Exploring Male Caregiving for People Living with Dementia

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Part of the National Alzheimer's and Dementia Resource Center webinar series sponsored by the Administration for Community Living.
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Alzheimer’s Family Support Center of Cape Cod
• 8-year primary caregiver
• Sandwich generation
• Researched dementia caregiving while caring for mother with dementia
The AFSC provides an array of free, evidence-based programs and services to families and individuals living with cognitive loss.

- Consultations & care planning
- NYU Caregiver Counseling Intervention
- Support Groups for people living with Alzheimer’s/dementia and caregivers
- SHINE counseling & long-term care insurance support
- Telephone support
- Education for family and professional caregivers
- Savvy Caregiver
- Annual dementia conference with Teepa Snow
- Caregiver bereavement services
- Alzheimer’s Volunteer Program
- Social & cultural programming
- Daily electronic communications
Effective Alzheimer’s/dementia caregiving requires a skill set and understanding that is not entirely intuitive for anyone who undertakes it.

For men these challenges are heightened due to the fact that they may not be socialized to be caregivers. This does not mean that males aren’t eager to assume the role of caregiver, be it for partners or parents with a dementia diagnosis. However, because of the dynamic nature of dementia disease, caregiving cannot be approached as a problem to be solved.

This webinar will discuss burdens specific to male caregivers, including caregiving skill acquisition, the need for asking for and receiving help, and self-care.
• 40% of caregivers are male (16 million men).
• Male caregivers are a demographically diverse group.
• Male caregivers will do whatever is necessary for those in their care.
• When caregivers feel alone, 72 percent report feeling high emotional stress, compared to just 24 percent of those who do not feel alone.
• For caregivers, positive emotions often coexist with feelings of isolation, stress, or strain. Half of caregivers feel their role as a caregiver gives them a sense of purpose or meaning in life (51 percent).
• Caregivers of someone with an emotional or mental health issue report high difficulty finding affordable services (37 percent) as do caregivers of someone with memory problems (36 percent).
• Many caregivers could use more information on or help with caregiving topics, with 62 percent needing help with at least one topic.
• Women caregivers report a greater reliance on friends and family (47 percent vs. 38 percent of men caregivers), as do caregivers who do not live with their care recipient (47 percent vs. 37 percent of those who co-reside).
• More than one-third of male caregivers do not tell their employers they are caregiving but nearly half took time off from work due to caregiving.
CAREGIVING in the U.S. 2020

The number of Americans providing unpaid care has increased over the last five years.*

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

Nearly one in five (19%) are providing unpaid care to an adult with health or functional needs.**

<table>
<thead>
<tr>
<th>Category</th>
<th>2015</th>
<th>2020</th>
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<tbody>
<tr>
<td>More Americans are caring for more than one person.</td>
<td>18%</td>
<td>24%</td>
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<tr>
<td>More family caregivers have difficulty coordinating care.</td>
<td>19%</td>
<td>26%</td>
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<tr>
<td>More Americans caring for someone with Alzheimer's disease or dementia.</td>
<td>22%</td>
<td>26%</td>
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<tr>
<td>More family caregivers report their own health is fair to poor.</td>
<td>17%</td>
<td>21%</td>
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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

*Source: ©2018 AARP Foundation and Caregiving in the U.S., 2015
**Source: ©2018 AARP Foundation and Caregiving in the U.S., 2015

For more information, contact: CaregivingInfo.org

Visit AARP.org/caregiving

5.8 million Americans are living with dementia disease.

1 in 10 Americans over the age of 65 have Alzheimer’s dementia.

Almost 2/3 of Americans with dementia disease are women.

By 2050, it has been projected that 13.8 million Americans may have Alzheimer’s dementia.

More than 16 million Americans provide unpaid care for people with Alzheimer’s or other dementias.

In 2019, caregivers of people with Alzheimer’s or other dementias provided an estimated 18.6 billion hours of informal (that is, unpaid) assistance, a contribution to the nation valued at nearly $244 billion.

The total lifetime cost of care for someone with dementia was estimated at $357,297 in 2019 dollars.

Compared with caregivers of people without dementia, twice as many caregivers of those with dementia indicate substantial emotional, financial and physical difficulties.

Fifty-nine percent of family caregivers of people with Alzheimer’s or other dementias rated the emotional stress of caregiving as high or very high. Nearly half of dementia caregivers (49%) indicate that providing help is highly stressful compared with 35% of caregivers of people without dementia.
A Zoom Conversation with Male Caregivers

On Tuesday, January 19, we interviewed 20 male caregivers about their caregiving experiences.

They represent a swathe of the dementia caregiving community: some are caring for female spouses, others are caring for male spouses, and still others are caring for parents. Some care recipients have passed away.

All caregivers in this cohort have received, or are currently receiving, AFSC services. This video is an excerpt of that conversation.
Almost half of male family caregivers experienced moderate to severe physical strain due to caregiving responsibilities (AARP, 2017).

