Appendix B: Detailed Methodology

Caregiving in the U.S. 2015 is based primarily on 7,660 online interviews among adults, age 18 and older, conducted in late 2014 using GfK's national, probability-based online KnowledgePanel®. The base study includes full interviews with caregivers of an adult and comes from four separate samples: a national, general population sample, a targeted African-American sample, a targeted Hispanic sample, and a targeted Asian-American sample.

The base study resulted in 1,248 full online interviews with 698 non-Hispanic White, 206 non-Hispanic African-American, 208 Hispanic, and 95 Asian-American[1] caregivers of an adult, as well as 41 caregivers of another race. The remaining 6,412 online interviews were comprised of non-caregivers, caregivers of a child under the age of 18 only, or caregivers of an adult who did not complete the full interview.

Three oversamples groups were conducted, in addition to the base study, to strengthen the analysis of key groups. 1) Caregivers age 65 to 74 and 2) age 75 or older were oversampled using GfK's KnowledgePanel®, for a total of 213 caregivers age 65 to 74 and 269 caregivers age 75 or older (combined caregivers of an adult from the base study plus the age-specific online oversamples). 3) Asian-American caregivers were oversampled using a blended landline-cell phone sample to yield 201 Asian-American caregivers (combined caregivers of an adult from the base study online plus the targeted phone oversample).

The sections below describe, in more detail, the research and sample design for *Caregiving in the U.S. 2015*. Also included is a discussion of prevalence estimation, weighting, and response rate.

A. Research Design

The research design of this study is based on achieving two key goals for National Alliance for Caregiving and AARP Public Policy Institute. First: estimate prevalence of caregiving for someone of any age within both the U.S. population and households. This goal is achieved by administering a screener to all respondents, regardless of caregiver status or the age(s) of care recipient(s). Second: describe the characteristics, roles, and needs among caregivers who provide care to an adult age 18 or older. This is achieved through administering a full online interview to caregivers of an adult only.

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[1] Asian-American is inclusive of those caregivers who are of Asian origin, background, or descent, including the regions of the Indian subcontinent, Far East, Southeast Asia, or Pacific Islands.

Special areas of focus for this year's full interview are medical/nursing tasks, hospitalization, issues faced by working caregivers, and the especially vulnerable experience among caregivers who provide 21 or more hours of care weekly.

Caregiving in the U.S. 2015 utilized a national, probability-based, online panel in lieu of the traditional random digit dial (RDD) landline-only telephone study used in prior waves (1997, 2004, and 2009). This change was necessitated by the ever-changing technological shift occurring in the United States away from landline ownership and toward cell phone use. A majority of adults in the United States now use only their cell phone (43%) or primarily use their cell phone (16.6%)[2] for phone calls.

Due to the shift in data collection, *Caregiving in the U.S. 2015* should be considered a standalone research effort, and should not be compared to prior waves conducted via landline telephone only (1997, 2004, or 2009).

We would have lost our ability to trend to prior waves, even if we continued to collect data via telephone, as we would have had to incorporate cell phone interviewing, which prior waves had not. Including cell phone sample would have changed the sampling frame and necessitated changes to the way substantive results are weighted[3]. Transitioning to online interviews, as we chose to do in *Caregiving in the U.S. 2015*, also changes the sampling frame and weighting of substantive results.

Caregiving in the U.S. 2015 establishes a new baseline for examining changes to caregiving in the future.

B. Questionnaire Design

The questionnaire was drafted by Greenwald & Associates, drawing from the NAC/AARP study, *Caregiving in the U.S. 2009*. The questionnaire, shown in Appendix A, has two components to meet the two core goals of the study.

First: the screener is used to establish the presence of any caregiver, caring for someone of any age, in the household and to obtain demographic information from a randomly-selected respondent. The screener is administered regardless of the presence of caregiving in the household or the age(s) of the care recipient(s). This allows estimation of the national prevalence of caregiving for

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[2] CDC/NCHS, National Health Interview Survey, Early Release Program Jan-Jun 2014 data.

[3] In prior waves of *Caregiving in the U.S.*, conducted in 1997, 2004, and 2009, a household level weight was applied to substantive results, as initial respondents who reported the presence of a caregiver in their household, but who they themselves were not a caregiver, were able to pass the phone to said caregiver. Therefore, caregivers in prior reports were representative of households with caregivers in them, rather than caregivers at a population level.

someone of any age (child and/or adult recipients), at both the individual and household levels.

Second: the core of the online interview, which includes the questions about caregiving, which was administered to all caregivers of adult care recipients. Only the randomly-selected initial respondent who was a caregiver of an adult was eligible to complete the full interview.

The questionnaire was programmed into two versions, both shown in Appendix A. The first, used for 1,457 full online interviews (1,248 base study and 209 age-targeted), was a computer-aided web interviewing system (CAWI), programmed by GfK and administered to their KnowledgePanel®. The second, used for 106 Asian-American caregiver interviews, was a computer aided telephone interviewing system (CATI) administered by National Research, LLC. For both modes of survey administration, Greenwald & Associates closely monitored all development of programming and fielding.

The CAWI questionnaire was professionally translated into Spanish, building from the translation of the 2009 CATI questionnaire and modifying for self-administration.

