



NOVEMBER 2021 NATIONAL REPORT  
**CAREGIVING IN A DIVERSE AMERICA:**

BEGINNING TO UNDERSTAND  
THE SYSTEMIC CHALLENGES  
FACING FAMILY CAREGIVERS



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The National Alliance for Caregiving is proud to present *Caregiving in a Diverse America: Beginning to Understand the Systemic Challenges Facing Family Caregivers*. This secondary analysis was made possible through sponsorship by Amgen, Inc. and with generous support from the Diverse Elders Coalition and in partnership with the National Minority Quality Forum. NAC developed the study methodology and conducted the data analysis independently. Data analysis and the draft report were then reviewed by the Advisory Committee. Amgen, DEC, and NMQF received a preliminary briefing on the findings of the report prior to the Advisory Committee review; all editorial decisions were made by NAC and the Advisory Committee, without input from the report sponsor.

### Caregiving in the U.S.

The data underlying this analysis is from the *Caregiving in the U.S. 2020* study, commissioned by the National Alliance for Caregiving (NAC) and AARP, and conducted by Greenwald Research ([www.greenwaldresearch.com](http://www.greenwaldresearch.com)). To learn more about the Caregiving in the US 2020 study and its sponsorship visit: [www.caregiving.org/caregiving-in-the-us-2020/](http://www.caregiving.org/caregiving-in-the-us-2020/).

### Author's Note

*Caregiving in the U.S. 2020* was fielded in 2019, prior to the COVID-19 pandemic. While some data reported in the study may have changed due to the pandemic, the crisis heightened some of the challenges that caregivers face, including feelings of loneliness, financial and emotional strain, and work balance while providing care.

Bose, M., Tokarewich, L., Bratches, R. W. R., & Barr, P. J. Caregiving in a Diverse America: Beginning to Understand the Systemic Challenges Facing Family Caregivers. Washington, D.C.: National Alliance for Caregiving. November 2021.

<sup>1</sup>Unpaid caregivers were defined as those described in the following question: "At any time in the last 12 months, has anyone in your household provided unpaid care to a relative or friend 18 years or older to help them take care of themselves? This may include helping with personal needs or household chores. It might be managing a person's finances, arranging for outside services, or visiting regularly to see how they are doing. This adult need not live with you."

## ACKNOWLEDGMENTS

### Leadership

C. Grace Whiting, JD, President and CEO, National Alliance for Caregiving  
Michael Reese Wittke, MPA, Vice President, Research and Advocacy, National Alliance for Caregiving

### Authors

Mousumi Bose, PhD, Assistant Professor, Department of Nutrition and Food Studies, College of Education of Human Services, Montclair State University

Lauren Tokarewich, MLIS, Research Manager, National Alliance for Caregiving

Reed W.R. Bratches, MPH, PhD Candidate, The Dartmouth Institute for Health Policy and Clinical Practice; The Center for Technology and Behavioral Health, Dartmouth College

Paul J. Barr, PhD MSc, Associate Professor, Health Policy and Clinical Practice, The Dartmouth Institute for Health Policy & Clinical Practice; The Center for Technology and Behavioral Health, Dartmouth College

### Contributors

Alyssa Smolen, BS, Department of Nutrition and Food Studies, College of Education of Human Services, Montclair State University

Lisa Weber-Raley, MA, Chief Research Officer, Greenwald Research

Feylyn Lewis, PhD, Research Fellow, University of Sussex

Gabriela Prudencio, MBA

Karen L. Marshall, JD

Charlotte Davidson

### Advisory Committee

Rita B. Choula, MA, Director, Caregiving, AARP Public Policy Institute

Yanira Cruz, MPH, DrPH, President and CEO, National Hispanic Council on Aging

J. Nicholas Dionne-Odom, PhD, RN, ACPN, FPCN, Assistant Professor, School of Nursing, The University of Alabama at Birmingham

Eboni Green PhD, RN, Caregiver Support Services

Tamryn F. Gray, PhD, RN, MPH, Instructor in Medicine, Dana-Farber Cancer Institute, Brigham and Women's Hospital, Harvard Medical School

Tim R. Johnston, PhD, Senior Director of National Projects, SAGE

Ocean Le, BSBA, MS, Senior Program Coordinator, Diverse Elders Coalition

Sandy Magaña, PhD, MSW, Professor in Autism and Neurodevelopmental Disabilities, University of Texas at Austin School of Social Work

Jared Make, Vice President, A Better Balance

Lauren Pongan, MA, National Director, Diverse Elders Coalition

Regina A. Shih, PhD, Senior Policy Researcher, RAND Corporation Aaron Tax, Director of Advocacy, SAGE

Jahdziah O. St. Julien, Research Associate at the Better Life Lab, New America

Gretchen C. Wartman, Vice President for Policy and Program, National Minority Quality Forum



## FOREWORD

NAC is proud to present *Caregiving in a Diverse America: Beginning to Understand the Systemic Challenges Facing Family Caregivers*. In the Diverse Elders Coalition's eleventh year of existence, coalition members like the National Hispanic Council on Aging, continue to ensure that the needs and perspectives of vulnerable older adults are heard when and where it matters. Reading this report, you will find many examples of the challenges experienced by caregivers of diverse backgrounds. It is our hope that readers, policy makers, programs developers, and innovators will use our efforts to work toward creating solutions that will address these challenges.

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This report expands on the diverse experiences of family caregivers and provides important policy recommendations to help aid family caregivers in their important tasks.

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*Familism* (a strong identification with and prioritization of family over personal needs), is common not only among Latino cultures but many other cultures. It imbues us with a sense of obligation to care for the older adults in our families (our abuelas, padres, tias, and tios) that often results in our failure to self-identify as caregivers—even though that is exactly what we are. Too often, we think of caregivers as paid staff and fail to acknowledge our own contributions, challenges, and stressors. Our failure to identify as caregivers may result in missed opportunities to access existing resources that can assist us with the inherent challenges of caregiving.

Different cultures value respect for the autonomy of our older adults, preservation of their dignity, and maintenance of their roles within our families, and it is one of the most beautiful aspects of these cultures! Often, our elders have paved the way for us to accomplish and achieve our goals. Caring for our older adults can give us a sense of pride, but it is not an easy job. Caregiving can be costly, in terms of finances, time, and our own health. By recognizing our roles as caregivers in our families, we can open ourselves to the information and resources that exist to aid us with this difficult but necessary task.

As a family caregiver myself, I know firsthand the joys and struggles that come from caring for loved ones. It can be an isolating experience, but know that you are not alone. This report expands on the diverse experiences of family caregivers and provides important policy recommendations to help aid family caregivers in their important tasks.

Yanira Cruz, MPH, DrPH  
 President and CEO  
 National Hispanic Council on Aging

# CHANGING PARADIGMS IN CAREGIVER RESEARCH

This report highlights significant disparities in support, caregiving intensity, health, and financial impacts among caregivers of color, LGBTQ caregivers, as well as caregivers across different income brackets and geographical areas. While this report substantially adds to the knowledge base in the characterization of the diverse experiences of caregivers in the United States, it is undoubtedly clear that this is only a preliminary step and that there is an urgent need for additional research that purposefully establishes objectives related to a better understanding of caregivers from diverse backgrounds. More inclusive, transparent, and representative primary data collection is an imperative next step to help continue the effort in reducing existing disparities and ensuring more equitable delivery of programs, resources, and services for caregivers and their care recipients.

While the recommendations in this report focus primarily on next steps for improving some of the key limitations uncovered during our research, the data analysis highlights some general themes that can meaningfully improve the caregiver experience for diverse populations:

- Acknowledging, incorporating, and continually improving cultural literacy into the development of programs, resources, and services designed for caregivers of diverse racial and ethnic backgrounds.
- Ensuring that the eligibility criteria for programs and services designed for caregivers offer an inclusive definition of “family”—to include siblings, aunts, uncles, cousins, nieces, nephews, grandparents, grandchildren, and domestic partners.
- Recognizing and increasing access to caregiver programs, resources, services, and support networks that are designed to go beyond traditional notions of the family structure and are inclusive of the LGBTQ+ community.
- Facilitating better access to programs, services, and resources to caregivers in rural areas and where access to technology is less readily available or counter-productive to the needs of the caregiver or person receiving care.

**The following recommendations that precede the findings in this report aim to offer next steps and recommendations for researchers in the field who are continuing to develop datasets that better represent the heterogeneity of the caregiver experience.**

## INVEST IN CAREGIVING RESEARCH AND DATA COLLECTION

We need multicultural data for meaningful patient and family engagement in U.S. health and social care systems. To ensure a robust and inclusive system of services and supports that intentionally address health disparities and systemic barriers, we must overcome the challenges related to the cost or inconvenience of integrating diverse populations into research design. Rather than stating “we know best” based on unrepresentative data and outdated cultural understandings of need, it’s past time to move forward and become more inclusive and transparent in our data collection efforts to ensure interventions are person- and family-centered and improve caregiver and patient health and well-being. Programs need to be designed to reach those they intend to serve, and we need to ensure the services provided are in line with personal, cultural, and ethic preferences.



It is undoubtedly clear that this is only a preliminary step and that there is an urgent need for additional research that purposefully establishes objectives related to a better understanding of caregivers from diverse backgrounds.

Partnerships and outreach to tribal governments can yield opportunities to speak with caregivers.

Following are some recommendations for future data collection efforts that will ensure we are reaching a broader range of people who are underrepresented in the current data set.

## ADDRESS THE LACK OF AMERICAN INDIAN/ALASKA NATIVE REPRESENTATION

This study does not include an in-depth examination of caregivers within the American Indian/Alaska Native (AI/AN) population. The primary reason for this exclusion is related to the method of data collection. The data on ethnic and racial minorities in this present study was taken from the *Caregiving in the U.S. 2020* data set, which was collected from a nationally representative online panel. Although additional online and telephone surveys to supplement the initial random sample were conducted via targeted sampling of some racial/ethnic groups, it's clear that the methodology used severely impacted our ability to properly sample and explore the lives of American Indian and Alaska Native caregivers.

In fact, few studies have been done to examine American Indian/Alaska Native caregivers. The Centers for Disease Control (CDC) found that one in four AI/AN adults are caregivers, meaning a significant number of the population requires caregiver recognition, support, and services.<sup>2</sup> A 2011 study conducted by Goins et al. explores in-depth the cultural and demographic profile of AI caregivers, as well as how their culture affects being a caregiver.<sup>3</sup> Understanding the role of culture in AI/AN caregivers is as important to knowing how to help them as it is in all other communities sampled in this report. While this general understanding of the AI/AN cultural impact on caregiving is necessary, it is important to remember that numerous federally-recognized AI/AN tribes<sup>4</sup> are themselves diverse and may connect to their cultures and their caregiving role in different ways.

Little research has been conducted on AI/AN caregiver health. Understanding how quality of life and stress levels for AI/AN caregivers can be affected as a result of their caregiving role is essential for creating effective interventions. One such study found that American Indian caregivers' health was related to the type of care that they provided, but much more research needs to be done in order to understand sources of stress and how to relieve them.<sup>5</sup> In general, studies have shown that, regardless of caregiver status, the AI/AN community has shouldered a disproportionate disease burden, and their life expectancy is 5.5 years lower than the average of all other Americans.<sup>6</sup> According to the U.S. Department of Health and Human Services, AI/AN are at a higher risk for mental health strain and suicide, unintentional injury, obesity, substance abuse, SIDS, diabetes, liver disease, and hepatitis. The leading causes of death among the community are heart disease, cancer, diabetes, and stroke. It is important to note that members of the AI/AN community frequently face difficulties accessing and receiving quality medical care, whether due to language/cultural barriers, geography, or low income.<sup>7</sup> Housing on reservations can be overcrowded and lack access to plumbing.<sup>8</sup> When considering AI/AN health, it is very important to recognize that prevalent diseases and conditions are often a result of years of systemic oppression and mistreatment, and are not inherent to the community.

Since so little has been done to conduct research with AI/AN caregivers, we must understand the general relationship of AI/AN to caregiving. Caregivers often have a hard time realizing or admitting they are caregivers. Cultural factors can turn the idea of being a caregiver into a negative connotation or can cause rejection of the idea that helping to care for someone else is burdensome or stressful. Respect for elders is a significant central value in AI/AN culture.<sup>9</sup> One American Indian study participant explained that taking care of one another is how American Indians have managed to survive. This same study also found that it is common practice for community members to help elders they aren't related to, a strength in the AI/AN population that has not been studied enough

<sup>2</sup>Alzheimer's Disease and Healthy Aging. (2019). American Indian/Alaskan Native Adults. Centers for Disease Control and Prevention. Retrieved 2021, September 27 from <https://www.cdc.gov/aging/data/infographic/2017/american-indian-adults-caregiving.html>.

<sup>3</sup>Goins, R.T., Spencer, S.M., McGuire, L.C., Goldberg, J., Wen, Y., & Henderson, J.A. (2011). Adult caregiving among American Indians: The role of cultural factors. *The Gerontologist*, 51(3), 310–20. Doi: 10.1093/geront/gnq101.

<sup>4</sup>Federal and State Recognized Tribes. National Conference of State Legislatures. Retrieved 2021, September 27 from <https://www.ncsl.org/legislators-staff/legislators/quad-caucus/list-of-federal-and-state-recognized-tribes.aspx#State>.

<sup>5</sup>Spencer, S.M., Goins, R.T., Henderson, J.A., Wen, Y., & Goldberg, J. (2013). The influence of caregiving on health-related quality of life among American Indians. *Journal of the American Geriatrics Society*, 61(9), 1615–20. Doi: 10.1111/jgs.12409.

<sup>6</sup>Disparities. (2019, October). Indian Health Service. Retrieved 2021, September 27 from <https://www.ihs.gov/newsroom/factsheets/disparities/>.

<sup>7</sup>Office of Minority Health. (2021, September 24). Profile: American Indian/Alaskan Native. Retrieved 2021, September 27 from <https://minorityhealth.hhs.gov/omh/browse.aspx?lvl=3&lvlid=62>.

<sup>8</sup>Housing and Infrastructure. National Congress of American Indians. Retrieved 2021, September 27 from <https://www.ncai.org/policy-issues/economic-development-commerce/housing-infrastructure>.

<sup>9</sup>Elders. National Congress of American Indians. Retrieved 2021, October 7 from <https://www.ncai.org/policy-issues/education-health-human-services/elders>.

<sup>10</sup>Jervis, L.L., Boland, M.E., & Fickensher, A. (2010). Journal of Cross-Cultural Gerontology, 24(4), 355–69. Doi: 10.1007/s10823-010-9131-9.

<sup>11</sup>Urban Indian Health. Urban Indian Health Institute. Retrieved 2021, October 13 from <https://www.uihi.org/urban-indian-health/data-dashboard/>.

as it relates to caregiving. There was also some expressed concern that this cultural respect and care for elders has been slowly disappearing.<sup>10</sup> Younger generations of the AI/AN population have been migrating to more urban areas, increasing the need for research and outreach in order to understand their caregiving needs.<sup>11</sup> It is extremely important to connect with AI/AN caregivers to better understand their relationship to their role, the cultural factors that play a part in their role, and how the role may be affecting their own health.

There are several strategies that may be effective options to better engage AI/AN caregivers. Partnerships and outreach to tribal governments can yield opportunities to speak with caregivers. Caregivers can be recruited through community centers, health clinics, and centers and services geared toward senior citizens. Outreach needs must be accessible, such as through phone surveys and translating surveys into the participants' preferred language. Studies and research teams need to make a deliberate effort to include AI/AN caregivers in a significant way so that they can be comparably sampled to other communities and have their needs and experiences represented.

