



Declining Self Sufficiency and Caregiving:
Analysis of the 2015 Caregiver and Cognitive Decline Modules
Louisiana Behavior Risk Factor Surveillance System

May, 2018

The Behavioral Risk Factor Surveillance System (BRFSS) is the nation's premier system of health-related telephone surveys that collects state data about U.S. residents regarding their health-related risk behaviors, chronic health conditions, and use of preventive services. Established in 1984 with 15 states, BRFSS now collects data in all 50 states as well as the District of Columbia and three U.S. territories. BRFSS completes more than 400,000 adult interviews each year, making it the largest continuously conducted health survey system in the world.

(<https://www.cdc.gov/brfss/about/index.htm>)

Information is collected from non-institutionalized residents of Louisiana aged 18 years and older using randomly selected cell phone and landline telephone numbers. All data is self reported and subject to associated bias. If the respondent did not know the answer to a question or declined to answer the question, the data was set to missing.

For further information please contact:

Laurie Freyder, MPH

Louisiana BRFSS Coordinator

(504) 568-8191

laurie.freyder@la.gov

Bureau of Informatics

Office of Public Health, Louisiana Department of Health

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Introduction

The need for caregivers will increase over the next 30 to 40 years as baby boomers age and medical advances make it possible for people to live longer with chronic conditions.

People aged 80 and older are considered to be the most likely to need long term care and those between the ages of 45 to 64 are the most likely to be the primary caregivers. The AARP defines the Care-Giver Support Ratio as the number of potential caregivers aged 45-64 for each person 80 and older. In Louisiana, it is anticipated that this ratio will drop from 8.3 in 2010 to 3.4 in 2050.¹

Louisiana	2010	2030	2050
	8.3	4.4	3.4

In an effort to gain a better understanding of the type of care that will be needed, the average weekly time spent in caregiving, the health conditions of the care recipient and the relationship of the caregiver to the recipient, the Behavior Risk Factor Surveillance System included the Caregiver module in the 2009 and the 2015 survey.

Data from the 2009 BRFSS survey revealed that caregivers to persons with Alzheimer's Disease (AD) or other dementia were more likely to be older and to provide self-care services (bathing, dressing, eating) when compared to caregivers to persons with other conditions. They also had been providing care longer and reported increased stress and health problems when compared to non-dementia caregivers.²

Alzheimer's Disease (AD) is the sixth leading cause of death in the United States. The death rate has increased 55% from 1990 to 2014. In addition, more persons with AD are dying at home. These conditions point to an increased need for caregivers willing to provide more intensive, personal care in a stressful environment.³

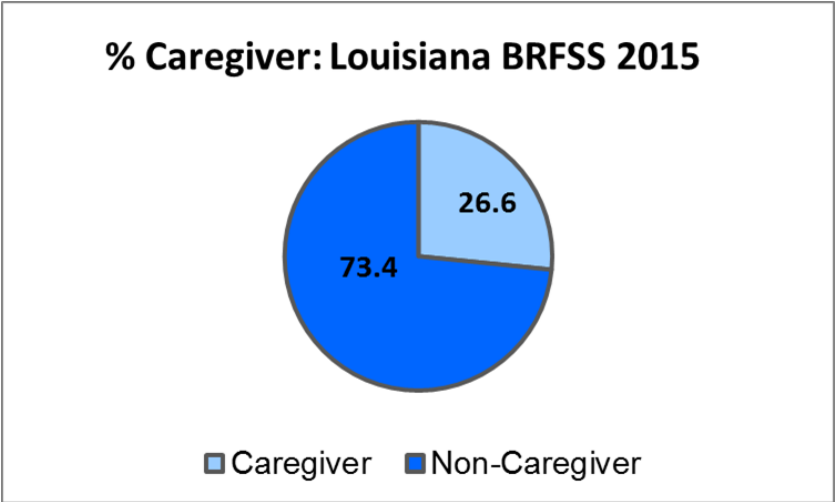
Strategies to provide funding and to develop programs to provide education, respite care and case management services for these caregivers are in place, but cost and service projections are dependent on accurate predictions of the size of the AD population over the next few decades. BRFSS developed the Cognitive Decline module to help meet that need by identifying respondents age 45 and older who claimed Subjective Cognitive Decline (SCD) defined as self-reported increased confusion or memory loss over the last few years that cannot be detected by cognitive tests. In studies and clinical settings SCD is seen as a precursor stage to Mild Cognitive Impairment (MCI), which in turn can progress to AD. Community and clinic-based studies have shown that SCD can also be a manifestation of physical and mental conditions such as depression, anxiety, personality traits, physical health, functional impairment, sleep problems and concurrent medication use.⁴

The Caregiver and Cognitive Decline data from the Louisiana BRFSS 2015 survey were analyzed to:

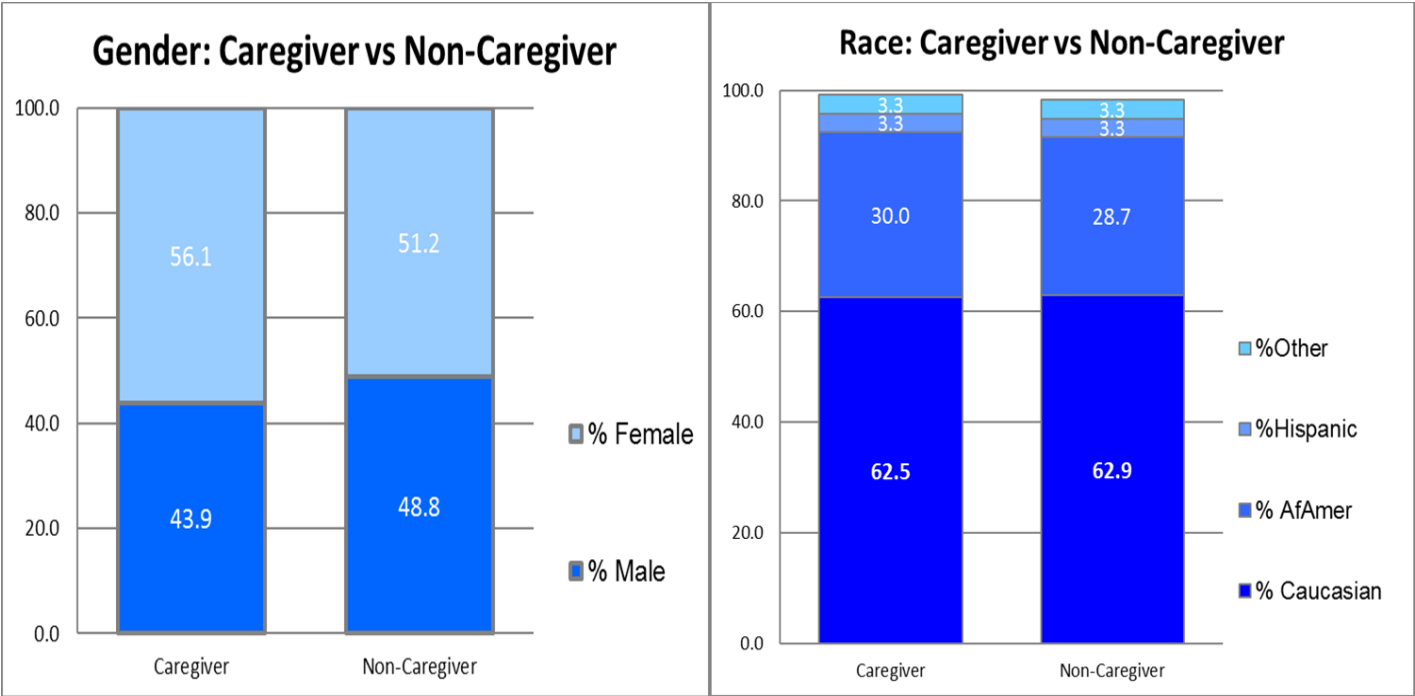
- I. Compare caregivers to non-caregivers**
- II. Compare caregivers of dementia care recipients to caregivers of non-dementia care recipients**
- III. Compare the caregiver and SCD populations to the age specific population that did not identify as either caregivers or having SCD**
- IV. Describe factors specific to caregivers, care recipients and to those with SCD**

I. COMPARISON OF CAREGIVERS TO NON-CAREGIVERS

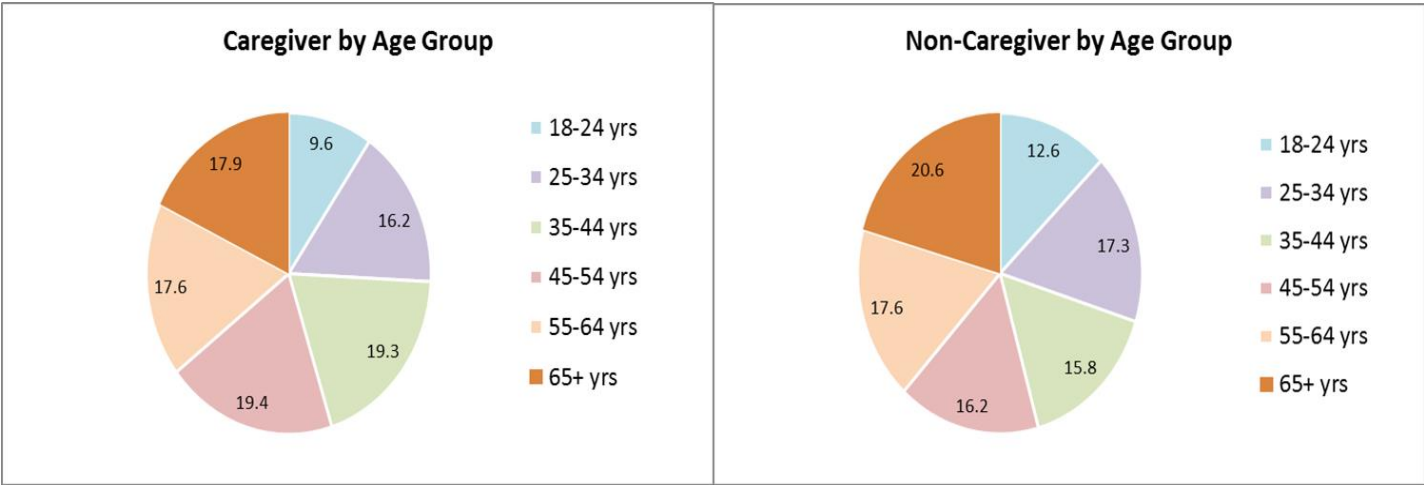
In 2015, 26.6% (24.7-28.4) of respondents to the Louisiana BRFSS reported they provided care or assistance to a friend or family member who has a health problem or disability during the last 30 days.



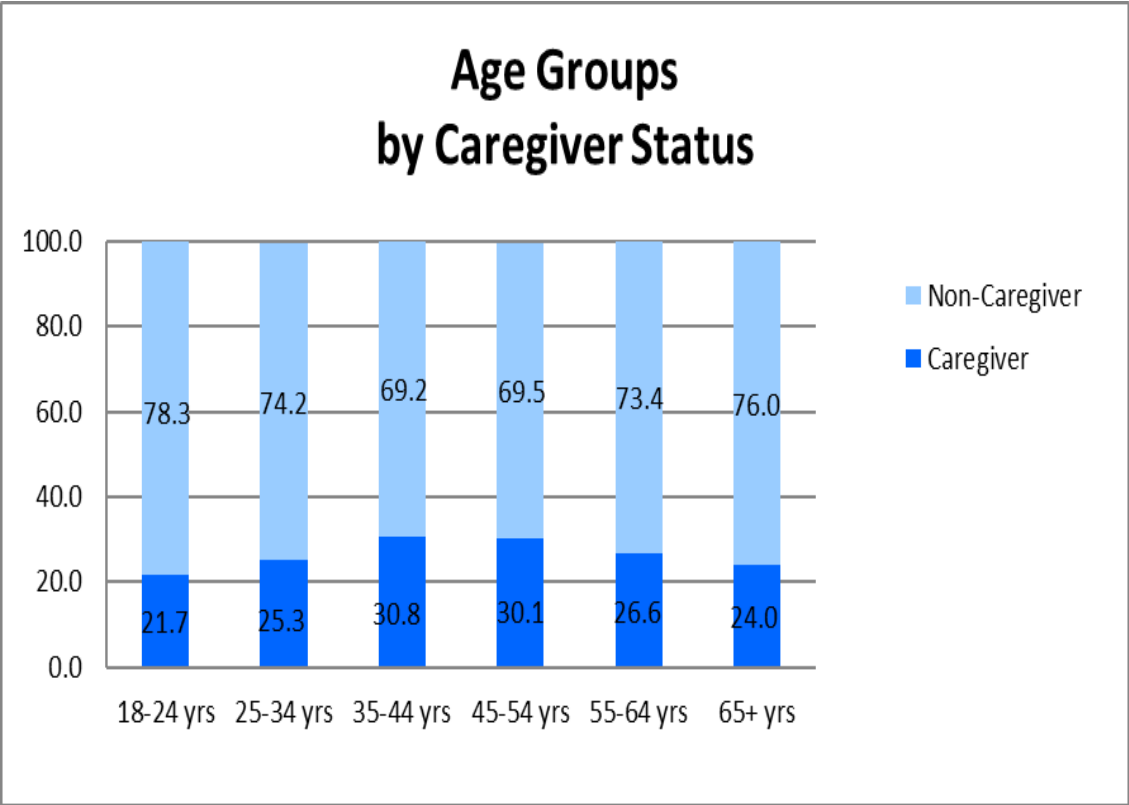
The gender and race distribution for caregivers is very similar to non-caregivers. There are 4.9% more women in the caregiver population while the race breakout is almost identical.