C. Sample

As described above, the base study is comprised of four samples, all conducted online. 1) A random general population sample, which aimed to get 1,000 online interviews with caregivers of adults. 2) Targeted oversample of African-Americans, to reach 200 total African-American caregivers from the general population sample plus the targeted oversample. 3) Targeted oversample of Hispanic, to reach 200 total Hispanic caregivers from the general population sample plus the targeted oversample. 4) Targeted oversample of Asian-Americans, to reach as many Asian-American caregivers from the general population sample plus the targeted oversample[4].

The base study was conducted using GfK's web-enabled KnowledgePanel®, a probability-based panel, designed to be representative of the U.S. population. GfK selects panelists scientifically by a random selection of telephone numbers and residential addresses. Persons in those selected households are then invited by telephone or by mail to participate in the web-enabled KnowledgePanel®. For those who agree to participate, but do not already have internet access, GfK provides, at no cost, a laptop and ISP connection. People who already have computers and internet service participate in the panel using their own equipment. Panelists then receive unique log-in information for accessing

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[4] GfK's KnowledgePanel contained a limited amount of Asian-American respondents, of which we maximized to obtain a total of 95 Asian-American caregivers.

surveys online, and then are sent emails throughout each month inviting them to participate in research.

Those four samples – the general population sample, plus the three racial/ethnic targeted oversamples – produced the following number of completed online interviews and screened respondents for the base study:

Base Study	Completed Interviews	Additional Screened Respondents
General population	1,015	5,308
African-American targeted	104	536
Hispanic targeted	59	287
Asian-American targeted	70	281
Total	1,248	6,412

In addition to the 1,248 online caregiver interviews in the base study, GfK utilized an age-targeted online sample to reach an additional 209 caregivers age 65 or older (11 age 65 to 74 and 198 age 75 or older), to obtain a total of 213 caregivers ages 65 to 74 and 269 caregivers ages 75 or older.

In addition to the online interviews conducted via KnowledgePanel®, an additional 106 interviews were conducted via telephone with Asian-American caregivers, 65 coming from landline contacts and 41 coming from cell phone contacts. The limited number of Asian-Americans in KnowledgePanel® required this supplementation. The sample dialed was 64% landline and 36% cell phone.

For the Asian-American targeted landline sample, the study used an Asian surname sample within a 30% or greater density area. For the Asian-American targeted cell phone sample, the study used an Asian surname sample. Both sample components came from Survey Sampling International and Opinionology (SSI), the premier global provider of sampling. Due to the mode difference, the Asian-American caregivers interviewed via telephone are not included in the base study results or estimates of prevalence, but are folded into analyses of Asian-American caregivers. Combining all modes (online and telephone), we obtained 201 full interviews with Asian-American caregivers of an adult[5].

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[5] The combination of online and telephone modes for the Asian-American caregivers may result in some mode effects *within* this subgroup. However, the benefit of insights into Asian-American caregivers overall, as a result of obtaining additional completes, was deemed to outweigh the limitation of mode effect.

D. Field Methodology

A randomly selected respondent was selected for participation in *Caregiving in the U.S. 2015* from GfK's KnowledgePanel® from the base study samples[6]. The online interview began with the screener among these randomly-selected respondents, and proceeded to the substantive portion of the questionnaire, *only if* the randomly-selected respondent was identified as a caregiver of an adult.

Only caregivers of adults were eligible to complete the full interview, though caregiver of a child status was ascertained in the screener portion, to maintain the ability to estimate prevalence at a household and population level.

Pertinent demographic data were collected or provided by GfK for all of these initial, randomly-selected respondents (age, race, and gender), regardless of their caregiver status. Furthermore, data on the household were gathered for the national study (family or non-family status of household members, age of householder, and race of householder).

The screening questions used to identify the presence of a caregiver in the household are as follows[7].

To identify caregiver of an adult:

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.

To identify those caring for a child with special needs[8], used in estimating national prevalence of caregiving only:

In the last 12 months, has anyone in your household provided unpaid care to any child under the age of 18 because of a medical, behavioral, or other condition or disability? This kind of unpaid care is more than the normal care required for a child of that age. This could include care for an ongoing medical condition, a serious short-term condition, emotional or behavioral problems, or developmental problems.

If the randomly-selected respondent reported no caregiver in the household, or if the randomly-selected respondent was not a caregiver but reported that someone else in the household was a caregiver, the interview ended after obtaining the demographic data for the individual and the household. If the

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[6] Again – this includes the general populations sample, African-American targeted oversample, Hispanic targeted oversample, and Asian-American targeted online oversample.

[7] These questions copy those used in *Caregiving in the U.S. 2009* for telephone administration, but are adjusted for self-administration.

[8] Those caring for a child only are included in prevalence estimates, but only caregivers of adults were eligible for the full study.

randomly-selected respondent was a caregiver of an adult, the respondent was administered the full online interview. Only one caregiver per household was interviewed.

For the oversamples of caregivers ages 65 and older and Asian-American caregivers, only the first question above, about caring for an adult, was asked. For the Asian-American caregivers, if the initial respondent reported that there was no caregiver of an adult present in the household, the interview was ended and no household screening data was collected. For the older caregivers, if the initial respondent reported that they themselves were not a caregiver of an adult, the interview was ended and no household screening data was collected.

