

Stand By Me: Lessons Learned from a Family Caregiver and Caregiving Scientist

Celebrating a Second Chance at Life
Survivorship Symposium

April 27 – May 3, 2024



Allison Applebaum PhD

Associate Attending Psychologist and
Founding Director, Caregivers Clinic,
Memorial Sloan Kettering Cancer Center

Disclosures

- Blue Note Therapeutics
- Beigene

Former First Lady,
Rosalynn Carter:



“There are only four kinds of people in the world: ...those who have been caregivers, ...those who are currently caregivers, ...those who will be caregivers, ...and those who will need caregivers.”



National
Caregiving
Crisis

Mental
Health
Crisis

Family
Caregivers

For Some Caregivers, Trauma Lingers

How Getting High Made Me a Better Caregiver

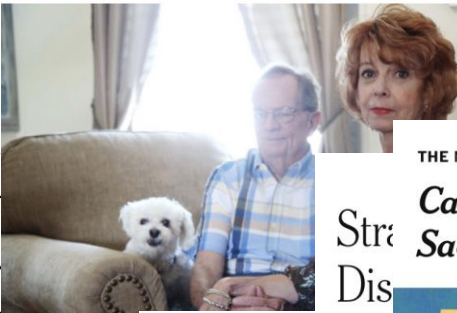
By Tom Huth

April 16, 2016

75, Taking Care of Mom, 'We Did Not Think She Would Live This Long'

THE NEW OLD AGE

Caregiving Is Hard Enough. Isolation Can Make It Unbearable.



Marcy Sherman-Lewis, 75, and her husband, Bub, who has Alzheimer's disease.

By Paula Span

Gina Rinehart, 73, is helping her father at his home in Chicago. Bub Hall has been helping her for 13 years. David Ryc...

By Paula Span

March 10, 2017

THE NEW OLD AGE

Caregiver, Plus M.D. or R.N.



THE NEW OLD AGE

Caregivers Sometimes Must Sacrifice Their Careers

Struggling to Dis...

means providing... New York Times



Joyce Hesselberth

By Paula Span

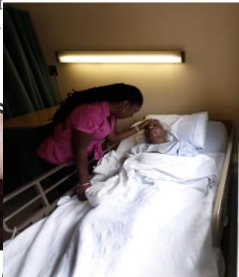
Dec. 4, 2015

Her supervisors empathized. They knew why Marcy Sherman-Lewis, a customer service agent, was missing workdays:

apartment in... mother, Ivana, ... mia. Jeenah

THE NEW OLD AGE

Training Needed. Care Is Lacking



By Judith Graham

"H" from Chicago, I heard you when you joined a... dementia... benefits at



June 15, 2017

When Medicaid Squ...

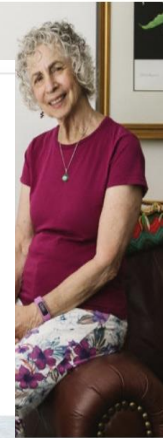
Nicholas challenge learned stress. I

By Cath...

July 28, 2

"This... herself. "It's nowhere near

Will Suffer Medicaid Cuts



Reynaldo Leal, 99, and her wife, ... New York Times



choice but to... lives around a loved

Antonio Fuentes, 28, a Medicaid managed care patient who has cerebral palsy and cannot speak, requires a home attendant. Reynaldo Leal for The Texas Tribune

"Ladysitting: My Year With Nana..."

By Becca Aaronson

Oct. 4, 2012

The abrupt exodus of thousands of South Texas Medicaid patients from one



What Do Caregivers Do?

- Instrumental support
 - Activities of daily living (ADL) and Instrumental activities of daily living (IADL)
- Emotional support
- On average, caregivers provide care for 8.3 hours/day for 13.7 months
- Annual economic value of caregiving in the U.S. was recently estimated at \$600 billion
- *Caregivers are critical to our healthcare system.*

National Alliance for Caregiving, 2020; AARP, 2023

Caregivers of Patients with Cancer

Depression

Anxiety

Insomnia

PTSD

**Prolonged
Grief**

Suicidality

Existential Distress in Caregivers

- Hopelessness
- Demoralization
- Loss of meaning and purpose
- Loss of sense of self
- Loss of dignity
- Feeling like a burden to others
- Desire for hastened death

