

Welcome!

Before we begin...

**Today's session will
be recorded**

**Please add your name
and hospital in the
chat**





Monday, September 11, 2023 • 11:30 am CST/12:30 pm EST

Health Equity & Caregiving: Meeting the Needs of African American/Black Caregivers ECHO

**Session 4:
Mental Health & Caregiving**

Today's Agenda

1 **Housekeeping, Agenda Preview, and Introductions**

10 minutes

2 **Didactic Lecture: Mental Health & Caregiving**

Fawn Cothran, PhD, RN, GCNS-BC, FGSA

National Alliance for Caregiving

10 minutes

3 **Didactic Q/A**

10 minutes

4 **Case Presentation: Infirmity Cancer Care**

Kay Jernigan, BSN, RN

5 minutes

5 **Case Presentation Recommendations and Discussion**

20 minutes

6 **Post Session Poll & Wrap Up**

5 minutes

Welcome to Session 4: Mental Health & Caregiving

Health Equity & Caregiving: Meeting the Needs of African American/Black Caregivers ECHO



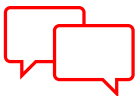
Each ECHO session will be recorded and **may** be posted to a publicly-facing website



You will be muted with your video turned off when you join the call. Use the buttons in the *black* menu bar to unmute your line and to turn on your video. **If you do not wish to have your image recorded, please turn OFF the video option.**



Today's materials will be made available on our [ACS ECHO website](#)



Please type your full name, the full name of your organization, and e-mail in the chat box



This ECHO session takes place on the Zoom platform. Click [here](#) to review Zoom's privacy policy.



Questions about Zoom? Type in the chat box [@Beth Graham](#)

This project is funded by EMD Serono



embracing carers

Introductions

Meet Our Health Equity & Caregiving: Meeting the Needs of African American/Black Caregivers ECHO HUB



Rachel Cannady
Strategic Director, Caregiving,
American Cancer Society
ACS ECHO Program Lead



Siobhan Aaron,
PhD, MBA, RN, FNP-BC
Assistant Professor,
Frances Payne Bolton
School of Nursing
Case Western Reserve
University
ECHO Facilitator



Mindi Odom
American Cancer Society
Director, Project ECHO



Beth Graham,
MPH, CHES
American Cancer Society
Program Manager,
Project ECHO



Allison Rosen, MS
American Cancer Society
Director, Project ECHO



Beth Dickson-Gavney,
MS, MA
American Cancer Society
Senior Director, Project ECHO

Introductions

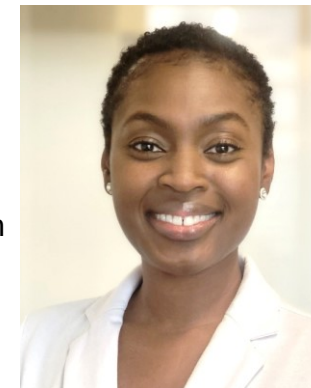
Meet Our Health Equity & Caregiving: Meeting the Needs of African American/Black Caregivers ECHO HUB Subject Matter Experts (SMEs)



Robert A. Winn, MD
Director and Lipman Chair in
Oncology, Sr. Assoc. Dean
for Cancer Innovation and
Prof. of Pulmonary Disease
and Critical Care Medicine
VCU Massey Cancer Center



Joseph E. Ravenell, MD
Assoc. Dean for Diversity Affairs
and Inclusion,
Director, Diversity in Research,
Perlmutter Cancer Center,
Assoc. Prof., Dept. of Pop. Health
NYU Langone Health



Olufunke Awosogba, PhD
Asst. Prof. and Vice Chair
of Diversity, Equity, and
Inclusion in Dept. of Psychiatry,
Director, Behavioral Health Program
in Hem/Onc Outpatient Clinic
Parkland Hospital
UT Southwestern Medical Center



**Fawn Cothran, PhD, RN,
GCNS-BC, FGSA**
Hunt Research Director
**National Alliance for
Caregiving**



**Cardinale B. Smith,
MD, PhD**
Prof. of Medicine (Hem/Onc) and
Prof. of Geriatrics and Palliative
Medicine, Chief Medical Officer –
Tisch Cancer Hospital
**Icahn School of Medicine at
Mount Sinai**



**Katrina R. Ellis, PhD, MPH,
MSW**
Asst. Prof. Social Work and Faculty
Assoc., Research Center for Group
Dynamics, Institute for Social
Research
University of Michigan









Siobhan Aaron,
PhD, MBA, RN, FNP-BC
Assistant Professor, Frances Payne
Bolton School of Nursing

Session 4

ECHO Subject Matter Expert (SME) & Participant Site Introductions

Welcome to our Participant Learning Sites

ALABAMA	GEORGIA	LOUISIANA	MISSISSIPPI	SOUTH CAROLINA	VIRGINIA
Infirmity Cancer Care	Northside Hospital Cancer Institute	Our Lady of the Lake Cancer Institute	Singing River Health System Cancer Center	Beaufort Memorial Keyserling Cancer Center	Sentara Healthcare
O'Neal Comprehensive Cancer Center at the University of Alabama at Birmingham – Wallace Tumor Institute	Phoebe Cancer Center	Woman's & Mary Bird Perkins – Our Lady of the Lake Cancer Center Breast & GYN Cancer Pavilion	St. Dominic's Comprehensive Cancer Services	Prisma Health Cancer Institute	VCU Massey Cancer Center
					



Have a question? Don't wait to ask! Feel free to enter it in the Q&A box at any time.



Mental Health & Caregiving

Fawn Cothran, PhD, RN, GCNS-BC, FGSA
Hunt Research Director
National Alliance for Caregiving



National Alliance for Caregiving (NAC)



ABOUT US

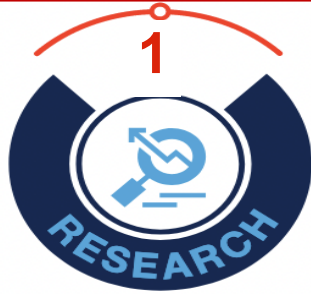
Established in 1996, the National Alliance for Caregiving (NAC) is a membership-based organization catalyzing system change to build **health, wealth, and equity** for America's 53 million family caregivers.



OUR NETWORK



NAC's Core Strategies



We elevate national family caregiving **RESEARCH** by: 1) developing credible, transformative, original research; 2) providing open data sets to researchers; and 3) leading a peer-to-peer network of national and international experts.



We catalyze public and private sector actors, including regulatory bodies, to develop **INNOVATIVE** services and supports for family Caregivers.