In order to be validated as a caregiver of an adult and complete the full interview, all self-identified caregivers from all samples had to report providing help with at least one Activity of Daily Living (ADL), Instrumental Activity of Daily Living (IADL), or medical/nursing task.

Interviews from the GfK national sample were conducted September 18 through September 29, 2014. The African-American, Hispanic, and online Asian-American oversamples were conducted September 25 through October 7, 2014. The oversample of caregivers ages 65 and older was conducted October 9 through October 14, 2014. KnowledgePanel® respondents were given the option of conducting the interview in Spanish or English, and 45% of Hispanic respondents chose Spanish.

The Asian-American caregiver phone interviewing was conducted by National Research. A six-call design was used for interviewing, so that every number was dialed at least six times in an attempt to establish contact. Every soft refusal was followed by another attempt to convert the refusal into a completed interview. The Asian-American phone oversample was conducted September 11 through November 5, 2014.

The completed interviews averaged 23.8 minutes in length online (20 minute median) and 24.7 minutes via phone (24 minute median). See Appendix A for both full CAWI-formatted and CATI-formatted questionnaire with all instructions.

E. Weighting

Data from all samples in the base study[9] were combined and weighted. The oversample phone interviews of Asian-American caregivers and online older

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[9] The base study is comprised of four online samples: the general population nationally-representative sample, the African-American targeted oversample, the Hispanic targeted oversample, and the Asian-American targeted oversample.

caregivers were combined later for analyses specific to these subgroups of caregivers, in a manner described below.

A population weight was derived to estimate the prevalence of caregiving among the U.S. adult population and to analyze the substantive results from the full interviews. The household weight was used to weight the base study results in order to estimate the prevalence of caregiving in U.S. households.

In prior waves, the household level weight was applied to analyze substantive results from the full interviews, as the household was the sampling frame. If the randomly-selected initial respondent reported that s/he was not a caregiver, then another household member who *was* a caregiver was still eligible to complete the full interview. In 2015, only the randomly-selected initial respondent was eligible to complete the full interview. This changed the 2015 sampling frame to individuals, rather than households, thereby necessitating a change in the weight used to analyze results[10].

Population Weights

Population weights were based on the subset of fully screened respondents in the base study who were the randomly-selected initial individuals. They were weighted using a single-stage weighting procedure by age, sex, and race/ethnicity to population estimates from the public-use data file (IPUMS) of the March 2014 Current Population Survey, conducted by the U.S. Census Bureau.

The same population-based weighting process was applied to each of the three non-base study oversamples: phone Asian-American caregivers, caregivers ages 65 to 74, and caregivers 75 or older. Weighting targets for caregiver age, sex, and race/ethnicity were developed from the population-weighted base study caregivers who matched the oversample group. Then, the oversample caregivers were combined with the like-caregivers from the base study, and their combined distribution was then weighted to the targets.

More specifically, the 106 oversample phone Asian-American caregivers were combined with the 95 unweighted online Asian-American caregivers, and then weighted to the population-weighted distribution of Asian-American caregivers from the base study by age and sex. The 11 oversample caregivers ages 65 to 74 were combined with the 202 unweighted caregivers ages 65 to 74, and then weighted to the population-weighted distribution of caregivers ages 65 to 74 in the base study by race/ethnicity and sex. The same process followed for the 198 oversample caregivers ages 75 or older in combination with the 71 unweighted caregivers ages 75 or older from the base study. To create the ability to analyze

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[10] This change in weighting would still have resulted had we chosen to do a landline RDD with cell phone supplement design, as cell phones are not household-based.

caregivers ages 65 or older, those age 65 to 74 and those age 75 and older were weighted in proportion to their occurrence in the caregiving population.

Household Weights

Household weights involved a multi-stage weighting procedure, closely mirroring that of the 2009 process. In the first stage, all base study data were weighted by householder race/ethnicity, and in the second stage, by householder age and household type (family or non-family). The weighting was based on all respondents who were fully screened in the base study, and who did not terminate during the screening process.

The dataset included screened respondents who reported no caregivers in the household, caregivers who completed the interview, and respondents who reported the presence of caregivers who chose not to participate in the full interview or who only partially completed it. Weighting targets came from the public-use data file (IPUMS) of the March 2014 Current Population Survey, conducted by the U.S. Census Bureau.

Weighting Substantive Results

For reporting the substantive results of the national study in this report among the 1,248 caregivers interviewed, data are weighted by the population weight.

For researchers looking to project substantive results to the U.S. population, multiply any percentages by the estimated 39.8 million U.S. adults estimated to be caring for an adult.

F. Estimating Prevalence of Caregiving

Population Prevalence

Using the 7,660 randomly-selected initial respondents in the base study weighted with population weights, we find that 1,227 are caregivers of adults in the prior twelve months, as validated through a complete or partial online interview. In addition, 177 reported they were caregivers of someone any age, but did not continue the online interview to validate that caregiving status. However, among the initial respondents who initially reported being a caregiver of an adult and continued far enough in the online interview to validate their status, 92.8% were ultimately validated.

