



NOVEMBER 2019 NATIONAL REPORT
**BURNING THE CANDLE
AT BOTH ENDS:**

SANDWICH GENERATION CAREGIVING IN THE U.S.



IN PARTNERSHIP WITH

MassMutual

SpecialCare
a special needs program developed by MassMutual

ACKNOWLEDGMENTS

National Alliance for Caregiving and Caring Across Generations are proud to present *Burning the Candle at Both Ends: Sandwich Generation Caregiving in the U.S.* This research was made possible through generous support from Caring Across Generations and from MassMutual's SpecialCareSM program.

Authors

Lisa Weber-Raley, MA: Senior Vice President, Greenwald & Associates

Project Directors

Gabriela Prudencio, MBA, Hunt Research Director, National Alliance for Caregiving

Michael Reese Wittke, MPA, Senior Director, Public Policy & Advocacy, National Alliance for Caregiving

Charlotte Dodge, MPP: Senior Policy Associate, Caring Across Generations

Contributing Editors

C. Grace Whiting, JD, President and CEO, National Alliance for Caregiving

Karen Lindsey Marshall, JD, Director of Advocacy and Engagement, National Alliance for Caregiving

Josephine Kalipeni, MA, MHP, Director of Policy and Partnerships, Caring Across Generations

Antonia Madian, Communications Associate, Caring Across Generations

David Krantz, MA, former Research Director, Greenwald & Associates

Daniel Vance, Research Assistant, Greenwald & Associates

Christina Baydaline, Data Manager, Greenwald & Associates

Advisory Committee

Joe Caldwell, PhD, Brandeis University

Feylyn Lewis, PhD, University of Sussex

Margaret Longacre, PhD, Arcadia University

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FOREWORD

By Sarita Gupta, Co-Founder, Caring Across Generations

With this report, we are excited to finally shed light on what many of us have long referred to as sandwich generation caregivers, henceforth referred to as *sandwich caregivers*: those who are caught between the demands of both childcare and caring for an adult family member. This report is a critical tool to educate policymakers and stakeholders on this growing group of family caregivers who live at the heart of a system of care in this country that no longer works for today's families.

For this population in particular, caregiving responsibilities for children and adult family members are forcing families to cut back on work hours and navigate a system of care with little to no formal supports. We know that women, who make up the majority of family caregivers, are especially strained from these competing demands of work and care.

I know all too well that being pulled in both directions can be complicated and overwhelming; I am a working sandwich caregiver. My father was diagnosed with Alzheimer's disease about five years ago. For a while, my mother served as his sole care provider but in recent years she has developed health issues of her own and now relies on my sister and me to navigate both of their care needs as they age. At the same time that I'm caring for my parents, I also have a young daughter to raise.

Like many families, both my husband and I work full time outside of the home. According to the Department of Labor, in roughly 60 percent of two-parent households with children under age 18, both parents work.¹ For some parents, it is a choice, but for most, two incomes are required to make ends meet. With both parents working, families must rely on a system of childcare that is unaffordable for most.

On the other end of the spectrum, in an unprecedented demographic shift, 10,000 baby boomers reach retirement age *every single day*.² Stagnant incomes and diminished savings are no match for longer life spans, the rising cost of treating chronic medical conditions, and long-term care needs. Often the financial burden of care falls directly onto family caregivers, who, on average, spend almost \$7,000³ out-of-pocket per year on caregiving. It's not hard to see how we, the sandwich caregivers, are being squeezed like never before.

Millions of us are headed down this road, attempting to juggle the challenges of caring for their children, their aging parents, and family members. Our system for supporting caregiving as a whole – from childcare to long-term care – is broken and we face a real care crisis that affects us all. The time is now for us to come together and work with policymakers to build a flexible system of care that reflects the financial and cultural realities of today's modern families and sandwich caregivers. We simply cannot afford to simply maintain the current status quo.

¹Bureau of Labor Statistics, The Department of Labor, "Employment in Families With Children in 2016," *The Economics Daily*, <https://www.bls.gov/opub/ted/2017/employment-in-families-with-children-in-2016.htm>.

²D'Vera Cohen and Paul Taylor, "Baby Boomers Approach 65 – Glumly," *The Pew Research Center*, <https://www.pewsocialtrends.org/2010/12/20/baby-boomers-approach-65-glumly/>.

³AARP, "Surprising Out-of-Pocket Costs for Caregivers," *Financial and Legal*, <https://www.aarp.org/caregiving/financial-legal/info-2017/out-of-pocket-cost-report.html>.

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INTRODUCTION

By C. Grace Whiting, President & CEO, National Alliance for Caregiving

Recently, I was sitting in a presentation on sandwich caregivers – those unpaid friends or family members who are juggling care for children with care for an adult. “I feel less like a sandwich and more like a panini,” one woman shared. It is true that now, more than ever, families are feeling the squeeze and that they need support.



This report shines a light on the current state of sandwich caregiving. Impacting at least 11 million Americans, sandwich caregivers represent that generation that so often gets lost in headlines between baby boomers and millennials. The typical sandwich caregiver was born between 1965-1980, and is, on average, 41 years old, about 12 years younger than caregivers without children living in the home. These families are asked to juggle numerous care responsibilities. The way families care for one another is changing, too – rather than the nuclear family of the mid-twentieth century, most households are now dual-income without a dedicated individual to take on care work.⁴ Caregiving becomes a chore, as families try to fit caregiving in between school, work, self-care, and other responsibilities of daily living.

Typically, when it becomes difficult to balance caregiving with work, or if the demands of work come into conflict with one’s caregiving responsibilities, caregivers are forced to compromise. The findings outlined in this report support the need for policymakers to find sustainable solutions, such as workplace flexibility, long-term care improvements, and a robust national infrastructure sufficient to support and augment the care provided by caregivers across the lifespan. Robust family friendly policies will not only provide support to today’s sandwich caregivers, but also future generations. After all, the need to balance life and care with increasing demands on time and family is a challenge facing Gen X that may repeat as the millennial generation comes of age.

To tell the story of the sandwich caregiver, we partnered with Caring Across Generations and three researchers serving in our Advisory Committee: Joe Caldwell, PhD, Brandeis University; Feylyn Lewis, PhD, University of Sussex; and, Margaret Longacre, PhD, Arcadia University, who all graciously ensured that the most significant data was being shared with the reader. The Advisory Committee also drafted “Expert Commentary” on this subpopulation based on their own research and professional experience. These sections include data from sources beyond *Caregiving in the U.S. 2015*⁵ to help broaden the scope of the report. They each focus on key aspects of caregiving that can be used to further the work being done to understand and address the needs of this group of caregivers.

With grants from Caring Across Generations and Mass Mutual, we are honored to share this report on sandwich caregivers. We look forward to continuing the conversation on how to foster research and advocacy for caregivers. Let us know your thoughts as we embark on this endeavor, either by emailing NAC’s Hunt Research Director, Gabriela Prudencio, at gabriela@caregiving.org, or by calling 202-918-1022.

⁴“The Rise in Dual-Income Families,” Pew Research Center. https://www.pewresearch.org/fact-tank/2019/06/12/fathers-day-facts/ft_16-06-14_fathersday_dual_income/.

⁵The National Alliance for Caregiving and AARP Public Policy Institute, “Caregiving in the U.S. 2015,” *Caregiving in America*. <https://www.caregiving.org/caregiving2015/>.

METHODOLOGY

Caregiving in the U.S. 2015 is a nationally representative study of adults, ages 18 and older, conducted in late 2014 using GfK's probability-based online KnowledgePanel®.⁶ *Caregiving in the U.S. 2015* aimed to achieve two goals for the National Alliance for Caregiving and the AARP Public Policy Institute. The first goal was to estimate the prevalence of caregiving for persons of any age as a share of both the U.S. population and U.S. households. The second was to describe the characteristics, roles, and needs among caregivers who provide care to an adult age 18 or older.⁷

To qualify for the study, respondents must have self-identified as a current unpaid caregiver of an adult or one who has provided care at some point during the 12 months prior to the survey. Self-identified caregivers also had to report providing help with at least one Activity of Daily Living (ADL), Instrumental Activity of Daily Living (IADL), or medical/nursing task. Surveys were conducted between September 18 and November 5, 2014 and averaged 24 minutes to complete.

This paper examines the responses of 328 sandwich caregivers identified in the *Caregiving in the U.S. 2015* study, with select comparisons to 906 caregivers who had no children living in their home (non-sandwich caregivers). Results about select subgroups of sandwich caregivers are presented as a snapshot or profile.⁸

Caregiving in the U.S. 2015 used a complex, six-part sampling design, with four parts comprising the nationally-representative sample. All data about sandwich caregivers and the comparison group of non-sandwich caregivers are drawn from this four-part nationally-representative sample and use the individual-level weight as developed for analysis of that sample.

STUDY LIMITATIONS

As you consider findings in this report, it is important to consider some limitations. These are primarily due to availability of data from the larger study, *Caregiving in the U.S. 2015*. The current report defines sandwich caregiver as an individual providing care to an adult of any age while simultaneously having a child under 18 years of age residing in their home. Other studies, however, have varied in how this population is conceptualized and defined. For example, a major study by PEW in 2013 defined sandwich caregivers as individuals providing financial support to a child under 18 or an adult child (18 or over) while also caring for a parent 65 and older.⁹ Of particular note, the PEW study emphasized the rise of intergenerational families in the U.S., where adult relatives are continuing to reside with parents or rely on them for financial support.

In addition to intergenerational families, caregivers of adults (over 18) with disabilities may also be caring for aging parents or other older individuals. It is common for adults with lifelong intellectual and developmental disabilities and significant mental illness to co-reside with aging parents.¹⁰ In these situations, aging parents may provide care to an aging spouse. Siblings, who typically take over care when aging parents can no longer continue, may even find themselves in a situation where they face triple caregiving roles: caring for their adult sibling with disabilities, an aging parent, and their own children. These variations and other situations of so-called "compound" caregiving are not fully captured in this report.¹¹



To qualify for the study, respondents must have self-identified as an unpaid caregiver of an adult either currently or at some point in the 12 months prior to the survey.

⁶GfK's KnowledgePanel® is a probability-based online panel, designed to be representative of the U.S. population.

⁷To see complete study results, questionnaires, or detailed study methodology, please see *Caregiving in the U.S. 2015* full report and Appendices A and B. <https://www.caregiving.org/research/caregivingusa/>.

⁸Note that this report features a Snapshot titled *Childcare and Sandwich Caregivers*. This snapshot does not include the experiences of any of the 328 sandwich caregivers identified in the *Caregiving in the U.S. 2015* report.

⁹Kim Parker and Eileen Patten, "The Sandwich Generation: Rising Financial Burdens for Middle-Aged Americans," *The Pew Research Center*. <https://www.pewsocialtrends.org/2013/01/30/the-sandwich-generation/>.

¹⁰Tamar Heller, Joe Caldwell, and Alan Factor, "Aging Family Caregivers: Policies and Practices," *Mental Retardation and Developmental Disabilities Research Reviews*, 13, no. 2 (2007), 136-142.

¹¹Elizabeth A. Perkins and William E. Haley, "Compound Caregiving: When Lifelong Caregivers Undertake Additional Caregiving Roles," *Rehabilitation Psychology*, 55, no. 4 (2010), 409-417.

Another limitation to consider is the lack of detail about the child caregiving situation. No information is available about the age of the child, the relationship, whether the child has a disability or special health condition, or if care is being provided to multiple children. Given the changing demographics of American families, some individuals may provide shared childcare to children not living in the same home. Additional information about these households would provide opportunities to examine, in greater detail, how these characteristics impacted responses.¹²

READING THIS REPORT

This report, in select places, compares the experience of sandwich caregivers to that of caregivers who do not have any children or grandchildren under the age of 18 living in their home – for brevity, referred to as non-sandwich caregivers. This report also highlights subgroups of sandwich caregivers to better understand the unique and diverse experiences of these caregivers.