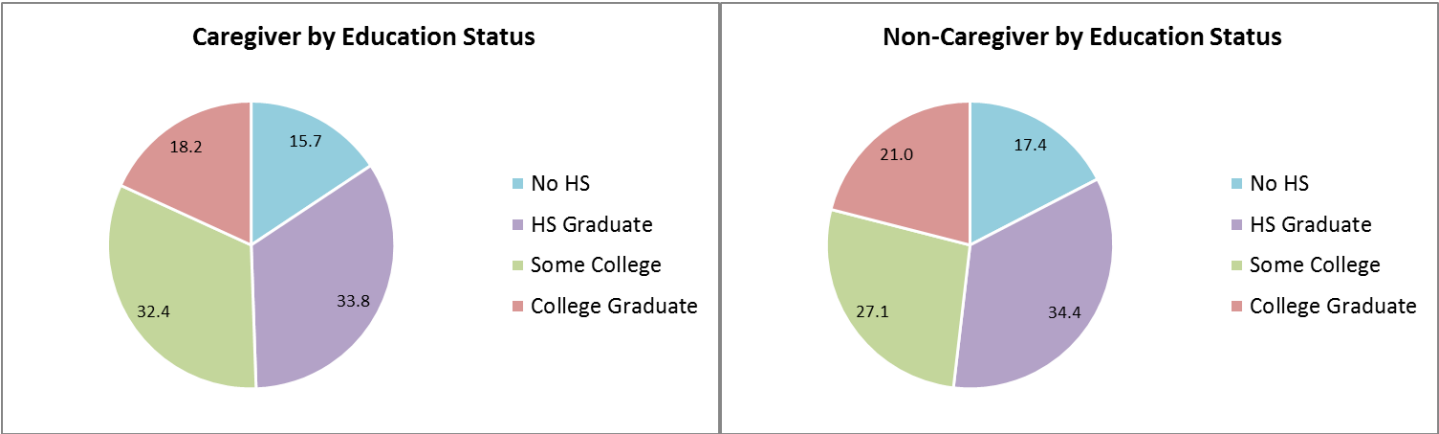
Age



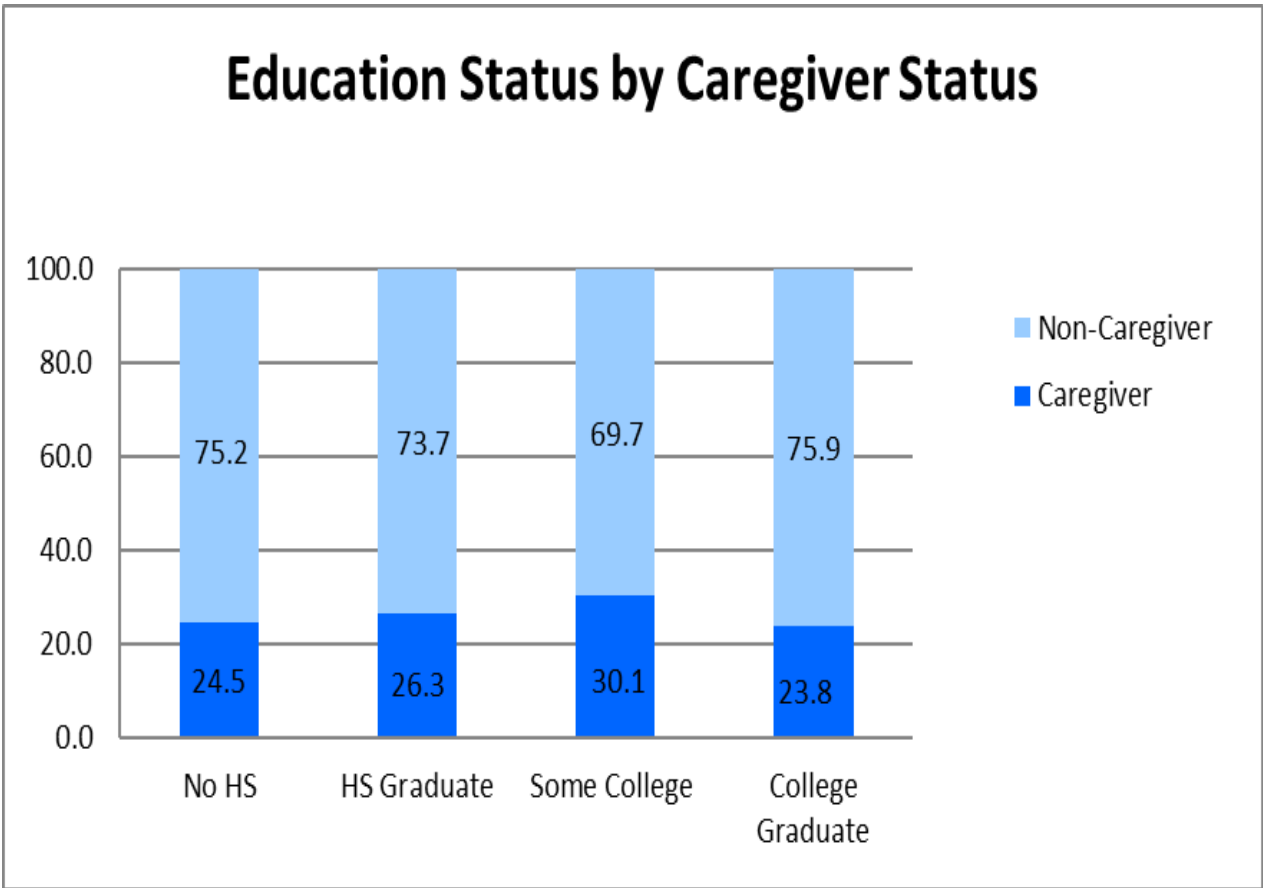
Caregivers are distributed across all the age groups ranging from a low of 21.7% for 18 to 24 year olds to highs of 30.8% and 30.1% for the 35 to 64 years age groups. The age composition for the two groups is very similar with slightly more caregivers in the 35 to 54 years age range and more non-caregivers in the 18 to 34 years and the 65 an older age range. The difference between caregivers and non-caregivers is close to significant for percent of population in the 35 to 44 years group ($p=0.0646$) and for the 45 to 54 years group ($p=0.0644$).