We are a recognized **THOUGHT-LEADER** and **GO-TO** source for caregiving research, advocacy, and innovation insights and connections.



Our **ADVOCACY** work advances caregiving as a public health issue and builds awareness that fosters national conversation that will empower caregivers to thrive at home, work, and life.

Our Impact Priorities

**Build Caregiver
Health & Wellness**



**Champion
Economic Justice
For Caregivers**



**Mobilize Community
Support for Caregivers**

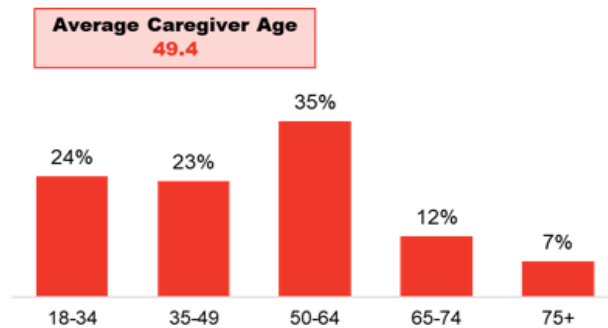
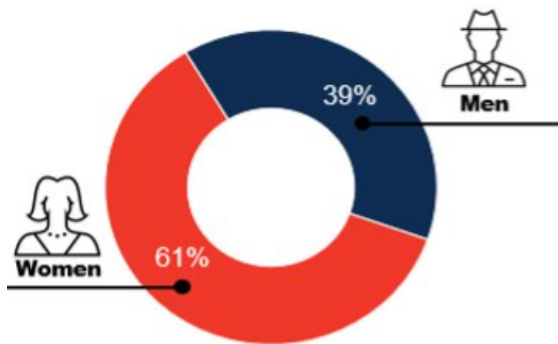


**Build Caregiver
Equity & Inclusion**



CAREGIVERS

53 million 2020



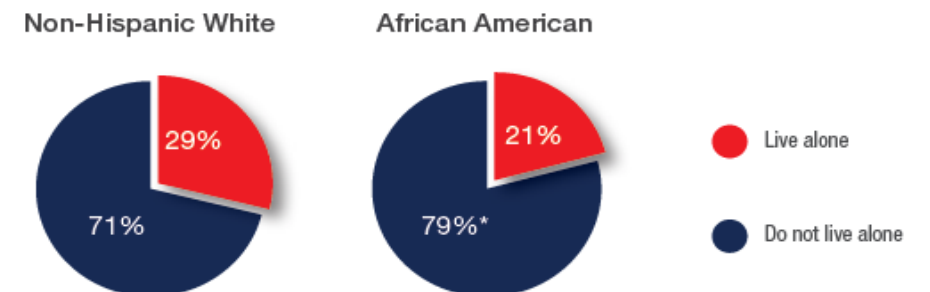
2020 Base: Caregivers of Recipient Age 18+ (n=1,392)

AFRICAN AMERICAN/BLACK CAREGIVERS



- 47.7 YEARS of AGE
- Unmarried
- Lower household income
- 31.2 hours of care/week

Figure 5: Care Recipients Who Live Alone



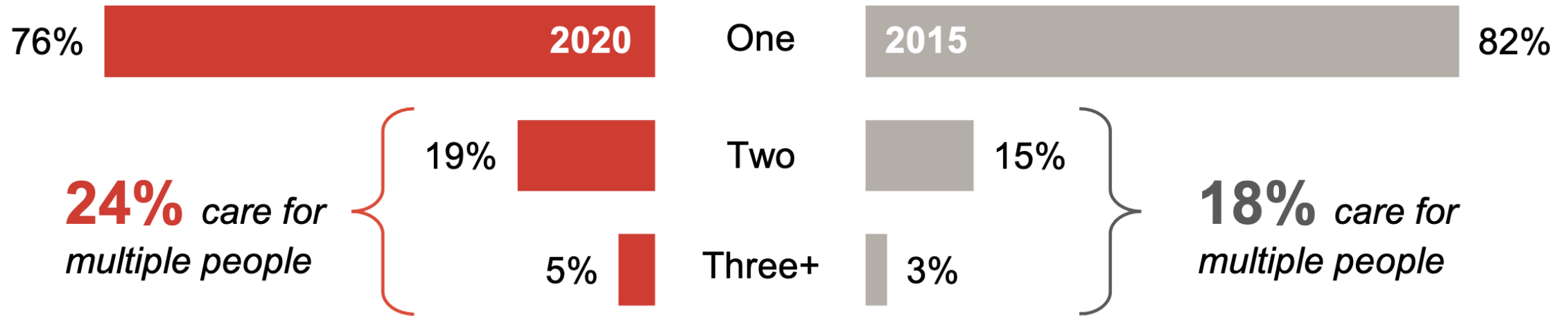
*Indicate significantly different from Non-Hispanic White caregivers. Results are rounded and/or multiple response; results may not add to 100 percent.