All demographic information about caregivers is based on the period of caregiving of the provider – either current caregiving or caregiving provided in the past 12 months. All data are in reference to the caregivers’ experience and situation at the time of survey or 12 months prior to it.

The sample sizes (n) noted in each table or graphic represent the unweighted number of respondents who answered each question. All reported results shown are weighted and rounded to the nearest whole number. Note that “don’t know” or “refused to answer” responses are not always presented in charts and tables, therefore, some charts and tables will not total 100 percent. The results for multiple-response questions may total more than 100 percent. All results were tested for statistical significance at the 95 percent confidence level using the appropriate test, depending on the result presented.¹³ All differences between sandwich caregivers and non-sandwich caregivers discussed in the text are statistically significant. In all tables and graphs, a notation of * shown on a result indicates that the value is statistically significantly higher than that of the comparison group.

This report compares the experience of sandwich caregiving to those who are providing unpaid care to an adult but who do *not* have any children or grandchildren under the age of 18 living in their home.



¹²The limitations section of this study was authored by Joseph Caldwell, PhD, Lurie Institute for Disability Policy, Brandeis University.

¹³Statistical testing applied to comparison of dementia caregivers and non-dementia caregivers were: Independent t-test for means with assumption of equal variances and Independent z-test for percentages with assumption of unpooled proportions.

KEY FINDINGS

- We estimate **11 million caregivers (28 percent of all caregivers) provide unpaid care to an adult while also caring for children living in their home.** We refer to this sub-group as sandwich caregivers.
- A distinctive characteristic of sandwich caregivers is that they are more ethnically diverse, younger, and newer to caregiving. At an average age of 41, these caregivers are about 12 years younger than caregivers without children at home and are often from the Gen X and millennial generations.
- Sandwich caregivers are often a part of a care team. About half of sandwich caregivers report having help from other unpaid caregivers (53 percent) and one in four report receiving help from paid aides or services (26 percent) in order to care for their adult care recipient.
- Sandwich caregivers help their care recipient with Instrumental Activities of Daily Living (IADLs), Activities of Daily Living (ADLs), or more complex and skilled medical/nursing tasks. Sandwich caregivers most commonly help with transportation (80 percent), housework (76 percent), and preparing meals (62 percent). Very few are prepared to do the medical/nursing tasks (19 percent).
- These sandwich caregivers are **often juggling work responsibilities** in addition to caring for both an adult and a child in their home. They report dedicating, on average, 22 hours per week to caring for their loved one.
- **Sandwich caregivers often lack workplace benefits**, such as paid leave, that might help them manage their multiple responsibilities. As a result, sandwich caregivers miss work or cut down work hours during their prime working and long-term saving years. One in five sandwich caregivers report feeling financial strain as a result of being a caregiver.
- Not surprisingly, roughly a third of sandwich caregivers report a high level of emotional stress, and a fifth of these caregivers report a high level of financial and physical strain. Among these sandwich caregivers, those co-residing with their care recipients and those caring for a close relative are most likely to report high strain.
- Younger sandwich caregivers are more likely to receive preparation than older, non-sandwich caregivers – perhaps because of their newer ‘tenure’ as caregivers, or because they grew up in an era where information has always been accessible, often at their fingertips.
- 85 percent of sandwich caregivers report needing more information on at least one caregiving related topic, including managing stress (44 percent).
- About 25 percent of sandwich caregivers said it was difficult to find affordable services for their care recipient.
- Rural caregivers were more likely to report that their care recipients live in their own home (66 percent) or alone (35 percent).
- Rural caregivers living and caring in rural areas find themselves with few supports or services, such as transportation (15 percent) and respite care (17 percent), meaning responsibility for performing these services falls on the caregiver.
- Among financial supports programs to offset caregiving related costs, sandwich caregivers found paid-care programs that compensate caregivers for some of their time (33 percent) and income tax credit programs (31 percent) most appealing.



We estimate 11 million caregivers (28 percent of all caregivers) provide unpaid care to an adult while also caring for children living in their home.



Policy Consideration:

Development and Greater Implementation of Culturally Competent, Evidence-Based Interventions that Promote Caregiver Health and Well-Being.

POLICY RECOMMENDATIONS

To ensure a wholistic approach in addressing the needs and challenges of sandwich generation caregivers across the entire lifespan, we have identified a set of policy recommendations, which you can find here. We have also inserted a variety of policy considerations throughout the report to incite further discussion.

Address Needed Improvements to Our Long-Term Care System

- Lift asset requirements as a qualifier for Medicaid eligibility.
- Document and educate caregivers upon discharge of those needing care from care facilities.
- Add non-acute long-term services and supports with a focus on home and community-based services to Medicare.
- Create a national strategy to recruit and retain direct-care workers and increase the national wage floor so that direct-care workers earn a living wage and have access to additional training.
- Provide an expansive definition of family to include individuals with which the employee has a close association that is the equivalent to a familial relationship, such as a child, parent, domestic partner, grandparent, grandchild, or sibling.

Provide Paid Family and Medical Leave Across the Lifespan

- Provide all workers with the ability to earn paid time away from work to care for themselves or a family member. Ensure availability and access to all employees.
- Cover a minimum of 12 paid weeks of leave.
- Replace at least 67 percent of a workers' average weekly wages while on leave.
- Include provisions that protect workers against discrimination or retaliation for needing or taking leave.
- Expand the definition of family to include individuals whom the employee considers to be family, in equivalent status to a familial relationship, such as a child, parent, domestic partner, grandparent, grandchild, or sibling.

Provide Family Caregiver Tax Credits

- Provide a refundable tax credit to help families defray the cost of caregiving roles and responsibilities.
- Credits must be available to caregivers across the lifespan.
- Credits must cover all caregiving-related expenses.

Increase Access to Affordable Quality Childcare and Early Learning Options

- Address childcare needs for children 0-13.
- Address populations that are especially challenged in finding childcare such as families with non-traditional work hours and families with a child with a disability.
- Allow families to have childcare options in the setting of their choice without excluding family, friend, or neighbor providers.
- Provide all families with access to quality childcare. Any quality investments and requirements for programs must take into consideration both families and child providers, including the need to compensate childcare providers with a living wage.

Increase Use and Standardize Caregiver Assessment Tools

- Ensure all health systems and caregiver support programs work with appropriate stakeholders to increase the use of evidence-based caregiver assessment tools.
- Assessment tools should determine specific problems, needs, strengths, and resources of family caregivers, and provide referrals for family caregiver supportive services.

Social Security Caregiver Credit Act

- Provide a Social Security credit so that time taken off from work to provide care would count towards future Social Security benefits.
- Ensure that caregivers are not losing Social Security retirement benefits while taking time out of the workforce to care for a loved one.



DETAILED FINDINGS

PREVALENCE

For this report, sandwich generation caregivers are defined as those who provide unpaid care to an adult, while also having responsibility for children living in their home, referred to in this report for shorthand as sandwich caregivers. *Caregiving in the U.S. 2015* – from which the data for this report are drawn – estimates that 39.8 million Americans are providing care to an adult age 18 or older. Approximately 28 percent of those caregivers (or 11 million caregivers) also had a child or grandchild living in their home while also providing care to an adult.

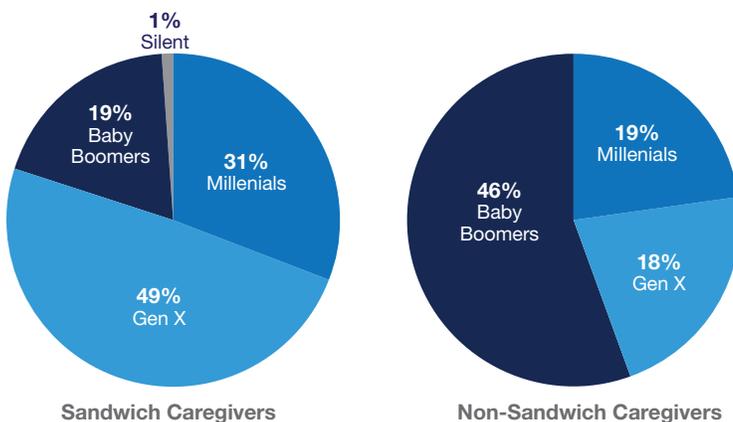
For this report, sandwich caregivers are those who provide unpaid care to an adult, while also having responsibility for children living in their home.

BASICS OF THE CAREGIVING SITUATION

Age, Gender, Race/Ethnicity of the Caregiver

Approximately three in five sandwich caregivers are female (61 percent), while two in five are male (39 percent). At an average of 41 years of age, sandwich caregivers are about 12 years younger than caregivers without children at home. Eighty percent of sandwich caregivers are millennials (31 percent) and Gen X (49 percent). In comparison, non-sandwich caregivers are predominately baby boomers (46 percent).¹⁴

Figure 1: Generational Profile of Sandwich Caregivers



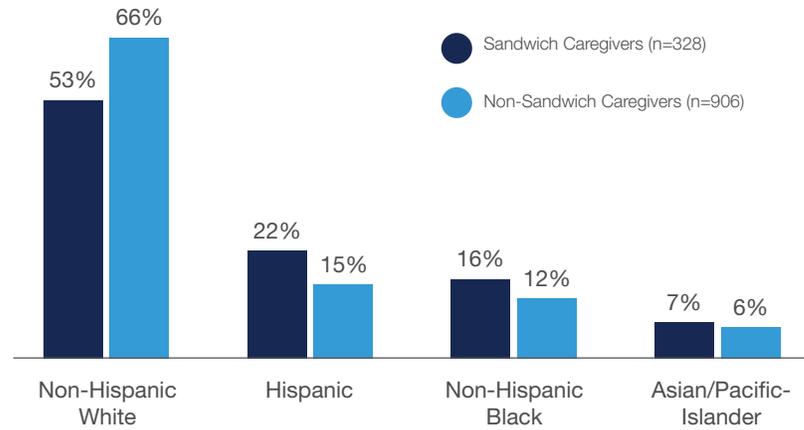
¹⁴For the purposes of this report, generations are based on respondent age reported at the time of the survey in late 2014. Millennials at the time were between 18 and 34 years old, (born between or during 1981 and 1996); Gen X includes those who reported ages between 34 and 51 (born between or during 1964 and 1980); baby boomers were 51 – 70 years old (born between or during 1944 and 1963).



Half of sandwich caregivers are caring for a parent or parent-in-law (53%).

Sandwich caregivers are more racially and/or ethnically diverse than non-sandwich caregivers. About one in five are either Hispanic (22 percent) or non-Hispanic Black (16 percent) and about half are non-Hispanic White (53 percent). This is in line with the race/ethnicity composition of the United States generally, where younger generations are more diverse than older generations.¹⁵

Figure 2: Racial/Ethnic Diversity of Sandwich Caregivers Compared to Non-Sandwich Caregivers

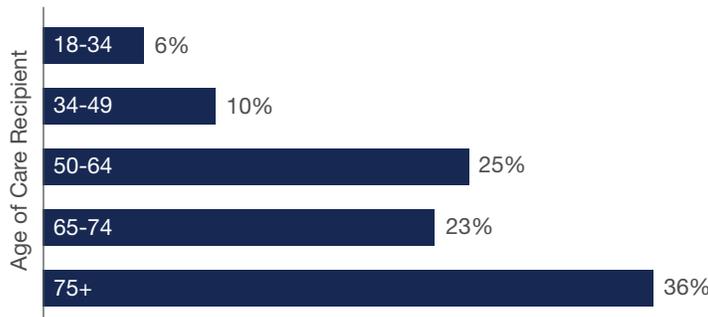


Please see Demographic Profile (beginning on page 29) for additional demographic information about sandwich and non-sandwich caregivers.

Duration of care

Approximately 67 percent of sandwich caregivers are caring for a woman who is 66 years old, on average, five years younger than non-sandwich caregivers’ care recipients (71 years old, on average).