Bone Marrow Transplantation (2016) 51, 1416–1422

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www.nature.com/bmt

REVIEW

A scoping review of caregiver burden during allogeneic HSCT: lessons learned and future directions

AJ Applebaum¹, M Bevans², T Son¹, K Evans¹, M Hernandez¹, S Giralt¹ and K DuHamel¹

The extant literature documents burden among caregivers of patients undergoing a hematopoietic stem cell transplantation (HSCT), but little is known about the burden of caregivers of patients receiving outpatient and homebound HSCTs. This scoping study sought to evaluate what is known about the burden of the increasing number of adult caregivers of patients receiving outpatient HSCTs and to create practice guidelines for how to best support this vulnerable group. Online databases were searched for studies that evaluated caregiver burden in adult caregivers of HSCT patients since 2010 (the publication date of the most recent systematic review on HSCT caregiver burden). Of the 1271 articles retrieved, 12 met the inclusion criteria, though none specifically examined outpatient or homebound caregivers. Overall, studies corroborated existing literature on the experience of significant burden among HSCT caregivers across the HSCT trajectory, and highlighted the emotional costs of outpatient transplants on caregivers and the need to identify caregivers at high risk for burden early in the transplant process. Future studies of outpatient caregivers should include a comprehensive assessment of burden and seek to identify points along the transplant trajectory at which caregivers are at particular risk for negative outcomes and when intervention is most appropriate.

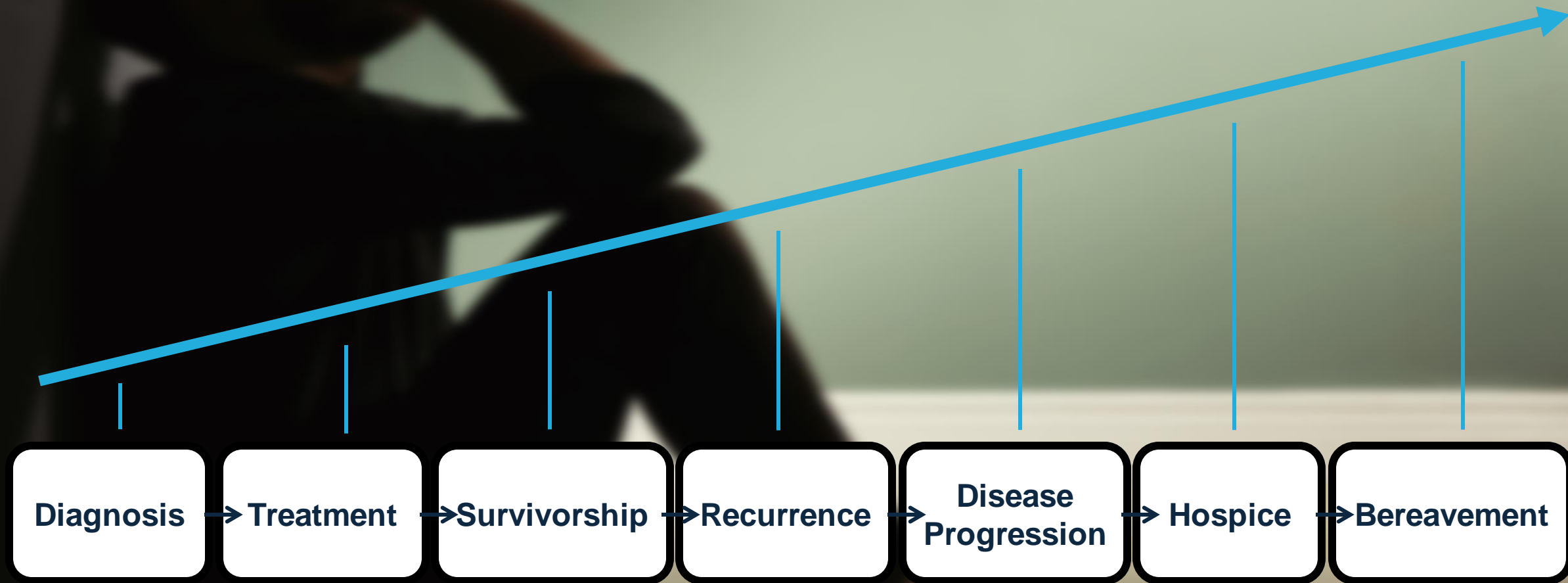
Bone Marrow Transplantation (2016) 51, 1416–1422; doi:10.1038/bmt.2016.164; published online 13 June 2016