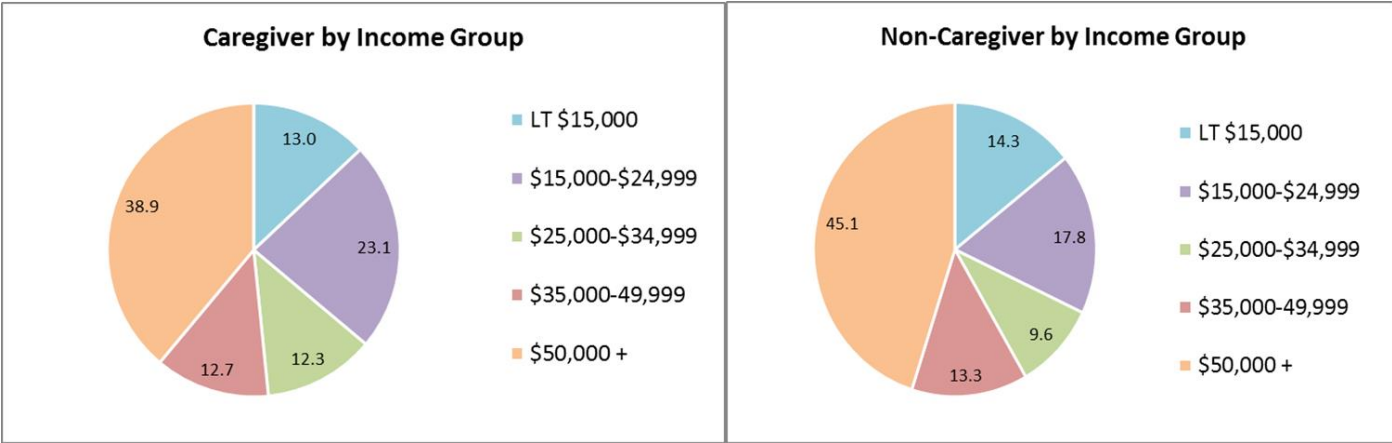
Education



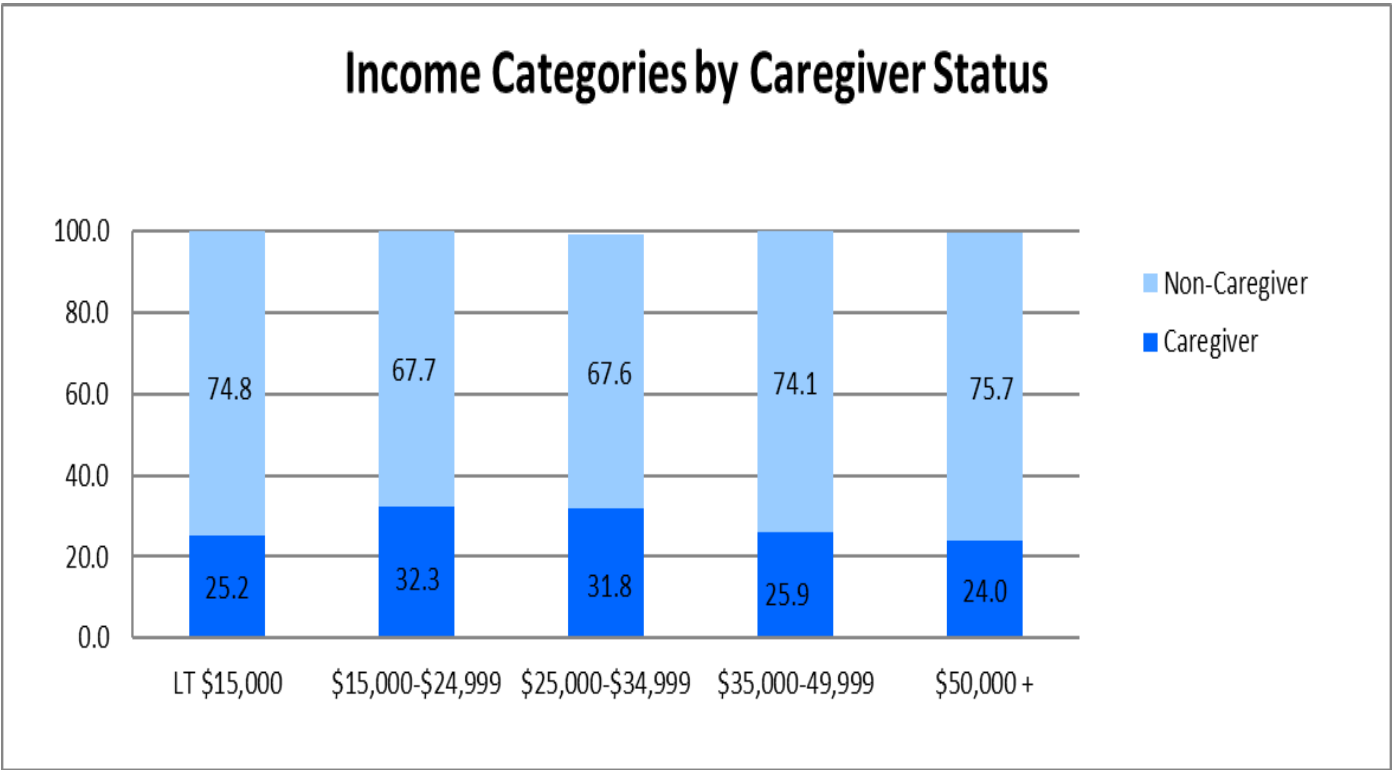
Education status is very similar for the two groups. Non-caregivers have slightly more of their population in the no high school and the college degree categories while caregivers have a greater proportion in the high school graduate and the some college or technical school categories. There is a significant difference between the groups for the some college category ($p=0.0159$)



Income



Caregivers have more of their population in the \$15,000 to \$34,000 income groups than non-caregivers. There were significant differences between caregivers and non-caregivers for the percent of the population in the \$15,000 to \$24,000 ($p=0.0106$) and the \$50,000 plus ($p=0.0181$) income categories.