Stress & Psychosocial Functioning

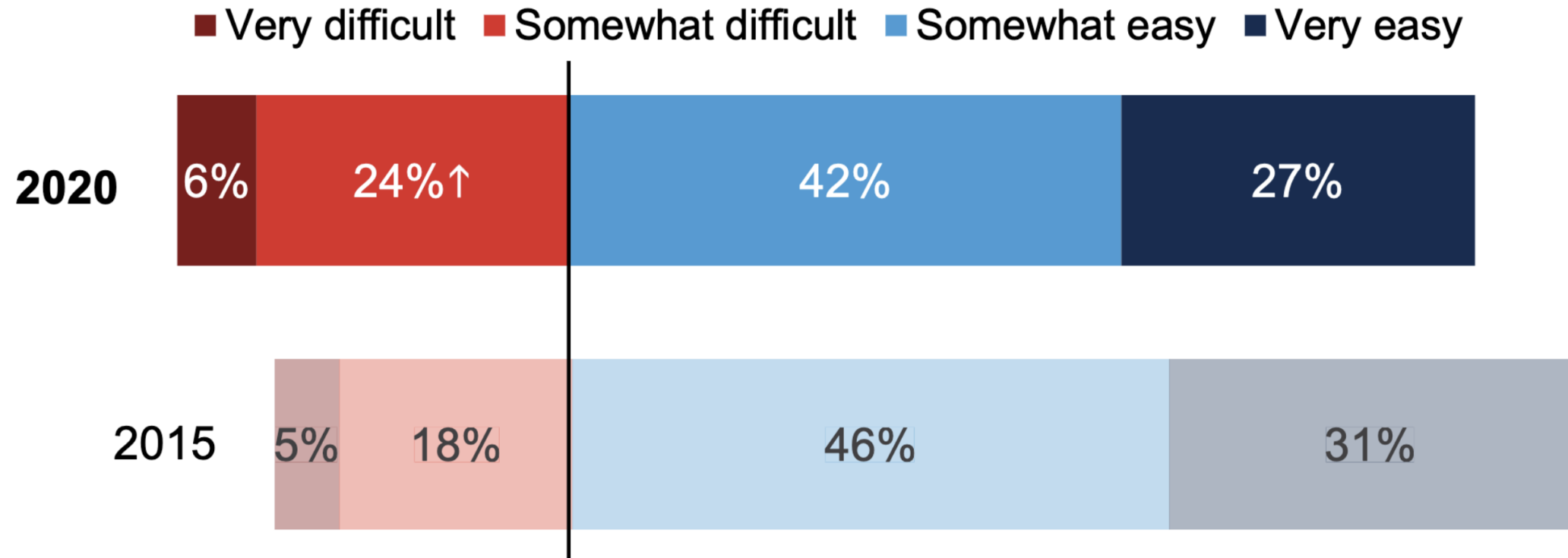
CARE RESPONSIBILITIES

More family caregivers are *caring for more people*



CARE COORDINATION

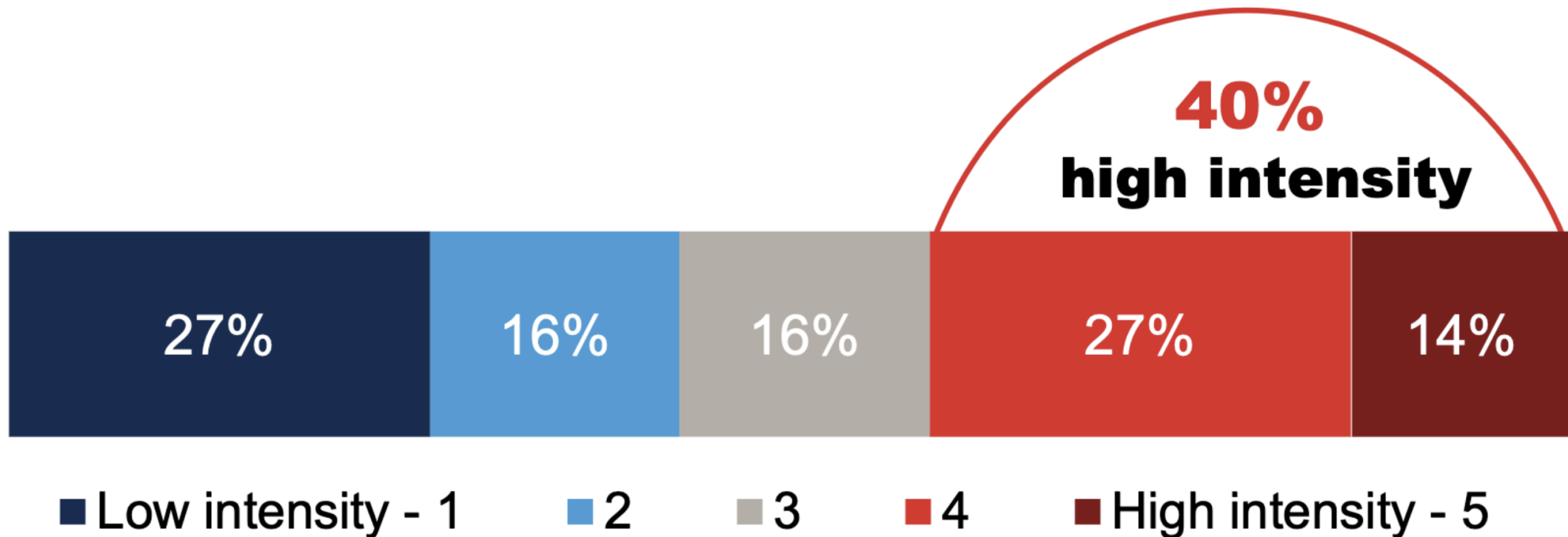
More family caregivers are finding it **difficult to coordinate** care for their loved ones