Figure 3: Care Recipient Age (n=328)



Relationship

Half of sandwich caregivers are caring for a parent or parent-in-law (53 percent). About one in ten provide care to a grandparent or grandparent in-law (11 percent) or to a spouse (8 percent).¹⁶ Gen X and millennial sandwich caregivers reported caring for a friend or neighbor (15 percent vs. 8 percent of baby boomers). Millennial sandwich caregivers are more often providing care to a grandparent or grandparent-in-law (23 percent vs. 10 percent of Gen X sandwich caregivers). Lower income sandwich caregivers are more than twice as likely to care for a friend or neighbor (18 percent vs. 8 percent of those with \$50,000 or more in household income).

¹⁶Analyses of sandwich caregivers by relationship suggest that spousal caregivers have an especially difficult time in providing care while also having children in their home, with 41 percent indicating that their caregiving duties create a high level of financial strain. Due to low sample size among this group (n=27), however, we interpret these data with caution and feel further research is needed to understand the unique demands of caregiving for a spouse while also raising children.



SPOTLIGHT: CARING FOR A PARENT WHEN KIDS ARE AT HOME

This section shines a spotlight on those caregivers who have children under 18 living at home while also caring for a parent or parent-in-law (as opposed to a spouse, any other relative, friend, or neighbor). Of the sandwich caregivers identified in this report, approximately 43 percent are caring for a parent and have children in the home.



NATURE OF THE CAREGIVER

- Typically, a 41-year-old daughter caring for her 70-year-old mother. 81 percent of these sandwich caregivers live with their care recipients or within 20 minutes.
- Has provided care for 3.2 years, on average.
- Fifty-two percent are also employed while providing care.

CARE SITUATION

- Provides 24 hours of care each week, on average.
- More often has helped with managing finances (58 percent) and advocating with providers (56 percent).

IMPACT ON THE CAREGIVER

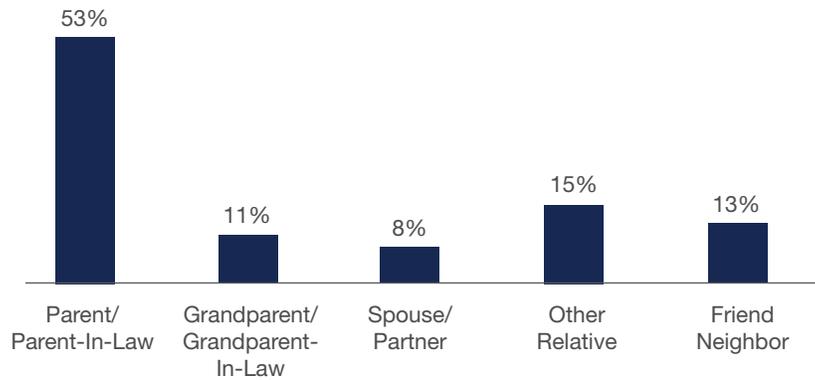
- Forty percent face high levels of emotional stress.
- Twenty-three percent report high financial strain.
- Have other unpaid caregivers helping (58 percent).

A hallmark of these sandwich caregivers is the proximity of the caregiver and their parent: 82 percent live within 20 minutes of their parent (including one third who live in the same home). These sandwich caregivers are mostly women (61 percent) caring for their mother or mother-in-law (70 percent). Most commonly, the parent needs care due to surgery or wounds (11 percent), “old age” or frailty (9 percent), Alzheimer’s confusion or dementia (9 percent), or diabetes (8 percent).

More than three in five sandwich caregivers perform medical/nursing tasks (63 percent), with one in five reporting difficulty doing so. They perform 1.8 ADLs and 4.3 IADLs and spend 24 hours a week providing care, on average. Perhaps because they are caring for a parent, they often take on the businesses of care: managing finances, paying bills, filling out insurance claims (58 percent), and advocating for their parent with providers or agencies (56 percent).

Four in ten report a high level of emotional stress and nearly half want more help or information about managing that stress (48 percent). One in four report a high level of financial strain due to caring for their parent (23 percent), more than double the financial strain of caring for another relative or friend (10 percent). Around half report working while also providing care to their parent (52 percent). Many have help in providing care: 58 percent report having at least one other unpaid caregiver helping their parent; only 26 percent say they alone are the primary caregiver for their parent.

Figure 4: Sandwich Caregiver and Recipient Relationship (n=328)



INSIGHTS

Hispanic sandwich caregivers more often reported that their care recipient lives with them or in someone else’s home (59 percent compared to 40 percent of non-Hispanic whites).

For sandwich caregivers whose care recipient lives in a rural area, that recipient is more often living in their own home (66 percent vs. 44 percent of non-rural care recipients) and more often living alone (35 percent vs. 20 percent).

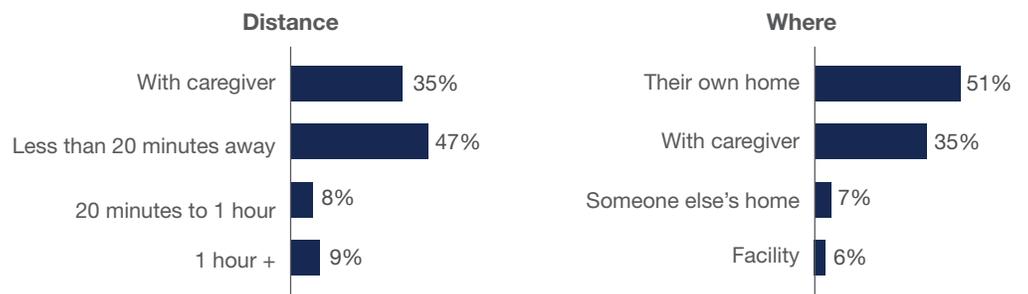
Distance and Location

Sandwich caregivers tend to live close to their care recipients, with 82 percent living with or within twenty minutes of their care recipient (compared to 72 percent of non-sandwich caregivers). Half reported that their care recipient lives in their own home and only 6 percent live in a care community or facility (e.g., independent living or retirement community, assisted living, nursing care, or long-term care facility). Only one in four sandwich caregivers report that their recipient lives alone (25 percent).



Policy Consideration: Increased Funding for Caregiver Programs, such as the National Family Caregiver Support Program and Lifespan Respite

Figure 5: Care Recipient Living Arrangements and Distance from Sandwich Caregiver (n=326)



Rural Status

Fewer than one in five sandwich caregivers live in a rural area (15 percent), although 33 percent reported their care recipient lives in a rural area. Therefore, one in five sandwich caregivers lives in an urban/suburban area and travels to a rural area to provide care (20 percent), doing so more often than non-sandwich caregivers (15 percent). Two out of three sandwich caregivers live and provide care in a suburban/urban setting (65 percent), 13 percent live and provide care in a rural area, and only 2 percent live in a rural setting and travel to the suburbs/city to provide care.



NATURE OF THE CAREGIVER

- Typically, a 40-year-old caring for a 63-year-old, on average.
- Seventy-seven percent typically caring for a female.

CARE SITUATION

- Recipient less often lives alone (15 percent).
- 28.5 hours of care provided weekly, on average.
- More often assist with at least one Activity of Daily Living (74 percent).
- High Burden of Care Index (47 percent).

IMPACT ON THE CAREGIVER

- 66 percent work while providing care for 35.4 hours a week on average.
- 22 percent cut back work hours to provide care.
- 63 percent have household income under \$50,000.

Hispanic sandwich caregivers are slightly younger on average, reflecting some general demographic trends in the U.S. population as a whole. Hispanic sandwich caregivers have a relatively demanding care situation: they spend a high number of hours providing care weekly (28.5 hours on average), more often perform Activities of Daily Living (74 percent), and have a relatively high Burden of Care (47 percent vs. 29 percent of non-Hispanic whites).

Hispanic sandwich caregivers, however, reported high emotional stress as a result of caregiving less often (30 percent vs. 41 percent of non-Hispanic whites). The impact of this demanding care situation may be eased by the many hands around to help: few care recipients live alone (15 percent vs. 28 percent for non-Hispanics) and many report the presence of other unpaid caregivers (60 percent).

While 66 percent have worked in the past year while providing care, 22 percent report having to cut back their work hours to provide care (compared to 9 percent of non-Hispanic whites). The median household income of Hispanic sandwich caregivers is \$40,700, about \$23,000 less than non-Hispanic whites; yet only 18 percent of Hispanic sandwich caregivers report high financial strain from caregiving (compared to 21 percent of non-Hispanic whites).

SPOTLIGHT: HISPANIC/ LATINO SANDWICH CAREGIVERS

**Approximately one
in five sandwich
caregivers are
Hispanic/Latino
(22 percent).**



¹⁴Hispanic/Latino sandwich caregivers tend to be younger than sandwich caregivers overall (40 years old on average vs 42 for non-Hispanics) and their care recipients tend to be younger as well (63 years old on average vs 67 for non-Hispanics). According to Pew Research Center, nearly half of U.S.-born Latinos are under 18, and 58% are Millennials or younger: <http://www.pewhispanic.org/2016/04/20/the-nations-latino-population-is-defined-by-its-youth/>. Latinos tend to have children at a younger age too, potentially yielding younger



SPOTLIGHT: MILLENNIAL SANDWICH CAREGIVERS

Nearly a third (31 percent) of sandwich caregivers are millennials (age 18 to 33 at the time of caregiving in late 2014).* The nature of their caregiving is distinct from other sandwich caregivers.



NATURE OF THE CAREGIVER

- Typically, a 27-year-old caring for someone 60 years old, on average.
- 34 percent care for a parent; 23 percent a grandparent; 16 percent a friend or neighbor.
- Has been providing care for 2.1 years, on average.

CARE SITUATION

- Provides 17.3 hours of care per week, on average.
- Less often performing medical/nursing tasks (52 percent).
- Less often arranging outside services (22 percent), advocating for recipient (35 percent), or communicating with care providers (51 percent).

IMPACT ON THE CAREGIVER

- 76 percent are employed while providing care.
- Only 44 percent have flexible work hours, 31 percent have sick leave, and 13 percent have employee support programs.

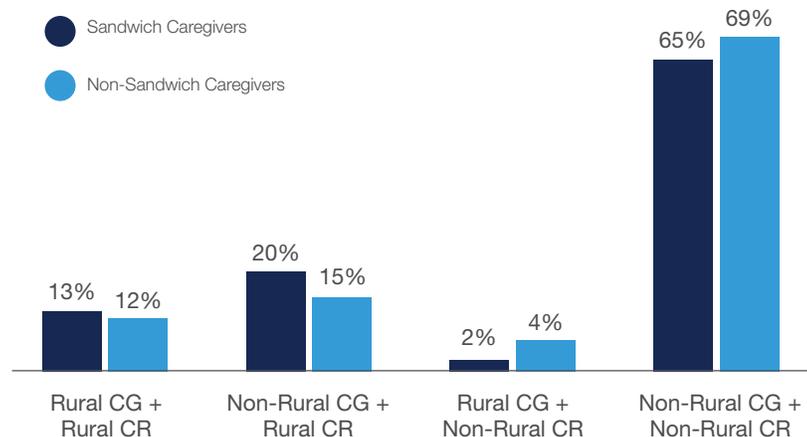
One in three millennial sandwich caregivers provide care for a parent (34 percent) and 23 percent care for a grandparent (more than older generation caregivers), indicating an intergenerational aspect to millennial caregiving. Millennials have been providing care for a shorter amount of time (2.1 years), on average, and more often expect it to be a temporary role, with just 37 percent expecting to be caring for any adult five years in the future.

Millennial sandwich caregivers tend to play a supporting role in caregiving for their adult care recipient, providing 17.3 hours of care per week and helping less often with formal care or services and supports tasks such as: medical/nursing tasks (52 percent compared to 72 percent of baby boomer sandwich caregivers), arranging outside services (22 percent vs. 45 percent of baby boomer sandwich caregivers), advocating for their care recipient (35 percent vs. 57 percent of baby boomer sandwich caregivers), or communicating with care professionals (51 percent vs. 73 percent of baby boomer sandwich caregivers). On average, millennial sandwich caregivers help with 1.7 Activities of Daily Living and 4.0 Instrumental Activities of Daily Living weekly.