Further research is needed to understand the experiences of AI/AN caregivers as a community. As the AI/AN community itself can be extremely diverse based on geography and culture, caregiving needs will vary. This will require different solutions to provide caregiver support. According to the National Congress of American Indians, there are 574 federally-recognized Indian Nations. In addition, there are tribes across the nation recognized by individual state governments.<sup>12</sup> These tribes can be differentiated from each other through linguistic, community, spiritual, and cultural practices in every way imaginable. While understanding the general needs and make-up of the AI/AN caregiving community is important, researchers and policy makers need to be aware of how these needs may change among tribes and geographies.

Finally, the historical interactions between the AI/AN community and American federal and state governments, including the health care systems, have been poor, to say the least. The AI/AN community has been continuously overlooked, mistreated, and under-supported by systems that are meant to help. This may affect the willingness of AI/AN caregivers to engage in research surveys. The goal in conducting research on AI/AN caregivers is not only to learn more about them, but to drive future policy and develop interventions that will improve their lives. With this goal in mind, it is extremely important to fund research studies being conducted by members of the AI/AN community, to work with community-based organizations and local services that already support AI/AN caregivers and communities, and to continue to work toward fostering an equitable relationship where the health care system and those involved are held accountable for the work they conduct.

## ADDRESS THE LACK OF INTERSECTIONALITY AND SEGMENTATION IN RESEARCH

The main groups for the *Caregiving in the U.S. 2020* survey were split into the following categories: Non-Hispanic White, Hispanic, African American, Asian American/Pacific Islander and LGBTQ+. As a result of these limited categories, our study tends to paint different ethnic and diverse groups in broad brushstrokes of interpretation, limiting our understanding of the data and how these populations are affected other than as a general categorized whole.

There is further segmentation within these groups that can be explored to gain a better understanding of caregiver experiences, conditions, and needs, and especially how culture and identity may affect caregiver strain. Hispanics as a demographic category cover a wide range of ethnicities, identities, languages, and peoples, from Mexican to Spanish to Latin American. For example, even among Latin Americans, Brazilians may have a different understanding and relationship to caregiving than El Salvadorians; further, the term Latino may be preferred to Hispanic.<sup>13</sup>

It is extremely important to fund research studies being conducted by members of the AI/AN community, to work with community-based organizations and local services that already support AI/AN caregivers and communities.

<sup>12</sup>Tribal nations and the United States: An introduction. National Congress of American Indians. Retrieved 2021, September 27 from <https://www.ncai.org/about-tribes>.

<sup>13</sup>Lopez, M.H., Krogstad, J.M., & Passel, J.S. (2021, September 23). Who is Hispanic? Pew Research Center. Retrieved 2021, September 27 from <https://www.pewresearch.org/fact-tank/2020/09/15/who-is-hispanic/>.



People identify themselves in numerous unique and personal ways, and their identities can affect their relationship to culture, family members, the world, and caregiving. Ignoring any of these identities creates gaps in research.

African American, as a definition, is widely understood to be those in America of African descent. However, the Black ethnic identity has largely emerged as the preferred term for those who feel no connection to descendants of Africa or have come to America from a country other than Africa, such as Haiti or Denmark.<sup>14</sup> Some have argued that neither “Black” nor “African American” truly covers the heterogeneity among these groups.<sup>15</sup>

Asian American is also an incredibly broad term for the people, cultures, and identities it is meant to encompass. “Asian Americans” could mean people of Chinese, Korean, Vietnamese, Thai, Singaporean, Cambodian, or Filipino heritage, among others. Although not deeply explored in this data set, many researchers also include the geographically close racial/ethnic group of Pacific Islanders, which includes those from Polynesia, Samoa, Tonga, Tahiti, and other countries of origin. The Asian American and Pacific Islander communities consist of about 50 different ethnic groups that speak over 100 different languages.<sup>16</sup>

Within the LGBTQ+ community, there are numerous ways to identify, each carrying their own personal meaning. Beyond identifying as lesbian, gay, bisexual, transgender and/or queer, there are members of the community that identify as pansexual, asexual, non-binary, unlabeled, and more. It becomes difficult to claim that quantitative analysis can fully represent these populations and their needs when there is so much cultural and identity diversity within individual families.

This analysis does not account for intersectionality among groups. For example, those who identify as Black may also identify as Hispanic, which our study did not explore, minimizing insight that could be gained from the Afro-Latin population in America. Further, the LGBTQ+ portion of this study was analyzed by comparing those caregivers who identified as LGBTQ+ to those who did not. No research was done on what the differences and similarities might be among different race/ethnicity groups that identified as LGBTQ+. Socially constructed dimensions and how they interact as dynamic, rather than static forces, can be an essential tool in attempting to understand these interrelating powers.<sup>17</sup>

People identify themselves in numerous unique and personal ways, and their identities can affect their relationship to culture, family members, the world, and caregiving. Ignoring any of these identities creates gaps in research; our study did not gather any data, for example, from American Indian/Alaska Native, or Middle Eastern communities. Creating a greater understanding of what we can do to help caregivers requires conducting research that accounts for both segmentation and intersectionality and provides the widest range of ethnic, racial, gender, and sexual identities as possible without oversaturating, and with input and understanding from the populations being studied. Doing so will allow us to explore these populations in greater detail with a better sense of cultural competency, humility, and awareness, and ultimately, will allow us to provide real, significant support and help to caregivers in these underrepresented and marginalized populations.

<sup>14</sup>Adams, C. (2020, June 18). Not all Black people are African American. Here's the difference. CBS News. Retrieved 2021, September 27 from <https://www.cbsnews.com/news/not-all-black-people-are-african-american-what-is-the-difference/>.

<sup>15</sup>Agyemang, C., Bhopal, R., & Bruijnzeels, M. (2005). Negro, Black, Black African, African Caribbean, African American or what? Labeling African origin populations in the health arena in the 21st century. *Journal of Epidemiology & Community Health* 59, 1014–18. Doi: 10.1136/jech.2005.035964.

<sup>16</sup>Asian American and Pacific Islander. National Alliance for Mental Illness. Retrieved 2021, September 27 from <https://www.nami.org/Your-Journey/Identity-and-Cultural-Dimensions/Asian-American-and-Pacific-Islander>.

<sup>17</sup>Misra, J., Curington, C.V., & Green, V.M. (2020). Methods of intersectional research. *Sociological Spectrum*, 41(1), 9–28. Doi: 10.1080/02732173.2020.1791772.



# METHODOLOGY

To complete this study, the National Alliance for Caregiving (NAC) analyzed and interpreted data from the *Caregiving in the U.S. 2020* dataset (n=1,392 caregivers), a report that was conducted in partnership with the AARP Public Policy Institute and includes nationally representative quantitative data on African American, Hispanic, Asian American<sup>18</sup> and Pacific Islander caregivers, in addition to LGBTQ populations, and caregivers stratified by income level and geographical location.<sup>19</sup> All caregivers were interviewed using a national, probability-based online panel, with surveys conducted between May 29 and July 27, 2019. To find more information about the methodology, including the sampling frame or additional information about the probability-based panel, please see Appendix B in *Caregiving in the U.S. 2020*.<sup>20</sup>

The survey identified the presence of a caregiver in the home and asked if the caregiver provided unpaid care to a child, relative, or friend twelve months prior to the survey, and if he/she/they provided support with activities of daily living (ADL), instrumental activities of daily living (IADL), or medical/nursing tasks. The sample sizes (N) noted in each table or graphic represent the unweighted number of respondents who answered each question and is rounded to the nearest whole number.

Results presented are statistically significant (as determined by independent samples Z-test) at the 0.05 level unless otherwise noted. In tables and graphs, a bolded figure or a notation of \* denotes that the value is statistically significantly higher/lower than the comparison table. Some charts/tables may not total 100 percent since “don’t know” or “refused to answer” responses may not be represented in the charts and tables. The results for multiple-response questions may total more than 100 percent due to rounding.

The following table shows the number of unweighted, completed surveys from different groups of caregivers.

**Figure 1: Unweighted Sample Size by Population**

	All caregivers of an adult age 18+	Sample details
Non- Hispanic White	801	Includes any Non-Hispanic White caregivers found in the online national sample only (part of base sample)
African- American	199	Includes any Non-Hispanic African American or Blacks found in the base sample (online national sample + online African American targeted oversample)
Hispanic	205	Includes any Hispanics found in the base sample (online national sample + online Hispanic targeted over-sample)
Asian American and Pacific Islander*	197	Includes any Asian Americans and Pacific Islanders found in the base sample (online national sample + online Asian American and Pacific Islander targeted oversample) and the phone Asian American and Pacific Islander oversample
Other Race and Ethnicity	68	Includes 7 American Indian or Alaska Native, and 61 respondents with two or more races.
LGBTQ	100	Includes any LGBTQ caregivers found in the base study (online national sample)

Note: These numbers do not add up to 1,392 as the groups are not mutually exclusive. Results are rounded and/or multiple response; results may not add to 100 percent.

All caregivers were interviewed using a national, probability-based online panel, with surveys conducted between May 29, 2019, and July 27, 2019.

<sup>18</sup>Asian American is defined to align with the U.S. Census and is inclusive of those of origin, background, or descent of areas of Southeast Asia, the Indian subcontinent, and East Asia, as well as the Pacific Islands.

<sup>19</sup>For the purposes of this report, these are the populations we are referring to when referencing “diverse caregivers.”

<sup>20</sup>Appendix B of *Caregiving in the U.S. 2020* was accessed at <https://www.caregiving.org/wp-content/uploads/2020/05/Appendix-B-Caregiving-in-the-United-States-2020.pdf>.



To account for possible confounding variables that may unknowingly impact the association between groups and outcomes, NAC commissioned researchers at Dartmouth College to conduct multiple logistic regression analyses to determine if associations exist independent of confounding variables. Specifically, the analysis examined the relationship between caregiver characteristics and important caregiver outcomes, including physical, financial, and emotional strain, performed *Activities of Daily Living (ADL)* and *Instrumental Activities of Daily Living (IADL)*, *Intensity of Care Index*, which combines hours of care and care tasks provided<sup>21</sup> and information/services used, where caregivers were asked what *respite, transportation, home modification services, or information from medical care providers* they had received as caregivers. Associations that were explored in this analysis accounted for the following characteristics of the caregiver: gender, age, income, and care-recipient condition. The overarching research question of the logistic regression analysis was:

Do caregivers identifying with diverse backgrounds, including race/ ethnicity, income, and LGBTQ status, experience different outcomes regarding strain, Intensity of Care Index, ADLs/IADLs, and information/services used?

Results for the regression analyses are reported as odds ratios and p-values. An odds ratio is the chance of an occurrence relative to the chance of non-occurrence; an odds ratio of 1 means that there is no increase or decrease in odds of occurrence (see table below).

**Figure 2: Odds Ratio Interpretation and Meaning**

Result	What is it?	What does an odds ratio look like?	How is it interpreted?	What does it mean?
Odds Ratio (OR)	The ratio between the probability of an occurrence over the probability of non-occurrence	Typically presented as a ratio, e.g., 1.25, or a percent, e.g., 25% greater	OR=1 Exposure Does Not Affect Odds of Outcome  OR > 1 Exposure Associated with Higher Odds of Outcome  OR <1 Exposure Associated with Lower Odds of Outcome	It means that the odds of experiencing an outcome are increased or decreased

The analysis examined the relationship between caregiver characteristics and important caregiver outcomes, including physical, financial, and emotional strain, performed *Activities of Daily Living (ADL)* and *Instrumental Activities of Daily Living (IADL)*, *Intensity of Care Index*.

## REFERENT GROUPS

When using logistic regression, it is important to note that the results are interpreted in relation to particular categories, called “referent groups.” Logistic regression models allow us to see whether there are a higher or lower odds of experiencing the outcome (in this case, odds of economic or financial strain, or odds of having high level of caregiving intensity), but this requires a comparison: the results are higher or lower than a different group. Choosing which group to use as the referent group is based on the category being compared. For categories with a defined order, such as age or income level, a best practice is to use an end-group to more easily identify trends in the data. For categories with no defined order, such as race and ethnicity, a best practice is to use the largest group to allow for more precision when comparing.

<sup>21</sup>For detail on calculation of burden of care index, see *Caregiving in the U.S. 2020* ([www.caregiving.org/caregiving2015](http://www.caregiving.org/caregiving2015)).

For this study, referent groups were selected based on the following best practice: first or last group for ordered groups, and the groups with the largest number of survey respondents for non-ordered groups. This resulted in our referent groups being Non-Hispanic White caregivers; caregivers with an income greater than \$150,000; non-LGBTQ caregivers, caregivers ages 18–29, and care recipients ages 18–29. It is important to note that these groups are mutually exclusive, meaning the referent groups are only applicable within that specific group. A caregiver can belong to one referent group and not the other; our referent groups should not be interpreted as suggesting a “typical” caregiver, nor should they be seen as indicating that the experience of the referent groups is “typical,” “normal,” or “ideal.” Referent groups were chosen solely on statistical best practice.<sup>22</sup>

A detailed methodology of the approach taken to produce the advanced statistical analysis is provided in the Appendix.

Additionally, the report includes a series of snapshots of caregivers from diverse backgrounds—narrative stories personalizing caregiving journeys and offering insight into caregivers’ daily lives. While statistics are critical to understand the state of caregiving in the United States, these stories are aimed to further portray the many faces of caregiving in our country.

The *Caregiving in the U.S. 2020* dataset is one of the few caregiving datasets with a vast demographic representation of family caregivers in the United States. It is the largest representative survey of caregivers in the United States, with a robust approach to recruitment through KnowledgePanel®, using a probability-based sample that most completely represents the demographics of the public.<sup>23</sup> The oversampling of the data also occurred solely from the probabilistic panel.

Despite the robustness of this dataset, the study has some scope limitations in understanding diverse caregivers. *Caregiving in the U.S. 2020* is a cross-sectional study; therefore, it is not possible to determine causality between predictors and outcomes; the possibility of a bi-directional relationship exists.

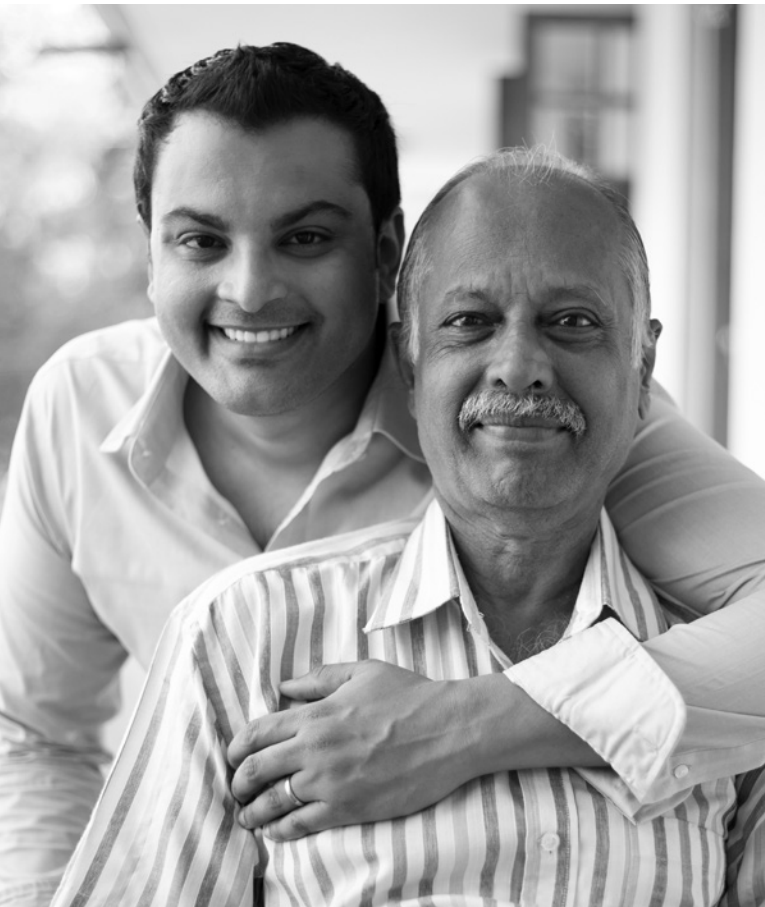
One limitation of this data collection is that the data was mostly gathered electronically, with only 1,499 full surveys, except for Asian American and Pacific Islander caregivers, who were oversampled using a blended landline and cell phone sample. Individuals without access to the internet were provided a device to enable them to respond to surveys. This approach enabled us to scientifically randomize the sample based on residential addresses. Nevertheless, the electronic-based data collection approach may have caused self-selection for a population with enhanced internet access. Additionally, the survey was fielded in English and Spanish only.