Caregiving in the U.S. 2020, National Alliance for Caregiving and AARP, 2020

INTENSITY OF CAREGIVING

4 in 10 family caregivers are in **high-intensity** situations



AFRICAN AMERICAN/BLACK CAREGIVERS

More often in high **intensity care** situations

Provide
more hours
of care

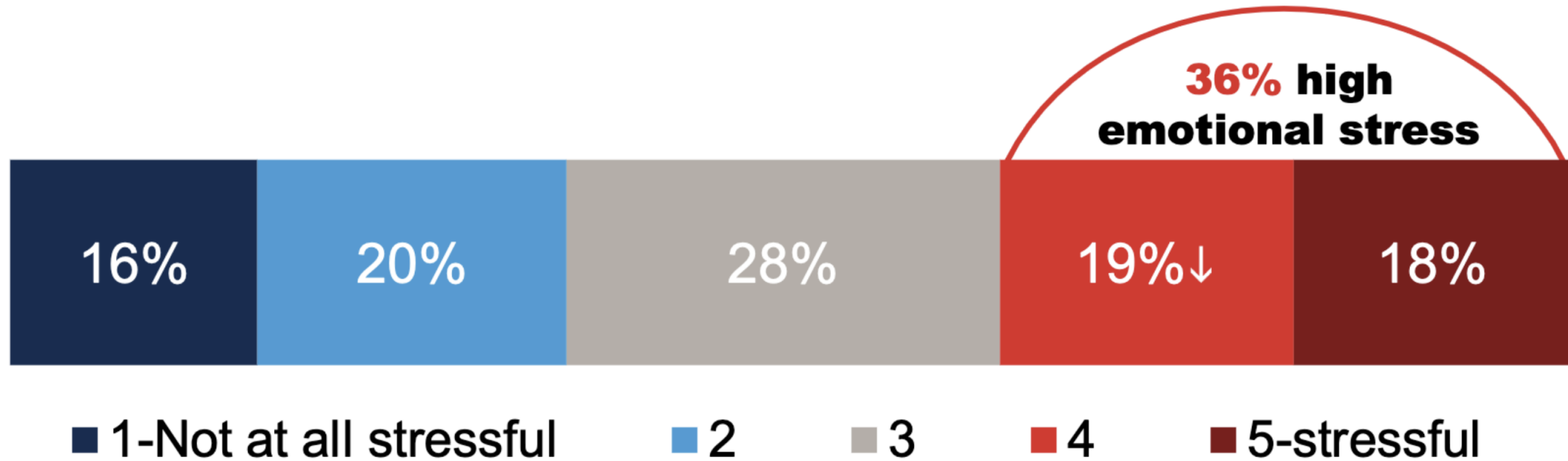


Provide more
ADLs, IADLs,
and medical/
nursing tasks



EMOTIONAL IMPACTS

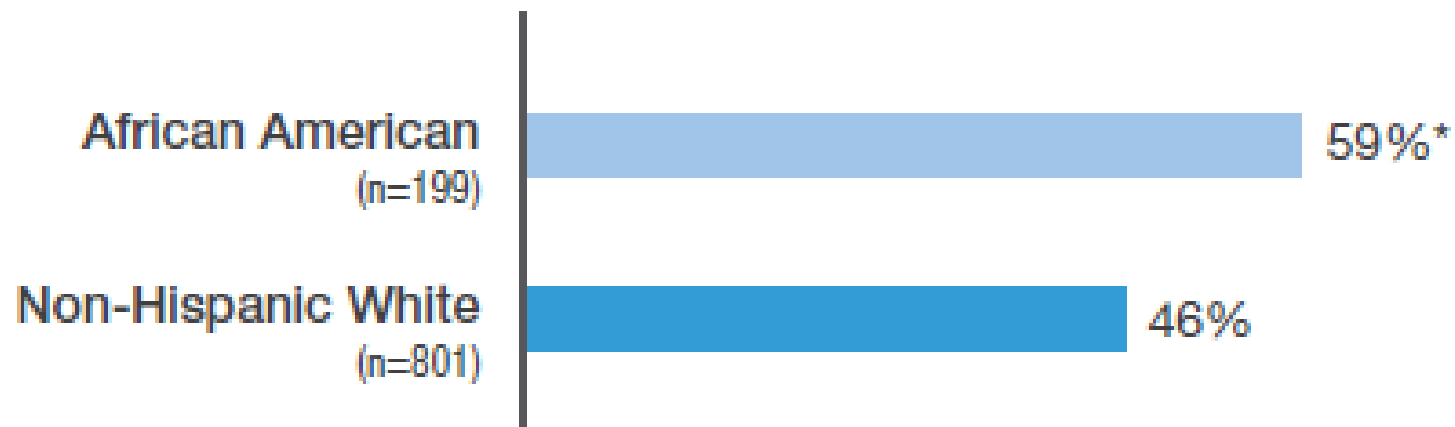
Nearly 4 in 10 family caregivers experience **high emotional strain**



AFRICAN AMERICAN/BLACK CAREGIVERS

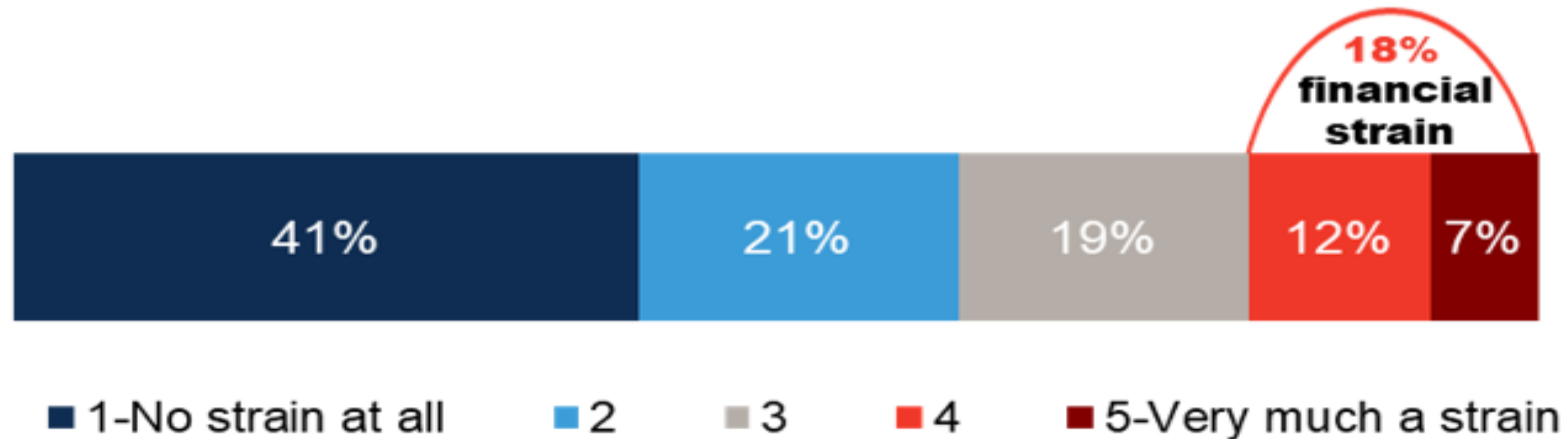
HOWEVER, African American caregivers report **less emotional strain** and caregiving brings **more meaning** to their lives