Applying this percentage to the 177 non-validated caregivers of any age results in n=164 additional caregivers. The 1,227 plus 164 caregivers, on a base of 7,660 total screened respondents, leads to a population prevalence rate of

18.2% and an estimate of 43.5 million individual caregivers in the U.S. The prevalence for each race/ethnicity is shown in the following table.

	Prevalence	Number of Adults Age 18+ in the U.S.	Estimated Number of Adult Caregivers in the U.S.
Overall	18.2%	239,340,657	43.5 million
White (Non-Hispanic)	16.9%	156,772,568	26.5 million
African-American	20.3%	27,670,111	5.6 million
Asian-American	19.7%	13,791,579	2.7 million
Hispanic	21.0%	36,307,496	7.6 million
Other	21.3%	4,798,903	1.0 million

We are able to analyze the prevalence of caregivers in the U.S. by the age of care recipient(s). It is estimated that 16.6% of American adults, or 39.8 million adults, have provided care to an adult age 18 or older in the prior twelve months. We also estimate 4.3% of American adults, or 10.2 million adults, have provided care to a child with special needs in the prior twelve months[11].

	Prevalence	Number of Adults Age 18+ in the U.S.	Estimated Number of Adult Caregivers in the U.S.
Overall	18.2%	239,340,657	43.5 million
Only child recipients	1.6%	239,340,657	3.7 million
Only adult recipients	13.9%	239,340,657	33.3 million
Both adult and child recipients	2.7%	239,340,657	6.5 million
Caregivers of Recipients Age 50+	14.3%	239,340,657	34.2 million

The population prevalence of caregivers of someone at least 50 years of age (shown above) is 14.3%, based on a total of 1,095 caregivers out of 7,660 screened individuals. The 1,095 caregivers of someone age 50 or older were identified as follows. First, 1,061 of the initial respondents were validated caregivers of an older recipient. An additional 37 were non-validated caregivers of age 50+ recipients; these were multiplied by 92.8%—the proportion of initially-reported caregivers who were asked validating questions and ultimately were confirmed to be caregivers. This results in 34 additional caregivers.

Household Prevalence

There were 7,660 total screened households in the base study. Using household weighted figures, 1,212 of these households contained at least one caregiver of an adult in the prior twelve months, as validated through a complete online

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[11] These are not mutually exclusive groups, in that some caregivers are providing care to both an adult age 18 or older, as well as a child age 0-17.

interview (n=1,190) or through a partial online interview (n=22). In addition, there were 610 households who reported presence of a caregiver of someone of any age, but who did not continue the interview through to validate the caregiver[12].

However, among the respondents who initially reported a caregiver of an adult in the household and continued far enough in the online interview to validate their presence, a very large proportion (93.7%) were ultimately validated. Accordingly, we also count as caregivers 93.7% of the 610 households (resulting n=572) who reported a caregiver of someone any age, but did not complete the full online interview. Thus 1,212 validated adult caregivers plus an estimated 572 additional caregivers of someone any age, on a base of 7,660 total screened households, leads to a household prevalence rate of 23.3%.

	Prevalence	Number of Households in the U.S.	Estimated Number of Caregiving Households
Overall	23.3%	122,854,716	28.6 million
White (not Hispanic)	21.7%	83,628,928	18.2 million
African-American (not Hispanic)	24.9%	15,228,833	3.8 million
Asian-American	25.2%	5,926,848	1.5 million
Hispanic	28.6%	15,756,754	4.5 million
Other	27.9%	2,313,353	0.6 million

The study also examined prevalence of households containing a caregiver of a recipient at least 50 years of age, estimated at 17.8%. This comes from the following figures: of the 7,660 screened households, there were 1,050 indicating someone in the household cared for a recipient age 50+. An additional 332 indicated someone cared for a recipient age 50+, but did not complete enough of the interview to be validated. These 332 suspected caregivers of someone 50+ were multiplied by 93.7%—the proportion of the *households* with reported caregivers who went far enough in the online interview to be validated—resulting in 311 additional caregivers. A total of 1,361 caregivers divided by 7,660 screened households leads to the 17.8% prevalence estimate.

	Prevalence	Number of Households in the U.S.	Estimated Number of Caregiving Households
Caregivers of Recipients Age 50+	17.8%	122,854,716	21.8 million

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[12] Validation means the caregiver continued far enough in the survey to report that they performed at least one Activity of Daily Living (ADL), Instrumental Activity of Daily Living (IADL), or medical/nursing task for their adult care recipient.

Drop in Prevalence

It must be noted that the prevalence estimates are lower in *Caregiving in the U.S. 2015* than they were in the similar 2009 study. First, it is possible that some decline in caregiving prevalence has occurred since the 2009 study, for whatever reason.

Recent research on this topic has revealed a lower prevalence in line with our 2015 estimates. As part of their *Hidden Heroes: America's Military Caregivers* study, conducted online in late 2013, RAND estimated 9.4% or 22.6 million U.S. adults were current caregivers to an adult[13]. If the *Caregiving in the U.S. 2015* proportions of 56% current and 44% in the past year are projected onto that 9.4% prevalence, it rises to 16.8% of American adults providing care to an adult, comparable to our 16.6% estimate.