Another limitation of this study was the ability to reach a large sample of diverse caregivers of people under age 50, particularly LGBTQ and Asian American and Pacific Islander caregivers, due to the lower prevalence of this population. While probabilistic sampling can reduce overall margins for sampling error, targeted non-probability sampling is more efficient to reach multicultural populations.

While statistics are critical to understand the state of caregiving in the United States, these narrative stories personalizing caregiving journey are aimed to further portray the many faces of caregiving in our country.

<sup>22</sup>Sperandei, S. (2014). Understanding Logistic Regression Analysis. *Journal of Biochemical Medicine*, 24(1), 12–18. Doi: 10.11613/BM.2014.003.

<sup>23</sup>Hays, R.D., Liu, H. & Kapteyn, A. (2015). Use of internet panels to conduct surveys. *Behavior Research Methods*, 47(3), 685–90. doi:10.3758/s13428-015-0617-9.



## DETAILED FINDINGS

### PREVALENCE

One in five Americans are providing care to an adult or a child because of a health care need or functional disability.<sup>24</sup> Therefore, we estimate that 53.0 million Americans are caregivers today, up from 43.5 million in 2015.<sup>25</sup> An estimated 61 percent are Non-Hispanic White, 17 percent are Hispanic, 14 percent are African American, 5 percent are Asian American and Pacific Islanders. The below table details the prevalence of diverse caregivers within each population both in 2020 and in 2015.<sup>26</sup> As the table shows, it is highest among African Americans (28.1 percent) and Hispanics (21.9 percent), followed by Non-Hispanic Whites (19.8 percent), and Asian American and Pacific Islanders (19.2 percent). The table also shows that among African American caregivers, prevalence increased significantly from 2015, from 20.3 percent to 28.1 percent. Further research is needed to understand the drivers of prevalence among the African American community.<sup>27,28</sup>

**Figure 3: Prevalence by Racial/Ethnic Group\***

	Prevalence of Caregivers (%) and Margin of Error*		Number of Adults Ages 18+ in the United States**		Estimated Number of U.S. Adults Who Are Caregivers to an Adult or a Child with Special Needs	
	2020	2015	2020	2015	2020	2015
<b>Overall</b>	21.3%* +/- 0.9%	18.2% +/- 0.9%	249.2 million	239.3 million	53.0 million	43.5 million
<b>African American</b>	28.1%* +/- 3.0%	20.3% +/- 2.6%	29.6 million	27.7 million	8.3 million	5.6 million
<b>Hispanic</b>	21.9% +/- 2.3%	21.0% +/- 2.3%	40.5 million	36.3 million	8.9 million	7.6 million
<b>Non-Hispanic White</b>	19.8% +/- 1.1%*	16.9% +/- 1.1%	158.2 million	156.8 million	31.3 million	26.5 million
<b>Asian American and Pacific Islander</b>	19.2% +/- 3.6%	19.7% +/- 3.7%	15.7 million	13.8 million	3.0 million	2.7 million

\*Significantly higher than in 2015. Results are rounded and/or multiple response; results may not add to 100 percent.

<sup>24</sup>The National Alliance for Caregiving and AARP. (2020, May). Caregiving in the U.S. 2020. Retrieved October 7, 2020, from [https://www.caregiving.org/wp-content/uploads/2020/06/AARP1316\\_RPT\\_CaregivingintheUS\\_WEB.pdf](https://www.caregiving.org/wp-content/uploads/2020/06/AARP1316_RPT_CaregivingintheUS_WEB.pdf).

<sup>25</sup>Population estimate from the public-use data file (IPUMS) of the March 2019 Current Population Survey, conducted by the U.S. Census Bureau.

<sup>26</sup>The National Alliance for Caregiving and AARP. (2020, May). Caregiving in the U.S. 2020. Retrieved October 7, 2020, from [https://www.caregiving.org/wp-content/uploads/2020/06/AARP1316\\_RPT\\_CaregivingintheUS\\_WEB.pdf](https://www.caregiving.org/wp-content/uploads/2020/06/AARP1316_RPT_CaregivingintheUS_WEB.pdf).

<sup>27</sup>All margins of error reported are for the prevalence result recorded, rounded to the nearest tenth of a percentage point.

<sup>28</sup>Population estimate from the public-use data file (IPUMS) of the March 2019 Current Population Survey, conducted by the U.S. Census Bureau.

\*Table adapted from Appendix B of Caregiving in the U.S. 2020, accessed at <https://www.caregiving.org/wp-content/uploads/2020/05/Appendix-B-Caregiving-in-the-United-States-2020.pdf>

**Figure 4: Care Recipient Relation to Caregiver**

	TOTAL (n=1,392)	Non- Hispanic White (n=801)	African American (n=199)	Hispanic (n=205)	Asian American and Pacific Islander (n=197)
	A	B	C	D	E
Relative	89%	90%	88%	92%	89%
Parent	42% <sup>C</sup>	43% <sup>C</sup>	33%	43%	52% <sup>ABC</sup>
Father	13% <sup>C</sup>	14% <sup>C</sup>	7%	12%	19% <sup>C</sup>
Mother	29%	29%	26%	30%	33%
Parent-in-law	8% <sup>C</sup>	9% <sup>C</sup>	3%	7%	7%
Grandparent or Grandparent-in-law	8% <sup>E</sup>	6% <sup>E</sup>	12% <sup>BE</sup>	14% <sup>ABE</sup>	2%
Spouse/partner	12%	14%	14%	9%	9%
Child	6% <sup>E</sup>	7% <sup>E</sup>	8% <sup>E</sup>	5%	3%
Sibling	5%	4%	10% <sup>BD</sup>	4%	9% <sup>B</sup>
Neighbor or Friend	10%	10%	11%	7%	11%
Friend	7%	7%	7%	4%	10% <sup>D</sup>
Neighbor	3% <sup>E</sup>	3% <sup>E</sup>	4% <sup>E</sup>	3% <sup>E</sup>	--
Other non-relative	1% <sup>C</sup>	1% <sup>C</sup>	--	0%	1%

Note: Letters in superscript indicate a figure is significantly higher than the figure in the comparison column at the 95 percent confidence interval level. Results are rounded and/or multiple response; results may not add to 100 percent.



One in five Americans are providing care to an adult or a child because of a health care need or functional disability. We estimate that 53.0 million Americans are caregivers today.



# AFRICAN AMERICAN FAMILY CAREGIVERS

Existing research has suggested that African American individuals are more likely to take on family caregiving roles compared to Non-Hispanic White individuals.<sup>29</sup> The vast disparities in healthcare for African Americans are evident in the experience of African Americans caregivers, often resulting in increased burden for the caregiver and decreased access to services and resources for the care recipient.

## OUR FINDINGS

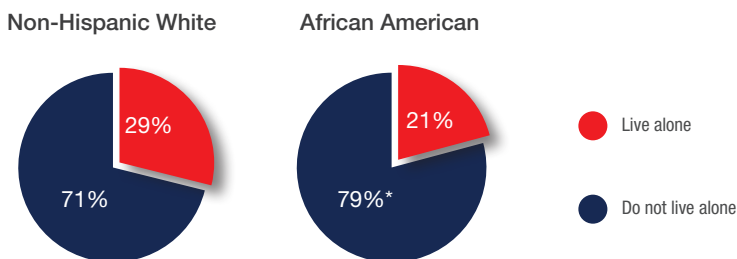
The growth in caring for an adult relative is up markedly among African American caregivers, from 77 percent in 2015 to 88 percent in 2020.

*Caring in the U.S. 2020* found that African American caregivers were, on average, 47.7 years old and typically caring for a parent, spouse, or grandparent who is 64.9 years old and has 1.7 conditions; usually a long-term physical condition. The growth in caring for an adult relative is up markedly among African American caregivers, from 77 percent in 2015 to 88 percent in 2020.

With respect to networks, African American caregivers are significantly more often the sole unpaid caregiver for their recipient compared to Non-Hispanic White caregivers (55 percent vs. 44 percent) as well as significantly more often receiving no help, paid or unpaid, with their caregiving duties (41 percent vs. 30 percent).

When asked about their *living situation*, 45 percent of African American caregivers reported living in the same homes as their care recipients, compared to 36 percent of Non-Hispanic White caregivers. This is nearly double the number reported by African American caregivers co-residing with their care recipients in 2015 (28 percent). Twenty-two percent reported that their care recipient lived alone, less often than Non-Hispanic White caregivers (33 percent).

**Figure 5: Care Recipients Who Live Alone**



<sup>29</sup>Dilworth-Anderson P, Williams I.C., & Gibson B.E. (2002). *Issues of race, ethnicity, and culture in caregiving research: A 20-year review (1980–2000)*. *The Gerontologist* 42(2), 237–72. Doi: 10.1093/geront/42.2.237.

\*Indicate significantly different from Non-Hispanic White caregivers. Results are rounded and/or multiple response; results may not add to 100 percent.



## SNAPSHOT: BRENDA AND ROB

**Brenda and Rob were active in the caregiving community while raising their children. Today, they care for their older grandson, who has been diagnosed with ADHD, and Brenda often cares for Rob.**

Rob was in a car accident years ago, which means Brenda normally has to take him to doctor appointments and help him with his medication. In addition to Rob's medical condition, the couple care for their daughter and grandson, whom they often help through daily life. Their daughter has a condition that requires she often be reminded of things, and Brenda and Rob manage and help control any emotional outbursts from her and their grandson. Due to the Covid-19 pandemic forcing virtual schooling, Brenda also keeps her grandson on track with his work.

Brenda and Rob are active in their caregiver support group, PALS. For many years, Rob was the only male in the group, but he never felt like an outsider. He and Brenda have been in the group for over twenty years and have enjoyed getting to know their peers and watching the other care recipients grow up. Though Rob and Brenda understood they'd be providing lifelong care for their daughter as soon as she was born, it was in the PALS group that they fully came to realize their roles as caregivers.

They are extremely proud of the work they do within the group, where they provide support for other caregivers and participate in group trips. They often promote the group to other caregivers who might find it helpful. In fact, the thing they find most rewarding about being caregivers is not only that they can be there to their family, but

that they can support others in realizing that they can help their own families through caregiving, as well.

Fortunately, the pandemic has not stopped Brenda and Rob from attending their support group, which meets virtually over Zoom. However, the inability to leave the house is very challenging for them. Rob mentions that they try to keep busy helping their family members and watching soap operas, and that they're not too concerned about the future because they'll keep doing what they've always done.

As African American caregivers, Brenda and Rob find themselves the figureheads of a large, multi-generational family. All of their relatives are supportive of Brenda and Rob's caregiving endeavors, and they are often the first call a family member makes when they need any sort of help or advice.

Brenda and Rob have petitioned locally through their caregiving group for policies that better support caregivers but have yet to see much change. They believe that caregivers need to be paid for the work they do taking care of their families. They are also proud of the group's ability to disseminate information to the wider community, because they believe they are a good source of trust. In these difficult times, Rob simply wants everyone to be safe.



Only a third of African American caregivers rated their own health as excellent or very good.

**Figure 6: Care-Recipient's Living Situation**

	Non-Hispanic White (n=800)	African American (n=198)
Care recipient lives in their own home	45%	38%
Care recipient lives in caregiver's household	36%	45%*
Care recipient lives in someone else's home	4%	6%
<b>Total: care recipient lives in any facility</b>	<b>15%</b>	<b>8%*</b>

\*Indicate significantly different from Non-Hispanic White caregivers.

Results are rounded and/or multiple response; results may not add to 100 percent.

When reporting on *caregiving activities and level of care*, African American caregivers provided more average hours of care per week and helped with more ADLs and IADLs. ADLs and IADLs were assessed individually for our *adjusted logistic regression analysis*. Compared to Non-Hispanic White caregivers, African American caregivers have increased odds of assisting their care recipient in getting in or out of the bath or shower (OR=1.64, p=0.015) and assisting their care recipient with incontinence (OR=1.73, p=0.017). With respect to IADL, African American caregivers have increased odds of assisting their care recipient with managing finances (OR=1.56, p=0.028), and managing medications (OR=1.52, p=0.03), compared to Non-Hispanic White caregivers.

In the past five years, African Americans have experienced notable changes in the role they take in *shared decision making with their care recipients*, including advocating for their care recipients, monitoring the severity of their care recipients' health conditions, and communicating with health care professionals about their care recipient's health:

- In 2020, roughly two thirds of African American caregivers (62 percent) advocated for their care recipients with health care providers, community services, and government agencies, compared to less than half of African American caregivers in 2015 (47 percent).
- Approximately 74 percent of 2020 African American caregivers monitored the severity of their care recipient's conditions so that they could adjust care accordingly, compared to 62 percent in 2015.
- Roughly 71 percent of 2020 African American caregivers communicate with health care professionals such as doctors, nurses, or social workers about their care recipients, compared to 56 percent in 2015.

With respect to *self-reported health*, only a third of African American caregivers rated their own health as excellent or very good, significantly lower than Non-Hispanic White caregivers (45 percent). Despite this finding, our adjusted logistic regression analysis showed that African American caregivers showed *decreased odds* of experiencing emotional strain compared to Non-Hispanic White caregivers (OR=0.63, p=0.004). Additionally, African American caregivers (59 percent) report that being a caregiver gives them a sense of purpose or meaning in life, significantly more than Non-Hispanic White (46 percent) caregivers.

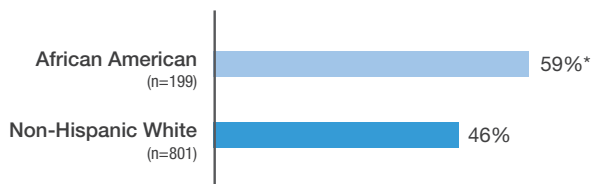


**Figure 7: Caregiver’s Self-Reported Health**

	Non-Hispanic White 2020 (n=801)	African American 2020 (n=199)	Non-Hispanic White 2015 (n=698)	African American 2015 (n=206)
Total: Excellent/Very Good	45%	34%*	47%	44%
Total: Fair/Poor	19%	25% <sup>^</sup>	16%	16%

\*Indicates significantly different from non-Hispanic White caregivers.  
<sup>^</sup>Indicates significantly different from African American caregivers in 2015. Results are rounded and/or multiple response; results may not add to 100 percent.

**Figure 8: Being a Caregiver Gives Meaning to My Life**



\*Indicate significantly different from Non-Hispanic White caregivers. Results are rounded and/or multiple response; results may not add to 100 percent.