The majority of millennial sandwich caregivers work while providing care (76 percent), but fewer report having workplace benefits like flexible work hours (44 percent), paid sick days (31 percent), or employee support programs (13 percent). Millennial sandwich caregivers report comparable levels of financial strain (15 percent high strain).

*For further reading on Millennials as caregivers, see: Flinn, Brendan. *Millennials: The Emerging Generation of Family Caregivers*. May 2018, AARP Public Policy Institute.

Figure 6: Urbanicity of Sandwich Caregiver (CG) and Care Recipient (CR) (n=328)

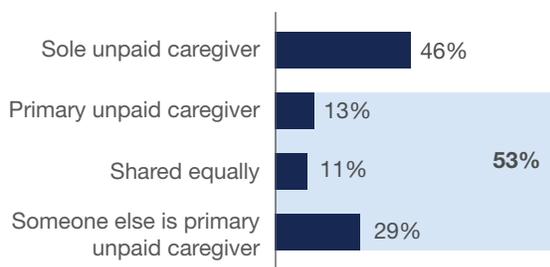


A Team-Based Care Approach

Often, sandwich caregivers are a part of a network of people who contribute to the care of the recipient. Slightly more than half indicated that someone else has provided unpaid care during the last twelve months (53 percent), including 13 percent who indicated that they are the primary unpaid caregiver among others, 11 percent who shared caregiving equally with others, and 29 percent who reported that someone else provided the bulk of unpaid care.

A care team may include a direct care worker as well. In fact, 26 percent of sandwich caregivers reported employing a direct care worker, such as home health aides or housekeepers. Nearly 19 percent of sandwich caregivers reported having difficulty coordinating care among all the care providers, payers, and servicers of their care recipient. Sandwich caregivers who provide the most care – 20 or more hours each week – are especially likely to have difficulty with care coordination (29 percent).

Figure 7: Caregiving Responsibility (n=328)



Primary Reasons Recipient Needs Care

Sandwich caregivers indicate a variety of main conditions or illnesses prompting the need for care. Most common is aging or frailty (12 percent), followed by wounds or surgery (10 percent), mobility issues (7 percent), mental illness or behavioral health issues (7 percent), or diabetes (7 percent).¹⁸

INCREASED BURDEN ON RURAL CAREGIVERS

For the 13 percent of sandwich caregivers who live and provide care in a rural area, the surrounding support can be limited. Fewer than half have other unpaid caregivers helping out (48 percent) and only 20 percent reported that their recipient has paid help.

Rural sandwich caregivers rarely reported their recipient lived in a facility of some sort (2 percent)¹⁷ and also reported using low levels of services and supports, such as respite care (17 percent) or transportation services (15 percent).

Sandwich caregivers may be making up for service shortfalls by doing more themselves: 38 percent reported having made home modifications in order to provide care. They also reported that they perform 21 hours of care each week, on average.

¹⁷Facility includes an independent living or retirement community, assisted living, or nursing home.

¹⁸Respondents were only allowed to pick one main condition or illness, although many respondents provide care for multiple conditions. For this table, only conditions affecting 6 percent or more of care recipients were listed; sixteen other conditions affect between 1 percent and 5 percent of care recipients each.



 **INSIGHTS**

Baby boomer sandwich caregivers are more often the primary caregiver, serving either as the sole caregiver, or providing the highest amount of care among unpaid caregivers (68 percent vs. 52 percent of millennials). However, baby boomers are more often providing care to a close relative (e.g., spouse, parent/parent-in-law, or adult child) while millennial sandwich caregivers care for a more diverse set of adults (including grandparents and non-relatives).

Sandwich caregivers who co-reside with their care recipient more often are the primary caregivers (83 percent compared to 47 percent of those not living together).

Figure 8: Main Condition for Which Recipient Requires Care

“Old Age” / frailty	12%
Wounds or surgery	10%
Mobility issues	7%
Mental illness or behavior health issues	7%
Diabetes	7%
Cancer	6%
Back problems	6%
Alzheimer’s confusion or dementia	6%

Although only 6 percent of sandwich caregivers specify Alzheimer’s as the main condition requiring care, 20 percent of sandwich caregivers are providing care to someone who suffers from Alzheimer’s or other mental confusion, either as the *main* condition or co-morbid condition.

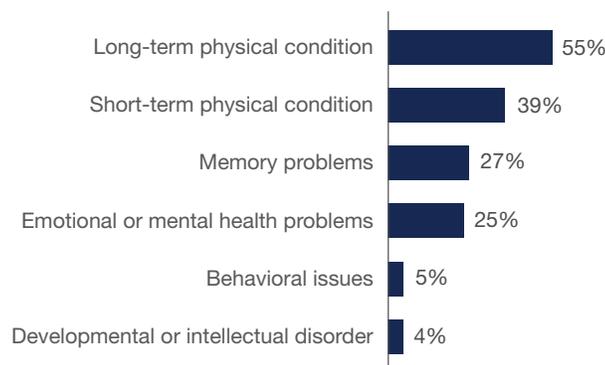


Policy Consideration: Expand and Implement the CARE Act

Reasons for Requiring Care

More broadly, sandwich caregivers most often describe their care recipient’s condition as a long-term physical condition (55 percent) requiring ongoing care. Four in ten describe the reason for care as a short-term physical condition, although one in four cite memory problems and emotional or mental health problems.

Figure 9: Care Recipient Condition Categories (n=328)



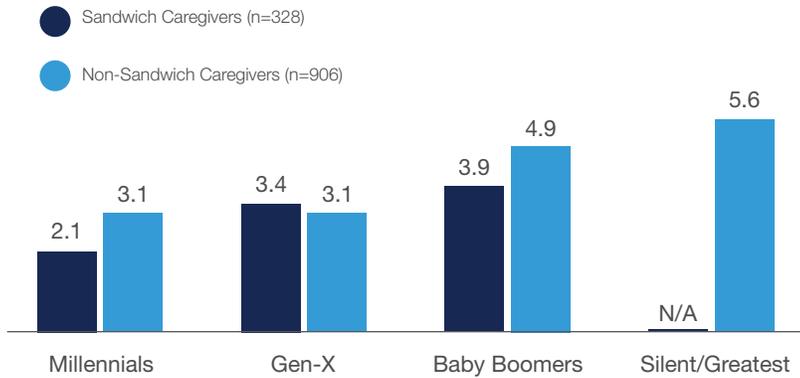
Policy Consideration: Expand Medicaid’s Ability to Compensate Family Caregivers

Caregiving Activities and Intensity of Care

Length of Care

The majority of sandwich caregivers have been providing care for five years or less (80 percent), averaging 3.1 years of care (compared to 4.4 years among non-sandwich caregivers). This shorter length of care seems to reflect the younger age of sandwich caregivers. Sandwich caregivers are overwhelmingly millennial and Gen X. Millennials reported a shorter average duration of care at 2.1 years and Gen X reported 3.4 years of care. Baby boomers and the silent/greatest generation, who make up the bulk of caregivers without children in their home, reported an average of 4.9 and 5.6 years of care, respectively. For both sandwich caregivers and those without children in their home, as caregiver age increases, so too does length of time having provided care.

Figure 10: Average Years of Care Provided, Sandwich Caregivers Compared to Non-Sandwich Caregivers

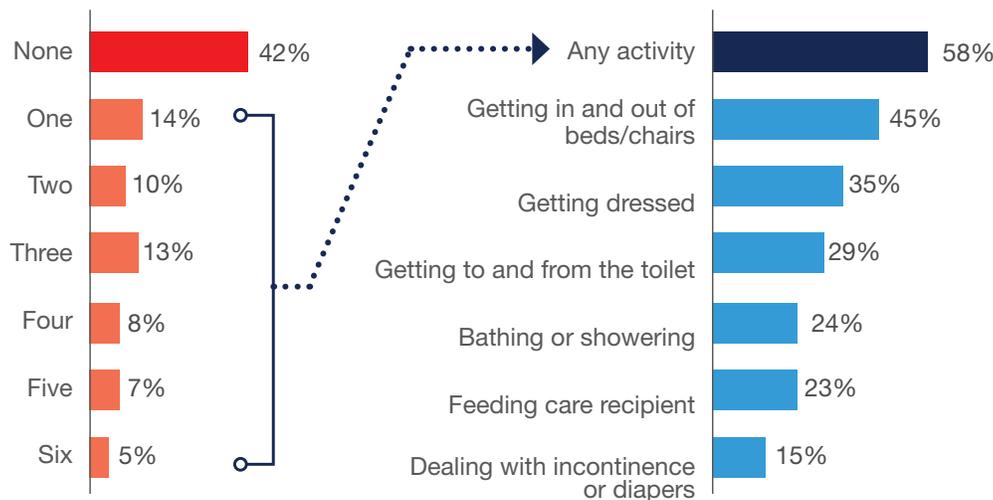


Activities of Daily Living (ADLs)

Activities of Daily Living, or ADLs, are personal care and mobility tasks that an unpaid caregiver may help their adult care recipient with, such as dressing, bathing, or feeding. Three in five sandwich caregivers help their loved one with at least one Activity of Daily Living (ADL), on average, performing 1.7 ADLs (out of a possible six tasks). The most common ADL that caregivers help with is getting in and out of chairs or beds (45 percent).

Sandwich caregivers have been providing care for 3.1 years, on average.

Figure 11: ADLs Performed by Sandwich Caregivers (n=328)




INSIGHTS

Male sandwich caregivers help more often than females with arranging services (37 percent vs. 25 percent), although female sandwich caregivers help more often with meal preparation (69 percent vs. 52 percent).

Baby boomer sandwich caregivers help more often with arranging outside services as well (45 percent), more than both Gen X (27 percent) or millennial (22 percent) sandwich caregivers.

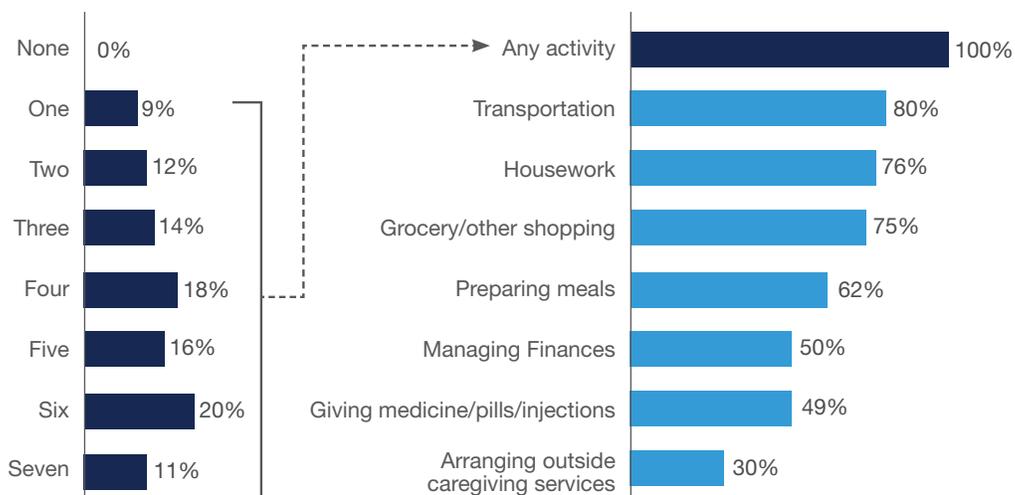
Roughly two in ten sandwich caregivers reported having difficulty assisting with these Activities of Daily Living (18 percent), fewer than non-sandwich caregivers (25 percent). ADLs tend to be physically demanding tasks, so sandwich caregivers' relative youth compared to non-sandwich caregivers may make them more easily able to handle ADLs.