Recipient Characteristics

The person receiving care is most often the caregiver's mother (21.0%) or a family member, but 15.3% are non-relatives or family friends.

Relationship	% of Those Receiving Care	95% Confidence Interval
Mother	21.0	17.8-24.3
Father	9.9	7.1-12.7
Mother-in-Law	3.6	2.3-4.8
Child	8.9	6.7-11.1
Husband	5.4	3.9-6.9
Wife	5.3	3.8-6.8
Brother or Brother-in-Law	3.9	2.4-5.3
Sister or Sister-in-Law	4.8	3.2-6.5
Grandmother	8.2	5.6-10.7
Grandfather	2.8	1.3-4.3
Other Relative	9.2	6.9-11.4
Non-Relative/Family Friend	15.3	12.3-18.4

Those receiving care have a range of health problems or disabilities.

Health Problem/Disability	% of Those Receiving Care	95% Confidence Interval
Arthritis/Rheumatism	6.0	4.1-8.0
Cancer	9.9	7.1-12.8
COPD	3.7	2.1-5.3
Dementia and other Cognitive Impairment Disorder	9.4	7.1-11.8
Developmental Disabilities	3.1	1.7-4.5
Diabetes	6.3	4.1-8.5
Heart Disease, Hypertension	6.0	4.1-7.8
Mental Illnesses (Anxiety, Depression, Schizophrenia)	3.3	2.1-4.6
Other Organ Failure or Diseases (Kidney or Liver Problems)	2.5	1.1-3.9
Other	47.8	43.6-52.1

Caregiver Responsibilities

30.6% of Caregivers have provided care for more than 5 years.

Time Providing Care	% of Caregivers	95% Confidence Interval
Less than 30 days	17.2	14.3-20.1
1 to 6 Months	14.3	11.3-17.3
6 Months to 2 Years	19.1	15.7-22.5
2 Years to less than 5 Years	18.8	15.8-21.8
More than 5 Years	30.6	26.8-34.4

Most (52.3%) provide care for up to 8 hours per week, but 20.2% provide care for 40 hours or more.

Hours per Week Providing Care	% of Caregivers	95% Confidence Interval
Up to 8 hours per week	52.3	48.1-56.5
9 to 19 Hours per Week	13.5	10.5-16.6
20 to 39 Hours per Week	14.0	11.2-16.8
40 Hours or More	20.2	16.9-23.5

54.4% (50.3-58.5) manage personal care such as giving medications, feeding, dressing or bathing. 76.5% (73.0-80.1) manage household tasks such as cleaning, managing money or preparing meals. 48.6% (44.5-52.7) provide both types of care.

When asked to select the support service that they most needed, 81.1% (77.8-84.4) of caregivers reported that they did not need any of the listed services. 10.1% (7.6-12.6) reported needing help in getting access to services.

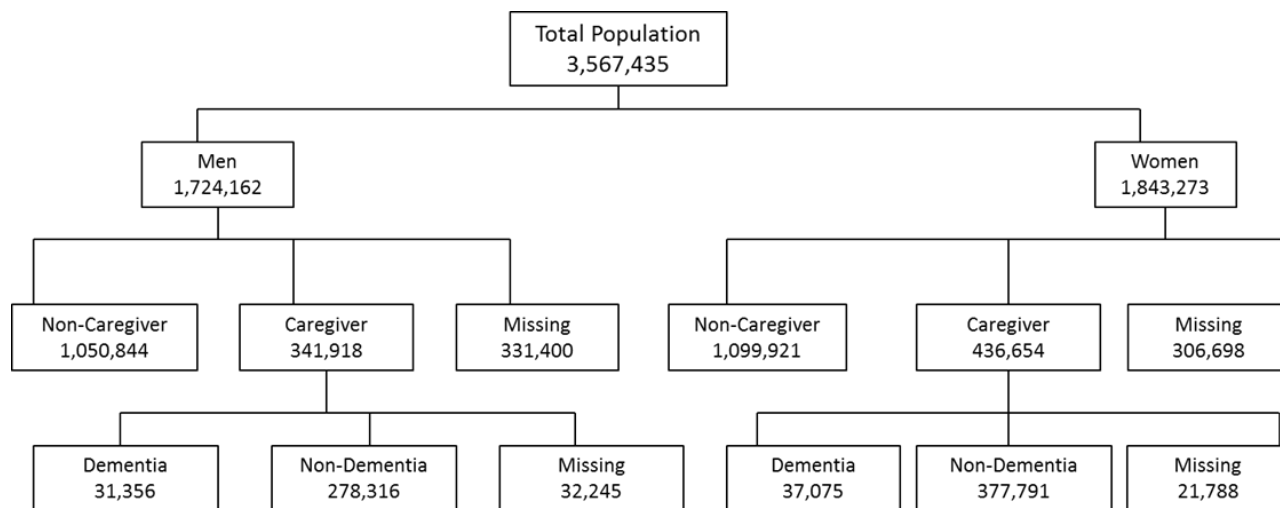
Support Service	% of Caregivers	95% Confidence Interval
Help in Getting Access to Services	10.1	7.6-12.6
Support Groups	1.6	0.7-2.6
Individual Counseling to Help Cope with Giving Care	3.8	2.2-5.4
Respite Care	1.3	0.7-2.0
Do Not Need Any of These Support Services	81.1	77.8-84.4

19.9% (17.8-22.1) of those respondents who did not claim to be a current caregiver report that they expect to provide care or assistance to a friend or family member who has a health problem or disability sometime in the next two years.