When asked about *financial status*, nearly half (47 percent) of African American caregivers reported a household income of under \$50,000 USD, compared to 32 percent of Non-Hispanic White caregivers. African Americans also experienced significantly more financial impacts, including having to take on more debt, being late or missing bill and student loan payments, borrowing money from friends, using up savings, and filing for bankruptcy.

Nearly half (47 percent) of African American caregivers reported a household income of under \$50,000 US.

**Figure 9: Caregiver’s Self-Reported Financial Impacts**

	Non-Hispanic White (n=801)	African American (n=199)
<b>Any of these</b>	<b>42%</b>	<b>55%*</b>
Took on more debt (credit cards, loans, lines of credit)	21%	30%*
Missed or was late paying for a student loan	4%	11%*
Borrowed money from family or friends	12%	24%*
Filed for bankruptcy (medical or personal)	2%	8%*
Been unable to afford basic expenses like food	9%	14%
Left bills unpaid or paid them late	14%	31%*
Used up your personal short-term savings	21%	23%
Used long-term savings, like retirement or education, to pay for other things	10%	16%*
Stopped saving	26%	35%*
Moved to a less expensive home, apartment, or other living arrangement	5%	8%
Was evicted or had a home foreclosed	2%	5%
Put off retirement or deciding to never retire	9%	11%
Had to start working, work more, or find a second job	8%	20%*

\*Indicate significantly different from Non-Hispanic White caregivers. Results are rounded and/or multiple response; results may not add to 100 percent.

There is a need for more concerted efforts in directly addressing caregiver burden and impact in African American caregivers.

When asked about *future care plans* for their care recipients, such as instructions for handling financial matters, healthcare decisions, or living arrangements, only 39 percent of African American caregivers reported that they have these plans in place, lower than Non-Hispanic White caregivers (49 percent).

With respect to *information and services used*, according to our *adjusted logistic regression analysis*, African American caregivers were less likely to receive respite services (OR=0.5, p=0.005) and information from medical care providers (OR=0.59, p=0.006), compared to Non-Hispanic White caregivers.

**Figure 10: Access to Services, Supports and Information for African American Caregivers (Adjusted Logistic Regression Analysis)**

	Non-Hispanic White (n=801)	African American (n=199)
Requested info through internet	0.91 (0.60–1.38)	0.654
Respite services	0.5 (0.31–0.81)	<b>0.005</b>
Outside services (transportation, food)	0.71 (0.47–1.06)	0.092
Home modifications	0.82 (0.56–1.21)	0.322
Provider asked what is needed	0.59 (0.40–0.86)	<b>0.006</b>

Results are presented as odds ratios (OR, referent category Non-Hispanic White Caregivers) with 95 percent confidence interval (CI). Bolded values indicate significantly different from referent category.

## SUMMARY AND CONCLUSION

There has been a considerable increase in the number of caregivers identifying as African Americans over the last 5 years.<sup>30</sup> Because of this and the unique experiences of African American caregivers, there is a need for more concerted efforts in directly addressing caregiver burden and impact in African American caregivers.

Our study found that African American caregivers, on average, are more often the sole caregiver for a care recipient, are co-residing with their care recipient, and earn less income and work more hours compared to Non-Hispanic White caregivers. Moreover, African American caregivers take part in more hours of care and more high-touch activities of daily living as well as instrumental activities of daily living. Differences were most profound when considering the tasks (both ADLs and IADLs) that caregivers assist with; the higher odds for African American caregivers to assist with time-consuming tasks like getting in and out of beds or baths, as well as the increased odds to assist with incontinence, could result in higher level of caregiving intensity. Previous studies have suggested increased caregiving demands among African American caregivers compared to Non-Hispanic White caregivers.<sup>31,32</sup>

African American caregivers are less likely to receive information about managing care for their care recipient from medical care providers compared to Non-Hispanic White caregivers. This may be due to racial bias in physician-patient relations, which has been previously demonstrated.<sup>33</sup> Less information from medical providers may be related to fewer African American caregivers having future care plans in place, as well as being less likely to receive respite services.

<sup>30</sup>National Alliance for Caregiving and AARP. (2020). *Caregiving in the U.S. 2020*. National Alliance for Caregiving. Retrieved 2021, September 27 from <https://www.caregiving.org/caregiving-in-the-us-2020/>.

<sup>31</sup>Dilworth-Anderson P., Williams I.C., & Gibson B.E. (2002). Issues of race, ethnicity, and culture in caregiving research: A 20-year review (1980-2000). *The Gerontologist* 42(2), 237–72. Doi: 10.1093/geront/42.2.237.

<sup>32</sup>Pinquart, M. & Sörensen, S. (2005). Ethnic differences in stressors, resources and psychological outcomes of family caregiving: A meta-analysis. *The Gerontologist* 45(1), 90-106. Doi: 10.1093/geront/45.1.90.

<sup>33</sup>Ferguson, W.J. & Candib, L.M. (2002). Culture, language and the doctor-patient relationship. *Family Medicine and Community Health Publications*, 34(5), 353–61. <https://fammedarchives.blob.core.windows.net/imagesandpdfs/pdfs/FamilyMedicineVol34Issue5Ferguson353.pdf>.



## SNAPSHOT: GINA

### **Gina believes there should be compensation to caregivers who are not able to work a traditional job while caregiving.**

Gina cares for four people in total: two of her five children and both of her parents. Gina has a 14-year-old son with undiagnosed schizophrenia and diabetes, an 11-year-old son with autism, a father with heart disease, and a mother recovering from a brain tumor. Though she splits the care of her mother with her sister, Gina is a caregiver for them all.

Since Gina's sons live with her, they get the bulk of her attention. Her 14-year-old son requires diabetes care management, with Gina watching his blood sugar levels and providing medication, and she also sits with him during telehealth therapy sessions while supporting his mental health. To care for her 11-year-old son, she sometimes has to calm him down after episodes. Gina has had to learn how to perform intensive homecare for both children.

Gina's father had open-heart surgery in 2019 and has no vehicle of his own. Although Gina lives an hour away from her parents, she takes her father to his many post-surgery doctor appointments. Her mother has had three brain surgeries to help treat her brain tumor, and the aftermath of the surgeries has required an increased level of care. Gina assists in helping with her activities of daily living, and her mother needs to be watched constantly due to the dementia-like symptoms she began experiencing after her surgeries.

Gina's realization that she was a caregiver hit her when she began creating a program to help others who provide care for family members or friends. As she did the research, she realized that she fit the description

exactly, and that she was, in fact, a caregiver. However, this did not change how she treated or thought about her experience; somebody has to take care of her family, and she is the one to do it.

Gina finds caregiving most challenging with all the appointments she has to juggle in order to care for four people. Often, she finds herself responsible for delivering someone to two or three appointments in one day, and she has to manage her time and the technicalities of doing so. Yet, through the process, she has seen her son get better, which she finds rewarding. It's tangible proof that her caring for him is helping.

Gina has a background working at a group home, so she had some previous knowledge of how to find resources to help care for her sons. However, no one, in the medical field or otherwise, has offered her resources or ways to find help, and Gina has had to do the research on her own time.

She cannot imagine how she would have done so if she hadn't known where to start thanks to her work at the group home. Gina has never had to anyone ask what she needs to take care of her own health and does not believe she has the time to do so. To her, she's lucky if her kids are in bed on time and she has a few hours to herself to read.

Like many African Americans, Gina's culture has affected her caregiving in that she believes family should take care of family. Alongside this belief, she and her mother both worked in nursing homes in the past, and Gina has experienced instances where paid caregivers do not

provide a good level of care, while for her, family caregivers always do. When reaching out to diverse family caregivers on health matters such as vaccines, Gina thinks it's very important for the information to come from a reliable, neutral, and 100 percent factual medical source.

The pandemic has made it harder for Gina to provide care. Her sons are high risk, so she is nervous about sending them back to school. However, she knows they require specialized schooling that she cannot provide. Her father is significantly high risk. Prior to the pandemic he could occasionally get a ride from someone else or go to the store on his own, but now Gina doesn't want him going anywhere. This leaves both her father and sons stuck at home with no outlets for exercise.

The most important policy Gina can think of to help caregivers like her is twofold; both have to do with financials. First, she believes workplaces need policies in place that prevent them from penalizing and even firing caregivers who need time off to provide care for their loved ones. Second, she believes there should be compensation to caregivers who are not able to work a traditional job while caregiving. Family caregivers are performing a job no one else would be doing otherwise, and they should not be struggling to live off Social Security or applying for benefits they never receive. Being a caregiver is stressful and exhausting, and there should not be the added worry of feeding a family and paying bills.



The differences in emotional strain across groups may be important in identifying important coping mechanisms that may be useful in addressing the overall experience for all caregivers.

Despite increased caregiver burden and lower self-reported health, our study showed that African American caregivers are less likely to experience emotional strain and more likely to find meaning in their caregiver experience compared to Non-Hispanic White caregivers. Previous studies have also reported less psychological stress in African American caregivers compared to white caregivers.<sup>34,35</sup> However, a recent review and meta-analysis by Badana and colleagues (2021) report that considerable methodological limitations and selection bias in data collection may be misrepresenting emotional impact of caregiving in communities of color.<sup>36</sup> On the other hand, despite experiential disparities in caregiving in African American caregivers compared to Non-Hispanic White caregivers, the differences in emotional strain across groups may be important in identifying important coping mechanisms that may be useful in addressing the overall experience for all caregivers. More

research on the cultural perception of caregiving in communities of color as well as accounting for methodological limitations in research will be important factors in understanding the complexities within the emotional burden of caregiving among diverse communities.

Overall, our findings suggest that there is a need for more and better access to federally-based and community-based programs to support African American caregivers. This aligns with a recent qualitative study that found African American caregivers of patients with dementia strongly desired more community resources to assist with their caregiving responsibilities.<sup>37</sup> These supports include: increased access to services such as respite, financial planning resources, stipends or compensation for caregiving duties, increased training for caregiving responsibilities using a culturally relevant approach, and increased education in cultural competency for medical care providers to promote inclusion of African American caregivers and other caregivers of color as important stakeholders in the management of care for patients.

<sup>34</sup>Dilworth-Anderson P., Williams I.C., & Gibson B.E. (2002). Issues of race, ethnicity, and culture in caregiving research: A 20-year review (1980-2000). *The Gerontologist* 42(2), 237-72. Doi: 10.1093/geront/42.2.237.

<sup>35</sup>Pinquart, M. & Sörensen, S. (2005). Ethnic differences in stressors, resources and psychological outcomes of family caregiving: A meta-analysis. *The Gerontologist* 45(1), 90-106. Doi: 10.1093/geront/45.1.90.

<sup>36</sup>Badana, A.N.S., Marino, V. & Haley, W.E. (2019). Racial differences in caregiving: Variation by relationship type and dementia care status. *Journal of Aging and Health* 31(6), 925-946.

<sup>37</sup>Abramsohn, E.M., Jerome, J., Paradise, K., Kostas, T., Spacht, W.A., & Lindau, S.T. (2019). Community resource referral needs among African American dementia caregivers in an urban community: A qualitative study. *BMC Geriatrics* 19(311). Doi: 10.1186/s12877-019-1341-6.

Overall, our findings suggest that there is a need for more and better access to federally-based and community-based programs to support African American caregivers.

# HISPANIC FAMILY CAREGIVERS

Previous research has suggested family caregivers in Hispanic and Latino communities often assume their roles as family caregivers out of familial obligation.<sup>38</sup> This and other unique cultural contextual factors within Hispanic communities may influence different outcomes regarding the caregiver experience.



## OUR FINDINGS

*Caring in the U.S. 2020* found that Hispanic caregivers are typically 43.3 years old caring for someone 66.9 years old. Hispanic caregivers are typically caring for a parent (43 percent) or grandparent (14 percent) with an average of 1.8 conditions. Nearly two-thirds (61 percent) of Hispanic care recipients have a long-term physical condition.

**Figure 11: Reasons Why Care Recipient Needs Care**

	Non-Hispanic White (n=801)	Hispanic (n=205)
Short-term physical conditions	28%	38%*
Long-term physical conditions	64%	61%
Emotional or mental health problems	24%	32%*
Behavioral issues	8%	10%
Memory problems	32%	29%
Count of conditions care recipient has/had	1.6	1.8

\*Indicate significantly different from Non-Hispanic White caregivers.

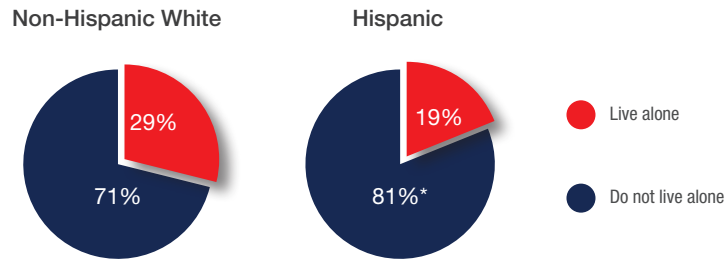
Results are rounded and/or multiple response; results may not add to 100 percent.

With respect to *networks*, 40 percent of Hispanic caregivers receive no other help, paid or unpaid, and 75 percent of Hispanic caregivers lack access to paid help, significantly higher than Non-Hispanic White caregivers.

When asked about their *living situation*, nearly half (48 percent) of Hispanic caregivers reported that they live in the same homes as their care recipient and are significantly less likely to have their care recipient live in an outside living facility compared to Non-Hispanic White caregivers (5 percent vs. 15 percent). Care recipients of Hispanic caregivers were less likely to live alone compared to care recipients of Non-Hispanic White caregivers.

<sup>38</sup>Llanque, S.M. & Enriquez, M. (2012). Interventions for Hispanic caregivers of patients with dementia: A review of the literature. *American Journal of Alzheimer's Disease & Other Dementias* 27(1), p. 23–32. Doi: 10.1177/1533317512439794.

**Figure 12: Care Recipients Who Live Alone**



\*Indicate significantly different from Non-Hispanic White caregivers. Results are rounded and/or multiple response; results may not add to 100 percent.

Hispanic caregivers provided more hours of care to their care recipient compared to Non-Hispanic White caregivers.

**Figure 13: Care-Recipient's Living Situation**

	Non-Hispanic White (n=800)	Hispanic (n=205)
Care recipient lives in their own home	45%	41%
Care recipient lives in caregiver's household	36%	48%*
Care recipient lives in someone else's home	4%	6%
Total: care recipient lives in any facility	15%	5%

\*Indicate significantly different from Non-Hispanic White caregivers. Results are rounded and/or multiple response; results may not add to 100 percent.

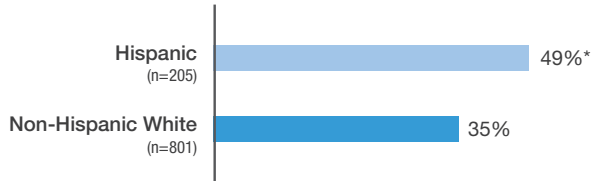
When reporting on *caregiving activities and level of care*, Hispanic caregivers provided more hours of care to their care recipient compared to Non-Hispanic White caregivers. Hispanic caregivers are significantly more likely to assist with one ADL and to perform more IADL than Non-Hispanic White caregivers. In our adjusted logistic regression analysis, Hispanic caregivers showed increased odds of having a higher caregiving intensity index (OR=1.4, p=0.05) when compared to Non-Hispanic White caregivers. Hispanic caregivers showed significantly increased odds of assisting their care recipient in feeding (OR=2.31, p<0.001), grocery or other shopping (OR=1.62, p=0.049), arranging for outside services such as nursing/home health care or Meals on Wheels (OR=1.56, p=0.021), and managing medications.