Instrumental Activities of Daily Living (IADLs)

Instrumental Activities of Daily Living, or IADLs, are household tasks that an unpaid caregiver may help their adult care recipient with, such as shopping, chores, or arranging services. On average, sandwich caregivers assist their care recipient with 4.2 Instrumental Activities of Daily Living (IADLs) out of seven total tasks. Sandwich caregivers most commonly help with transportation (80 percent), housework (76 percent), and preparing meals (62 percent).

Sandwich caregivers who are the primary caregiver more often help with IADLs, such as housework (82 percent vs. 68 percent of non-primary sandwich caregivers), shopping (82 percent vs. 63 percent), meal preparation (70 percent vs. 50 percent), and managing finances (62 percent vs. 33 percent).

Figure 12: IADLs Performed by Sandwich Caregivers



Policy Consideration: Innovate on New Approaches to Support Caregivers (Reasons for Requiring Care, Caregiving Activities and Intensity of Care)

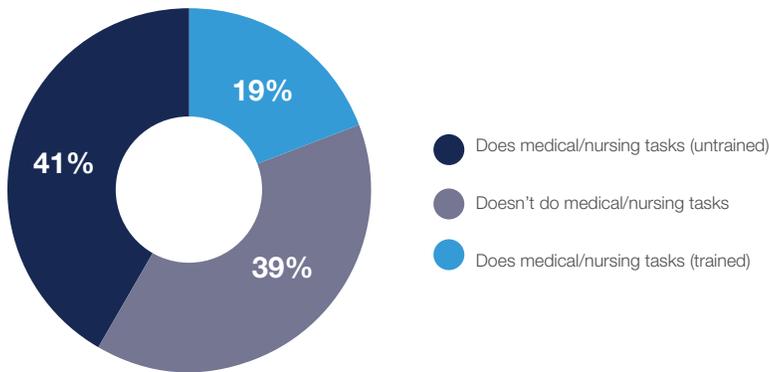
Medical/Nursing Tasks

Nearly three out of five sandwich caregivers help their care recipient with medical/nursing tasks, a body of highly skilled caregiving tasks that may have typically been handled by someone such as a healthcare aide, nurse, or other healthcare professional.¹⁹ Such tasks include, but are not limited to, injections, tube feeding, and catheter and colostomy care.

About four in ten sandwich caregivers reported that they are performing these skilled tasks without any prior preparation or training (41 percent). About one in five reported they have gotten some preparation prior to taking on these tasks, although it is important to note that a minority of caregivers, regardless of their age, are receiving this kind of training. 15 percent of sandwich caregivers say it is difficult to perform medical/nursing tasks.

¹⁹This includes giving medicines like pills, eye drops, or injections; preparing food for special diets; tube feedings; wound care; monitoring blood pressure or blood sugar; helping with incontinence; or, operating equipment like hospital beds, wheelchairs, oxygen tanks, nebulizers, or suctioning tubes. See: Reinhard, S.C., Levine, C., & Samis, S. *Home Alone: Family Caregivers Providing Complex Chronic Care*. AARP Public Policy Institute & United Hospital Fund, 2012.

Figure 13: Medical/Nursing Tasks and Training



Policy Consideration: Increase Caregiver Training and Education

Caregiving Support Activities

Sandwich caregivers often perform other activities to help support their recipient's care, such as monitoring condition severity (68 percent) and communicating about care with providers (62 percent). Half of sandwich caregivers advocate for their recipient with various providers or services.

In general, sandwich caregivers providing care to a parent/parent-in-law (61 percent) or spouse (56 percent) more often take on the role as an advocate than those caring for a recipient with some other relationship (40 percent). Similarly, sandwich caregivers who are the primary caregiver more often take on the role as an advocate (57 percent vs. 40 percent of non-primary), as well as the role of care communicator (68 percent vs. 53 percent of non-primary).

Sandwich caregivers who are the primary caregiver more often take on the advocate role (57% vs. 40% of non-primary), as well as the role of care communicator (68% vs. 53% of non-primary).

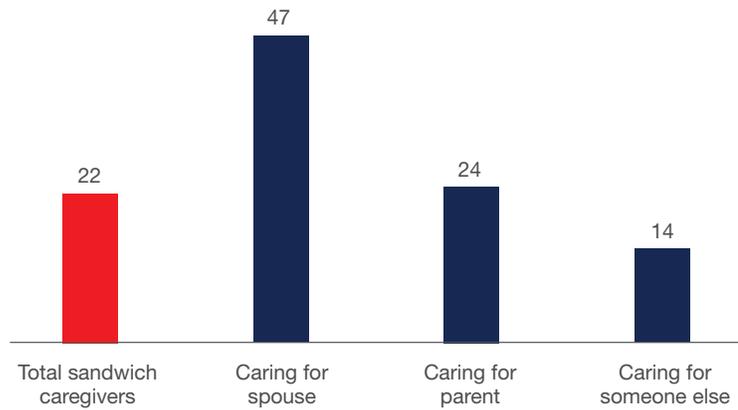
Figure 14: Caregiving Support Activities (n=328)



Hours of Care

To assist with the many caregiving tasks they perform, sandwich caregivers must dedicate a considerable portion of their week to caring for their adult recipient: on average, 22 hours per week—the equivalent of a part-time job. Those caring for a spouse spend 47 hours weekly while those caring for a parent/parent-in-law provide care for 24 hours weekly, on average.

Figure 15: Hours of Care Provided by Sandwich Caregivers by Relationship to Care Recipient (n=328)

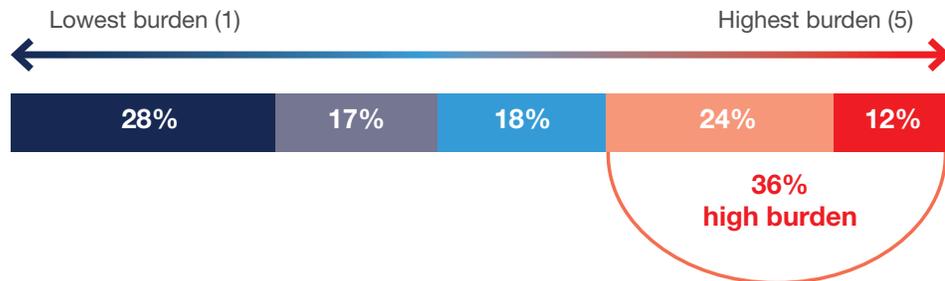


The Burden of Care Index was created to gauge the complexity and challenges of caregiving. About one in three sandwich caregivers (36%) are in a high burden care situation.

Burden of Care Index

The Burden of Care Index was created to gauge the complexity and challenges of caregiving. This index combines information about the care tasks and hours of care performed. This index measures the burden of care situation on the caregiver. About one in three sandwich caregivers (36 percent) are in a high burden care situation. For more information on the construction of the Burden of Care Index, refer to Appendix B of the *Caregiving in the U.S. 2015* report.

Figure 16: Burden of Care Index Among Sandwich Caregivers (n=328)



Strain and Stress

Many sandwich caregivers face challenges as a result of caring for an adult while also having responsibility for children living in their home. One in three reported a high level of emotional stress due to caregiving (33 percent). One in five reported a high level of financial strain (20 percent) and physical strain (18 percent) as a result of caregiving, while 20 percent reported that caregiving has made their health worse.

²⁰Burden of care is an index combining hours of care and care tasks provided. For detail on calculation of burden of care index, see *Caregiving in the U.S. 2015 Full Report* (www.caregiving.org/caregiving2015).

INSIGHTS

Female sandwich caregivers more often reported higher levels of emotional stress (38 percent vs. 27 percent of men).

Sandwich caregivers who live with their care recipient may be especially at risk because of the demands of caring for children and an adult in the same household. They reported higher levels of physical strain (26 percent high strain vs. 13 percent not living together), financial strain (27 percent vs. 16 percent), and a more negative impact on their health (30 percent vs. 14 percent). They also less often feel they had a choice in taking on their role (40 percent vs. 62 percent).

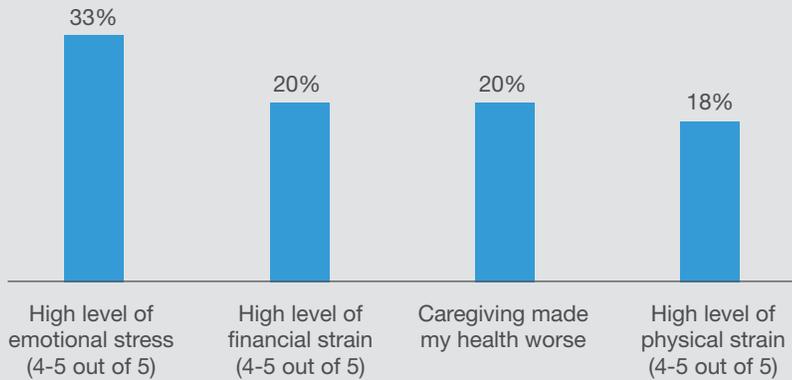
Those caring for a close relative, such as a parent/parent-in-law or spouse, also seem to have greater stress and strain: 40 percent reported high emotional stress and 26 percent say that they are facing high financial strain (compared to 22 percent and 10 percent respectively among those caring for other relatives or non-relatives).

Sandwich caregivers who are caring for a spouse may be at special risk due to their co-residing and close relationship status: 41 percent reported high financial strain and 40 percent say caregiving has negatively impacted their health.²³

²²In *Caregiving in the U.S. 2015*, results showed that having no choice in taking on the caregiving role could result in feeling higher levels of emotional stress and strain, with 53 percent of those who had no choice feeling high levels of emotional stress (compared to 38 percent of caregivers overall).

²³Confidence in these figures as representative of the population is moderate due to a small sample size. Further study of sandwich caregivers caring for a spouse or partner is recommended in order to further investigate the impacts of spousal caregiving with children in the home, especially related to household finances and ability of the caregiver to maintain or improve their own health.

Figure 17: Stress and Strain on Sandwich Caregivers (n=342)



Slightly more than half of sandwich caregivers feel they had a choice in taking on their role of caregiver (54 percent). For the 45 percent of sandwich caregivers who felt they had no choice, the perception of emotional and physical strain can often be worse.²²

Working Caregivers

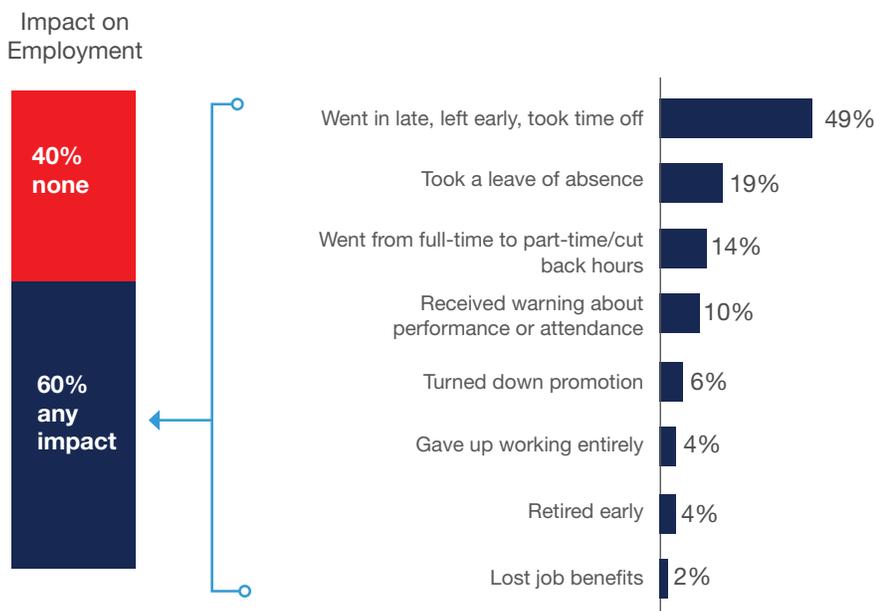
Sandwich caregivers have the dual responsibilities of providing care to an adult recipient and a child on top of their work responsibility. Sandwich caregivers more often reported being employed while also caregiving (67 percent), as compared to 57 percent of non-sandwich caregivers. On average, sandwich caregivers work 36 hours per week.