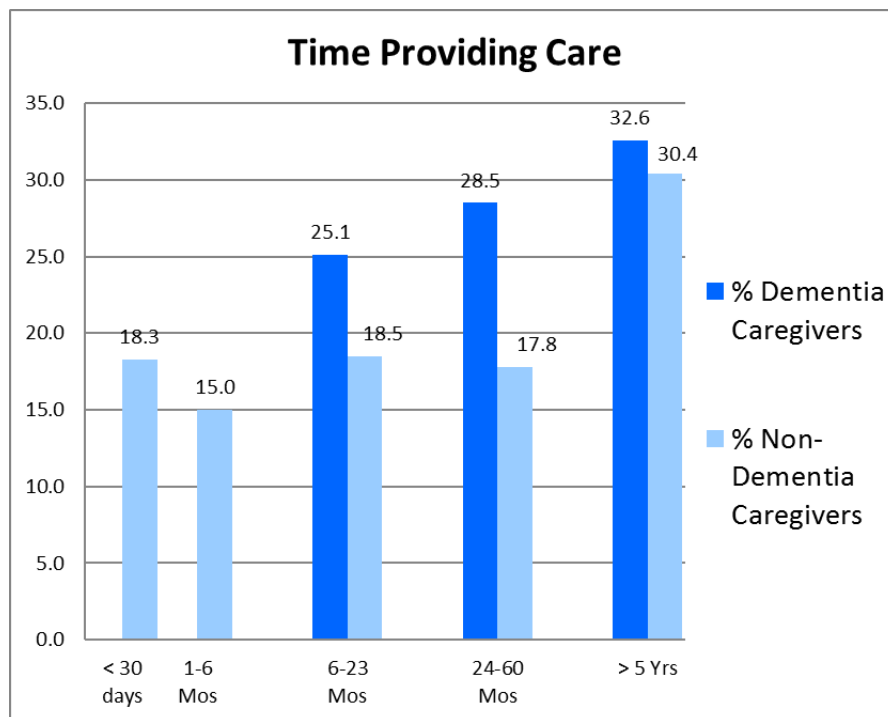
II. CAREGIVERS OF DEMENTIA CARE RECIPIENTS vs CAREGIVERS OF NON-DEMENTIA CARE RECIPIENTS

The following analysis compares two caregiver populations: Caregiver to those with Dementia and Caregiver to those with all other problems or disabilities combined.

These are the weighted N for each of the categories defined. All missing values are removed during weighted analysis when generating prevalence estimates.

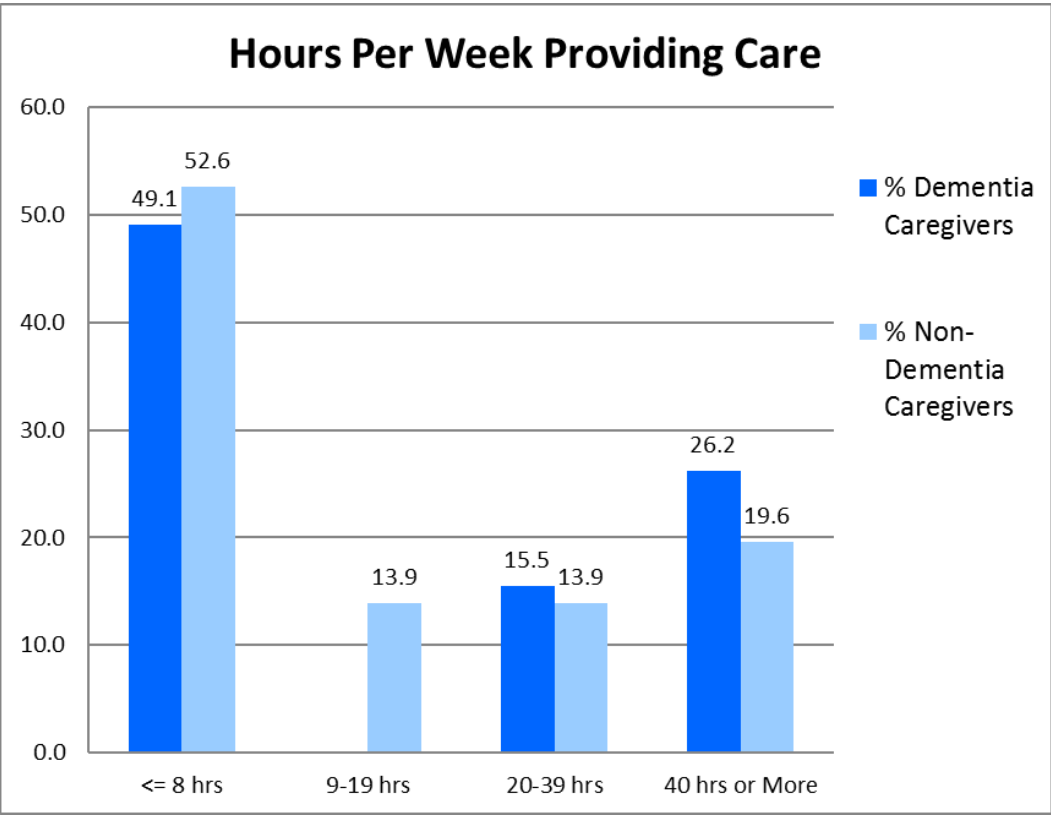


9.4% (7.1-11.8) of all caregivers assist friends or family members with dementia and other cognitive impairment disorders. A greater proportion of caregivers to those with dementia have spent time providing care in the 6 to 23 month, 24 to 60 months and greater than 5 years categories than caregivers to non-dementia recipients.



