CARING FOR CAREGIVERS: ADDRESSING THEIR EVOLVING NEEDS

Eve Escalante, MSW, LCSW
Manager of Program Innovation
Social Work and Community Health
Rush University Medical Center
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Disclosure Slide

No Disclosures
E4 Center of Excellence for Behavioral Health Disparities in Aging

Engage, Empower, and Educate health care providers and community-based organizations for Equity in behavioral health for older adults and their families across the US.

To learn more, please visit e4center.org
Introduction

Social Work and Community Health, Rush University Medical Center

- Social service agency w/in a hospital
- Programs include:
  - Mental Health
  - Community Care Management
  - Macro/policy work
  - Center for Excellence in Aging
  - Rush Caregiver Initiative
  - Health Promotion/Disease Prevention
  - Center for Health and Social Care Integration
Learning Objectives

• Review the current landscape of caregivers in the US
  – Focus on diverse populations
• Identify common challenges those caring for individuals living with dementia may encounter
• Describe common reasons why a caregiver may engage in mental health services and discuss how to engage caregivers
• Discuss innovative programming
• Case study
Caregiver Landscape
Caregiver Landscape
Caregiver Landscape

CAREGIVING in the U.S. 2020
The number of Americans providing unpaid care has increased over the last five years.*

43.5 million 2015
53 million 2020
18% 2015
21% 2020

NEARLY ONE IN FIVE (19%) ARE PROVIDING UNPAID CARE TO AN ADULT WITH HEALTH OR FUNCTIONAL NEEDS.**

More Americans are caring for more than one person.

18% 2015
24% 2020

More family caregivers have difficulty coordinating care.

19% 2015
26% 2020

More Americans caring for someone with Alzheimer’s disease or dementia.

22% 2015
26% 2020

More family caregivers report their own health is fair to poor.

17% 2015
21% 2020

23% OF AMERICANS SAY CAREGIVING HAS MADE THEIR HEALTH WORSE.

Who are today’s family caregivers?

39% MEN
61% WOMEN
45% HAVE HAD AT LEAST ONE FINANCIAL IMPACT
61% WORK

Caregiver Landscape

• Why the increase?
  – Older adults are living longer; “boomers”
  – Limitations in long-term care
  – Increase in self-identification of caregiver status
  – States shifting to home and community-based services

Caregiver Landscape

- Diversity of caregivers is one thing that has **not** shifted
  - All generations
  - All races/ethnicities
  - All income and education levels
  - All gender identities
  - All family types
  - All sexual orientations

Caregiver Landscape

- Over 34 million individuals in the U.S. provide unpaid assistance and support to an older adult (50+), including many individuals dually eligible for Medicare and Medicaid
  - 60% of caregivers of older adults are female; over half are 50 years and older
  - 14% are friends, neighbors, or other non-relatives of the care recipient
Caregiver Landscape

• **89% take care of a relative**
  – 42% caring for parents
  – 8% caring parent-in-law
  – 12% caring for spouse

• **10% care for friend, neighbor or non-relative**

• **Long-term caregivers (5 yrs or longer)**
  – more often caring for blood relative

Alzheimer’s dementia is the most common form of dementia, accounting for 60-80% of dementia cases.

Others include:
- Vascular
- Mixed
- Dementia with Lewy bodies
- Frontotemporal dementia

Caregivers of Individuals w/ Dementia

• Caregivers of those living with dementia typically provide care longer-term when compared to other conditions
• 2/3 rd of dementia caregivers identify as female
• 80% of individuals with dementia receive care in the home
• 2019 - Americans provided estimated $18.5 billion of unpaid care to individuals with dementia

Caregiver Landscape

- **Terms/language**
  - Formal vs informal caregiver
  - Paid vs unpaid caregiver
  - Blood family vs chosen family
Common Challenges Faced by Caregivers
Common Challenges for Caregivers

- Anxiety
- Medical Illness
- Depression
- Cognitive Impairment
- Economic Insecurity

Social Stressors
Common Challenges for Caregivers

• Complexity of tasks
  – 50% of all family caregivers perform complex medical/nursing tasks
    • Administering medications
    • Dressing changes
    • Handling complex medical equipment in the home
  – Despite this, caregivers are rarely asked “are you able and willing to provide this care?”