Nearly two-thirds of male family caregivers indicated that their caregiving experience was moderately to very stressful.

About 72 percent of all male family caregivers who performed medical and nursing tasks indicated that no one prepared them to do so.

Compared with male caregivers for an aging parent, male caregivers for a spouse were more likely to be managing finances, shopping for groceries or other necessities, doing housework, preparing meals, and transportation.

Male family caregivers were more likely than female family caregivers to arrange for outside services. Sons caring for an aging parent or in-law were more likely to arrange for outside services compared with male family caregivers caring for a spouse.
Gender Differences in Caregiving


- Male caregivers are not as likely as women to be aware of nor to use support services.

- Males may perceive that by accepting community services they admit being weak and losing control.

- Males are more task oriented.

- Women experience more distress and use more services than men.

- Men fare better than women on all measures of the Zarit Burden Scale EXCEPT for loneliness- males 10% higher on loneliness scale that female caregivers.
Male Caregiver Burden


- Male caregivers have weak support networks and are less likely to seek out programs which increase their caregiving capabilities and help them cope with burden (Lopez-Anuarbe & Kohli, Healthcare, 2019).

- All male caregivers experience physical, emotional, and financial burden, particularly elevated emotional stress, with sons reporting the highest emotional and financial strain levels. Assisting with personal care is the most stressful task and caregivers vastly under-utilized support and training. (Lopez-Anuarbe & Kohli, Healthcare, 2019).

- Long hours of care provision are more stressful for male caregivers than for female caregivers. (Lin, F., et al. (2012). Negative and Positive Caregiving Experiences: A Closer Look at the Intersection of Gender and Relationships. Family Relationships.)
This study investigated coping strategies of nine husband caregivers of their cognitively impaired wives. Research identified six utilized care strategies:

- Exerting force
- Focusing on tasks
- Blocking emotions
- Minimizing disruption
- Distracting attention
- Self-medicating
Male Caregivers Psychological/Emotional Burden

- In a study of 71 male caregivers, while not all male caregivers perceive themselves to be grieving, the expressions of loss were present in all statements. (Sanders, S., et al. (2002). *The Expressions of Loss and Grief Among Male Caregivers of Individuals with Alzheimer's Disease.*)

- 68% of the 71 male caregivers were experiencing symptoms of grief even though the spouse was still alive.

- Male caregivers mentioned feelings of “losing control” or are embarrassed by having trouble handling feelings of grief and loss.

- Male caregivers may provide care “at all costs” or duty driven care.

- Increase in depressive symptoms in male caregivers following facility placement may be due to a sense of betrayal or failure.

- Male caregivers may not access social supports in the same way as female caregivers.

- Men may not feel comfortable sharing feelings of grief and loss.

- Male caregivers may have been dependent on their spouse for their social connections and could become isolated when the spouse loses their ability to maintain their connections.
Considerations for Future Work Related to Male Caregiving

• More evidence-based research on male caregiving.
• Increased educational offerings for male caregivers.
• Caregiver trainings specific to personal hygiene and incontinence care.
• Increased and easily accessible support services for caregivers, including support groups.
• Increase in respite services.
• Increase in long-term planning services, including in-home care options.
• Pragmatic framework for managing neuropsychiatric symptoms of dementia diseases.
• Connection to social supports and reduce caregiver isolation.
• Challenge the “caregiving is a problem to be solved” mentality.
• Male or female, lose the pride and seek help early. (Vaughn Harding, LICSW, AFSC Clinical Director)
Caregiving Perspectives: Bob O’Brien

• Met wife Annmarie as seniors in high school, married 52 years
• BS, Massachusetts Maritime Academy, 1967
• Merchant Marine, Chief Engineer, 1967-1987
• MA, Massachusetts Maritime Academy, 2005
• Retired 2014 to care full time for Annmarie, who had Alzheimer’s, until her passing in 2020
BIBLIOGRAPHY


BIBLIOGRAPHY, cont’d.


• Sanders, S, et al. (2008). The Expressions of Loss and Grief Among Male Caregivers of Individuals with Alzheimer’s Disease. https://doi.org/10.1300/J083v39n04_02

My Two Elaines: Learning, Coping, and Surviving as an Alzheimer’s Caregiver

Martin J. Schreiber

“I felt compelled to write this book in hope that relating my experiences in caring for my wife with Alzheimer’s disease would help other caregivers learn, cope and survive.

While sharing this message man to man was a primary objective, those who looked over this manuscript told me they believed this book would help a wider audience as well.

I invite families and friends to use it to better understand Alzheimer’s, how to assist the caregiver, and help the patient experience moments of joy even as they face daily the overwhelming sadness of the disease.” - Martin J Schreiber

Reading List

My Two Elaines: Learning, Coping, and Surviving as an Alzheimer’s Caregiver

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Alzheimer’s Family Support Center

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Thank you for your attendance today.

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- Search term: Alzheimer’s Disease Programs Initiative (ADPI)