Drivers of Continued and Increased Distress

- Increasing number of patients living with advanced disease
- Increasing number of patients with significant comorbidities
- Push to outpatient/home-based care that depends on caregivers
- Increased complexity of medical care at home
- Increased pre-death period of incapacity at home
- Increased cost of medical and home-based care
- Increased remote/distance caregiving

(Dionne-Odom, 2022)

Distress across the Caregiving Trajectory





Caregivers Clinic Memorial Sloan Kettering Cancer Center



Cancer Caregiver
Support & Help

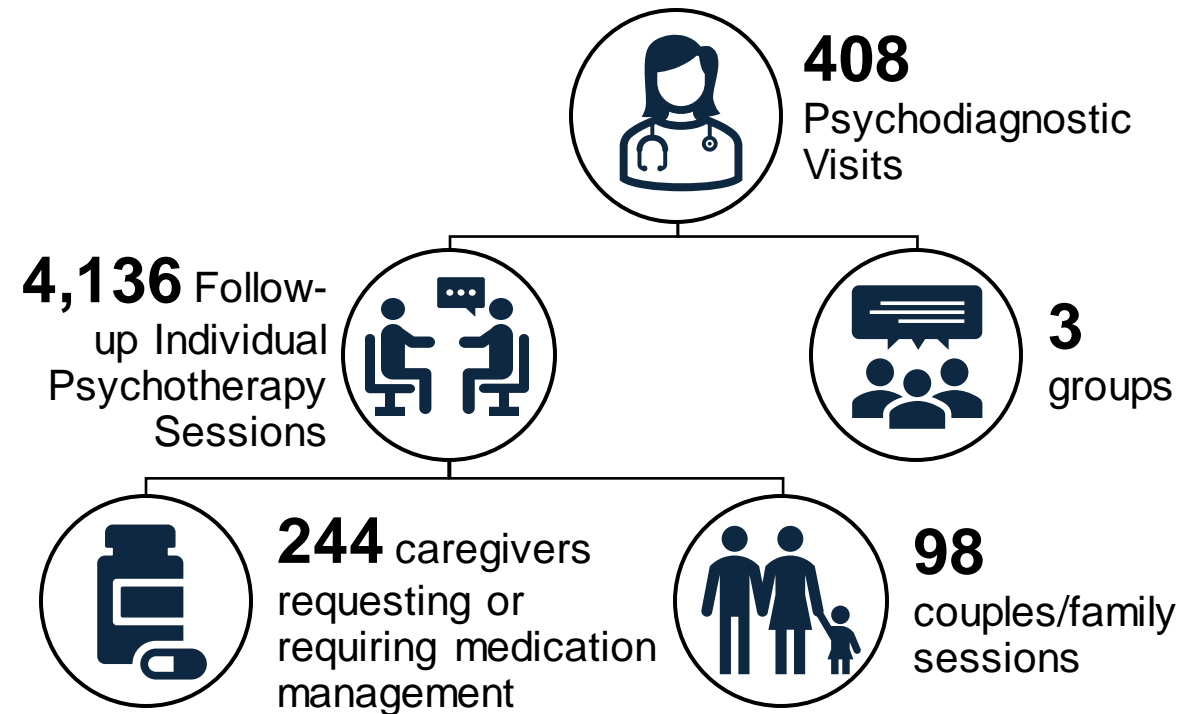
Cancer Caregiver
Counseling Services

Support for Grieving
Family & Friends

Cancer Caregiver Counseling Services

English | Share

Caregivers are an essential part of the care team for every person who has cancer. Though caregivers aren't personally going through treatment, we understand that the demands they experience can often be quite difficult and stressful. At MSK, we want you to know that as a caregiver, you are never alone.