Figure 8: Being a Caregiver Gives Meaning to My Life



FINANCIAL IMPACTS

1 in 5 family caregivers experience **financial strain**



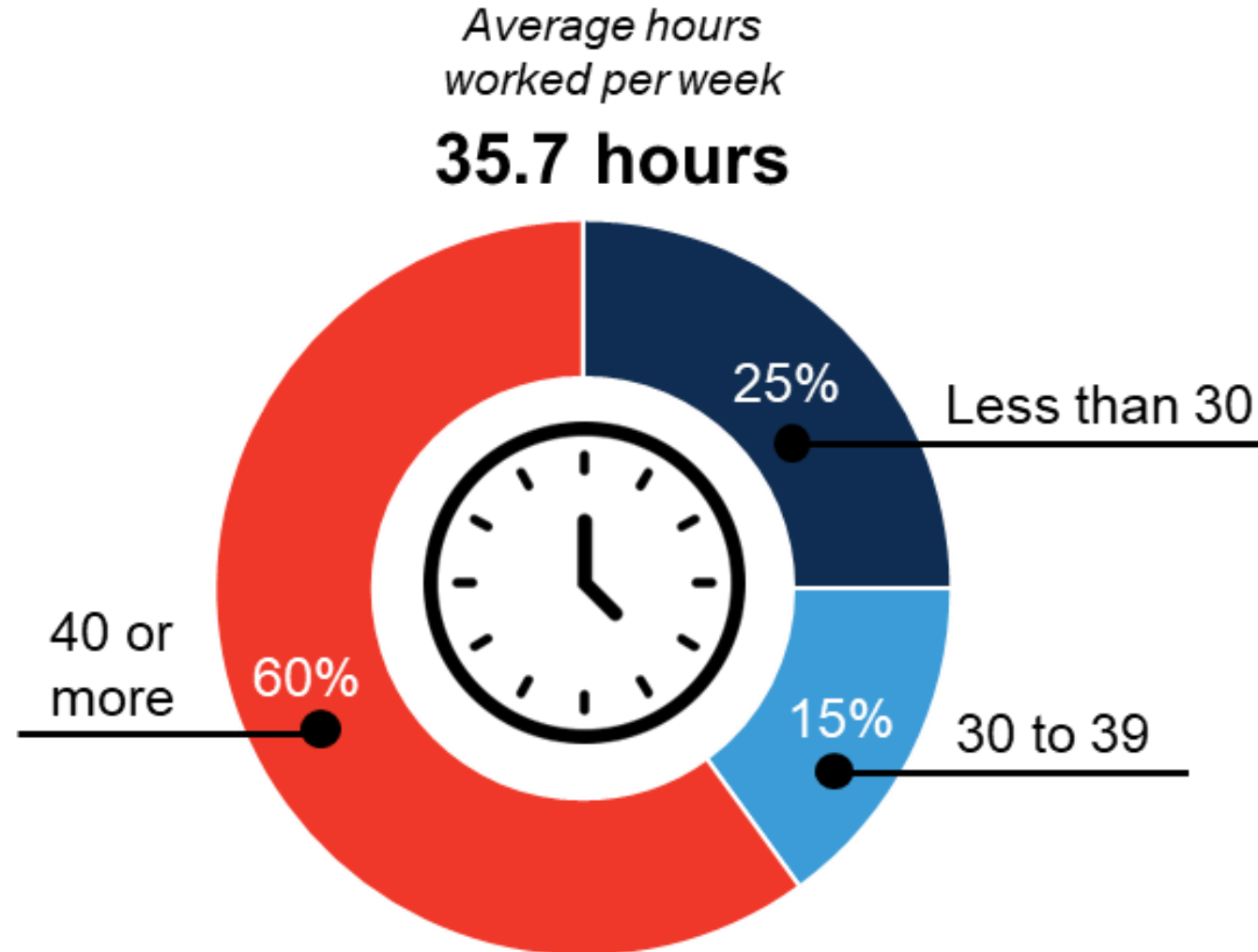
African American/Black Caregivers' Self-Reported Financial Impacts



	Non-Hispanic White (n=801)	African American (n=199)
Any of these	42%	55%*
Took on more debt (credit cards, loans, lines of credit)	21%	30%*
Missed or was late paying for a student loan	4%	11%*
Borrowed money from family or friends	12%	24%*
Filed for bankruptcy (medical or personal)	2%	8%*
Been unable to afford basic expenses like food	9%	14%
Left bills unpaid or paid them late	14%	31%*
Used up your personal short-term savings	21%	23%
Used long-term savings, like retirement or education, to pay for other things	10%	16%*
Stopped saving	26%	35%*
Moved to a less expensive home, apartment, or other living arrangement	5%	8%
Was evicted or had a home foreclosed	2%	5%
Put off retirement or deciding to never retire	9%	11%
Had to start working, work more, or find a second job	8%	20%*