Common Challenges for Caregivers

• **Stress and Burnout**
  – Caregivers have higher levels of stress than non-caregivers and caregivers with chronic stress may be at greater risk of cognitive decline
  – Causes include:
    • Managing multiple roles
    • Adapting to new roles (complex medical, domestic)
    • Isolation
    • Physical demands

Common Challenges for Caregivers

- Physical Health/Management of Their Own Conditions
  - Lifting
  - Bathing
  - Feeding
  - Grooming
  - 24-hr caregivers w/out respite
Common Challenges for Caregivers

- **Physical Health/Management of Their Own Conditions**
  - Caregivers who are “no choice” caregivers report higher physical strain
  - 17% of caregivers reported experiencing 14 or more physically unhealthy days per month
  - 36.7% of caregivers do not get adequate sleep
  - 40% of caregivers report having 2 or more chronic diseases
  - 33% of caregivers report having a disability


Common Challenges for Caregivers

• Vocational strain
  – 6 in 10 caregivers work while caregiving
  – 61% have experienced at least one work-related challenge
  – 1 in 10 working caregivers had to leave the job
    • Those individuals were 2x as likely to report financial strain
  – 61% of caregivers report having no paid family leave at their place of employment

Common Challenges for Caregivers

• **Financial Concerns**
  • Loss of income
  • Increase in bills/costs that are often shared
  • Lack of systematized reimbursement for care
Common Challenges for Caregivers

• Financial Concerns
  – Include
    • Taking on debt
    • Stopped saving
    • Used up short-term savings
    • Bills unpaid
    • Borrowed money
  – Half of all caregivers report at least one financial strain and 34 percent have experienced 2 or more financial strains
  – Financial impact more prevalent with younger caregivers (age 18-49)

Common Challenges for Caregivers

• **Financial Concerns**
  - LGBTQ caregivers are at higher risk of financial strain
  - Primary caregivers and those who live with care recipient report higher impacts
  - Caregivers who have less than college degree at higher risk
  - Black and Latino caregivers at higher risk of financial impact
  - 1/3\(^{rd}\) of financially strained caregivers report:
    • Borrowing money from others
    • Unable to afford basic needs such as food
    • Drying up of savings

The National Alliance for Caregiving (NAC) and AARP. (2020).
https://www.caregiving.org/caregiving-in-the-us-2020/
Common Challenges for Caregivers

- **Social isolation**
  - 1 out of 5 caregivers report social isolation
  - Those who report isolation have higher rates of emotional stress (72%) and health concerns
Common Challenges for Caregivers

- **Social isolation**
  - Individuals residing with care recipient as well as "no choice" caregivers indicate increased social isolation
  - Caregivers of homebound older adults reported 44% rate of social isolation
  - As years of providing care increase, so does sense of isolation
Common Challenges for Caregivers

Health Impacts of Social Isolation

- Infection
- Hypertension, heart disease
- Obesity
- Weakened immune system
- Depression, anxiety
- Disrupted sleep
- Cognitive decline
- Longer hospital admissions
- Morbidity and mortality

_Prolonged social isolation has been found to be as harmful as smoking 15 cigarettes per day_

Common Challenges for Caregivers

• Abuse, Neglect and Exploitation
  – More common of a concern than recognized
  – Types
    • Physical abuse
    • Sexual abuse
    • Emotional abuse
    • Confinement
    • Willful deprivation
    • Passive neglect
    • Financial exploitation

Common Challenges for Caregivers

- Abuse, Neglect and Exploitation
  - Older adults
    - 1 in 10 US older adults
    - 5 million older adults per year
    - Only 1 in 24 cases are reported
  - Adults with disabilities are 1.5x more likely to be victims of violence

Common Challenges for Caregivers

- **Caregivers and Abuse, Neglect and Exploitation**
  - Connection between burden, mental health of the caregiver and intensity of caregiver duties
  - Perpetrators:
    - All genders
    - In 60% of cases, perpetrator is a family member
    - 2/3rds of perpetrators are spouses or adult children
  - Protective factors:
    - Caregivers with a higher perception of positive aspects of care
    - Caregivers who had a prior good relationship with care recipient
    - Less functional dependency

Common Challenges for Caregivers

- Abuse, Neglect and Exploitation
  - Know your mandate
  - Seek consultation/supervision
  - Follow your professional code of ethics
  - Abuse/neglect of all age groups is highly under-reported
  - All that is needed is suspicion
  - Don’t forget disabled adults who fall between 18-59
  - Approach with perpetrator and victim in sensitive and non-punitive fashion
Common Challenges for Caregivers

• Health literacy
  – *Personal health literacy*: the degree to which individuals have the ability to find, understand, and use information and services to inform health-related decisions and actions for themselves and others
  – *Organizational health literacy*: the degree to which organizations equitably enable individuals to find, understand, and use information and services to inform health-related decisions and actions for themselves and others
  – One study found:
    • One fifth of caregivers had problems with health literacy
    • Navigation of health and support systems was over 2x more difficult


Common Challenges for Caregivers

Consider....