**Figure 14: Hours Spent Providing Care**

	Non-Hispanic White (n=801)	Hispanic (n=205)
Total: 0-20 Hours	72%	63%*
Total: Over 21 Hours	27%	36%*
Mean/average	21.2	26.0*

\*Indicate significantly different from Non-Hispanic White caregivers. Results are rounded and/or multiple response; results may not add to 100 percent.

**Figure 15: Percentage of Caregivers Experiencing High Care Intensity Levels (4-5)**



\*Indicate significantly different from Non-Hispanic White caregivers. Results are rounded and/or multiple response; results may not add to 100 percent.



**Figure 16: Caregiving Intensity, ADLs and IADLs Hispanic Caregivers Assisted their Care Recipient With (Adjusted Logistic Regression Analysis)**

	OR (95% CI)	p
Level of care-giving intensity	1.4 (1.00–1.96)	<b>0.05</b>
Getting in and out of beds and chairs	1.34 (0.92–1.93)	0.123
Getting to and from the toilet	1.34 (0.88–2.03)	0.175
Getting in/out of the bath/shower	1.28 (0.86–1.92)	0.225
Incontinence	1.03 (0.63–1.67)	0.909
Feeding	2.31 (1.59–3.36)	<b>&lt;0.001</b>
Managing Finances	1.34 (0.92–1.94)	0.13
Grocery shopping	1.62 (1.00–2.61)	<b>0.049</b>
Housework (dishes, laundry, etc.)	1.44 (0.91–2.29)	0.121
Meal prep	1.41 (0.96–2.07)	0.081
Transportation	0.9 (0.59–1.38)	0.633
Arrange out-side services	1.56 (1.07–2.28)	<b>0.021</b>
Manage medication	1.92 (1.33–2.77)	<b>&lt;0.001</b>

Results are presented as odds ratios (OR, referent category Non-Hispanic White Caregivers) with 95 percent confidence interval (CI). Bolded values indicate significantly different from referent category.

Hispanic caregivers more often reported that caregiving “brought meaning to their life” compared to Non-Hispanic White caregivers.

With respect to *self-reported health*, 35 percent of Hispanic caregivers rate their own health as excellent or very good, significantly lower than Non-Hispanic White caregivers. This is a decrease from 2015, where 51 percent of Hispanic caregivers rating their own health as excellent or very good. In our adjusted logistic regression analysis, Hispanic caregivers showed higher odds of reporting physical strain (OR=1.36, p=0.011) compared to Non-Hispanic White caregivers. Interestingly, Hispanic caregivers less often reported that caregiving had made their health worse, and more often reported that caregiving “brought meaning to their life” compared to Non-Hispanic White caregivers.

**Figure 17: Hispanic Caregiver’s Self-Reported Health**

	Non-Hispanic White 2020 (n=801)	Hispanic 2020 (n=205)	Non-Hispanic White 2015 (n=698)	Hispanic 2015 (n=208)
Total: Excellent/Very Good	45%	35%*^	47%	51%
Total: Fair/Poor	19%	23%	16%	21%

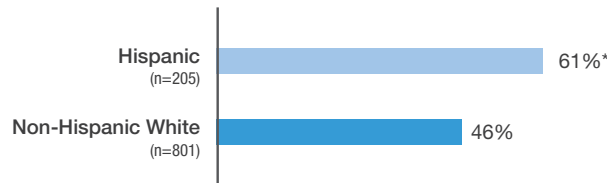
\*Indicates significantly different from Non-Hispanic White caregivers.

^Indicates significantly different from Hispanic caregivers in 2015.

Results are rounded and/or multiple response; results may not add to 100 percent.

Hispanic caregivers report experiencing more financial impacts due to caregiving, are less likely to be able to pay bills, save, or afford basic expenses like food compared to Non-Hispanic White caregivers.

**Figure 18: Being a Caregiver Gives Meaning to My Life**

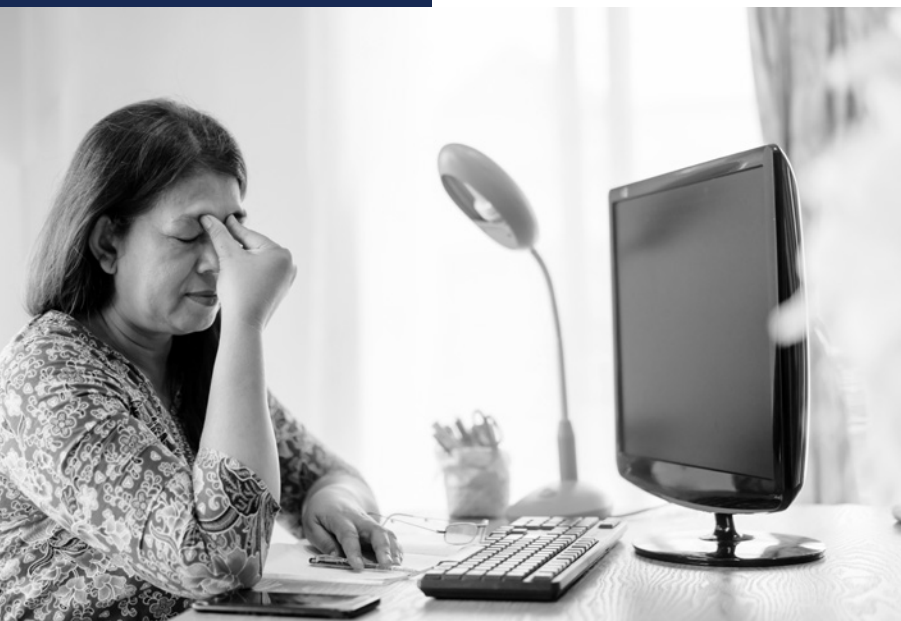


\*Indicate significantly different from Non-Hispanic White caregivers.

Results are rounded and/or multiple response; results may not add to 100 percent.

When asked about *financial and employment status*, 41 percent of Hispanic caregivers reported a household income of under \$50,000 USD, more than Non-Hispanic White caregivers (32 percent). Moreover, more Hispanic caregivers reported a household income of under \$15,000 USD per year. Hispanic caregivers report experiencing more financial impacts due to caregiving, are less likely to be able to pay bills, save, or afford basic expenses like food compared to Non-Hispanic White caregivers. Additionally, 12 percent of Hispanic caregivers report needing to move into less expensive housing as a result of the impact of caregiving on financial status, more than double than what was reported by Non-Hispanic White caregivers (5 percent).

Roughly 12 percent of Hispanic caregivers report having to give up work entirely, more than double that of Non-Hispanic White caregivers. Additionally, Hispanic caregivers report, on average, 1.4 impacts on their work life due to caregiving, significantly higher than non-Hispanic White caregivers.



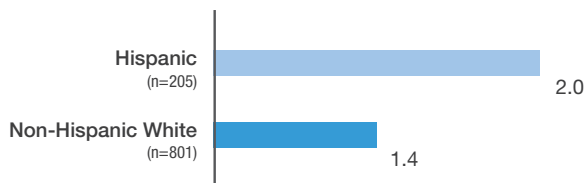


**Figure 19: Caregiver’s Self-Reported Financial Impacts**

	Non-Hispanic White (n=801)	Hispanic (n=205)
<b>Any of these</b>	<b>42%</b>	<b>48%*</b>
Took on more debt (credit cards, loans, lines of credit)	21%	25%
Missed or was late paying for a student loan	4%	5%
Borrowed money from family or friends	12%	18%
Filed for bankruptcy (medical or personal)	2%	4%
Been unable to afford basic expenses like food	9%	15%*
Left bills unpaid or paid them late	14%	25%*
Used up your personal short-term savings	21%	27%
Used long-term savings, like retirement or education, to pay for other things	10%	14%
Stopped saving	26%	33%
Moved to a less expensive home, apartment, or other living arrangement	5%	12%*
Was evicted or had a home foreclosed	2%	2%
Put off retirement or deciding to never retire	9%	9%
Had to start working, work more, or find a second job	8%	11%

\*Indicate significantly different from Non-Hispanic White caregivers. Results are rounded and/or multiple response; results may not add to 100 percent.

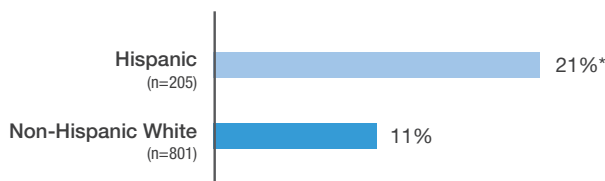
**Figure 20: Number of Financial Impacts**



\*Indicate significantly different from Non-Hispanic White caregivers. Results are rounded and/or multiple response; results may not add to 100 percent.

Approximately two in ten (21 percent) Hispanic caregivers also *lacked health insurance*, compared to 11 percent of Non-Hispanic White caregivers.

**Figure 21: Percentage of Caregivers Who Lack Access to Health Insurance**



\*Indicate significantly different from Non-Hispanic White caregivers. Results are rounded and/or multiple response; results may not add to 100 percent.



Approximately two in ten (21 percent) Hispanic caregivers also *lacked health insurance*, compared to 11 percent of Non-Hispanic White caregivers.

Hispanic caregivers report having significantly less access to resources and sources of information about caregiving than Non-Hispanic White caregivers. When asked about *future planning*, such as handling financial matters, healthcare decisions, or living arrangements for themselves or their care recipients, significantly fewer Hispanic caregivers report having plans for their own or their care recipient's future care, compared to Non-Hispanic White caregivers.

### Figure 22: Having Plans in Place for Future Care, Such as Instructions for Handling Financial matters, Healthcare Decisions, or Living Arrangements

	Non-Hispanic White	Hispanic
For caregivers	46%	37%*
For care recipients	49%	32%*

\*Indicate significantly different from Non-Hispanic White caregivers. Results are rounded and/or multiple response; results may not add to 100 percent.

Hispanic caregivers are often the sole caregivers for their care recipient, with few options for support.

## SUMMARY AND CONCLUSION

Hispanic caregivers are often the sole caregivers for their care recipient, with few options for support. Our data suggests that Hispanic caregivers spend more time on caregiving tasks, as well as experience a higher caregiving intensity compared to Non-Hispanic White caregivers. This may be related to increased odds of assisting with specific tasks and may also be related to the increased physical strain experienced by Hispanic caregivers. A previous study supports our finding, reporting that Latino caregivers spend more time caregiving compared to Non-Hispanic White caregivers.<sup>39</sup>

Hispanic caregivers reported significantly lower levels of psychological and physical well-being than Non-Hispanic White caregivers when caring for care recipients with dementia in a previous study.<sup>40</sup> Additionally, Hispanic populations have demonstrated higher scores on the Family Caregiver Medication Administration Hassles Scale (FCMAHS), which measures the level of difficulty in managing medications; the presence of medication hassles can result in the perception of greater strain associated with caregiving.<sup>41,42</sup> Hispanic populations in our sample were almost 70 percent more likely to report managing medications than caregivers identifying as Non-Hispanic White; this could be a contributor to their higher reported levels of strain.

The greater likelihood of managing medications as well as our findings showing that Hispanic caregivers are less likely to have information regarding future planning for their care recipient and themselves may be related to the amount of information and support that they receive from their care recipient's medical care team. Previous research shows that race, ethnicity, and language can affect the quality of the provider-patient relationship.<sup>43</sup> Patients from diverse ethnic backgrounds are less likely to have empathetic relationships with providers, and individuals from Spanish-speaking cultures have a demonstrated distrust and fear of non-Spanish speaking doctors.<sup>44</sup> Communication of medical information to non-English speaking caregivers, or those with limited English proficiency, is difficult for nurses and health care teams; one reported difficulty is educating family members about a patient's condition, and educating them about medication and side effects.<sup>45</sup> There has

<sup>39</sup>Rote, S.M. & Moon, H. (2016). *Racial/ethnic differences in caregiving frequency: Does immigrant status matter?* *The Journals of Gerontology, Series B*, 73(6), 1088–98. Doi: 10.1093/geronb/gbw106.

<sup>40</sup>Liu, C., Badana, A., Burgdorf, J., Fabius, C. D., Haley, W. E., & Roth, D. L. (2019). "Systematic review and meta-analysis of racial and ethnic differences in dementia caregiver well-being." *Innovation in Aging*, 3(1), S434–S434. doi:10.1093/geroni/igz038.1624.

<sup>41</sup>Travis, S. S., McAuley, W. J., Dmochowski, J., Bernard, M. A., Kao, H. F. S., & Greene, R. (2007). "Factors associated with medication hassles experienced by family caregivers of older adults." *Patient Education and Counseling*, 66(1), 51–57. doi:10.1016/j.pec.2006.10.004.

<sup>42</sup>Thornton, M., & Travis, S. S. (2003). "Analysis of the reliability of the modified caregiver strain index." *The Journals of Gerontology: Series B*, 58(2), S127–S132. doi:10.1093/geronb/58.2.S127.

<sup>43</sup>Ferguson, W. J. & Candib, L. M. (2002-5). *Culture, language, and the doctor-patient relationship*. UMass Medical School. Retrieved 2020, September 3 from [https://escholarship.umassmed.edu/fmch\\_articles/61](https://escholarship.umassmed.edu/fmch_articles/61).

<sup>44</sup>Ferguson, W.J. & Candib, L.M. (2002-2005).

<sup>45</sup>Goldsmith, J., Young, A. J., Dale, L., & Powell, M.P. (2017). *Plain language and health literacy for the oncology family caregiver: Examining an English/Spanish mHealth resource*. *Seminars in Oncology Nursing*, 33(5), 498–506. doi:10.1016/j.soncn.2017.09.008.



## SNAPSHOT: VERONICA

**Veronica says that in her Hispanic heritage, family takes care of one another. Veronica has been a caregiver of sorts ever since she emigrated from Peru to the United States.**

With a background in special education, Veronica had wanted to take care of a child with special needs, and she was quickly matched with Elena, who has cerebral palsy. When Veronica married, she trained her sister Giselle to take her place as Elena's carer, but still saw her about once a month. As Elena's parents aged, Elena was placed in a nursing home.

Veronica and her then-husband Carlos had two children of their own and then decided to adopt a young child with special needs. In 2003, they were blessed with Bianca, a two-year-old child from Romania with hearing impairment, a learning disability, and institutional autism. Several years later, when Veronica was visiting Elena at the nursing home, she realized that Elena was not thriving. After speaking with Elena's parents, Veronica received Elena's custody and, with Carlos' consent, brought Elena to their home to take care of her with the rest of her children.

Although Carlos and Veronica divorced several years ago, they continue to share some caregiving responsibilities. Veronica's caregiving duties are primarily focused on Elena and Bianca. Elena needs assistance around the clock with high touch activities of daily living, including bathing, eating, and exercising, and Bianca requires speech therapy and help with her learning disability.

Veronica's future for Bianca and Elena depends on her other children. It is understood that her daughters, Camille and Carla, will take care of Bianca and Elena when Veronica and Carlos are gone. Veronica and Carlos largely attribute this to their Hispanic heritage and the understanding that family takes care of one another. "Neither Carla nor Camille

will even consider dating someone who will not agree to include Bianca and Elena as parts of their lives," say Veronica and Carlos.

Veronica has recently remarried and says that the pandemic has not been easy on her or her family. Before the pandemic, Veronica had several companions who helped her with her caregiving duties but has had to let go of all but one. The risk of Elena getting Covid-19 is very high, and a terrifying thought considering that she is nonverbal and would not be able to express her needs in a hospital setting without Veronica there. Veronica has to spend all day with Elena, which takes attention away from Bianca, who also needs special care.