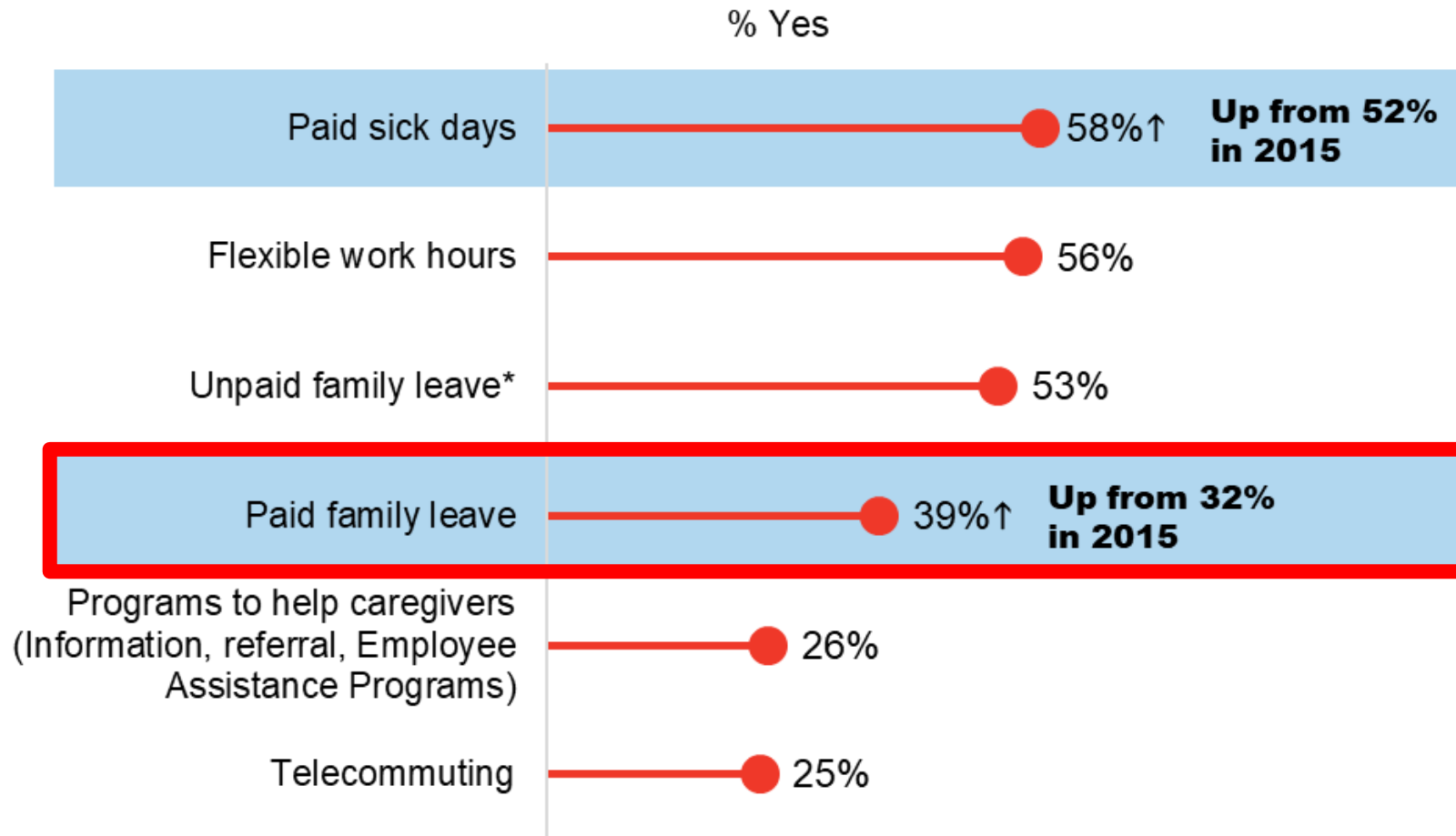
WORKING CAREGIVERS

Most caregivers work full-time



WORKING CAREGIVERS

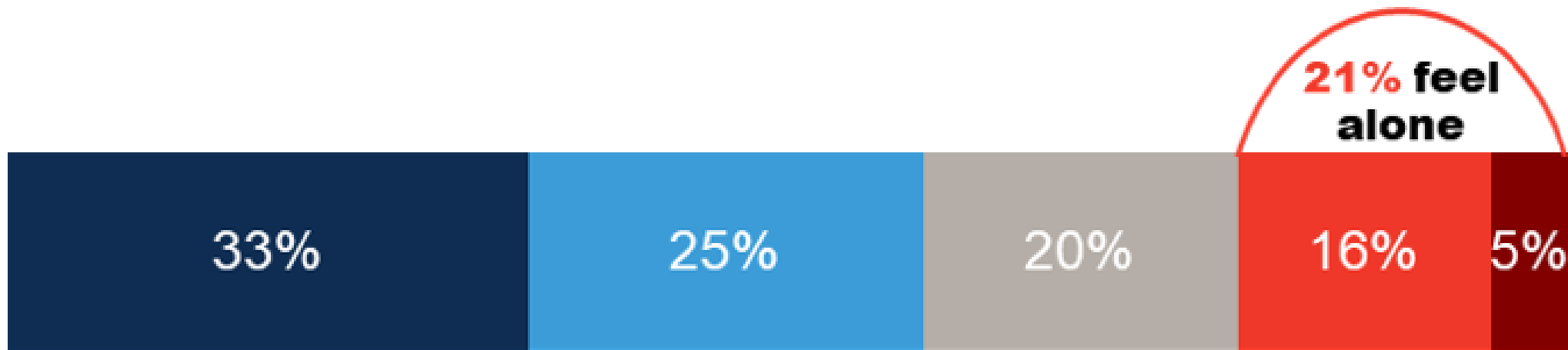
Most have **no** paid leave



*New in 2020

MENTAL HEALTH IMPACTS

Loneliness is a key factor in caregiver mental health



■ 1-Strongly disagree ■ 2-Disagree ■ 3-Neither ■ 4-Agree ■ 5-Strongly agree

AFRICAN AMERICAN/BLACK CAREGIVERS



More likely to...

Live with
their care
recipient(s)



Provide
care in
isolation



SELF-CARE

Few caregivers have been asked what they need for **self-care**

13%↓



Had a doctor, nurse, or social worker ask you about what you need/needed to help care for yourself

A FEW WORDS OF CAUTION...

1

More research is needed

2

Enhanced infrastructural support

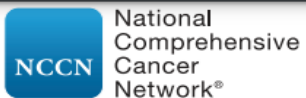
3

Unequal and complex caregiving



Assessing Caregiver Distress

DISTRESS THERMOMETER



NCCN Guidelines Version 2.2023 Distress Management

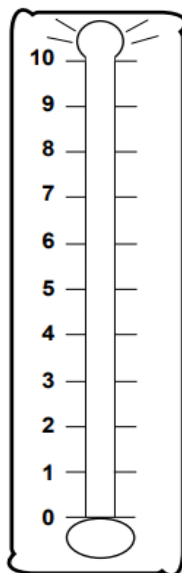
[NCCN Guidelines Index](#)
[Table of Contents](#)
[Discussion](#)

NCCN DISTRESS THERMOMETER

Distress is an unpleasant experience of a mental, physical, social, or spiritual nature. It can affect the way you think, feel, or act. Distress may make it harder to cope with having cancer, its symptoms, or its treatment.

Instructions: Please circle the number (0–10) that best describes how much distress you have been experiencing in the past week, including today.

Extreme distress



No distress

PROBLEM LIST

Have you had concerns about any of the items below in the past week, including today? (Mark all that apply)

Physical Concerns

- Pain
- Sleep
- Fatigue
- Tobacco use
- Substance use
- Memory or concentration
- Sexual health
- Changes in eating
- Loss or change of physical abilities

Emotional Concerns

- Worry or anxiety
- Sadness or depression
- Loss of interest or enjoyment
- Grief or loss
- Fear
- Loneliness
- Anger
- Changes in appearance
- Feelings of worthlessness or being a burden

Social Concerns

- Relationship with spouse or partner
- Relationship with children
- Relationship with family members
- Relationship with friends or coworkers
- Communication with health care team
- Ability to have children

Practical Concerns

- Taking care of myself
- Taking care of others
- Work
- School
- Housing
- Finances
- Insurance
- Transportation
- Child care
- Having enough food
- Access to medicine
- Treatment decisions

Spiritual or Religious Concerns

- Sense of meaning or purpose
- Changes in faith or beliefs
- Death, dying, or afterlife
- Conflict between beliefs and cancer treatments
- Relationship with the sacred
- Ritual or dietary needs

Other Concerns:

Cut off Score – 4

Implementation

- Initial visit
- Important time points
- New changes

Note: All recommendations are category 2A unless otherwise indicated.
Clinical Trials: NCCN believes that the best management of any patient with cancer is in a clinical trial. Participation in clinical trials is especially encouraged.

PREPAREDNESS FOR CAREGIVING SCALE



The Preparedness for Caregiving Scale

YOUR PREPARATION FOR CAREGIVING

We know that people may feel well prepared for some aspects of giving care to another person, and not as well prepared for other aspects. We would like to know how well prepared you think you are to do each of the following, even if you are not doing that type of care now.