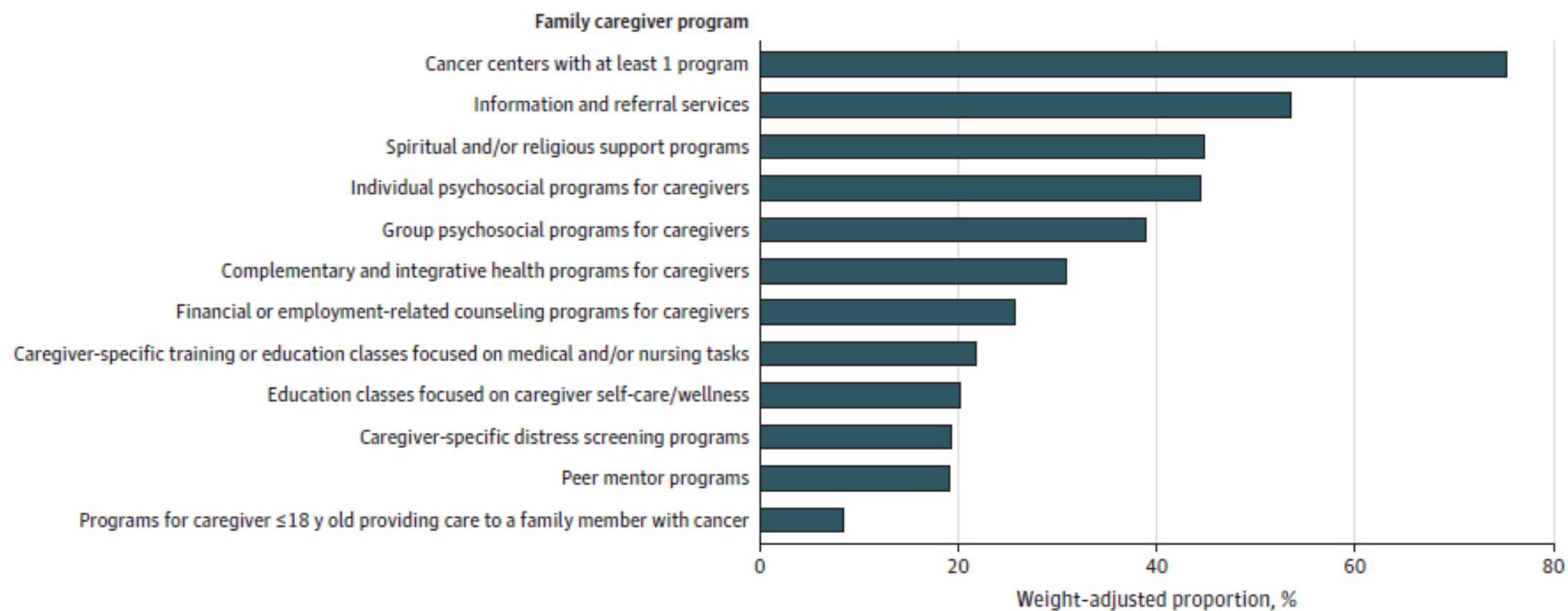


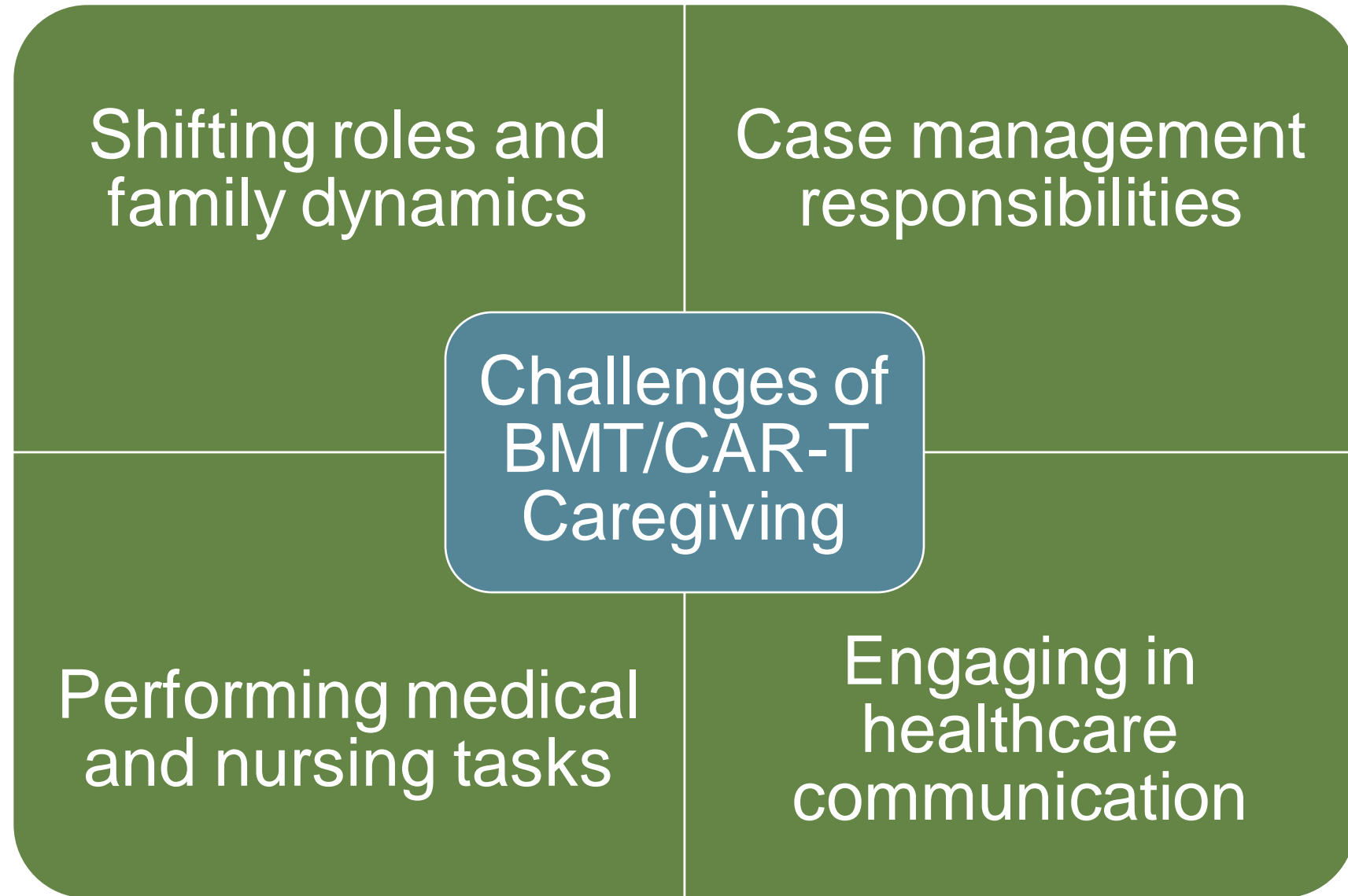
Original Investigation | Oncology

Availability of Family Caregiver Programs in US Cancer Centers

J. Nicholas Odom, PhD, RN; Allison Applebaum, PhD; Marie A. Bakitas, DNSc, CRNP; Tara Bryant, MD, BSN; Erin Currie, PhD, RN; Kayleigh Curry, MPH; Heidi Donovan, PhD, RN; Maria E. Fernandez, PhD; Betty Ferrell, PhD, RN; Andres Azuero, PhD, MBA; Tamryn F. Gray, PhD, MPH, RN; Bailey A. Hendricks, PhD, RN; Diane Meier, MD; Chandysten Nightingale, PhD; Susan Reinhard, PhD, RN; Timothy S. Sannes, PhD; Katherine Sterba, PhD, MPH; Heather M. Young, PhD, RN

Figure 1. Weight-Adjusted Proportion of US Cancer Centers Offering Family Caregiver Programs (N = 238)





Lesson 1: Caregivers experience shifting roles and family dynamics

- Impact of illness and caregiving on the relationship (e.g., parent/child, spouse/partner)
- Many losses experienced in the context of changing dynamics (i.e., loss of physical intimacy)
- Management of other responsibilities while caring for the patient at home (e.g., childcare, finances, household maintenance)
- Balancing caregiving with care for self, especially when caregivers have their own healthcare concerns

Lesson 2: Caregivers must balance caregiving with other responsibilities

- These responsibilities come as a surprise to many caregivers
- These may be more easily delegated than “hands-on” caregiving



Lesson 3: Caregivers are asked to perform medical and nursing tasks

- Caregivers are critical members of the healthcare team
- Caregivers are asked to assume responsibilities once held only by trained healthcare professionals
- Caregivers of patients receiving outpatient and homebound HCTs have some of the most profound and enduring responsibilities



ELSEVIER

Transplantation and Cellular Therapy

journal homepage: www.tctjournal.org



American Society for
Transplantation and Cellular Therapy

Fit for Duty: Lessons Learned from Outpatient and Homebound Hematopoietic Cell Transplantation to Prepare Family Caregivers for Home-Based Care