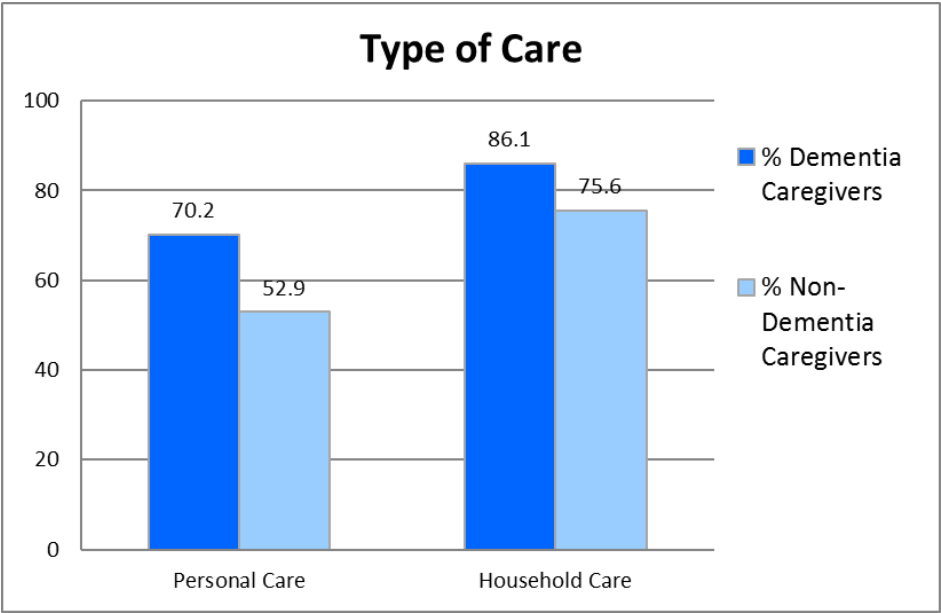
Note: Data is excluded when sample size was insufficient to generate a valid estimate

Dementia caregivers also spend slightly more hours per week providing care with the difference between the groups reaching 6.6 hours for the 40 hours or more category.



Note: Data is excluded when sample size was insufficient to generate a valid estimate

Dementia Caregivers report spending more time on both Personal Care and Household Care than all other types of Caregivers combined.

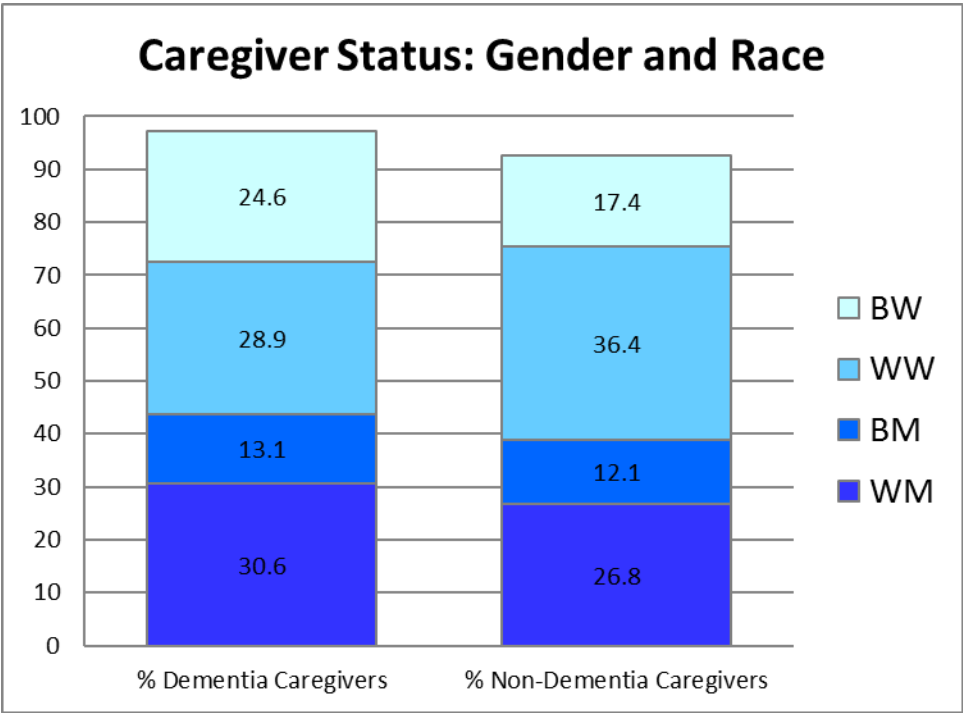


Note: Data is excluded when sample size was insufficient to generate a valid estimate

When asked about support services, 76.2% (65.3-87.1) of the dementia caregivers and 81.6% (78.1-85.1) of the non-dementia caregivers felt no need for the support services that were listed. Both groups did report a need for help in getting access to services: 12.5% (4.4-20.6) for the dementia Caregivers and 9.8% (7.2-12.5) for the non-dementia Caregivers.