Can the caregiver *use* the information besides just understanding it?

Can the caregiver make *informed* decisions vs “appropriate” decisions

Considerations for Diverse Populations
Caregiving Youth

• Care for siblings, parents, aging relatives
• 1.3-1.4 million caregiving youth, between ages of 8-18 (early 2000s so assume more now)

American Psychological Association. (2011). *Who are family caregivers?*
https://www.apa.org/pi/about/publications/caregivers/faq/statistics#:~:text=Nationwide%2C%20there%20are%20approximately%201.3%2C000%20family%20caregivers%2C%20Alliance%20for%20Caregiving%2C%202005
Caregiving Youth

• Developmental considerations
  – Age-appropriate care and decisions?
  – Medication mgmt
  – Lifting
  – Interpreting

• Emotional weight of decision-maker and care manager

• Impact on education
  – Tardiness
  – Absences

• Impact on socialization and participation in programs

• Aforementioned concerns around mental health/substance use
BIPOC Caregivers

African American Caregivers

• More likely to report lower income when compared to non-Hispanic white and Asian
• More often in high-intensity caregiver roles
• More likely to report concerns obtaining essential needs (food, etc)
• About 50% report feeling they had no choice in caregiving role
• Most employed outside of caregiver role
• Majority report finding meaning/purpose in role
Hispanic Caregivers

- Tend to be younger than other races
- 50% are sole, unpaid caregiver
- Most work at hourly jobs outside of caregiver role
- More likely to report concerns obtaining essential needs (food, etc)
- Report moderate-to-high level of physical strain due to caregiving duties

LGBTQ Caregivers

- Tend to be younger (42 yrs of age on average)
- Tend to be unmarried
- Most work outside of caregiving
- Most report care recipient lives with them or close by
- More vulnerable to financial strain as result of caregiver role
- Most feel they were “no choice” caregivers
- Increased risk of isolation

National Alliance for Caregiving and AARP. (2020, May). The “typical” LGBTQ caregiver.
https://www.aarp.org/content/dam/aarp/ppi/2020/05/lgbtq-caregiver.doi.10.26419-2Fppi.00103.012.pdf
Millennial Caregivers

- Average of 30 yrs of age (but range of 25-40)
- Most diverse group of caregivers
- Generally work outside of role of caregiver at an hourly job
- Most feel a sense of purpose
- Less likely to tell their job about caregiver role and more likely to have rec’d performance warnings
- Less likely to have insurance coverage
- Generally more interested in getting assistance from providers

Older Adult Caregivers

• Often caring for adult children who rely on them for ADLs
  – Intellectual/developmental disabilities
  – Serious mental illness
  – Brain injuries
  – Addiction

• Grandparents raising grandchildren
Older Adult Caregivers

- Strong need for long-term planning options
- “What happens when I die?”
- Often began caregiver role when it was not safe to discuss the disability, especially in case of SMI and/or ID/DD
- Flying under the radar
- Due to aging, at higher risk for physical/cognitive challenges
Rural Caregivers

- Report lower education and income than those in urban areas
- Typically don’t reside in rural area themselves
- Most have no paid help
- Typically also employed
- 50/50 split in reporting 1) they had a choice in caregiver role and 2) they find meaning and purpose in the role

Caregivers and Mental Health
How to Engage
Caregivers and Mental Health

• Caregivers report higher levels of depressive symptoms and anxiety than non-caregivers
• 40 to 70% of caregivers have clinically significant symptoms of depression
  – Caregivers of individuals with dementia have higher levels of depression and emotional stress

Caregivers and Mental Health

- Depressed caregivers have higher rates of
  - Anxiety
  - Substance abuse or dependence
  - Chronic disease

Caregivers and Mental Health

- Dysthymia and/or depression and anxiety in caregivers can be reflective of multiple factors that often co-exist
  - Caregiver stress and burden
  - Systemic racism and trauma
  - Multiple demands on time, finances and energy
    - “Self-care” becomes an additional demand
  - Care recipient symptom presentation
  - History of relationship difficulty with the care recipient
  - Lack of social support for caregiving
Caregivers and Mental Health