	Not at all prepared	Not too well prepared	Somewhat well prepared	Pretty well prepared	Very well prepared
1. How well prepared do you think you are to take care of your family member's physical needs?	0	1	2	3	4
2. How well prepared do you think you are to take care of his or her emotional needs?	0	1	2	3	4
3. How well prepared do you think you are to find out about and set up services for him or her?	0	1	2	3	4
4. How well prepared do you think you are for the stress of caregiving?	0	1	2	3	4
5. How well prepared do you think you are to make caregiving activities pleasant for both you and your family member?	0	1	2	3	4
6. How well prepared do you think you are to respond to and handle emergencies that involve him or her?	0	1	2	3	4
7. How well prepared do you think you are to get the help and information you need from the health care system?	0	1	2	3	4
8. Overall, how well prepared do you think you are to care for your family member?	0	1	2	3	4
9. Is there anything specific you would like to be better prepared for? _____					

MEAN SCORE of the number of items answered: _____					

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Stewart & Archbold (1986, 1994)



Best Practices in Nursing Care for Older Adults

A series provided by The Hartford Institute for Geriatric Nursing,
 NYU Rory Meyers College of Nursing
 EMAIL: nursing_high@nyu.edu HARTFORD: 860.205.3600 WEBSITE: www.hign.org
 CLINICAL NURSING WEBSITE: www.ConsultGerLong

CAREGIVER SELF-ASSESSMENT QUESTIONNAIRE



Caregiver Self-Assessment Questionnaire

How are YOU?

Caregivers are often so concerned with caring for the relative's needs that they lose sight of their own well-being. Please take just a moment to answer the following questions. Once you have answered the questions, turn the page to do a self-evaluation.

During the past week or so, I have ...

- | | | | |
|----------------------------------------------------------------------------------|----------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------|
| 1. Had trouble keeping my mind on what I was doing.... | <input type="checkbox"/> Yes <input type="checkbox"/> No | 13. Had back pain..... | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| 2. Felt that I couldn't leave my relative alone..... | <input type="checkbox"/> Yes <input type="checkbox"/> No | 14. Felt ill (headaches, stomach problems or common cold)..... | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| 3. Had difficulty making decisions..... | <input type="checkbox"/> Yes <input type="checkbox"/> No | 15. Been satisfied with the support my family has given me..... | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| 4. Felt completely overwhelmed..... | <input type="checkbox"/> Yes <input type="checkbox"/> No | 16. Found my relative's living situation to be inconvenient or a barrier to care..... | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| 5. Felt useful and needed | <input type="checkbox"/> Yes <input type="checkbox"/> No | 17. On a scale of 1 to 10, with 1 being "not stressful" to 10 being "extremely stressful," please rate your current level of stress. | _____ |
| 6. Felt lonely..... | <input type="checkbox"/> Yes <input type="checkbox"/> No | 18. On a scale of 1 to 10, with 1 being "very healthy" to 10 being "very ill," please rate your current health compared to what it was this time last year. | _____ |
| 7. Been upset that my relative has changed so much from his/her former self..... | <input type="checkbox"/> Yes <input type="checkbox"/> No | | |
| 8. Felt a loss of privacy and/or personal time..... | <input type="checkbox"/> Yes <input type="checkbox"/> No | | |
| 9. Been edgy or irritable..... | <input type="checkbox"/> Yes <input type="checkbox"/> No | | |
| 10. Had sleep disturbed because of caring for my relative..... | <input type="checkbox"/> Yes <input type="checkbox"/> No | | |
| 11. Had a crying spell(s)..... | <input type="checkbox"/> Yes <input type="checkbox"/> No | | |
| 12. Felt strained between work and family responsibilities... | <input type="checkbox"/> Yes <input type="checkbox"/> No | | |

Comments:

(Please feel free to comment or provide feedback.)

SOCIAL NEEDS SCREENING TOOL



Social Needs Screening Tool

HOUSING

1. Are you worried or concerned that in the next two months you may not have stable housing that you own, rent, or stay in as a part of a household?
 Yes
 No
2. Think about the place you live. Do you have problems with any of the following? (check all that apply)²
 Bug infestation
 Mold
 Lead paint or pipes
 Inadequate heat
 Oven or stove not working
 No or not working smoke detectors
 Water leaks
 None of the above

FOOD

3. Within the past 12 months, you worried that your food would run out before you got money to buy more.³
 Often true
 Sometimes true
 Never true
4. Within the past 12 months, the food you bought just didn't last and you didn't have money to get more.³
 Often true
 Sometimes true
 Never true

TRANSPORTATION

5. Do you put off or neglect going to the doctor because of distance or transportation?¹
 Yes
 No

UTILITIES

6. In the past 12 months has the electric, gas, oil, or water company threatened to shut off services in your home?⁴
 Yes
 No
 Already shut off

CHILD CARE

7. Do problems getting child care make it difficult for you to work or study?⁵
 Yes
 No

EMPLOYMENT

8. Do you have a job?⁶
 Yes
 No

EDUCATION

9. Do you have a high school degree?⁶
 Yes
 No

FINANCES

10. How often does this describe you? I don't have enough money to pay my bills.⁷
 Never
 Rarely
 Sometimes
 Often
 Always