A recent telephone study of Americans age 25 and older, conducted by EBRI, places the prevalence of caregiving of someone of any age closer to 19.5%[14], close to our prevalence estimate of caregiving by Americans age 25 and older (19.1%)[15].

This by no means implies a lack of need for the unpaid care provided by caregivers. In fact, demographic shifts[16] and medical advancements[17] have resulted in a rapidly aging population, one with chronic, ongoing conditions that is more in need of care than ever before, but with potentially fewer caregivers to provide needed supportive services[18].

Second, it seems as if the amount of care being provided from 2009 to 2015 has not changed, but rather, that fewer people are providing this care. In 2009, caregivers of adults provided 1,168 million hours of care[19]. In 2015, we estimate

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[13] Ramchand R, Tanielian T, & et al., (2014) Hidden Heroes: America's Military Caregivers, RAND Corporation, 2014.

[14] Their estimate of caregiving without correction for validation is 21% x validation rate of 92.8% results in an estimated 19.5% caregiver rate among a slightly older population (Americans age 25 or older). Helman, R., Copeland, C., & VanDerhei, J. "The 2015 Retirement Confidence Survey: Access to Savings Plan a Key Factor in Americans' Retirement Confidence," EBRI Issue Brief, no. 413 (Employee Benefit Research Institute, April 2015).

[15] Adults age 25 or older, in our study, provide care to an adult or child at a rate of 19.1%. In comparison, we find that 11.8% of adults age 18 to 24 provide care to someone (adult or child).

[16] Anderson, G.F. & Hussey, P.S. (2000) "Population aging: a comparison among industrialized countries" Health Affairs Vol. 19:3

[17] Hung, W.W., Ross, J.S. & et al., (2011) "Recent trends in chronic disease, impairment and disability among older adults in the United States" BMC Geriatrics Vol. 11: 47

[18] Redfoot, D., Feinberg, L., & Houser, A. The Aging Baby Boom and the Growing Care Gap: A Look at Future Declines in the Availability of Family Caregivers (Washington, DC: AARP Public Policy Institute, August 2013).

[19] The average hours of care provided in 2009 by caregivers of adults was 18.9 hours (weighted with population-level weights to match 2015 methodology) x 61.8 million caregivers of someone 18 or older = 1,168 million hours of care.

caregivers of adults are providing 1,134 million hours of care[20]. Today's caregivers seem to be doing a greater amount of care with less help from others, suggesting that though prevalence of caregiving may have dropped at a population level, care is becoming concentrated among fewer people. Further research is needed from the perspective of care recipients, to understand care recipients' ability to find sufficient caregiving help within their social network.

Third, it is also possible that the improving U.S. economy between 2009 and 2015 may be impacting caregiving prevalence. The 2009 study was conducted during the middle of a historic economic recession. There is some evidence in the 2015 data that it may be difficult to both work and provide care. In the 2015 study, non-caregivers are more likely to be working as a paid employee (51.1%) than are current caregivers (44.9%), while current caregivers are more likely to be self-employed (10.6%) than non-caregivers (6.2%). In both the 2009 and 2015 studies, employed caregivers provided fewer hours of care on average than unemployed caregivers.

Finally, we suspect there could be a mode effect, in that, for some reason, online respondents are less likely than telephone respondents to say they or someone in their household is providing care. One explanation for this mode effect is the social desirability bias that occurs with interviewer-administered telephone interviews. The literature shows that respondents are less likely to say they do socially 'good' things online than they do when speaking to an interviewer, as in a telephone study[21]. As we hold methodology consistent in future waves, we will be able to measure real change, without a concern for mode effect.

G. Calculation of the Level of Care Index

The calculation of the level of burden index begins by assigning points for the number of hours of care, as follows:

Hours of Care	
0 to 8 hours	1 point
9 to 20 hours	2 points
21 to 40 hours	3 points
41 or more hours	4 points

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[20] The average hours of care provided in 2015 by caregivers of adults was 28.5 hours x 39.8 million caregivers of someone 18 or older = 1,134 million hours of care.

[21] Joinson, A. (1998) "Social Desirability, Anonymity and Internet-based questionnaires" Behavior Research Methods, Instruments and Computers, Vol 31: 3.

Points are then assigned for the number of ADLs and IADLs performed:

Types of Care Provided	
0 ADLs, 1 IADL	1 point
0 ADLs, 2+ IADLS	2 points
1 ADL, any number of IADLs	3 points
2+ ADLs, any number of IADLs	4 points

Then, the total number of points is consolidated into five levels of care. In this report, analysis often further collapses the five levels into three categories of burden, with "high burden" equating to Levels 4 to 5, "medium burden" corresponding to Level 3, and "low burden" equating to Levels 1 and 2.

Consolidating Points into Five Levels of Care and Three Burden Categories		
2 to 3 points	Level 1	Low burden
4 points	Level 2	
5 points	Level 3	Medium burden
6 to 7 points	Level 4	High burden
8 points	Level 5	

H. Imputation on Constant Care (Hours of Care)

An imputation model was performed on the hours of care question to address potential mode effects of displaying "constant care" as a selection on the compute screen when asking caregivers the hours of care they provide/provided weekly. A linear regression model was used to impute a numeric hours of care provided weekly for caregivers who selected that they provide "constant care." The dependent variable was hours of care. Independent variables included employment while caregiving (dichotomous), co-residence of the care recipient in the caregiver's home (dichotomous), number of ADLs performed, number of IADLs performed, and the presence of other unpaid caregivers[22].