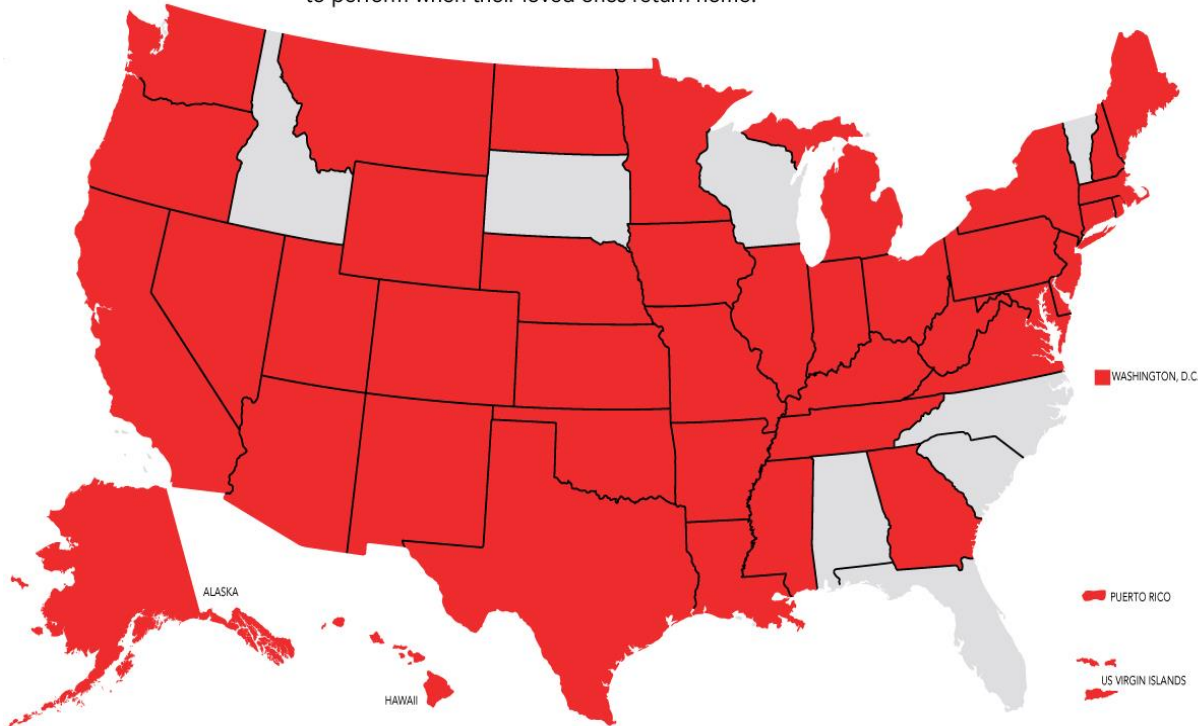
A.J. Applebaum^{1,*}, T. Sannes², H.R. Mitchell³, N.S. McAndrew^{4,5}, L. Wiener⁶, J.M. Knight⁷, A.J. Nelson⁸,
T.F. Gray², P.M. Fank⁹, S.C. Lahijani¹⁰, C. Pozo-Kaderman², M. Rueda-Lara¹¹, D.M. Miran¹²,
H. Landau¹³, H.L. Amonoo¹²

Caregiver Advise Record Enable (CARE) Act



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 ones return home.



CARE Act goes into effect:

Alaska, 1/1/17; Arkansas, 7/22/15; Arizona, 1/1/21; California, 1/1/16; Colorado, 5/8/15; Connecticut, 10/1/15; Delaware, 1/1/17; Georgia, 7/1/22; Hawaii, 7/1/17; Illinois, 1/27/16; Indiana, 1/1/16; Iowa, 7/1/19; Kansas, 7/1/18; Kentucky, 6/29/17; Louisiana, 8/1/16; Maine, 10/15/15; Maryland, 10/1/16; Massachusetts, 11/8/17; Michigan, 7/12/16; Minnesota, 1/1/17; Mississippi, 7/1/15; Missouri, 8/28/18; Montana, 10/1/17; Nebraska, 3/30/16; Nevada, 10/1/15; New Hampshire, 1/1/16; New Jersey, 5/12/15; New Mexico, 6/17/15; New York, 4/23/16; North Dakota, 8/1/19; Ohio, 3/21/17; Oklahoma, 11/5/14; Oregon, 1/1/16; Pennsylvania, 4/20/17; Puerto Rico, 12/31/15; Rhode Island, 3/14/17; Tennessee, 6/6/19; Texas, 5/26/17; Utah, 2/10/16; Virgin Islands, 3/30/16; Virginia, 7/1/15; Washington, 6/9/16; Washington, DC, 7/6/16; West Virginia, 6/8/15; Wyoming, 7/1/16

Updated on 5/5/2022

(1) Record name and contact info of family caregiver in the medical record of the care recipient.