As with all working caregivers, sandwich caregivers find that caregiving can impact their work. Six in ten working sandwich caregivers reported at least one impact on their work (60 percent). This most commonly includes having to go in late, leave early, take time off (49 percent), or taking a leave of absence (19 percent, more common than among working non-sandwich caregivers at 12 percent).



Policy Consideration: Pass the EITC Modernization Act

Figure 18: Impact of Caregiving on Employment



²⁴Confidence in these figures as representative of the population is moderate due to a small sample size. Further study of sandwich caregivers caring for a spouse or partner is recommended in order to further investigate the impacts of spousal caregiving with children in the home, especially related to household finances and ability of the caregiver to maintain or improve their own health.

SNAPSHOT: CHILDCARE AND SANDWICH CAREGIVERS



In 2015, Alexis’s mother was diagnosed with Alzheimer’s disease. At the time, Alexis had an eleven-year-old daughter and a three-year-old son. Alexis’s mother needed more care than her father, who was in his 80s and had health problems of his own, was able to provide. Alexis and her husband were both working outside the home and paying a mortgage on a new house. They decided to move in with Alexis’s parents to help. The move to Virginia meant additional childcare costs for which they hadn’t planned. It also required the family to face new, unexpected challenges related to caregiving. Looking back on this arrangement, Alexis says, “we didn’t have a plan.” They were simply trying to make it all work.

The lack of affordable, quality childcare is a critical issue for sandwich caregivers like Alexis, who, on top of the cost of care for their children, face out-of-pocket caregiving costs of nearly \$7,000 per year.²⁰ Studies show that access to high-quality, affordable childcare allows families with care responsibilities to continue to work. This is especially relevant to working sandwich caregivers. It is also critical for direct-care workers in order to support their own families, continue to support the families for whom they provide care, and allows them to remain in an industry that is desperate to retain workers.

Looking back, four years into this caregiving arrangement, Alexis says, “we didn’t have a plan... we’re simply trying to make it all work.”

Research has shown, however, that high-quality childcare is unaffordable for many families across all 50 states. The out-of-pocket costs of childcare vary greatly from state to state, but the national average is almost \$10,000 per year.²¹ Of those who qualify for state childcare assistance programs, only one in six children who are eligible actually receive the benefit. Most families are left to shoulder this burden without any public assistance. Families

with children with disabilities, parents of infants and toddlers, those with nontraditional work hours, and families that rely on after school and summer childcare are all faced with additional barriers in accessing high-quality and affordable childcare options that fit their needs.

In short, the lack of access to high-quality, affordable childcare can perpetuate the cycle of poverty and force families of all income levels to make impossible choices between caregiving and work. Affordable and accessible childcare options would allow more sandwich caregivers, especially women, to be able to enter and remain in the workforce. Additional targeted research is needed to further understand the impact of the childcare and early learning landscape on sandwich caregivers.

²⁰AARP. “Surprising Out-of-Pocket Costs for Caregivers,” *Financial and Legal*. <https://www.aarp.org/caregiving/financial-legal/info-2017/out-of-pocket-cost-report.html>

²¹Child Care Aware of America. “The US and the High Cost of Child Care: 2018.” *Child Care Aware® of America’s*, 2018. <https://usa.childcareaware.org/advocacy-public-policy/resources/research/costofcare/>

Workplace Support

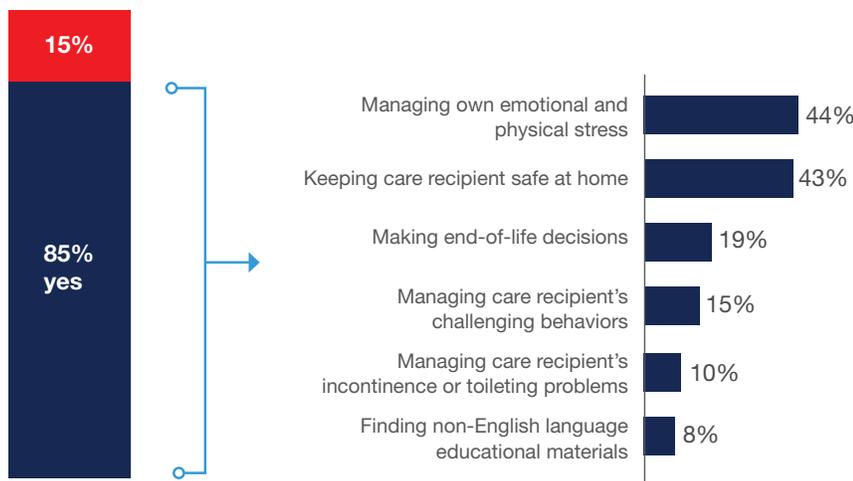
Increased workplace support could help all caregivers, including sandwich caregivers, to juggle these multiple demands on their time. About half of employed sandwich caregivers reported having flexible work hours (54 percent), only 36 percent reported having enough paid leave available to be able to take time off from work to care for a family member. Just one in four are offered telecommuting opportunities (24 percent) or an employee assistance program (EAP) that might help caregivers manage better (26 percent).

Information and Support Needs

Most sandwich caregivers indicate that they need more help or information about at least one caregiving-related topic (85 percent). The most reported needs for support or information are help managing their own emotional and physical stress (44 percent) and help keeping their care recipients safe at home (43 percent). One in five would like more help or information about making end of life decisions (19 percent).

Figure 19: Support for Sandwich Caregivers (n=212)

Seeking help?



Policy Consideration: Increase and Enhance the Existing National Support Infrastructure for Family Caregivers

Service Costs, Policy, and Long-Range Planning

About one in four sandwich caregivers say it is difficult to find affordable services for their care recipient in their local area or community (25 percent rating this need as 4 or 5 on a 5-point scale). When asked about financial support needed to assist in offsetting or paying for care,²⁴ the most popular policies among sandwich caregivers are paid-care programs (33 percent), where caregivers are compensated for some hours of care, or income tax credits (31 percent). Some sandwich caregivers would like relief from the dual burden of employment and caregiving: 13 percent prefer a partially paid leave of absence from work.²⁵ About a quarter of sandwich caregivers, however, were unsure which financial support policy they would find most helpful (23 percent).

Many sandwich caregivers reported a lack of long-range planning, either for themselves or their care recipient. Less than half indicate their care recipient has future care plans in place for living arrangements, health care decisions, or financial matters (43 percent). Even fewer sandwich caregivers have their own long-range plans (37 percent vs. 45 percent of non-sandwich caregivers).



INSIGHTS

The proportion of working sandwich caregivers who experience work impacts is especially pronounced for several groups:

- Those providing 21 or more hours of care each week (74 percent),
- Those who live with their care recipient (70 percent),
- Primary caregivers (66 percent), and
- Gen X sandwich caregivers (65 percent compared to baby boomers at 46 percent).



INSIGHTS

Gen X and baby boomer sandwich caregivers who work seem to have a greater access to benefits such as paid sick days (63 percent vs. 31 percent of millennial working sandwich caregivers) and EAPs (34 percent vs. 13 percent). This is perhaps due to having longer, more established careers.

²⁴Financial support policies described as: 1) a program where caregivers could be paid for at least some of the hours they provide care; 2) an income tax credit to caregivers, to help offset the cost of care; 3) a partially paid leave of absence from work, for caregivers who are employed.

²⁵For further reading on the workplace impacts of caregiving and how employers can address the need for paid leave, see <https://hbr.org/2018/11/caring-for-your-companys-caregivers>.



SPOTLIGHT: GEN X SANDWICH CAREGIVERS

Gen X is the largest group of sandwich caregivers in the U.S., comprising nearly half (49 percent) of all sandwich caregivers.



NATURE OF THE CAREGIVER

- Typically, 42 years old caring for a 67-year-old, on average
- 59 care for a parent or parent-in-law; 14 percent for a friend or neighbor
- Has been providing care for 3.4 years, on average

CARE SITUATION

- Average of 22.6 hours of care provided weekly
- More often in care situation with high Burden of Care (42 percent)
- 56 percent expect to be providing care in the next five years

IMPACT ON THE CAREGIVER

- Most often experience negative work impacts (65 percent)
- 26 percent have taken a leave of absence from work to provide care
- More often reported high financial strain (25 percent)

On average, Gen X sandwich caregivers are 42 years old. Three out of five Gen X sandwich caregivers provide care to a parent or parent-in-law (59 percent), with another 14 percent caring for a friend or neighbor. Three in ten Gen X sandwich caregivers reported that their recipient lives alone (29 percent vs. 18 percent of baby boomer sandwich caregivers).

Most Gen X sandwich caregivers are the primary caregiver for their recipient (61 percent) and provide 22.6 hours of care weekly. They help with 1.8 Activities of Daily Living and 4.1 Instrumental Activities of Daily Living, on average, with 59 percent helping with medical/nursing tasks. Four in ten are in a care situation that has a high burden of care (42 percent vs. 23 percent of millennial sandwich caregivers). 27 percent reported having paid help. They more often expect to continue to be a caregiver for some adult during the next five years (56 percent vs. 37 percent millennial sandwich caregivers).

Most Gen X sandwich caregivers reported having worked in the past year while providing care (64 percent), working 36.4 hours a week on average. These Gen X sandwich caregivers have experienced negative work impacts more often as a result of their caregiving role (65 percent vs. 46 percent of baby boomer sandwich caregivers), including 26 percent who took a leave of absence to provide care. Perhaps due to these work impacts, 25 percent of Gen X sandwich caregivers reported high levels of financial strain as a result of caregiving (compared to 12 percent for baby boomers).



This report highlights that millennial sandwich caregivers are more likely to engage in paid employment in comparison to other age groups of sandwich caregivers, but they are the least likely to have supportive workplace policies.

EXPERT COMMENTARY

FEYLYN LEWIS, PHD, UNIVERSITY OF SUSSEX: YOUNG CAREGIVERS

While the reported figure of 11 million sandwich caregivers (taken from the National Alliance for Caregiving and AARP Public Policy Institute's *Caregiving in the U.S. 2015* study)²⁶ may seem shocking, it is expected that this is only the tip of the iceberg. Indeed, the numbers of sandwich caregivers in the U.S. are likely much higher than reported. One reason for under-reported statistics include the issue of self-identification. Individuals providing care for family members often do not identify with the terminology of "caregiver" because they see themselves as loving, dutiful children or partners.²⁷

Furthermore, to qualify for the *Caregiving in the U.S. 2015* study, respondents must have self-identified as an unpaid caregiver providing help with at least one Activity of Daily Living or Instrumental Activity of Daily Living, or a medical/nursing task. These criteria may have excluded caregivers who perform emotional caregiving tasks, such as sitting with the care recipient, holding phone conversations, and general "spending time" with the care recipient. This can take a significant portion of time in the daily lives of caregivers, yet often goes unreported because of its informal nature.²⁸ Therefore, it is likely that caregivers are supplying more care than is reported in the study, meaning that the impacts of caregiving on their daily life is likely more substantial than indicated in the findings. This type of care provision is often common among younger age caregivers (young adults and children) and may also be common among older generation caregivers.²⁹

Finally, it follows that if caregivers *only* provide emotional tasks, they likely were not included in this study because of the exclusion criteria. Thus, this report should be considered with the understanding that the number of sandwich caregivers in the United States is likely much higher than reported, and the scope of the challenges facing this distinctive group of caregivers is far-reaching.