Using this model, nearly all caregivers providing "constant care" would have their numeric hours of care reassigned to values less than 168 hours weekly (true constant care, 24 hours a day, 7 days a week). However, only somewhere between zero and thirty-nine caregivers would be reassigned to a numeric hours

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[22] Other variables considered in modeling, but ultimately rejected included: Recipient's relationship to caregiver; Current vs. past caregiver; Care recipient's age; Care recipient's gender; Condition(s) of care recipient; Presence of Alzheimer's or other mental confusion; and Presence of paid help.

of care less than our key cut point of 41 hours or more, used for the Burden of Care Index calculations[23].

On average, the most conservative model suggests that those who selected ‘constant care’ perform 76 mean hours and 78 median hours of care weekly[24]. These results informed our decision to use a value of 77 hours per week in the mean calculations for anyone who self-selected ‘constant care’ on the online interview. For all others who actually typed in a numeric value of 98 hours of care per week or more, we continued the convention from prior waves of replacing their hours of care with a value of 98 for the mean calculation only.

I. Margin of Error and Response Rate

The margin of sampling error, at the 95% confidence level, for the overall sample and for the two age-specific subsets, which are the focus of separate companion reports, are shown in the following table. The margin of error will be larger for subgroups within each sample.

Sample (with unweighted n's)	Margin or error
Overall prevalence estimates Based on 7,660 screened interviews	1.1 percentage points
Results of entire substantive base study Based on 1,248 completed interviews	2.8 percentage points
Results for caregivers of 18- to 49-year olds Based on 159 completed interviews	7.8 percentage points
Results for caregivers of recipients ages 50 or older Based on 1,087 completed interviews	3.0 percentage points

The response rate of each sample is shown in the following table. For the online samples, this represents a cumulative response rate[25]. The response rates for

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[23] The variation in the reclassification is due to interpretation of the predicted values, as the linear model produces predicted values in the negative range without correction. However, the uncorrected predicted values are most conservative in estimates of what those providing ‘constant care’ would look like on average.

[24] Forcing the predicted values to have a minimum value of 0 hours of care weekly estimates those doing ‘constant care’ at a higher value (100 hour mean, 102 hour median) than we chose to use. The most aggressive correction of the predicted values, assuming there are some caregivers truly providing around-the-clock care and forcing the maximum value of 168 hours of care weekly, provides the most inflated estimates for those doing ‘constant care’ (116 hour mean, 118 hour median).

[25] The cumulative response rate takes into account panel recruitment rates, household profile rates, retention rate, and study-specific response and completion. Callegaro, M. & DiSogra, C. (2008). Computing response metrics for online panels. *Public Opinion Quarterly* 72(5). Pp. 1008-1032.

the telephone samples are based upon a standard method provided by the American Association for Public Opinion Research (AAPOR).[26]

Sample	Response Rate
Full online study, all samples	4.7%
General population online	4.7%
African-American targeted online	4.0%
Hispanic targeted online	2.8%
Asian-American targeted online	4.2%
Age 65-74 targeted online	8.3%
Age 75+ targeted online	6.9%
Phone study, all samples	8.6%
Asian-American targeted landline	6.9%
Asian-American targeted cell phone	11.4%

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[26] The American Association for Public Opinion Research. 2000. *Standard Definitions: Final Dispositions of Case Codes and Outcome Rates for Surveys*. Ann Arbor, Michigan: AAPOR. Response rate formula #2.

K. Banner Definitions

The banners used in the analysis of the main report are defined as follows. Banner 1 was also used for the report on caregivers of someone age 18-49.

BANNER #1 – MAIN Study (caregivers of recipients 18+)

	Description	Definition & weight WEIGHT BY IND14WGT unless otherwise indicated	N size
1	Total	(smptyp14<5 and year=2014 and status=1)	1248
CR Age			
2	18-49	(agecrcat=2)	159
3	50+	(agecrcat=3)	1087
4	50-64	(agecrcat=3 and agecr<65)	234
5	65+	(agecrcat=3 and agecr>64)	853
CG Race/Ethnicity			
6	White	(racecg=1)	698
7	Black	(racecg=2)	206
8	Hisp	(racecg=5)	208
9	Asian	((smptyp14<5 or smptyp14=7) and year=2014 and status=1 and racecg=3; WEIGHT by WGTAcg)	201
Primary CG			
10	Yes	(primary=1)	779
11	No	(primary=2)	462
Choice to care			
12	Yes	(q39=1)	622
13	No	(q39=2)	622
Burden Index			
14	Low	(burden<3)	504
15	Med	(burden=3)	218
16	High	(burden=4 or burden=5)	520
CR Lives			
17	In hhld	(q11=1)	428
18	Not hhld	(q11>1 and q11<6)	808
Distance			
19	Nohh <1 hr	(q11=2 or q11=3)	669
20	1 hr+	(q11=4 or q11=5)	139

Notes: N sizes are unweighted.