The one good thing Veronica and Carlos say that the pandemic has brought about is a structure and rhythm for their family, allowing them time for some activities they did not have in the past. For example, every weekend, Carlos gives a three-hour cooking lesson to Bianca via Zoom, which is a success as a social activity. "Caregiving doesn't stop regardless of the pandemic," says Carlos. "My role is to give them emotional and other support in any way I can, in the little things." In addition to the cooking lessons, Carlos provides support with some grocery shopping, keeping Bianca company, and in any way he can to support the family emotionally.

Veronica often finds herself stressed and feeling depressed. Veronica and her spouse have little energy to enjoy each other's company at the end of the day. They are stuck in the house 24/7 because they cannot be exposed to Covid-19. She hopes that the pandemic will come to an end soon and that life will become normal once again.

Previous studies have related familism to burden perception in Latino caregivers, suggesting that fostering a sense of familism among caregivers may have an impact on stress levels and perceived burden.

been a hypothesized link between language barriers and the quality of informed decision making for Spanish-speaking caregivers; our analysis supports the idea that barriers in language and cultural competencies among medical professionals inhibit the caregiver's ability to manage the care recipient's care.<sup>46,47</sup>

Despite the increased burden that Hispanic caregivers face with respect to caregiving tasks, self-reported health and finances, they are less likely to attribute this burden to the caregiving experience. Common cultural norms such as familism, the sense of loyalty to the family, and *marianismo*, the woman's role as the family caregiver, may provide additional contextual factors connecting these otherwise disparate concepts.<sup>48,49</sup> Previous studies have related familism to burden perception in Latino caregivers,<sup>50</sup> suggesting that fostering a sense of familism among caregivers may have an impact on stress levels and perceived burden, which in turn may beneficially affect overall quality of life in caregivers. Nevertheless, the potential mitigating effects of these cultural contextual factors may not alone buffer against the negative impact of caregiving on the health of Hispanic caregivers.<sup>51</sup> Future studies will need to control for the presence of these contextual factors to accurately assess the true impact of caregiving on Hispanic caregivers. There is a strong need for better support of Hispanic caregivers through policies and programs to clearly address the factors that affect their caregiving responsibilities.

<sup>46</sup>Zamora, E. R., Kaul, S., Kirchoff, A. C., Gwilliam, V., Jimenez, O.A., Morreall, D. K., Montenegro, R. E., Kinney, A. Y., & Fluchel, M. N. (2016). The impact of language barriers and immigration status on the care experience for Spanish-speaking caregivers of patients with pediatric cancer. *Pediatric Blood & Cancer*, 63(12), 2173–80. doi:10.1002/pbc.26150.

<sup>47</sup>Riera, A., Ocasio, A., Tiyyagura, G., Krumeich, L., Ragins, K., Thomas, A., Trevino, S., & Vaca, F.E. (2015). Latino caregiver experiences with asthma health communication. *Qualitative Health Research*, 25(1), 16–26. doi:10.1177/1049732314549474.

<sup>48</sup>Crist, J.D. & Speaks, P. (2011). Keeping it in the family: When Mexican American older adults choose not to care home healthcare services. *Home Healthcare Nurse* 29(5), 282–90. Doi: 10.1097/NHH.0b013e3182173859.

<sup>49</sup>Badger, T.A., Sikorskii, A., & Segrin, C. (2019). Contextual and cultural influences on caregivers of Hispanic cancer survivors. *Seminars in Oncology Nursing*, 35(4), 359–62. Doi: 10.1016/j.soncn.2019.06.008.

<sup>50</sup>Knight, B.G., Robinson, G.S., Longmire, C.V.F., Chun, M., Nakao, K., & Kim, J.H. (2002). Cross cultural issues in caregiving for persons with dementia: Do familism values reduce burden and distress? *Ageing International*, 27, 70–94. Doi: 10.1007/s12126-003-1003-y.

<sup>51</sup>Magaña, S., & Smith, M. (2016, March 20). Health outcomes of midlife and older Latina and Black American mothers of children with developmental disabilities. Northwestern University. Retrieved 2020, December 3 from <https://www.scholars.northwestern.edu/en/publications/health-outcomes-of-midlife-and-older-latina-and-black-american-mo>.



# ASIAN AMERICAN AND PACIFIC ISLANDER FAMILY CAREGIVERS

Asian Americans and Pacific Islanders (AAPI) are one of the fastest growing ethnic groups in the United States. Like other ethnic groups, cultural values and norms play a strong role in the experience of Asian American and Pacific Islander caregivers.<sup>52,53</sup> This may affect outcomes related to accessing resources related to caregiving as well as their own coping as a caregiver.



## OUR FINDINGS

According to *Caregiving in the U.S. 2020*, AAPI caregivers are 49.3 years old on average and are typically married or living with a partner. They typically care for a parent or parent-in-law who is 69.1 years old with an average of 1.7 conditions, usually a long-term physical condition.

**Figure 23: Reasons Why Care Recipient Needs Care**

	Non-Hispanic White (n=801)	Asian American and Pacific Islander (n=197)
Short-term physical conditions	28%	33%
Long-term physical conditions	64%	59%
Emotional or mental health problems	24%	29%
Behavioral issues	8%	13%
Memory problems	32%	28%
Count of conditions care recipient has/had	1.6	1.7*

\*Indicate significantly different from Non-Hispanic White caregivers.  
Results are rounded and/or multiple response; results may not add to 100 percent.

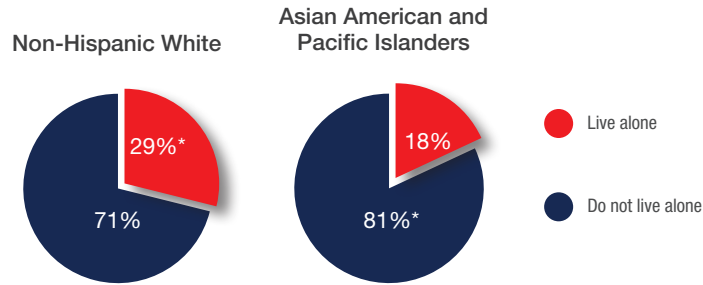
Like other ethnic groups, cultural values and norms play a strong role in the experience of Asian American and Pacific Islander caregivers.

<sup>52</sup>Sun, F., Ong, R., & Burnette, D. (2012). The influence of ethnicity and culture on dementia caregiving: A review of empirical studies on Chinese Americans. *American Journal of Alzheimer's Disease & Other Dementias*, 27(1), 13–22. Doi: 10.1177/1533317512438224.

<sup>53</sup>Kong, E. (2007). The influence of culture on the experiences of Korean, Korean American, and Caucasian-American family caregivers of frail older adults: A literature review. *Journal of Korean Academy of Nursing*, 37(2), 213–20. Doi: 10.4040/jkan.2007.37.2.213.

When asked about their *living situation*, 51 percent of Asian American and Pacific Islander caregivers live in the same homes as their care recipients, significantly more than Non-Hispanic White caregivers. Similarly, care recipients of AAPI caregivers are less likely to live alone than Non-Hispanic White caregivers.

**Figure 24: Care Recipients Who Live Alone**



\*Indicate significantly different from Non-Hispanic White caregivers. Results are rounded and/or multiple response; results may not add to 100 percent.

**Figure 25: Care-Recipient's Living Situation**

	Non-Hispanic White (n=800)	Asian American and Pacific Islander (n=195)
Care recipient lives in their own home	45%	33%*
Care recipient lives in caregiver's household	36%	51%*
Care recipient lives in someone else's home	4%	7%
<b>Total: care recipient lives in any facility</b>	<b>15%</b>	<b>9%</b>

\*Indicate significantly different from Non-Hispanic White caregivers. Results are rounded and/or multiple response; results may not add to 100 percent.

Asian American and Pacific Islander caregivers show increased odds of assisting with specific activities compared to Non-Hispanic White caregivers.



Regarding *caregiving activities and level of care*, Asian American and Pacific Islander caregivers reported similar hours and amounts of care related to overall ADL and IADL compared to Non-Hispanic White caregivers. However, according to our adjusted logistic regression analysis, Asian American and Pacific Islander caregivers show increased odds of assisting with specific activities compared to Non-Hispanic White caregivers, such as arranging outside services for their care recipient (OR=1.68, p=0.024), and managing medications for their care recipient (OR=1.96, p=0.003).

**Figure 26: ADLs and IADLs Asian American and Pacific Islander Caregivers Assisted their Care Recipient With (Adjusted Logistic Regression Analysis)**

	OR (95% CI)	p
Getting in and out of beds and chairs	1.24 (0.79–1.95)	0.348
Getting to and from the toilet	1.18 (0.69–2.00)	0.55
Getting in/out of the bath/shower	1.6 (0.99–2.60)	0.055
Incontinence	1.02 (0.58–1.81)	0.937
Feeding	1.07 (0.64–1.79)	0.796
Managing Finances	1.54 (0.96–2.45)	0.071
Grocery shopping	0.89 (0.54–1.49)	0.668
Housework (dishes, laundry, etc.)	0.71 (0.45–1.14)	0.155
Meal prep	1.19 (0.76–1.87)	0.446
Transportation	1.14 (0.64–2.02)	0.659
Arrange out-side services	1.68 (1.07–2.64)	0.024
Manage medication	1.96 (1.25–3.07)	<b>0.003</b>
Manage medication	1.92 (1.33–2.77)	<b>&lt;0.001</b>

Results are presented as odds ratios (OR, referent category Non-Hispanic White Caregivers) with 95 percent confidence interval (CI). Bolded values indicate significantly different from referent category.

The *self-reported health* of AAPI caregivers, like other ethnic groups in this report, has gone down over the last several years. Only 41 percent of AAPI caregivers reported their health as “good or excellent,” compared to 60 percent in 2015. Nearly half (44 percent) of Asian American and Pacific Islander caregivers report that caregiving is “emotionally stressful,” suggesting implications of caregiving for emotional health more than physical health.

Regarding *finances and employment*, although there were no significant differences between AAPI caregivers and other ethnic groups on overall financial strain, 16 percent of AAPI caregivers reported that they started working, worked more, or found a second job due to financial difficulties while caregiving, double that of Non-Hispanic White caregivers. Asian American and Pacific Islander caregivers also report, on average, 1.4 impacts on their work life due to caregiving, significantly higher than Non-Hispanic White caregivers.

According to our *adjusted logistic regression analysis*, AAPI caregivers were less likely to receive information from medical care providers compared to Non-Hispanic White caregivers (OR=0.47, p=0.003). Interestingly, significantly more Asian American and Pacific Islander caregivers report wanting doctors or other professionals to ask what they need to help care for the recipient compared to Non-Hispanic White caregivers. Specifically, Asian American and Pacific Islander caregivers reported needing guidance in filling out forms, navigating through information on choosing a home care agency, assisted living facility, or nursing home, managing their own emotional or physical stress, or finding non-English language materials regarding the care of the care recipient. Moreover, 62 percent of Asian American and Pacific Islander caregivers support “a partially paid leave of absence from work” for caregivers who are employed.

When asked about *future planning*, such as handling financial matters, healthcare decisions, or living arrangements for their care recipients, 38 percent of Asian American and Pacific Islander caregivers reported having plans for their care recipient’s future care, significantly less than Non-Hispanic White caregivers (49 percent).



62 percent of Asian American and Pacific Islander caregivers support “a partially paid leave of absence from work” for caregivers who are employed.



## SNAPSHOT: REY

### Rey has learned, through caregiving, “what matters more in life.”

When Rey immigrated from the Philippines in 1989 as a teen, he made his home in Los Angeles, earned his MBA, and worked in biotech at a Fortune 500 company. In 2014, Rey’s father had a stroke, and Rey left LA for St. Louis to take care of him.

Rey now lives with his parents, and though his father requires the bulk of his care, his mother also has underlying conditions; Rey helps her out as well. Rey assists his father with many activities of daily living: he makes his food, takes his blood pressure, administers medication, helps him shower, and prior to the COVID-19 pandemic, took him to multiple therapy sessions, support group meetings, and medical study sessions.

Rey realized he was a caregiver almost as soon as he moved back home. In the aftermath of his father’s stroke, his father was kept in a nursing home for a few weeks. There, Rey was told that life for his dad would never be the same, and that there would be a long journey ahead. At the time, Rey was visiting his dad every day, eight hours a day, so he had no problem accepting that he was now a caregiver.

When his father was discharged, Rey did not get the help he expected they would from healthcare professionals. He frankly called the information they received “inadequate.” He and his family had no idea what the next steps were, and no one at the nursing home told them. Rey had to chase down resources in support groups he found on his own, and since most of his family lives in LA, he was the solo caregiver.

The pandemic has made caregiving very challenging for Rey. His father can no longer attend therapy, and neither his father nor his mother can safely leave the house. Rey no longer goes out much so that he can better keep his parents safe during the pandemic. Rey usually finds his self-care in exercise, so not being able to go to the gym is an added stress. Still, Rey does find some peace in walks, meditation, eating right, and getting sleep. A doctor has never asked Rey what he might need help with as a caregiver.

Rey has learned a very rewarding lesson in caregiving. He has realized that he “knows what matters more in

life, sooner.” Caregiving has given him the viewpoint of appreciating his friends, family, and faith in the moment, and has allowed him to be quicker to forgive himself and others. However, caregiving has taught him a lesson in challenges, as well. Sometimes, Rey worries that his role as a caregiver has caused him to fall behind his peers when he should be further along in life. He knows that this is a problem due to his ego, but it has become a concern, especially with the pandemic layered on top of Rey’s long-term worry over how he will juggle caring for his family and a career in the future.

In the Philippines, it is very common to belong to a multi-generational household. With that culture comes a sense of responsibility to take care of the people within your household. Rey believes this feeling has influenced his role and outlook as a caregiver and thinks it may be even stronger because he is an immigrant who is still very close to his cultural roots.

Regarding building trust between diverse communities and the healthcare world, Rey believes that “the messenger counts.” Collaborating with agencies, faith organizations, or other trusted channels outside of the government can be an easier and more reliable way to get health information and policies out to diverse communities, and to ensure that the information is distributed in a reliable way.

As for suggested policies, Rey understands how financially damaging being a caregiver can be. Independent living homes or retirement homes can be incredibly expensive, requiring a need for easy and affordable access to paid caregiving help, services, and products that will allow people to live at home longer with health conditions. Rey acknowledges that it can be especially hard for people of color to navigate available benefits and insurance systems, and that available resources are not often presented in a way that’s easily understandable. There cannot be a one-size-fits-all approach for caregivers, and solutions need to be especially refined and customized for different, diverse populations. Caregivers help keep the country strong, and for that, they need to be supported.



## SUMMARY AND CONCLUSION

The impact of caregiving on Asian American and Pacific Islander caregivers is distinct from caregivers of other ethnicities, yet there are important inequities to be addressed. The self-reported health of Asian American and Pacific Islander caregivers has declined over the last five years, and this may be related due to the burden of tasks that AAPI caregivers experience. Additionally, Asian American and Pacific Islander caregivers receive less information from medical care providers about caring for their recipient compared to Non-Hispanic White caregivers; this may become a concern considering the support that may be required when assisting care recipients with tasks such as the management of medications or the arrangement of outside services.

The concept of filial piety, an attitude of respect and obligation to family elders, is prevalent in Asian American and Pacific Islander cultures. Many studies have attributed filial piety to AAPI caregiver beliefs, attitudes, and actions across multiple ethnicities.<sup>54,55</sup> Filial piety may explain certain outcomes related to the caregiver, such as the living situation. The sense of obligation associated with filial piety may contribute to the emotional stress experienced by AAPI caregivers, in addition to the financial impact of caregiving. A majority of Asian American and Pacific Islander caregivers (61 percent) feel they had no choice in taking on their caregiving responsibility. Research suggests that both familism and filial piety as cultural norms in different ethnic communities have both positive and negative impacts on caregiving experiences.<sup>56</sup> Again, more research is needed on how these philosophies influence caregiving in different populations to clearly understand what factors need to be considered in the development of useful and relevant programs for caregivers from different ethnic backgrounds.