This report has revealed that sandwich caregivers most commonly provide long-term care to individuals with age and frailty issues. Much focus is directed toward the health condition of the care recipient and how particular conditions can impact the experience of the sandwich caregiver. However, there is the strong likelihood that sandwich caregivers will possess their own health condition requiring care. Previous research has found that adult family caregivers often neglect their own need for medical attention, due to their focus on the care recipient³⁰ and the intensity of their caregiving responsibilities.³¹ Furthermore, family caregivers often experience health problems directly caused, or exacerbated by caregiving, such as depression or anxiety,³² or back strain from lifting the care recipient. The personal health issues of sandwich caregivers can compound the already stressful experience of care provision, and this aspect of caregiving should be reflected upon when considering the totality of "impact" upon sandwich caregivers.

As this report indicates that 31 percent of sandwich caregivers are millennials, it is important to draw attention to the issues particularly salient for this younger group of caregivers. This report highlights that millennial sandwich caregivers are more likely to engage in paid employment in comparison to other age groups of sandwich caregivers, but they are the least likely to have supportive workplace policies. Recalling that millennials may be at the beginning stages of their career, they may be in a more insecure employment position than older generations of sandwich caregivers. Their younger age may also mean that they have accumulated less personal wealth and assets and may in fact experience financial precarity.

²⁶The National Alliance for Caregiving and AARP Public Policy Institute, "Caregiving in the U.S. 2015," *Caregiving in America*. <https://www.caregiving.org/caregiving2015/>.

²⁷Deborah L. O'Connor, "Self-Identifying as a Caregiver: Exploring the Positioning Process," *Journal of Aging Studies*, 21, no. 2, (2007), 165-174.

²⁸Chris Dearden and Saul Becker, (2004). *Young Carers in the UK: The 2004 Report* (London: The Children's Society, 2004).

²⁹Janet Warren, "Young Carers: Conventional or Exaggerated Levels of Involvement in Domestic and Caring Tasks?" *Children & Society*, 21, no. 2, (2007), 136-146.

³⁰Susan C. Reinhard, Barbara Given, Nirvana Huhtala Petlick and Ann Bemis, "Supporting Family Caregivers in Providing Care," in *Patient Safety and Quality: An Evidence-Based Handbook for Nurses*, eds. R.G. Hughes (Rockville: Agency for Healthcare Research and Quality, 2008).

³¹Alana M. Boyczuk and Paula C. Fletcher, "The Ebbs and Flows: Stresses of Sandwich Generation Caregivers," *Journal of Adult Development*, 23, no. 1, (2015).

³²Martin Pinquart and Silvia Sorensen, "Differences Between Caregivers and Non-Caregivers in Psychological Health and Physical Health: A Meta-Analysis," *Psychology & Aging*, 18, no. 2, (2003), 250-267.

Previous research with the AARP found that one in three (34 percent) of employed millennial caregivers have an annual household income of less than \$30,000,³³ while spending a higher percentage of their income on family caregiving than any other age group. The unique economic burdens facing millennial sandwich caregivers warrant a prioritization of their needs in workplace policy, however, this group of caregivers remains overlooked. The only current federal leave policy available to some eligible millennial sandwich caregivers—the Family and Medical Insurance Leave Act (FMLA)—offers twelve weeks of leave within a one-year period, however, this leave is unpaid. Beyond paid leave policies, millennial sandwich caregivers would benefit from flexible working hours, a more empathetic workplace culture, and depending upon their job sector, the ability to telecommute.

Future research involving sandwich caregivers should examine the experience of sandwich caregivers who lack a care team, with particular attention given to single/unpartnered caregivers. The experience of those sandwich caregivers who identify as LGBT, as well as those from indigenous people groups, should also be included in future analysis. Previous research has shown that those groups of caregivers have unique experiences in their caregiving journey, and more often than not, face social isolation, financial difficulties due to caregiving, and barriers to accessing formal support.³⁴ It is recommended that future studies involving sandwich caregivers center and prioritize the experience of those who may be particularly vulnerable and isolated from support services.

MARGARET L. LONGACRE, PHD; DEPARTMENT OF PUBLIC HEALTH, COLLEGE OF HEALTH SCIENCES, ARCADIA UNIVERSITY: HEALTH SYSTEMS

A growing body of literature is illuminating the collective caregiving experience as well as the experiences of caring due to specific conditions. We know less about stage-of-life caregiving, including those who provide informal or family care to an adult while also caring for a child or children in the home. Thus, this report on sandwich caregivers provides a needed glimpse into this population of caregivers. Key points of this report relate to the: 1) the emotional, financial and employment strain experienced by sandwich caregivers; and, 2) the potential need for varied communication skills as evidenced by findings on the reasons for which care is provided and the roles and dynamics of such care (i.e., “care team”).

First, 33 percent of these sandwich caregivers indicated that caregiving was highly stressful. Although lower in proportion compared to all caregivers in the Caregiving in the U.S. 2015 report (38 percent)³⁵ and to caregivers of people suffering with cancer (50 percent),³⁶ this still represents approximately 3 in 10 caregivers. Caregiving is well known to be emotionally straining, presenting as elevated stress or distress or as clinical anxiety and/or depression.^{37, 38, 39} Having a poorer emotional response to caregiving can also have adverse implications for a caregiver’s own physical health as well as a care recipient’s emotional response.^{40, 41}

Caregiver and caregiving characteristics, including employment, can influence a caregiver’s emotional response.⁴² Given the younger age of these sandwich caregivers (41 years of age, on average), financial strain and employment impact might be particularly important to consider with respect to emotional strain. Twenty percent of these sandwich caregivers expressed high financial strain due to caregiving, and, of those who were employed (67 percent), many (60 percent) indicated making at least one type of employment modification (e.g., modifying hours or taking a leave of absence). Just over half (54 percent) indicated flexibility with work hours and fewer indicated having support in other ways, such as paid time off or the ability to telecommute. Future research

³³Brenda Flinn, “Millennials: The Emerging Generation of Family Caregivers,” AARP Public Policy Institute. <https://www.aarp.org/content/dam/aarp/ppi/2018/05/millennial-family-caregivers.pdf>.

³⁴Lesli Hokanson, Michael Gerhardt Quinn, Natalie Schütz, Kristy de Salas and Jenn Scott, “A Systematic Review of Indigenous Caregiver Functioning and Interventions,” *Quality of Life Research*, 27, no. 8, (2018), 2007-2017; S. Melinda Spencer, R. Turner Goins, Jeffrey A. Henderson, Yang Wen and Jack Goldberg, “Influence of Caregiving on Health-Related Quality of Life Among American Indians,” *Journal of the American Geriatrics Society*, 61, no.9, (2013), 1615-1620; Nancy J. Knauer, “LGBT Older Adults, Chosen Family, and Caregiving,” *Journal of Law and Religion*, 31, no. 2, (2016), 150-168. Joel G. Anderson and Jason D. Flatt, “Characteristics of LGBT Caregivers of Older Adults: Results from the National Caregiving in the U.S. 2015 Survey,” *Journal of Gay & Lesbian Social Services*, 2, (2018), 103-116.

³⁵The National Alliance for Caregiving and AARP Public Policy Institute, “Caregiving in the U.S. 2015,” *Caregiving in America*. <https://www.caregiving.org/caregiving2015/>.

³⁶Gail Gibson Hunt, Margaret L. Longacre, Erin E. Kent and Lisa Weber-Raley, “Cancer Caregiving in the U.S.: An Intense, Episodic, and Challenging Care Experience,” *National Alliance for Caregiving, Cancer Support Community and National Cancer Institute*, (2016).

³⁷Margaret F. Bevens and Esther M. Sternberg, “Caregiving Burden, Stress, and Health Effects Among Family Caregivers of Adult Cancer Patients,” *JAMA*, 307, no. 4, (2012), 398-403.

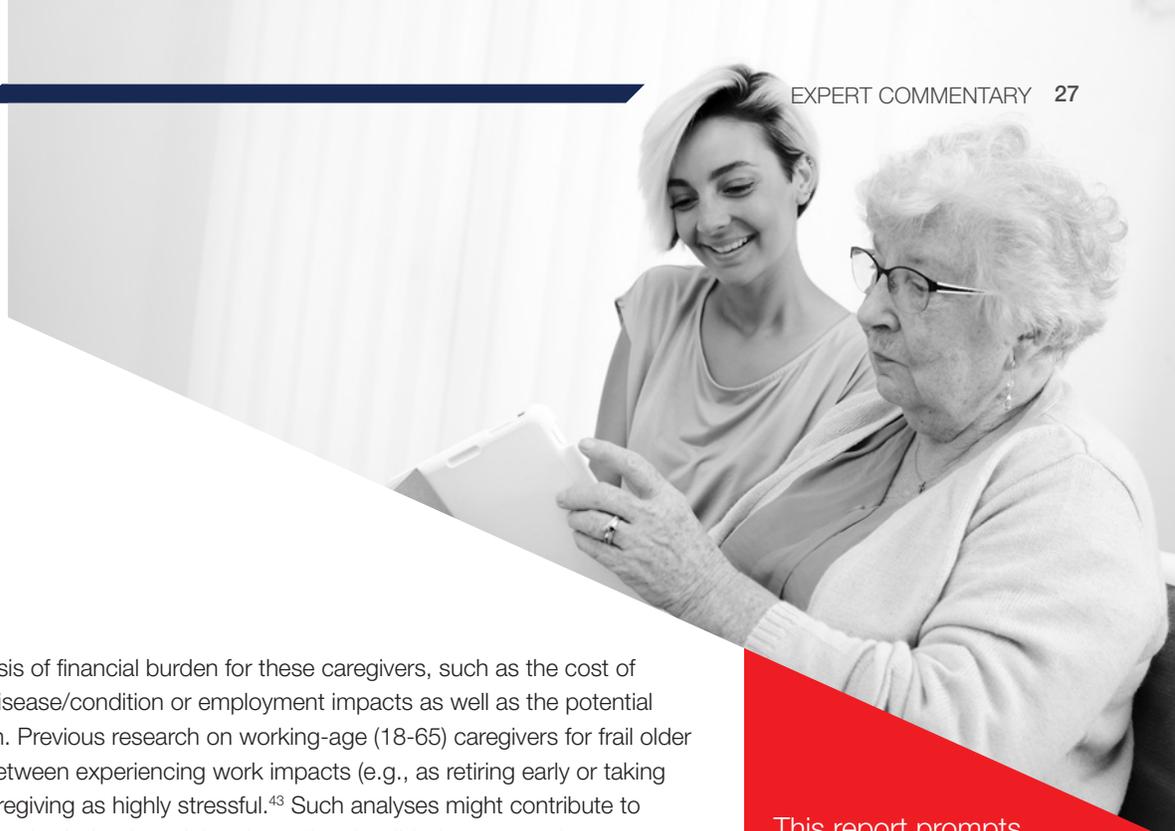
³⁸Laurel L. Northouse, Maria C. Katapodi, Ann M. Schafenacker and Denise Weiss, “The Impact of Caregiving on the Psychological Well-Being of Family Caregivers and Cancer Patients,” *Seminars in Oncology Nursing*, 28, no.4, (2012), 236-245.

³⁹Francesca Romito, Gil Goldzweig, Claudia Cormio, Mariet Hagedoorn and Barbara L. Andersen, “Informal Caregiving for Cancer Patients,” *Cancer*, 119, (2013), 2160-2169.

⁴⁰Kristin Litzelman and Robin Yabroff, “How Are Spousal Depressed Mood, Distress, and Quality of Life Associated with Risk of Depressed Mood in Cancer Survivors? Longitudinal Findings from a National Sample,” *Cancer Epidemiol Biomarkers and Prevention*, 24, no. 6, (2015).

⁴¹Paula R. Sherwood, Barbara Given, Heidi S. Donovan, Andrew Baum, Charles W. Given, Catherine M. Bender and Richard Schulz, “Guiding Research in Family Care: A New Approach to Oncology Caregiving,” *Psychooncology*, 17, no. 10, (2008), 986-996.