Columns 2 thru 8, 10 thru 20 are all subsets of Column 1. That is, they are based on year=2014, status=1 (completed questionnaires only), and smpltyp14<5 (base study, no oversample for Asian caregivers phone completes or oversample caregivers age 65+). Column 9 also includes smptyp14=7 (oversample of Asian-American caregivers).

BANNER #2 – MAIN Study (caregivers of recipients 18+)

	Description	Definition & weight WEIGHT BY IND14WGT unless otherwise indicated	N size
1	Total	(smptyp14<5 and year=2014 and status=1)	1248
Hours CG/week			
2	0-8	(hourscat=1)	564
3	9-20	(hourscat=2)	262
4	21+	(hourscat=3 or hourscat=4)	416
5	0-20	(banhours=1)	826
6	21+	(banhours=2)	416
Lives by hrs			
7	InHH 0-20	(q11=1 and banhours=1)	173
8	InHH 21+	(q11=1 and banhours=2)	253
9	Not 0-20	((q11>1 and q11<6) and banhours=1)	647
10	Not 21+	((q11>1 and q11<6) and banhours=2)	157
Yrs Cared			
11	<1YR	(q21cat=2 or q21cat=3)	596
12	1-4	(q21cat=4)	333
13	5+	(q21cat=5 or q21cat=6)	316
Physical Condtn			
14	Long-term	(q17b=1)	752
15	Short only	(q17b=2 and q17a=1)	309
16	None	(q17b=2 and q17a=2)	187
Mental Hlth Cond			
17	Yes	(q17c=1)	252
18	No	(q17c=2)	996
Alz/Demen			
19	Yes	(alzdem=1)	285
20	No	(alzdem=2)	963
Med/Nurse Tasks			
21	Yes	(n3=1)	722
22	No	(n3=2)	502
CG Gend/Marital			
23	Female Not	(sexcg=2 and D3=3,4,5,or 6)	247
24	Male Not	(sexcg=1 and D3=3,4,5,or 6)	161
25	Female Marr	(sexcg=2 and D3=1 or 2)	480
26	Male Marr	(sexcg=1 and D3=1 or 2)	338
CR Relationship			
27	Parent	(banrel=1)	614
28	Spouse	(banrel=2)	160
29	Other relative	(banrel=3)	282
30	Non-Relative	(banrel=4)	192

Notes: N sizes are unweighted.

Columns 2 thru 30 are all subsets of Column 1. That is, they are based on year=2014, status=1 (completed questionnaires only), and smpltyp14<5 (base study, no oversample for Asian caregivers phone completes or oversample caregivers age 65+).

BANNER #3 – MAIN Study (caregivers of recipients 18+)			
	Description	Definition & weight WEIGHT BY IND14WGT unless otherwise indicated	N size
1	Total	(smptyp14<5 and year=2014 and status=1)	1248
CG gender			
2	Male	(sexcg=1)	507
3	Female	(sexcg=2)	741
Caregiver age			
4	18-49	(agecg>17 and agecg<50)	503
5	50-64	(agecg>49 and agecg<65)	472
6	65+	(smptyp14<7 and year=2014 and status=1 and (agecg>64 and agecg<998); WEIGHT BY WGT65plus)	482
7	65-74	(smptyp14<6 and year=2014 and status=1 and (agecg>64 and agecg<75); WEIGHT BY WGT6574)	213
8	75+	((smptyp14<5 or smptyp14=6) and year=2014 and status=1 and (agecg>74 and agecg<998); WEIGHT BY WGT75plus)	269
CG Education			
9	HS or less	(educ=1 or educ=2)	454
10	Some clg	(educ=3 or educ=4)	347
11	Clg plus	(educ=5 or educ=6)	447
CG Income			
12	<$50K	(income<4)	578
13	$50K+	(income>3 and income<7)	670
14	<$30K	(income<3)	352
15	$30-49K	(income=3)	226
16	$50-99K	(income=4 or income=5)	387
17	$100K+	(income=6)	283
Worked+CG Past Yr			
18	Yes	((q32a=1 and q1=1) or q33=1)	724
19	No	(q33=2)	521
Kids inHH when CG			
20	Yes	(d6=1)	328
21	No	(d6=2)	906

Notes: N sizes are unweighted.

Columns 2 thru 5, 9 thru 21 are all subsets of Column 1. That is, they are based on year=2014, status=1 (completed questionnaires only), and smpltyp14<5 (base study, no oversample for Asian caregivers phone completes or oversample caregivers age 65+). Columns 6 and 8 also include smptyp14=5 (oversample of caregivers age 65-74). Columns 7 and 8 also include smptyp14=6 (oversample of caregivers age 75+).