Asian American and Pacific Islander caregivers report needing guidance in navigating the health care system as well as avenues for their own self-care. While this could be related to language barriers, it is possible that this need is due to Asian American and Pacific Islander caregivers receiving less information from medical care providers. There is a clear need for better provider-caregiver communication in Asian American and Pacific Islander families.




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The concept of filial piety, an attitude of respect and obligation to family elders, is prevalent in Asian American and Pacific Islander cultures.

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<sup>54</sup>Kong, E. (2007). *The influence of culture on the experience of Korean, Korean American and Caucasian-American family caregivers of frail older adults: A literature review*. *Journal of Korean Academy of Nursing*, 37(2), 213–20. Doi: 10.4040/jkan.2007.37.2.213.

<sup>55</sup>Sun, F., Ong, R., & Burnette D. (2012). *The influence of ethnicity and culture on dementia caregiving: A review of empirical studies on Chinese Americans*. *American Journal of Alzheimer's Disease & Other Dementias*, 13–22. Doi: 10.1177/1533317512438224.

<sup>56</sup>Schwartz, S.J., Weisskirch, R.S., Hurley, E. A., Zamboanga, B.L., Park, I.J.K., Kim, S.Y., Umaña-Taylor, A., Castillo, L.G., Brown, E., & Greene, A.D. (2010). *Communalism, familism, and filial piety: Are they birds of a collectivist feather? Cultural Diversity and Ethnic Minority Psychology*, 16(4), 548–60. Doi: 10.1037/a0021370.



# LGBTQ CAREGIVERS

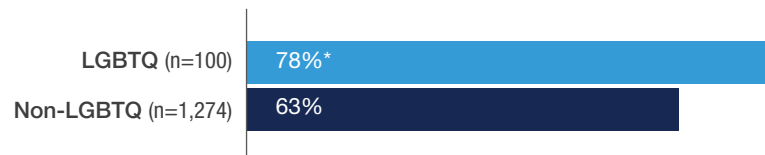
Currently, there is very little research on the experiences of the caregivers in the LGBTQ community. According to *Caregiving in the U.S. 2020*, LGBTQ caregivers are, on average, 42.4 years old, significantly younger than non-LGBTQ+ caregivers who are, on average, 50 years old. About 42 percent of LGBTQ caregivers are married or partnered, significantly lower than non-LGBTQ caregivers (63 percent). An estimated 59 percent of LGBTQ caregivers are Non-Hispanic White, 21 percent are African American, 13 percent are Hispanic, 3 percent are Asian American and Pacific Islander, and 5 percent are other races.

The average care recipient of an LGBTQ caregiver is 65 years old; the average care recipient of a non-LGBTQ caregiver is 69.4 years old. LGBTQ caregivers usually care for a parent (40 percent), parent-in-law (6 percent), grandparent (16 percent), or a spouse/partner (15 percent). LGBTQ caregivers are more likely to care for a grandparent than non-LGBTQ caregivers (16 percent vs. 8 percent).

When asked about *networks*, LGBTQ caregivers reported that they are more often the primary caregiver for their care recipient than non-LGBTQ caregivers (78 percent vs. 63 percent).

There was a stark increase from 2015 to 2020 in the percentage of LGBTQ caregivers who reside with their care recipient (from 31 percent to 47 percent).

**Figure 27: Primary Caregivers**



\*Indicate significantly different from Non-Hispanic White caregivers. Results are rounded and/or multiple response; results may not add to 100 percent.

With respect to *living situation*, there was a stark increase from 2015 to 2020 in the percentage of LGBTQ caregivers who reside with their care recipient (from 31 percent to 47 percent). Compared to non-LGBTQ caregivers, LGBTQ caregivers reported less frequently that their care recipient lived in their own home.

**Figure 28: Care-Recipient's Living Situation**

	LGBTQ (n=100)	Non-LGBTQ (n=1,274)
Care recipient lives in their own home	33%	44%*
Care recipient lives in caregiver's household	47%	39%
Care recipient lives in someone else's home	3%	5%
<b>Total: Care recipient lives in any facility</b>	15%	11%
An independent living or retirement community	4%	5%
In an assisted living facility where some care may be provided	6%	4%
A nursing care or long-term care facility	5%	3%

\*Indicates significantly different from non-LGBTQ caregivers. Results are rounded and/or multiple response; results may not add to 100 percent.

Regarding *caregiving activities and level of care*, LGBTQ caregivers spend about 28 hours a week providing care and assisting with 2.3 ADLs, compared to 1.6 ADLs among non-LGBTQ caregivers. According to our *adjusted logistic regression analysis*, LGBTQ caregivers had an increased odds of helping their care recipient in and out of the bath/shower (OR=1.92, p=0.007) and feeding (OR=1.62, p=0.046) compared to non-LGBTQ caregivers. There were no significant differences in care intensity between LGBTQ and non-LGBTQ caregivers in the adjusted logistic regression analysis.

**Figure 29: ADLs and IADLs That LGBTQ Caregivers Assisted Their Care Recipient With (Adjusted Logistic Regression Analysis)**

	OR (95% CI)	P
Getting in and out of beds and chairs	1.24 (0.78–1.96)	0.367
Getting to and from the toilet	1.44 (0.87–2.38)	0.153
Getting in/out of the bath/shower	1.92 (1.20–3.07)	<b>0.007</b>
Incontinence	1.22 (0.68–2.18)	0.505
Feeding	1.62 (1.01–2.59)	<b>0.046</b>
Managing Finances	0.8 (0.50–1.27)	0.335
Grocery shopping	1.41 (0.78–2.55)	0.256
Housework (dishes, laundry, etc.)	1.39 (0.78–2.47)	0.268
Meal prep	1.24 (0.76–2.01)	0.386
Transportation	1.25 (0.70–2.23)	0.458
Arrange out-side services	1.37 (0.86–2.19)	0.182
Manage medication	1.08 (0.68–1.69)	0.753
Manage medication	1.92 (1.33–2.77)	<0.001

LGBTQ caregivers spend about 28 hours a week providing care and assisting with 2.3 ADLs, compared to 1.6 ADLs among non-LGBTQ caregivers.

Results are presented as odds ratios (OR, referent category non-LGBTQ Caregivers) with 95 percent confidence interval (CI). Bolded values indicate significantly different from referent category.

In terms of *care coordination*, roughly 39 percent of LGBTQ caregivers find it difficult to coordinate care between providers, almost double from 2015 (23 percent).



More LGBTQ caregivers feel alone during their journeys as caregivers compared to non-LGBTQ caregivers.

## FINANCIAL STRAIN

Regarding *finances*, LGBTQ caregivers report greater financial impacts (2.4 on average compared to 1.6 among non-LGBTQ caregivers). This includes being unable to afford basic expenses and using up more savings. However, according to our adjusted logistic regression analysis, there was no significant difference in overall financial strain between LGBTQ and non-LGBTQ caregivers.

In the *workplace*, nearly two-thirds of LGBTQ caregivers report their supervisor is aware of their caregiving duties (63 percent). However, 17 percent of LGBTQ caregivers report feeling discriminated against at work due to caregiving, compared to 6 percent of non-LGBTQ caregivers.

Regarding *health*, 33 percent of LGBTQ caregivers report being in fair or poor health, significantly higher than non-LGBTQ caregivers (19 percent). Among LGBTQ caregivers, 34 percent would like doctors or other providers to ask about their self-care needs, compared to 21 percent among non-LGBTQ caregivers. Along these lines, more than one in three (36 percent) LGBTQ caregivers more often want help managing their physical or emotional stress compared to one in four (25 percent) non-LGBTQ caregivers.

According to our *adjusted logistic regression analysis*, there were no significant differences in the odds of a healthcare provider asking what a caregiver needs between LGBTQ and non-LGBTQ caregivers.

## SUMMARY AND CONCLUSION

Although there is substantial data showing health disparities in the LGBTQ community compared to the non-LGBTQ community, there is very little data on the experiences of LGBTQ caregivers. LGBTQ caregivers were found to differ demographically but experience similar outcomes to non-LGBTQ caregivers. We found that LGBTQ status had little effect on the outcomes assessed, though LGBTQ caregivers reported an increased likelihood for assisting their care recipient getting in/out of the bath/shower, and with feeding responsibilities. While prior literature indicated LGBTQ caregivers display more financial strain, this effect disappeared when controlling for caregiver income in our adjusted logistic regression analysis.

LGBTQ caregivers are more often the primary caregiver for their care recipient. As well, more LGBTQ caregivers feel alone during their journeys as caregivers compared to non-LGBTQ caregivers. LGBTQ adults are half as likely to have a partner, twice as likely to live alone, and four times as likely not to have children compared to non-LGBTQ individuals, likely due to continued bias and discrimination against same-sex marriage and family planning in the LGBTQ community.<sup>57</sup> This might lead to less formal familial structures and could result in overall less support for LGBTQ caregivers.

Although our study did not find differences across LGBTQ status with respect to individual provider relations, LGBTQ caregivers did more often report difficulty in managing care coordination across multiple care providers compared to non-LGBTQ caregivers. Secondary literature shows that LGBTQ caregivers may be unwilling to disclose their LGBTQ status to medical professionals, possibly due to fear of discrimination.<sup>58</sup> This perceived challenge with full disclosure may be a factor in blunting communication with medical care providers. Our data suggests that LGBTQ caregivers would like to have a doctor, nurse, or social worker inquire about needs for themselves and their care recipients.

In summary, there is still a great need for advocacy and awareness for the ongoing challenges that LGBTQ caregivers face, including individual and institutional discrimination. Continued progress in this sphere is necessary to improve the experiences of caregivers that identify as LGBTQ, particularly with respect to support from those around them and from medical care providers.

<sup>57</sup>SAGE. *The Facts of LGBT Aging*. Retrieved October 14, 2020, from <https://www.sageusa.org/wp-content/uploads/2018/05/sageusa-the-facts-on-lgbt-aging.pdf>.

<sup>58</sup>Shiu, C., Muraco, A., & Fredriksen-Goldsen, K. (2016). "Invisible care: Friend and partner care among older lesbian, gay, bisexual, and transgender (LGBT) adults." *Journal of the Society for Social Work and Research*, 7(3), 527–46. doi:10.1086/687325.



## SNAPSHOT: KAREN

**Karen is the only child of a small family. Her father had passed, so it was Karen's responsibility to help care for her mother Mimi as need be.**

Karen has the mindset that you do what you can to help family, so she began to do the shopping and other small tasks for her mother in 2010. In addition, Karen has a background in finance, so she helped her mother, aunt, and uncle with their finances.

By 2016, Mimi needed enough help to warrant getting a home health aide, so Karen facilitated this service while also figuring out how to have meals delivered and do other small things for her mother. Unfortunately, Mimi had a bad fall and was taken to the hospital. While there, medical providers found she had pneumonia, a life-threatening issue due to Mimi's chronic obstructive pulmonary disease. Karen did not enjoy the hospital experience; she feels it is daunting enough to deal with hospitals and healthcare in the wake of a catastrophic illness. With no siblings, Karen also had the added responsibility of being the sole decision maker for Mimi's care.

After the hospital, Karen considered putting her mother into assisted living, but Mimi's preference was to return home. Karen agreed that Mimi should return home but knew her mother would need 24/7 help. Karen hired a health aide because she could not care for her mother alone. Karen visited her mother two to three times a week to help with shopping, arrange medications, and take her to the doctor. When Mimi fell a second time, Karen knew the best option for her mother was a long-term care facility. Karen was still able to visit Mimi, help with her mother's medications, and ensure Mimi made it to her doctors' appointments.

The pandemic changed everything for Karen, making it even harder for her to provide care to her mother. Nursing homes were hit very hard and Karen was concerned for Mimi's health. She had a hard time getting in touch with her mother. Karen bought her a cell phone so that she could talk to her. The administration of the nursing home was uncommunicative and did not provide updates on

what was happening in regard to the pandemic or how Mimi was doing. Karen was not able to FaceTime her mother until May and could not have an outside visit with her until August. Additionally, Karen was concerned Mimi was not getting proper care, since services had been temporarily halted and she knew her mom was sitting in her room all day. Karen worried about her mother's laundry being done, and whether Mimi could reach her glasses or the phone.

Karen is part of a caregiver support group run by SAGE, an elder LGBTQ organization.

Karen feels respect and awe for stories she hears from caregivers who are caring for a parent who did not accept them or their sexuality. She says these individuals cannot imagine not giving their care recipient their best life possible. Although Karen never experienced the issue of not being accepted by her parents, she feels the same about caring for her mother the best she can for as long as Mimi lives. While not having a partner is common in the LGBTQ community, and although Karen has had friends and some ex-partners who have supported her throughout her caregiver journey, she has persevered primarily on her own.

From a policy standpoint, Karen believes there needs to be more communication with the public, especially after what she experienced with Mimi's nursing home. It is exhausting for her to have to continuously reach out to people to find out how her mother is being cared for. She doesn't believe she should have to experience that. There needs to be more planning and support around long-term care and the finances required for long-term care. Karen finds it rewarding that caregiving has shown her how strong she is, and the extent of her patience and resourcefulness, but she acknowledges that caregiving is tiring and stressful. Caregivers need support.



## INFLUENCE OF SOCIOECONOMIC STATUS ON CAREGIVING

Collectively, family caregivers spend over \$500 billion a year in costs associated with providing care to their care recipients.<sup>59</sup> These costs may create an additional burden for caregivers from low-income families compared to higher-income families.

Collectively, family caregivers spend over \$500 billion a year in costs associated with providing care to their care recipients.

For caregiving tasks, according to our *adjusted logistic regression analysis*, caregivers in the lowest income bracket (<\$15K per year) showed significantly higher odds of assisting with several caregiving tasks compared to caregivers at a higher income level (>\$150K per year). These include assisting their care recipient in and out of the bath/shower (OR=1.75, p=0.045), grocery shopping (OR=2.09, p=0.048), meal preparation (OR=1.92, p=0.025), and housework (OR=1.98, p=0.048). Caregivers in a lower- to middle-income bracket (\$15K to \$29.9K per year) also showed higher odds of assisting their care recipient in and out of the bath/shower (OR=1.63, p=0.03) and meal prep (OR=2.07, p=0.001). There was, however, no difference in caregiving intensity across different income brackets.

**Figure 30: ADLs and IADLs Caregivers in the Income Bracket <\$15K Per Year Assisted Their Care Recipient With (Adjusted Logistic Regression Analyses)**

	OR (95% CI)	P
Getting in and out of beds and chairs	1.63 (0.97–2.75)	0.067
Getting to and from the toilet	1.43 (0.82–2.51)	0.212
Getting in/out of the bath/shower	1.75 (1.01–3.01)	<b>0.045</b>
Incontinence	1.03 (0.55–1.93)	0.934
Feeding	1.02 (0.58–1.79)	0.944
Managing Finances	0.78 (0.46–1.32)	0.357
Grocery shopping	2.09 (1.01–4.33)	<b>0.048</b>
Housework (dishes, laundry, etc.)	1.98 (1.01–3.92)	<b>0.048</b>
Meal prep	1.92 (1.09–3.40)	<b>0.025</b>
Transportation	0.77 (0.42–1.43)	0.411
Arrange out-side services	0.65 (0.37–1.13)	0.13
Manage medication	1.13 (0.67–1.90)	0.65
Manage medication	1.92 (1.33–2.77)	<0.001

Results are presented as odds ratios (OR, referent category caregivers in the >\$150K income bracket) with 95 percent confidence interval (CI). Bolded values indicate significantly different from referent category.