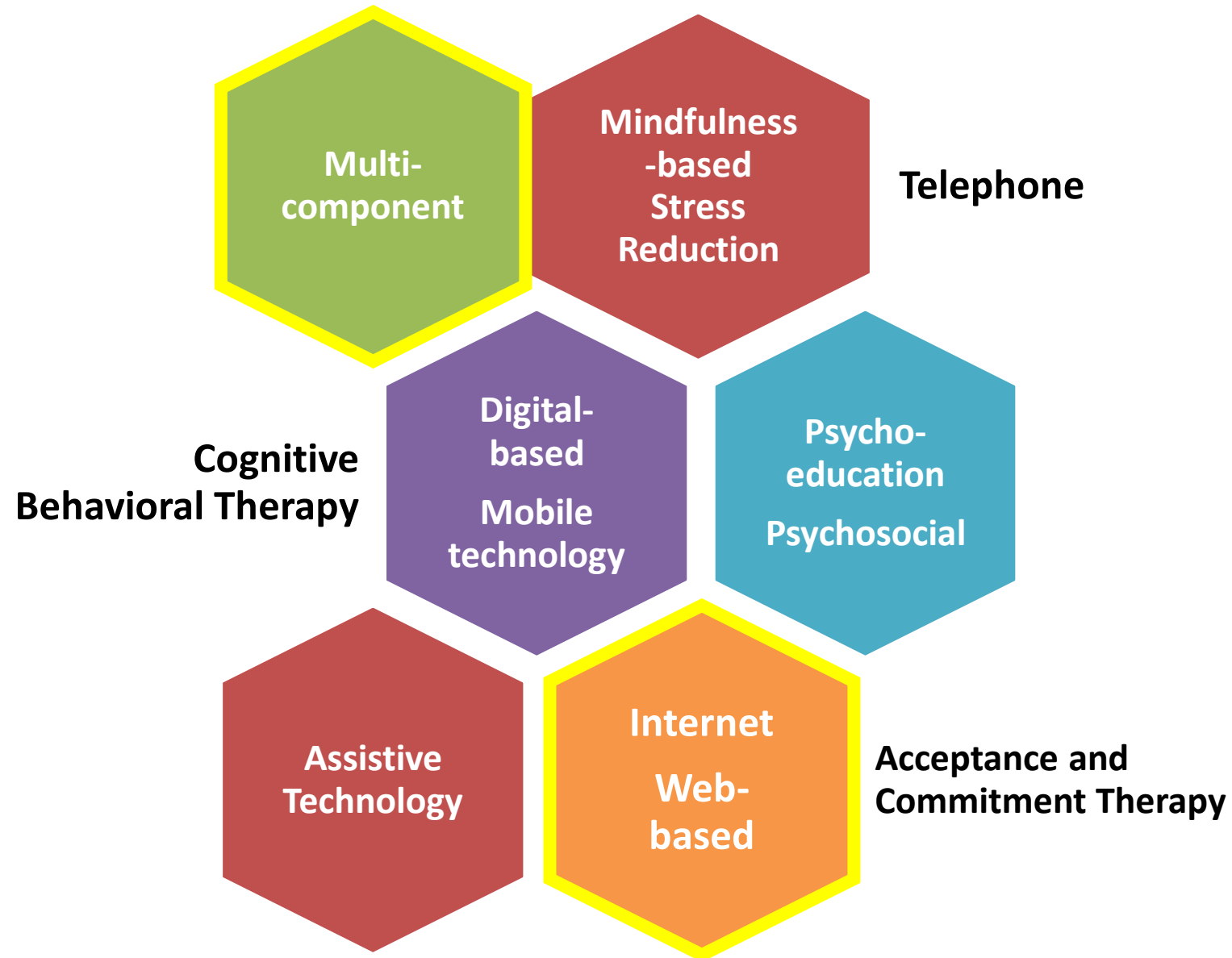
PERSONAL SAFETY

11. How often does anyone, including family, physically hurt you?⁸
 Never (1)
 Rarely (2)
 Sometimes (3)
 Fairly often (4)
 Frequently (5)
12. How often does anyone, including family, insult or talk down to you?⁸
 Never (1)
 Rarely (2)
 Sometimes (3)
 Fairly often (4)
 Frequently (5)



Evidence-Based Interventions

CLINICAL INTERVENTIONS



INFRASTRUCTURE

CMS CY 2024 Physician Fee Schedule



THANK YOU

fawn@caregiving.org



National Alliance for Caregiving



**Questions?
Please come off mute**



Session 4

Case Presentation

Infirmiry Cancer Care

Kay Jernigan RN, BSN
Infirmiry Cancer Care, Infirmiry Health
Mobile, AL

Session 4 Case Study

Provided by: KayJernigan RN, BSN
Infirmiry Cancer Care, Infirmiry Health System
Focus: Patient/Caregiver Case

Patient Hx

- 68 YO female
- Diagnosed with endometrial cancer in Feb of 2022
- Recurrence in Jan 2023
- Chronic kidney disease, hypertension, anemia, ongoing abdominal pain (abscess)
- Caregiver for 3 YO and 12 YO of a recently deceased family member (from brain tumor)
- Does not have legal guardianship of minor children
- Adult daughter unable to assist as caregiver

Key Elements

- Cancer treatments on hold due to fatigue & not being able to care for children
- Threatened with eviction for non-payment of rent
- Financial application assistance needed
- Mistrust/distrust of local agencies
- Older child struggling emotionally
- Unable to reach by phone
- 1st funding assistance was lost in mail

Barriers/Challenges

- Mistrust/distrust of local agencies
- Embarrassment—would only ask for assistance as a last resort
- No social worker currently on our team, Nurse Navigator assisting
- Miscommunication between team and patient
- Recognize need sooner
- Monitor missed/canceled appointments
- Resources for patient for older child who is struggling emotionally

Session 4 Case Study

Provided by: KayJernigan RN, BSN
Infirmiry Cancer Care, Infirmiry Health System
Focus: Patient/Caregiver Case

Discussion & Questions

- **Caregiver** – What to do when the patient is also a caregiver, and their treatment plan is suffering.
- **Young Caregiver** – Best practice sharing for supporting a dependent acting as the caregiver
- **Trust** – What are the strategies your teams use to gain the trust of patients who are mistrustful of the medical system/community?

Barriers/Challenges (reference)

- Mistrust/distrust of local agencies
- Embarrassment–would only ask for assistance as a last resort
- No social worker currently on our team, Nurse Navigator assisting
- Resources for patient for older child who is struggling emotionally
- Recognize need sooner
- Monitor missed/canceled appointments



Wrap up

ECHO Participation Post-Session Survey

Health Equity & Caregiving ECHO Session 4 Survey



How to Use a QR Code



1. **Turn on** your phone camera
2. **Aim** the camera at the code
3. A link will show up
4. **Tap** the link to go to the survey

Upcoming Sessions



Survey QR Code



Date/Time	Topic	Presenters
<p>October 12 11:30–12:30 CST 12:30–1:30 EST</p>	<p><i>Integrating the Family Voice in Palliative Care</i></p>	<p><u>Didactic:</u> Cardinale Smith, MD, PhD <i>Icahn School of Medicine, Mount Sinai</i></p> <p><u>Case Study:</u> Jimmie Wells, MSN, RN, OCN <i>St. Dominic Jackson Memorial Hospital</i></p>
<p>November 6 11:30–12:30 CST 12:30–1:30 EST</p>	<p><i>Practicing Cultural Humility While Providing Support to African American/Black Caregivers</i></p>	<p><u>Didactic:</u> Katrina Ellis, PhD, MPH, MSW <i>University of Michigan</i></p> <p><u>Case Study:</u> Denise Bradford, MSN, RN <i>Our Lady of the Lake Regional Medical Center</i></p>

Reminders

Slides, Recordings, & Resources will be made available within one week. All resources will be available on the [ACS ECHO Website](#).



Register Today for **Session 5**

October 12, 2023

11:30–12:30 CST/12:30–1:30 EST



Topic: *Integrating the Family Voice in Palliative Care*

Didactic Presenter: [Cardinale Smith, MD, PhD](#)

Case Presenter: [Jimmie G Wells, St Dominick Hospital](#)



Thank You



Survey QR Code