison

# CSC Affiliate and CCC Partnership

- Caregiver needs are integrated into programs and services
- Webinars for state coalitions

# Thoughts/Questions?

So that no one faces cancer alone<sup>®</sup>



THE GEORGE  
WASHINGTON  
UNIVERSITY  
WASHINGTON, DC

# Supporting Cancer Survivors through Comprehensive Cancer Control Programs

Research to Reality  
Cancer Caregiving in the Community  
November 29, 2016

**GW** Cancer Center

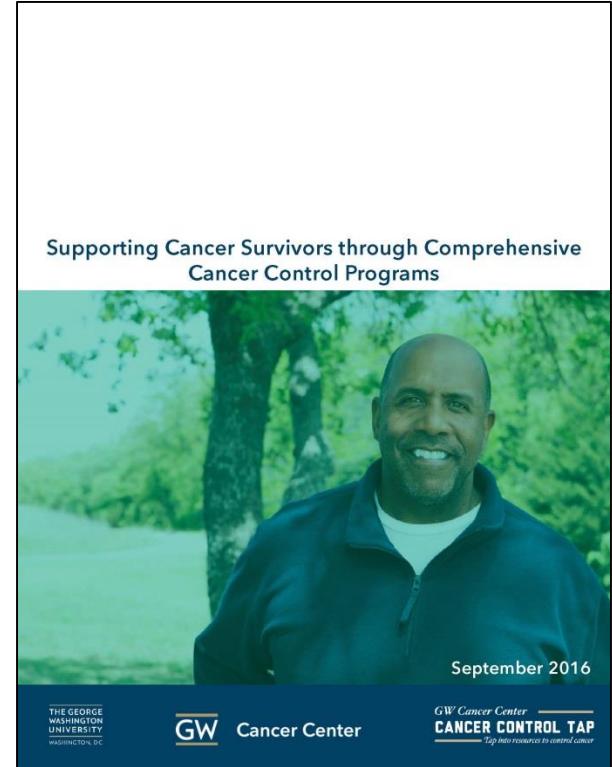
# Caregivers and Survivorship

- National Cancer Institute considers “family members, friends, and caregivers [as] part of the survivorship experience.”
- Cancer caregivers may also experience lower quality of life, psychosocial distress, trouble with relationships and lack of support (Mellon, Northouse & Weiss, 2006; Mosher et al., 2016; Trudeau-Hern & Daneshpour, 2012)



# Role of Comprehensive Cancer Control (CCC) Programs

- Public health needs of cancer survivors is a priority area for National Comprehensive Cancer Control programs and coalitions (Seef, 2010)
- GW Cancer Center released *Supporting Cancer Survivors through Comprehensive Cancer Control Programs* resource in September (<http://bit.ly/2016SurvivorshipReport>)
- Resource provides an introductory education about post-treatment survivorship needs, offers potential benchmarks that could be included in state cancer plans and identifies systems-level opportunities for supporting survivors and caregivers



# Examples of Benchmarks & Potential Measures

Benchmark	Measure
<ul style="list-style-type: none"><li>Increase use of Cancer Survivorship, Sexual Orientation and Gender Identity (SOGI), Anxiety and Depression and Caregiver Modules in BRFSS concurrently</li></ul>	<ul style="list-style-type: none"><li>Number of cancer caregivers participating in module</li><li>Identification of cancer survivor and caregiver needs at state level</li></ul>
<ul style="list-style-type: none"><li>Provide educational opportunities for survivors and caregivers to increase awareness of resources to address lifestyle, psychosocial and financial concerns through multiple channels to reach diverse and hard to reach populations</li></ul>	<ul style="list-style-type: none"><li>Number of survivors and caregivers engaged/educated</li><li>Learning outcomes based on event objectives</li></ul>
<ul style="list-style-type: none"><li>Support local health departments in implementing survivorship activities into their programs</li></ul>	<ul style="list-style-type: none"><li>Number of activities delivered focusing on post-treatment cancer survivors and caregivers</li><li>Number of resources distributed</li><li>Number of cancer survivors and caregivers reached</li></ul>

# Conclusion

- CCC programs and coalitions are uniquely positioned to address survivor and caregiver needs
- The Institute for Patient-Centered Initiatives and Health Equity (formerly the GW Cancer Institute) will continue to support CCC programs in their efforts through technical assistance made possible with a 5-year cooperative agreement with the Centers for Disease Control and Prevention