(2) Inform caregiver when care recipient is to be transferred or discharged.

(3) Provide caregiver with education and instruction for the medical tasks they will need to perform for the patient at home.

Lesson 4: Caregivers must often take responsibility for healthcare communication



Challenges of Healthcare Communication

With loved ones:

- Anxiety and fear of upsetting one another
- Desire to maintain hope
- Pre-existing family dynamics
- Conflicting prognostic understanding

With healthcare providers (HCPs):

- Many HCPs fail to initiate conversations
- Not knowing the “right words” to use
- Lack of consent between caregiver and patient before the appointment about communication goals



Consent Conversation

“Dad, I would really like to ask your doctor what treatments are available if this treatment stops working. Would that be ok? And is there anything that you want to be sure to bring up with her?”

I’m concerned about how difficult you’re finding it to remain adherent to your medications. I think it’s important that your doctor knows you aren’t taking them daily. Can we mention this to him next week?

Setting the Agenda

- *I know this is hard to talk about, but I would really like us to discuss _____*
- *It's important for me to know what you want so that I can be sure to carry out your wishes, if you can't tell the doctors what you want at that time.*
- *Can we talk about this?*

Goals of care will change.
This is a discussion that **MUST**
be repeated

Coping with changes in social support/caregiving network

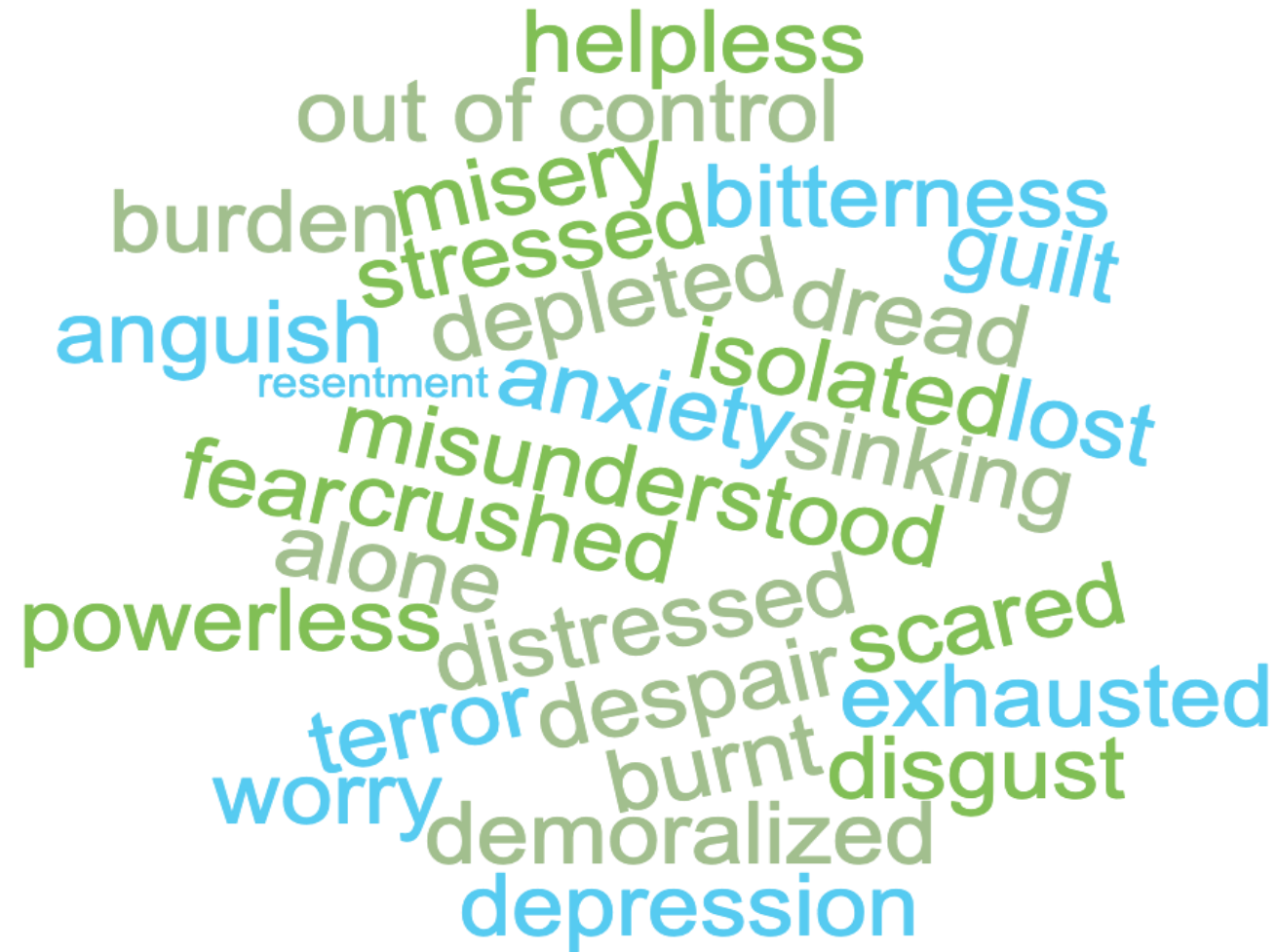
XYZ Technique

X: “I feel (or felt) X ”

Y: “When you say/do (said/did) Y ”

Z: “Because Z ”

Lesson 5: Caregivers must cope with difficult negative emotions



“How am I going to raise my son as a single mother?”

“He seems more out of breath, the cancer must be back...”

“The look on the doctor’s face meant...”

“My boss is going to fire me if I miss work again because of another family emergency...”



Emotions are
messengers that tell us
how to live more fully.

SADNESS

ANGER

DISGUST

WRONG
WAY

Lesson 6: Despite suffering, caregiving provides an opportunity to connect to meaning and purpose

- Experiencing meaning through connecting to your authentic sense of self
- Connecting to meaning through recognizing the historical context in which caregiving is occurring; caregiving inevitably shapes the legacy caregivers give to others
