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

Celebrating a Second Chance at Life Survivorship Symposium

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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
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.
Caregivers of Patients with Cancer

- Depression
- Anxiety
- Insomnia
- PTSD
- Prolonged Grief
- Suicidality

Acquati et al., 2020; Askari et al., 2012; Braun et al., 2007; Hudson et al., 2011; Moschopoulou et al., 2018; National Alliance for Caregiving, 2023; van Warmerdam et al., 2019
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
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

- Diagnosis
- Treatment
- Survivorship
- Recurrence
- Disease Progression
- Hospice
- Bereavement
Cancer Caregiver Counseling Services

Support for Grieving Family & Friends

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.

408 Psychodiagnostic Visits

4,136 Follow-up Individual Psychotherapy Sessions

244 caregivers requesting or requiring medication management

3 groups

98 couples/family sessions
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; Botty Ferro. PhD, RN; Andres Azuoro. PhD. MBA; Tamryn F. Gray. PhD. MPH, RN; Bailey A. Hendricks. PhD. RN; Diane Meier. MD; Chandlen 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)
Challenges of BMT/CAR-T Caregiving

- Shifting roles and family dynamics
- Case management responsibilities
- Performing medical and nursing tasks
- Engaging in healthcare communication
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
Fit for Duty: Lessons Learned from Outpatient and Homebound Hematopoietic Cell Transplantation to Prepare Family Caregivers for Home-Based Care

(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
“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
“The look on the doctor’s face meant…”

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

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

“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.
ANGER

SADNESS
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)
TRANSPLANT SURVIVOR COACH STUDY

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
Thank You!

applebaa@mskcc.org
Twitter/X @DocApplebaum
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

Visit our website: bmtinfonet.org

Email us: help@bmtinfonet.org

Phone: 888-597-7674 or 847-433-3313

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