Join the Research to Reality and George Washington Cancer Institute

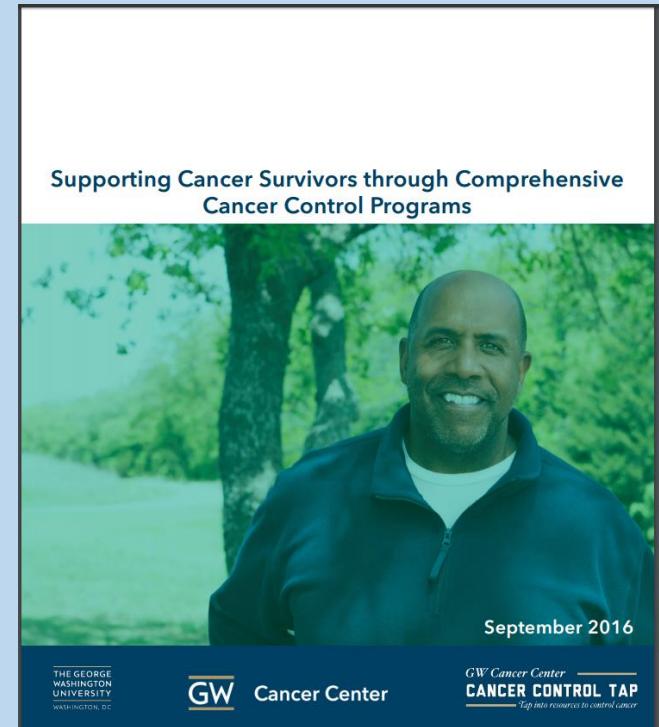
# *Supporting Cancer Survivors through Comprehensive Cancer Control Programs*

## COFFEE BREAK WEBINAR

TUESDAY, DECEMBER 13<sup>TH</sup>  
2 PM ET

This 20-minute conversation with lead author Allison Harvey will explore findings of the report and systems-level opportunities for supporting cancer survivorship in surveillance and applied research; communication, education and training; programs, policies and infrastructure; and access to quality care and services

Come with your questions and share your perspective.



Questions for Our Speakers?  
Tell Us About Your Experience!  
Use the Q&A Feature on the right of your screen.



**Erin Kent**  
*PhD, MS*

Epidemiologist and Program Director,  
Outcomes Research Branch,  
National Cancer Institute

**Kristen Cox Santiago**  
*MS*

Senior Director,  
Policy & Advocacy,  
Cancer Support Community

**Allison Harvey**  
*MPH, CHES*

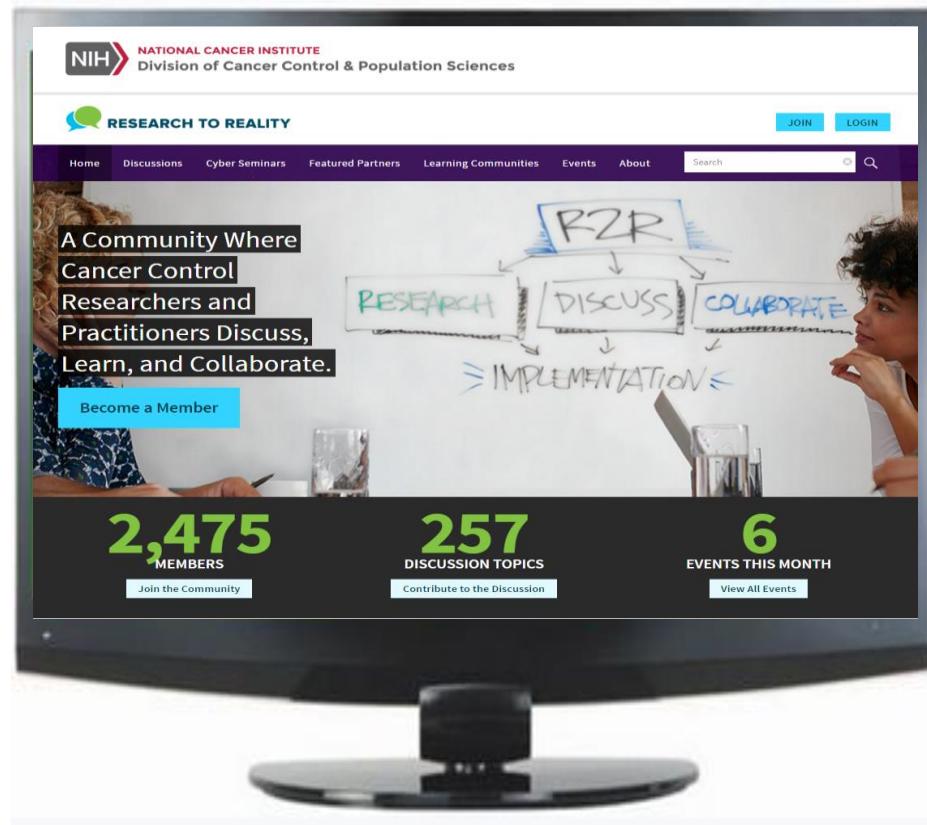
Senior Manager,  
Health Care Professional Education,  
George Washington Cancer Institute



# RESEARCH TO REALITY

- A link to a feedback survey will be sent to all registrants shortly.
- Continue the discussion on our Research to Reality Community of Practice:

[researchtoreality.cancer.gov](http://researchtoreality.cancer.gov)



We will be sending more information about the December 13th "Coffee Break" webinar to all registrants tomorrow morning.

U.S. Department of Health and Human Services  
National Institutes of Health | National Cancer Institute

<http://researchtoreality.cancer.gov>

1-800-4-CANCER

Produced November 2016