- Connecting to meaning through choosing your attitude
- Connecting to meaning through your five senses



Questions to help caregivers connect to meaning:

Since becoming a caregiver, what are the **specific limitations or losses** you have faced, and **how are you coping** or dealing with them?

In what ways has your **sense of identity changed** as a result of caregiving? What have you **learned about yourself** as a result of your caregiving role?

What are your responsibilities? Who are you **responsible to and for**?

Are you **proud of being a caregiver**? Why or why not?

Resources for support:

- Speak with nurse or social worker affiliated with your care partner's medical team
- If support provided by hospital staff is time limited, request a community referral before discharge
- Psychologytoday.com is a phenomenal resource to find community-based mental health professionals
- Many religious and spiritual institutions offer support
- Peer support is a wonderful adjunct to professional support (e.g., through BMT InfoNet Caring Connections)

Contact Us

CONTACT US TODAY to see if you are eligible or for more information!

Memorial Sloan Kettering Cancer Center

New York, NY

phone: 646-888-0081

email: gebertr@mskcc.org

Duke University

Durham, NC

919-613-1158

transplantcoach@duke.edu

Lead researchers of the Transplant Survivor Coach study!

Dr. Smith is the primary investigator at Duke University, and Dr. Applebaum is the primary investigator at Memorial Sloan Kettering Cancer Center.



Sophia Smith, PhD, MSW



Allison Applebaum, PhD

Resources

- [National Cancer Institute](#)
- [Multiple Myeloma Research Foundation](#)
- [International Myeloma Foundation](#)
- [Leukemia & Lymphoma Society](#)
- [National Center for PTSD](#)
- [Anxiety and Depression Assoc. of America](#)
- [Substance Abuse and Mental Health Services Administration](#)
- [Clinical Trials at Duke](#)
- [ClinicalTrials.gov](#)
- [National Suicide Prevention Line – 800-273-8255](#)

#CaregiverNation2023



A GUIDE TO NAVIGATING
MODERN, MEANINGFUL
CAREGIVING



STAND BY ME

Allison J. Applebaum, Ph.D.



Thank You!

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IG @drallisonapplebaum



Questions?



Allison Applebaum PhD

Associate Attending Psychologist and
Founding Director, Caregivers Clinic,
Memorial Sloan Kettering Cancer Center

Let Us Know How We Can Help You



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