<sup>59</sup>Chari A.V., Engberg, J., Ray, K.N., & Mehrotra, A. (2015). *The opportunity costs of informal elder-care in the United States: New estimates from the American Time Use Survey*. *Health Services Research*, 50(3), 871–82. doi: 10.1111/1475-6773.12238.

### *Influence of Socioeconomic Status on Caregiving Continued*

With respect to *information and services used*, caregivers in lower income brackets (\$15K to \$29.9K, \$30K to \$49.9K) had nearly double the odds of using respite services (OR=1.94, p=0.034; OR=1.99, p=0.015, respectively) compared to caregivers at an income level of >\$150K or more. Similar results were found in having home modifications due to caregiving (OR=1.93, p=0.003; OR=1.84, p=0.002, respectively). Caregivers in the lowest income bracket showed double the odds of requesting information regarding caregiving through the internet compared to caregivers at an income level of >\$150K or more (OR=2.03, p=0.032).

Caregivers in lower income brackets (\$15K to \$29.9K, \$30K to \$49.9K) had nearly double the odds of using respite services.

## CAREGIVERS OF CARE RECIPIENTS WHO LIVE IN A RURAL VS. AN URBAN SETTING

Geography can play a consequential factor in access to health care.<sup>60</sup> This section describes the experiences of caregivers who provide care to recipients in rural areas (24 percent of caregivers) vs. urban areas (76 percent of caregivers).

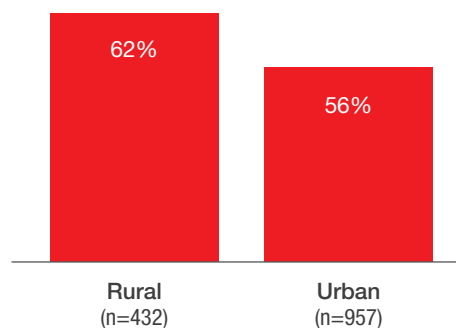


For *caregiving tasks*, caregivers of rural care recipients assist with 4.5 IADLs on average, significantly higher than in 2015 (4.0 IADLs). This includes increased assistance with transportation, housework, and meal preparation. Additionally, roughly 60 percent of caregivers advocate for their rural care recipients with health care providers, community services, and government agencies, compared to 42 percent in 2015.

Compared to caregivers of recipients who live in urban areas (56 percent), more caregivers of care recipients living in rural areas (62 percent) report they perform medical/nursing tasks, such as giving medicines, pills, or injections.

**Figure 31: Percentage of Caregivers of Rural Care Recipients Who Have Performed Medical/Nursing Tasks**

Results are rounded and/or multiple response; results may not add to 100 percent.



<sup>60</sup>National Center for Health Statistics. (2021). Reduced access to care. Centers for Disease Control and Prevention. Retrieved 2021, September 27 from <https://www.cdc.gov/nchs/covid19/pulse/reduced-access-to-care.htm>.

Caregivers of rural care recipients provide more hours of care on average, 26.3 hours compared to 22.5 hours of care by caregivers of urban care recipients. Roughly 32 percent of caregivers who provide care for rural care recipients say it is difficult to find affordable services, compared to 25 percent of caregivers who tend to urban care recipients.

With respect to *self-reported health*, caregivers of rural care recipients are more likely to be in fair/poor health, up to 23 percent from 15 percent in 2015. This aligns with increases in self-reported emotions from 2015.

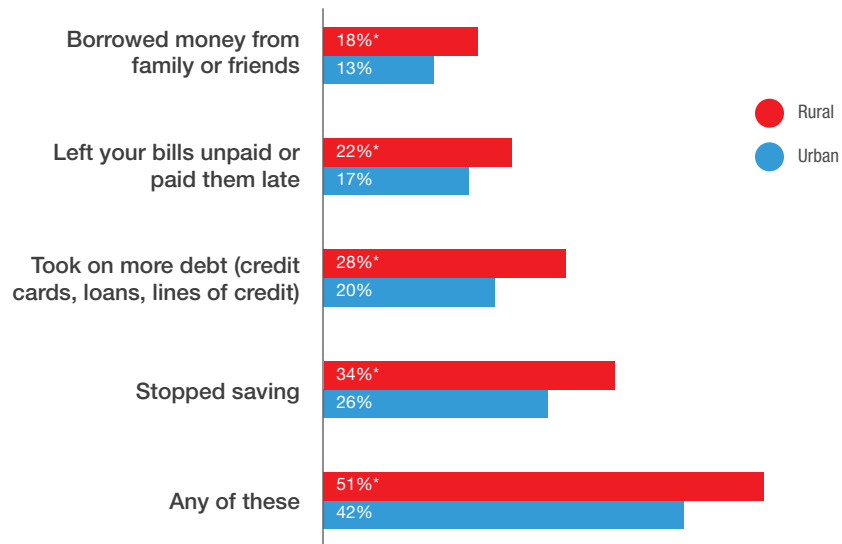
More than one in four caregivers (27 percent) who provide care to rural care recipients agree with the statement “I find/found it difficult to take care of my own health,” compared to one in five (21 percent) caregivers who tend to urban care recipients. Seventeen percent of caregivers of rural care recipients are not covered by any form of health insurance or health plan, compared to 11 percent of caregivers of urban care recipients.

Regarding *finances*, caregivers who tend to rural care recipients experience a high amount of financial stress. Nearly one in four (23 percent) report high financial strain, compared to 16 percent of caregivers who tend to urban care recipients. Caregivers of rural care recipients have experienced an average of 1.9 financial impacts, compared to 1.6 financial impacts experienced by caregivers of urban care recipients:

- Roughly one third (34 percent) of caregivers who tend to rural care recipients have stopped saving, compared to 26 percent of caregivers who tend to urban care recipients;
- More than one in five (22 percent) caregivers who tend to rural care recipients report leaving bills unpaid or paying them late, compared to 17 percent of caregivers who tend to urban care recipients;
- Over a quarter of caregivers who tend to rural care recipients (28 percent) have taken on more debt (credit cards, loans, lines of credit) than caregivers who tend to urban care recipients.
- Nearly one in five (18 percent) caregivers who tend to rural care recipients have borrowed money from family or friends, compared to 13 percent of caregivers who tend to urban care recipients.

Over a quarter of caregivers who tend to rural care recipients (28 percent) have taken on more debt (credit cards, loans, lines of credit) than caregivers who tend to urban care recipients.

**Figure 32: Selected Financial Impacts**



\*Indicate a figure is significantly higher than the figure in the column indicated. Results are rounded and/or multiple response; results may not add to 100 percent.



## SUMMARY AND CONCLUSION

Regarding financial income status, our findings show that caregivers in lower income brackets are more likely to assist with various tasks and are more likely to utilize services such as respite compared to higher income caregivers. These findings may be related to issues associated with resource access, though more research is needed on the impact of caregiving on wages and earnings.<sup>61</sup> However, our data did not suggest distinguishable correlation between socioeconomic status and caregiving intensity, as well as physical, emotional strain, or even financial strain. Inconclusive findings with respect to caregiver impact stratified by caregiver income level have been previously reported;<sup>62</sup> future studies will be needed to determine whether there are additional factors that may influence the impact of caregiver burden in caregivers in lower-income brackets.

Caregivers providing care to recipients in rural areas, according to our study, assist in more caregiving tasks, have poorer self-reported health, and experience greater financial stress compared to caregivers that provide care in urban areas. This aligns with previous studies that also find barriers to both financial wellbeing and health for caregivers in rural areas.<sup>63,64</sup> Greater access to resources for support in rural areas may be an important strategy to address the barriers faced by these caregivers.

Our findings show that caregivers in lower income brackets are more likely to assist with various tasks and are more likely to utilize services such as respite compared to higher income caregivers.



Caregivers providing care to recipients in rural areas, according to our study, assist in more caregiving tasks, have poorer self-reported health, and experience greater financial stress compared to caregivers that provide care in urban areas.

<sup>61</sup>Lilly M.B., Laporte, A., & Coyte, P.C. (2007). Labor market work and home care's unpaid caregivers: A systematic review of labor force participation rates, predictors of labor market withdrawal, and hours of work. *The Milbank Quarterly*, 85(4), 641–90. doi:10.1111/j.1468-0009.2007.00504.x.

<sup>62</sup>Cook, S.K., Snellings, L., & Cohen, S.A. (2018). Socioeconomic and demographic factors modify observed relationship between caregiving intensity and three dimensions of quality of life in informal adult children caregivers. *Health and Quality of Life Outcomes* 16(1), 169. doi:10.1186/s12955-018-0996-6.

<sup>63</sup>Bouldin, E.D., Shaull, L., Andresen, E.M., Edwards, V.J., & McGuire, L.C. (2018). Financial and health barriers and caregiving-related difficulties among rural and urban caregivers. *The Journal of Rural Health*, 34(3), 263–74. doi:10.1111/jrh.12273.

<sup>64</sup>Bigbee, J.L., Musil, C., & Kenski, D. (2011). The health of caregiving grandmothers: a rural-urban comparison. *The Journal of Rural Health*, 27(3), 289–96. doi:10.1111/j.1748-0361.2010.00340.x.

# APPENDIX:

## DETAILED METHODOLOGY OF THE ADVANCED STATISTICAL MODELING

### RESEARCH DESIGN

This analysis is based on the *Caregiving in the U.S. 2020* report conducted by the National Alliance for Caregiving and AARP. Participants were recruited primarily through Ipsos' national, probability-based online KnowledgePanel, which resulted in 1,499 completed online surveys. An additional sample of 240 surveys were added to create a demographically representative dataset of 1,739 completed surveys. Our overarching research question was: Do caregivers of diverse backgrounds, as defined by race/ethnicity, income, and LGBTQ status, experience different outcomes regarding strain, level of intensity, ADLs/IADLs, or resources used?

Our overarching research question was: Do caregivers of diverse backgrounds, as defined by race/ethnicity, income, and LGBTQ status, experience different outcomes regarding strain, level of intensity, ADLs/IADLs, or resources used?

### MEASURES

#### Sociodemographic Factors

An analysis was done on the association of race, ethnicity, income, and LGBTQ status on key caregiver outcomes, and whether these associations were present after adjusting for other covariates. To calculate odds ratios, referent categories were selected based on the research question; these referent categories allowed us to compare the results of the analysis to a particular group.

#### Race/Ethnicity

Participants were asked to which racial or ethnic group they most identified: Non-Hispanic White, African American, Asian American and Pacific Islander, Hispanic, or Other. For our analysis, Non-Hispanic White was used as the referent category.

#### Household Income

Household income was a six-level variable in which participants were asked the total earned household annual income. The options were \$15,000 or less; between \$15,000 and \$29,999; between \$30,000 and \$49,999; between \$50,000 and \$74,999; between \$75,000 and \$99,999; and \$100,000 or greater. For our analysis, \$100,000 or greater was used as the referent category.

#### LGBTQ Status

For our analysis, not identifying as LGBTQ was the referent category.

#### Care Recipient Age

Care recipient age was determined by asking the caregiver how old their care recipient was at the time of the survey. This was a continuous variable that was broken into eight discrete categories, beginning with ages 18–29, followed by ten-year increments until age 90+. For our analysis, ages 18–29 was the referent category.

#### Caregiver Age

Caregiver age was determined by asking the caregiver how old they were at the time of the survey. This was a continuous variable broken into seven discrete categories, beginning with ages 18–29, followed by ten-year increments until age 80+. Due to the small number of caregivers over age 90, we included them with caregivers between ages 80 and 89 in the 80+ category. For our analysis, ages 18–29 was the referent category.

## Conditions

Caregivers were asked a series of five binary yes/no questions regarding the condition(s) they provide care for. Options were non-exclusive and included short-term physical problems, long-term physical problems, behavioral problems, emotional and mental problems, and memory problems. Each option was included as its own variable in the analysis, consistent with the *Caregiving in the U.S. 2020* report.

## Outcome/Measures

### Physical, Emotional, and Financial Strain

Strain variables included physical, emotional, and financial strain, each consisting of a five-item Likert response scale in which 1 meant low strain and 5 meant high strain. Respondents were asked to rate how much of a physical, emotional, or financial strain they felt was caused by their caregiving.

### Level of Care Index

The Level of Care Index (LOC) is a composite measure created to convey the intensity or complexity of the caregiving situation. The index is based on the number of hours of care provided weekly, and the number of ADLs and IADLs performed. Points are assigned to categories representing the number of hours of care provided weekly.

### Box 1. Calculating Level of Care Index

Hours of care provided	Points	Types of care provided	Points
0 to 8 hours	1 point	0 ADLs*, 1 IADL^	1 point
9 to 20 hours	2 points	0 ADLs, 2+ IADLs	2 points
21 to 40 hours	3 points	1 ADL, any # of IADLs	3 points
41 or more hours	4 points	2 ADLs, any # of IADLs	4 points

### ADLs/IADLs

ADLs and IADLs are a six- and seven-item set of questions that ask whether the caregiver assists with a particular activity during their caregiving responsibilities, with a binary response (0=no; 1=yes).<sup>65,66,67</sup>

The ADLs include getting in/out of beds and chairs, getting to and from the toilet, getting in/ out of the bath or shower, incontinence, feeding, and managing medications; IADLs include meal prep, housework (dishes, laundry, and the like), grocery or other shopping, and managing finances.

### Information and Services

Information and Services are five questions with binary responses as to whether the service was used or not (0=no, 1=yes). Questions included requesting information through the internet, respite services, outside services, like transportation and food, home modifications, and the provider asking the caregiver what the caregiver needs to provide care.

## STATISTICAL ANALYSIS

Statistical analysis was performed in R. We examined outcome and covariate descriptive statistics such as proportions and means separately. We used the chi-square and t test as appropriate to examine intergroup comparisons, adopting an alpha level of 0.05.

After ensuring the proportional odds assumption was met, ordinal logistic regression was run on the physical, emotional, and financial strain variables, and on the level of care index variable.

Logistic regression was used to determine the strength and direction of the association of various confounders on each ADL and IADL. Results are reported as odds ratios, after adjusting for race/ ethnicity, income, LGBTQ status, caregiver age, care recipient age, and condition category.

Max.=4 points

Level of Care Index=Points for hours of care provided + Points for type of care provided (Range=2 to 8 points)

<sup>65</sup>Edemekong, P. F., Bomgaars, D. L., Sukumaran, S., & Levy, S. B. (2020). *Activities of daily living (ADLs)*. StatPearls Publishing. <http://www.ncbi.nlm.nih.gov/pubmed/29261878>.

<sup>66</sup>Gobbens, R. J. J., & Van Assen, M. A. L. M. (2014). "The prediction of ADL and IADL disability using six physical indicators of frailty: A longitudinal study in the Netherlands." *Current Gerontology and Geriatric Research*, 2014. doi:10.1155/2014/358137.

<sup>67</sup>Fieo, R. A., Austin, E. J., Starr, J. M., & Deary, I. J. (2011). "Calibrating ADL-IADL scales to improve measurement accuracy and to extend the disability construct into the preclinical range: A systematic review." *BMC Geriatrics*, 11(42). doi:10.1186/1471-2318-11-42.



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*Bob Bradway, CEO and Chairman Amgen*



**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](http://www.caregiving.org).

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](mailto:info@caregiving.org)  
[caregiving.org](http://caregiving.org)