• Ambiguous loss
  – “differs from ordinary loss in that there is no verification of death or no certainty that the person will come back or return to the way they used to be”
  – Impacts of ambiguous loss
    • Confuses loved ones
    • Prevents resolution of the loss
    • Freezes grief
    • Can paralyze family functioning

Caregivers and Mental Health

**Type 1: physical absence w/ psychological presence**
- Missing person
- Divorce
- Adoption
- Loss of contact during migration

**Type 2: psychological absence with physical presence**
- Emotional or cognitive absence
- Addiction
- TBI
- Dementia
- Chronic illness

Caregivers and Mental Health

Trauma: Moving to a More Liberal and Inclusive Definition

Trauma

- Physical Health
- Systemic Oppression
- Resilience
- Community
- Recovery
- Mental Health
Caregivers and Mental Health

Trauma and Caregivers

- Caregivers bring unique lived experiences
- Intergenerational trauma
- Systemic oppression is factor for already more vulnerable caregivers
- Increase in chronic conditions with trauma history
- Triggers of caregiving
Caregivers and Mental Health

Trauma

• Risk factors for caregiver developing PTSD
  – Previous relationship strain, enmeshment or chaos between caregiver and care recipient
  – Presence of comorbidities such as depression or pain
  – Presence of maladaptive coping mechanisms
  – Caregiver perception of care/treatment not being effective

Engaging Caregivers

• Market yourselves to caregivers!!!!
  – When confident you can serve this population, proudly include in list of populations served
  – Share your info as trusted referral with community-based organizations, hospitals, social workers, aging agencies etc

• Consider accessibility
  – Virtual sessions if preferred
  – Flexible scheduling and/or cancellation exceptions
## Engaging Caregivers

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<thead>
<tr>
<th>Common Concerns</th>
<th>Social Supports</th>
<th>Meaning/Purpose</th>
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<tbody>
<tr>
<td>Family Dynamics</td>
<td>Willingness</td>
<td>Mental Health Presentation/Dx</td>
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<tr>
<td>Safety</td>
<td>Coping mechanisms</td>
<td>Resiliencies</td>
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<tr>
<td>Cultural Considerations</td>
<td>Spiritual Aspects</td>
<td>Health of caregiver</td>
</tr>
</tbody>
</table>
Engaging Caregivers

Caregiver Trauma Lens

- Events
- Experience of events
- Effects

SAMHSA’s Trauma and Justice Strategic Initiative. (2014). *SAMHSA’s concept of trauma and guidance for trauma-informed approach.*
Engaging Caregivers

resilience

(noun) re-sil-i-ence

"...the process of adapting well in the face of adversity, trauma, tragedy, threats or significant sources of stress — such as family and relationship problems, serious health problems or workplace and financial stressors."

"It means 'bouncing back' from difficult experiences."

Source: American Psychological Association
Engaging Caregivers

Additional Screeners:

- PHQ-9
- GAD 7
- Burden Scale for Family Caregivers (BSFC-s)
- BRIEF Health Literacy screener
- SDoH
- Caregiver Efficacy Screener
Engaging Caregivers

Strengths-based Approaches

• Meaning/purpose
• Cultural obligations/responsibilities
• Intersectional identities
• Intergenerational impact
• Whole-person care
Innovative Programming
The CARE Act

• The Caregiver Advise, Record, Enable (CARE) Act
  – Enacted into law in 43 out of 50 states

• A patient who is hospitalized needs to be asked if they have a family caregiver, and that person needs to be entered into the electronic medical record

• Caregivers need to be notified of an impending discharge

• Caregivers need to be offered training on the care that will need to be provided post-discharge.
Caregiver Initiative at Rush University Medical Center

Thanks to a generous grant from the RRF Foundation for Aging (formerly the Retirement Research Foundation), we were able to begin a program to address caregivers at Rush in two ways:

1. To address how caregivers are identified within the Rush healthcare system, including how their contact information is entered into and updated in Epic.