⁴²Ibid.



should more fully explore the basis of financial burden for these caregivers, such as the cost of patient/care recipient care per disease/condition or employment impacts as well as the potential relationship with emotional strain. Previous research on working-age (18-65) caregivers for frail older adults showed an association between experiencing work impacts (e.g., as retiring early or taking time off work) and perceiving caregiving as highly stressful.⁴³ Such analyses might contribute to broader policy support to enhance both the financial and emotional well-being of caregivers.

Findings in this report also suggest the potential need to consider communication demands and skills among sandwich caregivers. For example, the most frequent reason for which a sandwich caregiver provided care was due to the main condition of “old age”/frailty (12 percent). Care was also provided due to conditions such as mental illness (7 percent), cancer (6 percent), and Alzheimer’s disease/dementia (6 percent). Moreover, 20 percent indicated that the care recipient had memory deficits, which was occurring for some in addition to a primary condition other than dementia. Most (82 percent) of these sandwich caregivers also live within twenty minutes of the care recipient including 35 percent residing with the care recipient; thus, the child/youth might likely have consistent interaction with the care recipient. Therefore, these caregivers may need assistance in communicating the care experience to a child or children living in the home.

Moreover, there is growing focus on the importance of communication among dyads (caregiver and care recipient) and triads (caregiver, care recipient, and provider) as some caregivers do not always know how to interact in clinical care (e.g., what questions to ask, how to get updates),⁴⁴ but are often part of clinical communication.⁴⁵ A majority (62 percent) of these sandwich caregivers (and 73 percent of the baby boomer sandwich caregivers) indicated communicating with the care recipients’ health care professionals. Furthermore, the report also highlights that many caregivers share the caregiving role (53 percent) and some utilize paid help (25 percent). Thus, inherent with this care team is the need to arrange and communicate with other informal or formal care providers to adequately assist the care recipient.

In sum, this report provides important first understandings that prompt questions for further study – e.g., might employment strain impact the caregivers’ emotional response for these caregivers, and, if so, how could policy reduce this burden? Also, how is the care experience articulated to those children living in the home or other care team members, and what programming or assistance might be needed to facilitate understanding and communication? This report and subsequent work that stems from it will contribute to improved understanding for this important subset of family caregivers.

This report prompts questions for further study: how is the care experience articulated to those children living in the home or other care team members, and what programming or assistance might be needed to facilitate understanding and communication?

⁴³Margaret L. Longacre, Vivian G. Valdmanis, Elizabeth A. Handorf and Carolyn Y. Fang, “Work Impact and Emotional Stress Among Informal Caregivers for Older Adults,” *The Journals of Gerontology Series B Psychological Sciences and Social Sciences*, 72, no. 3, (2017), 522-531.

⁴⁴Margaret L. Longacre, Thomas J. Galloway, Claudia F. Parvanta and Carolyn Y. Fang, “Medical Communication-Related Informational Need and Resource Preferences Among Family Caregivers for Head and Neck Cancer Patients,” *Journal of Cancer Education*, 30, no. 4, (2015), 786-791.

⁴⁵Gail Gibson Hunt, Margaret L. Longacre, Erin E. Kent and Lisa Weber-Raley, “Cancer Caregiving in the U.S.: An Intense, Episodic, and Challenging Care Experience,” *National Alliance for Caregiving, Cancer Support Community and National Cancer Institute*, (2016).

JOE CALDWELL, PHD; COMMUNITY LIVING POLICY CENTER, LURIE INSTITUTE FOR DISABILITY POLICY, BRANDEIS UNIVERSITY: DISABILITY

As the U.S. population ages, the number of individuals needing long-term services and supports is expected to more than double from approximately 12 to 27 million individuals by 2050.⁴⁶ An inadequate national system of financing long-term services and supports is placing a great burden on American families. Those from the Generation X and millennial generations are increasingly finding themselves in the role of a sandwich caregiver, providing unpaid care to an aging parent or other adult as well as raising children. This report provides a valuable profile of this population of caregivers.

One of the key findings of the report is the extent to which this population of caregivers is juggling extensive caregiving time demands with work.

One of the key findings of the report is the extent to which this population of caregivers is juggling extensive caregiving time demands with work. Two-thirds (67 percent) of these caregivers are employed. On average, they are working 36 hours per week and devoting 22 hours per week to care for an adult, all on top of raising children. Given these time demands, it is not surprising that other studies have similarly found that these caregivers report feeling stressed,⁴⁷ overwhelmed, and have less time to spend with friends and other family.⁴⁸ Other studies have also found negative impacts on well-being⁴⁹ and health-related behaviors, such as lower levels of exercise and self-care.⁵⁰ Moreover, as highlighted in this report, the majority (60 percent) report negative impacts on their employment and many, particularly millennials, report not having adequate workplace supports and flexibility.

The report also provides useful snapshots of various subpopulations of sandwich caregivers which can help inform policy and improve interventions. Consistent with other research,⁵¹ the report highlights greater racial and ethnic diversity among this population of caregivers, particularly higher rates of Hispanic (22 percent) and African American (16 percent) caregivers. Racial and ethnic minority caregivers are less likely to receive formal services and face barriers in receiving culturally competent interventions and supports.⁵² The report also highlights important issues concerning care in rural areas. While a third of care recipients of sandwich caregivers reside in rural areas, their caregivers are less likely to also reside there, which requires commuting and other strategies to coordinate care from a distance.

The report contributes to a better understanding of a population of caregivers that will significantly grow in the coming decades as the baby boom generation ages and acquires needs for long-term services and supports. Many characteristics and issues facing sandwich caregivers mirror those facing caregivers in general. However, the report highlights some important differences, particularly greater time demands and potential implications for health and economic well-being. Moreover, not only are sandwich caregivers more racially/ethnically diverse, there is great variation within this population. As highlighted in the report, there are many subpopulations even within this population. Also, many are providing care within a network of other unpaid and paid supports. The report reminds us of the need to develop policies and practices that are flexible and approach families holistically, using a person and family-centered approach based on assessment of their unique situation and needs.

⁴⁶U. S. Senate Commission on Long-Term Care, "U. S. Senate Commission on Long-Term Care: Report to the Congress, (Washington, D.C., 2013).

⁴⁷Rose M. Rubin and Shelley I. White-Means, "Informal Caregiving: Dilemmas of Sandwiched Caregivers," *Journal of Family and Economic Issues*, 30, (2009), 252–267.

⁴⁸Easter Seals, Inc, "Many Faces of Caregiving Study," (Washington DC: Easter Seals and Mass Mutual, 2015).

⁴⁹Leslie B. Hammer and Margaret B. Neal, "Working Sandwiched-Generation Caregivers: Prevalence, Characteristics, and Outcomes," *The Psychologist-Manager Journal*, 11, no. 1, (2008), 93-112.

⁵⁰Laurie Chassin, Jon T. Macy, Dong-Chul Seo, Clark C. Presson and Steven J. Sherman, "The Association Between Membership in the Sandwich Generation and Health Behaviors: A Longitudinal Study," *Journal of Applied Developmental Psychology*, 31, (2010), 38–46.

⁵¹Kim Parker and Eileen Patten, "The Sandwich Generation: Rising Financial Burdens for Middle-Aged Americans," *The Pew Research Center*. <https://www.pewsocialtrends.org/2013/01/30/the-sandwich-generation/>.

⁵²Evercare and National Alliance for Caregiving, *Hispanic Family Caregiving in the U.S. (Minnetonka and Bethesda: Evercare and National Alliance for Caregiving, 2008)*.

DEMOGRAPHIC PROFILE

Most sandwich caregivers are women (61%) and they are 41 years old, on average. Rural caregivers younger still at 37.6 years old. They are diverse with non-Hispanic Whites constituting just over half the racial/ethnic makeup.

Figure 20: Gender, LGBT Status, Age, Race and Ethnicity

	Sandwich Caregivers	Non-Sandwich Caregivers
Caregiver Gender		
Female	61%	59%
Male	39%	41%
Caregiver LGBT status		
Yes	4%	10%*
Age of Caregiver		
18 to 34	33%*	20%
35 to 49	44%*	15%
50 to 64	18%	40%*
65 to 74	3%	15%*
75 or older	<0.5%	10%*
Mean age	40.7	52.8*
Race/Ethnicity of Caregiver		
White Non-Hispanic	53%	66%*
Hispanic	22%*	15%
African-American Non-Hispanic	16%	12%
Asian/Pacific Islander	7%	6%
Other	2%	2%





The majority (77%) of sandwich caregivers are between 18 and 49 years of age (mean 40.7), while most non-sandwich caregivers (65%) are over the age of 50 (mean 52.8).

The majority (79 percent) of sandwich caregivers are married/partnered, while 59 percent of non-sandwich caregivers are married or partnered. The majority (77 percent) of sandwich caregivers are between 18 and 49 years of age (mean 40.7), while most non-sandwich caregivers (65 percent) are over the age of 50 (mean 52.8). About four in ten have a high school degree or less (39 percent), while 31 percent have a college degree or more. In comparison, 35 percent of non-sandwich caregivers have a high school degree or less, while 37 percent have a college degree or more. Half have a household income of \$50,000 or less with a median income of \$51,900, slightly less than non-sandwich caregivers (\$56,300). By comparison, the median household income in the United States in 2014 was \$53,718.⁵³ The table below further de-segregates income levels.

Figure 21: Marital Status and Household Income

	Sandwich Caregivers	Non-Sandwich Caregivers
Caregiver Marital Status		
Married	67%*	53%
Living with a partner	12%*	6%
Single, never married	13%	22%*
Divorced	4%	9%*
Separated	2%	1%
Widowed	1%	7%*
Caregiver Education		
Less than high school	11%*	6%
High school graduate	28%	29%
Some college	25%	20%
Technical school	7%	8%
College graduate	21%	20%
Graduate school	10%	17%
Caregiver Household Income		
Less than \$50,000 (net)	49%	46%
Less than \$15,000	10%	13%
\$15,000 to \$29,999	17%	15%
\$30,000 to \$49,999	21%	17%
\$50,000 or more (net)	51%	54%
\$50,000 to \$74,999	17%	18%
\$75,000 to \$99,999	11%	14%
\$100,000 or more	23%	23%
<i>Median Household Income</i>	\$51,900	\$56,300

⁵³U.S. Census Bureau, *Income and Poverty in the United States: 2014, (2015)*. <https://www.census.gov/content/dam/Census/library/publications/2015/demo/p60-252.pdf>.

About one in seven sandwich caregivers lives in a rural area (15 percent), while 33 percent of their care recipients live in a rural area. Most were employed while caregiving (67 percent), 8 percent have served on active duty in the military, and 4 percent reported being lesbian, gay, bisexual, and/or transgender.

Figure 22: Living Location, Employment Status, and Service in the Armed Forces

	Sandwich Caregivers	Non-Sandwich Caregivers
Care Recipient Living Location		
Non-Rural	67%	73%
Rural	33%*	26%
Caregiver Living Location		
Non-Rural	85%	84%
Rural	15%	16%
Caregiver Employment Status		
Employed in past year while caregiving	67%*	57%
Not employed	33%	43%
Caregiver Service in Armed Forces		
Ever served on active duty	8%	11%
Did not ever serve	92%	88%
Care Recipient Service in Armed Forces		
Ever served on active duty	10%	15%*
Did not ever serve	89%	83%





National Alliance for Caregiving

1730 Rhode Island Avenue NW
Suite 812
Washington, DC 20036

202.918.1013 phone
202.918.1014 fax
info@caregiving.org

caregiving.org



About the National Alliance for Caregiving

Established in 1996, the National Alliance for Caregiving is a non-profit coalition of national organizations focusing on advancing family caregiving through research, innovation, and advocacy. NAC conducts research, does policy analysis, develops national best-practice programs, and works to increase public awareness of family caregiving issues. Recognizing that family caregivers provide important societal and financial contributions toward maintaining the well-being of those they care for, NAC supports a network of more than 80 state and local caregiving coalitions and serves as Secretariat for the International Alliance of Carer Organizations (IACO). Learn more at www.caregiving.org.