The banners used in the analysis of caregivers of recipients age 50 or older are defined as follows:

BANNER #4 – Caregivers of recipients 50+			
	Description	Definition & weight WEIGHT BY IND14WGT unless otherwise indicated	N size
1	2015 Total CR 50+	(smptyp14<5 and year=2014 and status=1 and agecrcat=3)	1087
CR Age			
2	50-64	(and agecr<65)	234
3	65-74	(and agecr>64 and agecr<75)	239
4	75-84	(and agecr>74 and agecr<85)	316
5	85+	(and agecr>84)	298
CG Race/Ethnicity			
6	White	(and racecg=1)	613
7	Black	(and racecg=2)	178
8	Hisp	(and racecg=5)	175
9	Asian	((smptyp14<5 or smptyp14=7) and year=2014 and status=1 and agecrcat=3 and racecg=3; WEIGHT by WGTAcg)	186
Primary CG			
10	Yes	(and primary=1)	657
11	No	(and primary=2)	425
Choice to care			
12	Yes	(and q39=1)	542
13	No	(and q39=2)	541
Burden Index			
14	Low	(and burden<3)	438
15	Med	(and burden=3)	190
16	High	(and (burden=4 or burden=5))	454
CR Lives			
17	In hhld	(and q11=1)	348
18	Not hhld	(and q11>1 and q11<6)	730
Distance			
19	Nohh <1 hr	(and (q11=2 or q11=3))	600
20	1 hr+	(and (q11=4 or q11=5))	130

Notes: N sizes are unweighted.

Columns 2 thru 8, 10 thru 20 are all subsets of Column 1. That is, they are based on year=2014, status=1 (completed questionnaires only), agecrcat=3 (recipient age 50 or older), and smptyp14<5 (base study samples only, no oversamples). Column 9 also includes smptyp14=7 (oversample of Asian-American caregivers).

BANNER #5 – Caregivers of recipients 50+			
	Description	Definition & weight WEIGHT BY IND14WGT unless otherwise indicated	N size
1	2015 Total CR 50+	(smptyp14<5 and year=2014 and status=1 and agecrcat=3)	1087
Hours CG/week			
2	0-8	(and hourscat=1)	496
3	9-20	(and hourscat=2)	231
4	21+	(and (hourscat=3 or hourscat=4))	355
5	0-20	(and banhours=1)	727
6	21+	(and banhours=2)	355
Lives by hrs			
7	InHH 0-20	(and q11=1 and banhours=1)	136
8	InHH 21+	(and q11=1 and banhours=2)	211
9	Not 0-20	(and (q11>1 and q11<6) and banhours=1)	587
10	Not 21+	(and (q11>1 and q11<6) and banhours=2)	139
Yrs Cared			
11	<1YR	(and (q21cat=2 or q21cat=3))	503
12	1-4	(and status=1 and q21cat=4)	317
13	5+	(and (q21cat=5 or q21cat=6))	266
Physical Condtn			
14	Long-term	(and q17b=1)	695
15	Short only	(and q17b=2 and q17a=1)	251
16	None	(and q17b=2 and q17a=2)	141
Alz/Demen			
17	Yes	(and alzdem=1)	267
18	No	(and alzdem=2)	820
Med/Nurse Tasks			
19	Yes	(and n3=1)	638
20	No	(and n3=2)	429
CR Relationship			
21	Parent	(and banrel=1)	602
22	Spouse	(and banrel=2)	134
23	Other relative	(and banrel=3)	191
24	Non-Relative	(and banrel=4)	160

Notes: N sizes are unweighted.

Columns 2 thru 24 are all subsets of Column 1. That is, they are based on year=2014, status=1 (completed questionnaires only), agecrcat=3 (recipient age 50 or older), and smptyp14<5 (base study samples only, no oversamples).

BANNER #6 – Caregivers of recipients 50+			
	Description	Definition & weight WEIGHT BY IND14WGT unless otherwise indicated	N size
1	2015 Total CR 50+	(smptyp14<5 and year=2014 and status=1 and agecrcat=3)	1087
CG gender			
2	Male	(and sexcg=1)	440
3	Female	(and sexcg=2)	647
Caregiver age			
4	18-49	(and (agecg>17 and agecg<50))	415
5	50-64	(and (agecg>49 and agecg<65))	422
6	65+	(smptyp14<7 and year=2014 and status=1 and agecrcat=3 and (agecg>64 and agecg<998); WEIGHT BY WGT65plus)	442
7	65-74	(smptyp14<6 and year=2014 and status=1 and agecrcat=3 and (agecg>64 and agecg<75); WEIGHT BY WGT6574)	196
8	75+	((smptyp14<5 or smptyp14=6) and year=2014 and status=1 and agecrcat=3 and (agecg>74 and agecg<998); WEIGHT BY WGT75plus)	246
CG Education			
9	HS or less	(and (educ=1 or educ=2))	385
10	Some clg	(and (educ=3 or educ=4))	297
11	Clg plus	(and (educ=5 or educ=6))	405
CG Income			
12	<$50K	(and income<4)	502
13	$50K+	(and income>3 and income<7)	585
14	<$30K	(and income<3)	303
15	$30-49K	(and income=3)	199
16	$50-99K	(and (income=4 or income=5))	335
17	$100K+	(and income=6)	250
Worked+CG Past Yr			
18	Yes	(and ((q32a=1 and q1=1) or q33=1))	621
19	No	(and q33=2)	464

Notes: N sizes are unweighted.

Columns 2 thru 5, 9 thru 19 are all subsets of Column 1. That is, they are based on year=2014, status=1 (completed questionnaires only), agecrcat=3 (recipient age 50 or older), and smptyp14<5 (base study samples only, no oversamples). Columns 6 and 8 also include smptyp14=5 (oversample of caregivers age 65-74). Columns 7 and 8 also include smptyp14=6 (oversample of caregivers age 75+).