2. To provide services and supports for family caregivers that focus on their physical and emotional health and well-being.
Caregiver Initiative at Rush University Medical Center

Three Interventions

1) Skill-building with multidisciplinary team
   Teach-back approach to increasing confidence in providing care

2) “What Matters” Meetings
   Social worker targets 4Ms (medication, mentation/mind, mobility and what matters)

3) Care Team Planning
   Care team meets to clarify goals, caregiver needs and tailor person-centered care
Caregiver Initiative at Rush University Medical Center

Change in symptoms from T1 to T2
CGI Intervention

<table>
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<tr>
<th></th>
<th>Time 1</th>
<th>Time 2</th>
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<tbody>
<tr>
<td>PHQ-9: Depression</td>
<td>7.4</td>
<td>2.6</td>
</tr>
<tr>
<td>GAD-7: Anxiety</td>
<td>7</td>
<td>3.9</td>
</tr>
<tr>
<td>Burden</td>
<td>17.3</td>
<td>12.5</td>
</tr>
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</table>
Virtual Health Promotion/Disease Prevention

• Since beginning of pandemic, evidence-based workshops have been offered virtually to caregivers

• They include:
  – Chronic disease self-management
  – Chronic pain self-management
  – Tai Chi for arthritis
  – Fall prevention/Matter of Balance

• In FY 2021, Rush offered 22 virtual workshops, serving 213 participants

• 6 virtual workshops offered in Spanish
CATCH-ON Connect

• Common challenge to virtual interventions is access and utilization of technology

• Despite their interest and motivation, many caregivers and older adults may not have access to technology, and if they do, they may need additional guidance to help them learn to use it for what matters most to them
CATCH-ON Connect

- CATCH-ON connect
  - Launched in 2020
  - Provides older adults with a free tablet, free internet for one year and perhaps most importantly, access to one-on-one technological support
  - Through these efforts we have begun helping older adults use technology to connect with their medical providers, video chat with loved ones and supports, and learn functions such as email and social media
  - As of September 2021, 114 enrolled participants
“This program helped me connect with my family and see my adorable grandson, we chat often on Facebook Messenger with the skills I learned through the program. I can also share pictures via email and have them saved on my tablet as well as keep up with all my family and friends activities on Facebook. This tablet has really changed my life!”

-CATCH ON Connect Participant
Friendly Caller Program

- Program to connect socially isolated older adults from neighboring communities to regular calls from trained volunteers
- “friendly call” but volunteers can also escalate social care concerns
- Almost 500 friendly calls made in FY 2021
  - with 26% being referred by their provider
  - 71% referred by social worker
Case Study

- Beth is 53 yr old Black female caring for both of her parents
- Lives with parents in remote home in central IL
- Referred to Rush’s Caregiver Initiative for assistance with caring for her mother who has been living w/ dementia for 7 yrs
- Roles include going to appts, managing medication, overseeing home health care, cooking, cleaning and recreation for mom
- Beth is employed full-time on top of caregiver role; now needs to work remotely due to pandemic (so challenge has been managing caregiving duties while she is expected to work remotely)
- Dealing with stress related to tasks, social isolation because of shifts within her social network as a caregiver, and burnout related to challenging behaviors from her mother
- Unable to leave the home (no respite) for in-person programming
Case Study Discussion Questions

- Which of the common caregiver challenges are relevant to this case?
- How may you approach the emotional struggles, guilt, loss that Beth is feeling?
- Beth is remote caregiver—what innovative programs may you offer her to reduce isolation?
Case Study—Outcome

- SW called and introduced program, as well as virtual option
- SW sent materials needed for intervention (workbook for care planning) to her home
- Completed for calls w/in 4 weeks to explore supports
  - Involving additional members of family and community to support
  - Centered work on identification of “What Matters” to caregiver and care recipient
  - Discussed how to discuss caregiver situation with employer and explored benefits
Questions/Discussion
Resources

- “Trauma Stewardship”, Laura van Dernoot Lipsky
- Nationwide, Area Agencies on Aging provide local support to older adults and caregivers. To find your local AAA, google “local area agency on aging”
- National Alliance for Caregiving, [https://www.caregiving.org/](https://www.caregiving.org/)
- AARP [https://www.aarp.org/](https://www.aarp.org/)
- National Council on Aging, [https://www.ncoa.org/](https://www.ncoa.org/)
- [https://ncil.org/](https://ncil.org/) National Council on Independent Living
- Nationwide, states often provide in-home/caregiver support for individuals under 60. Google your state’s “department of rehabilitation services” or “developmental/intellectual disabilities supports”
- [https://www.napsa-now.org/](https://www.napsa-now.org/) National Adult Protective Services Association
- Alzheimer’s Association [www.alz.org](http://www.alz.org)
References

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