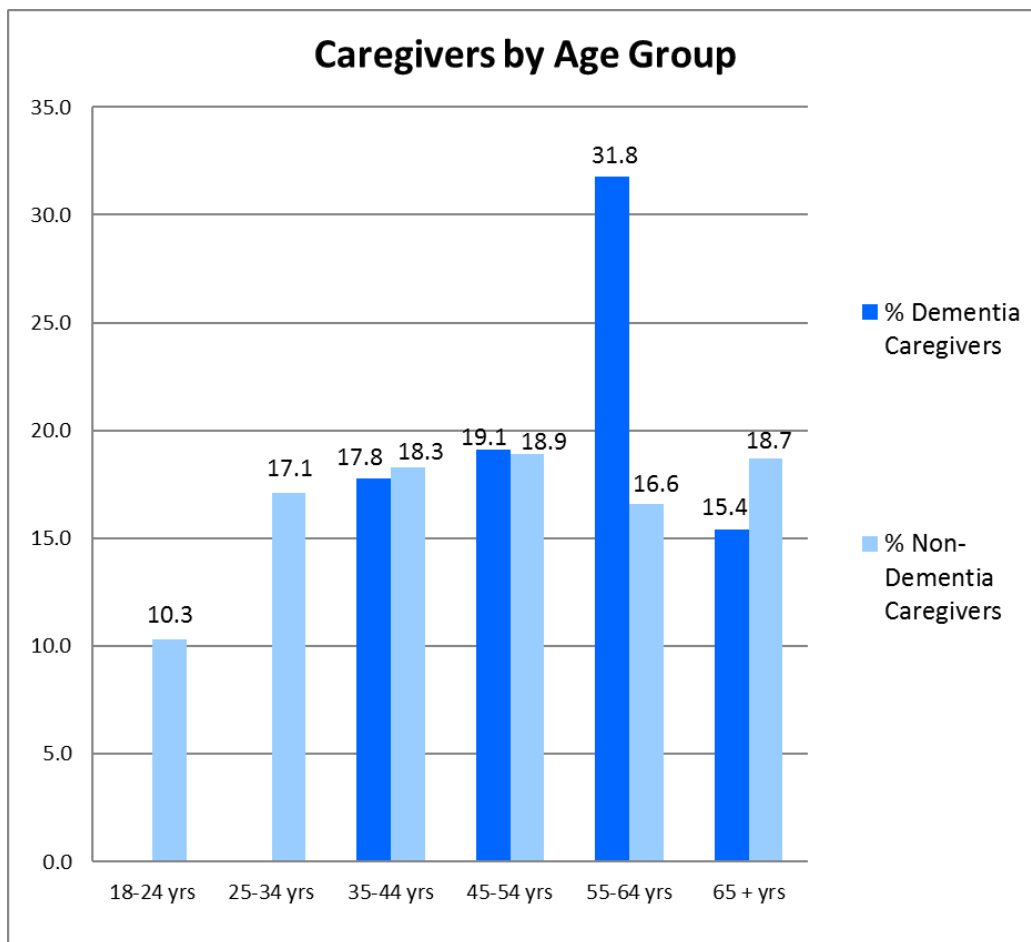
Demographics

The dementia caregiver gender and race composition is similar to the non-dementia caregivers.



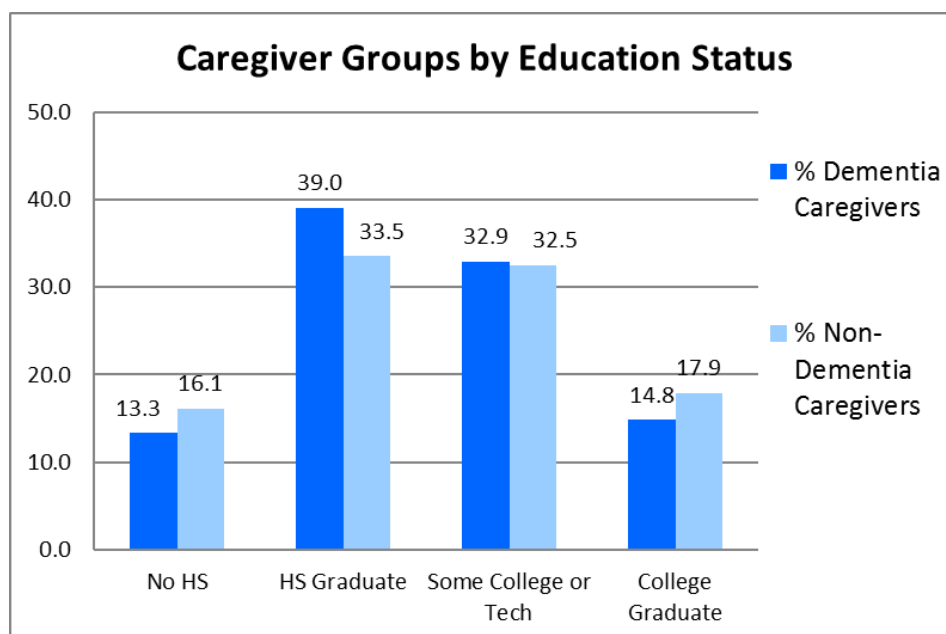
Note: Data is excluded when sample size was insufficient to generate a valid estimate

The proportion of white women in the non-dementia group was 7.5% higher than in the dementia group, while the proportion of black women was 7.2% higher in the dementia group than in the non-dementia group. There was only a 3.8% difference in the proportion of white men across the two caregiver groups. Sample size was too small to generate a valid estimate for dementia caregivers who were black men.

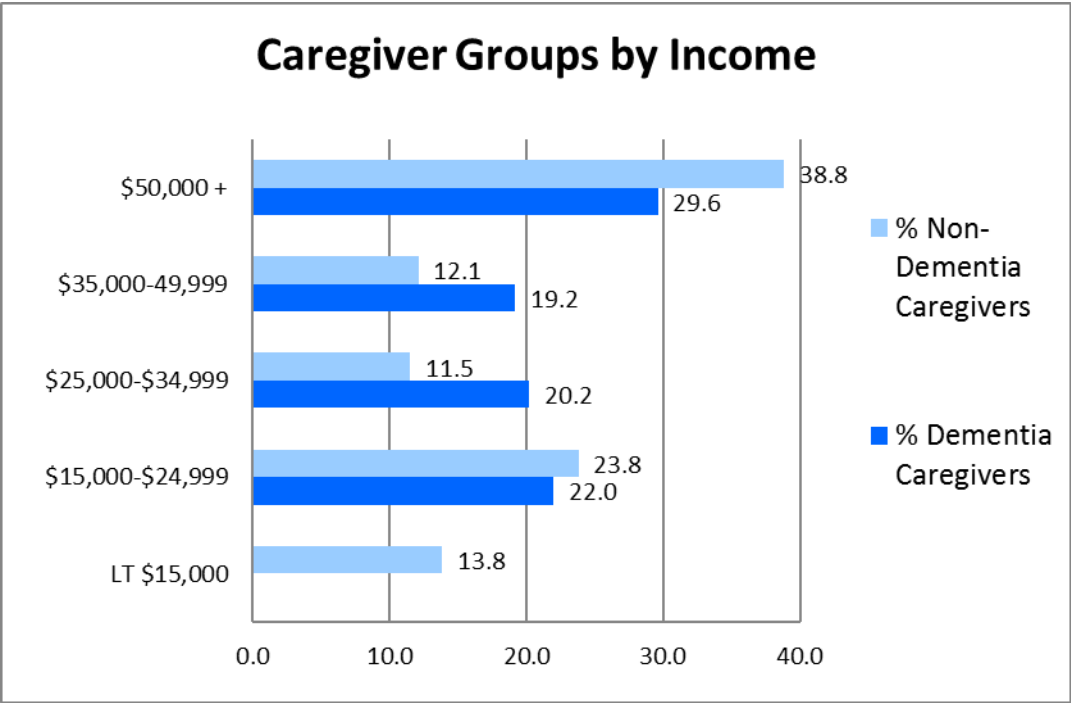


Note: Data is excluded when sample size was insufficient to generate a valid estimate

The two caregiver groups have very similar distributions across 10 year age groups with the exception of the 55 to 65 years age group. 31.8% of dementia caregivers are in the 55 to 65 years group compared to 16.6% for the non-dementia caregivers group, a difference of 15.2%. The two caregiver groups also have similar educational status.



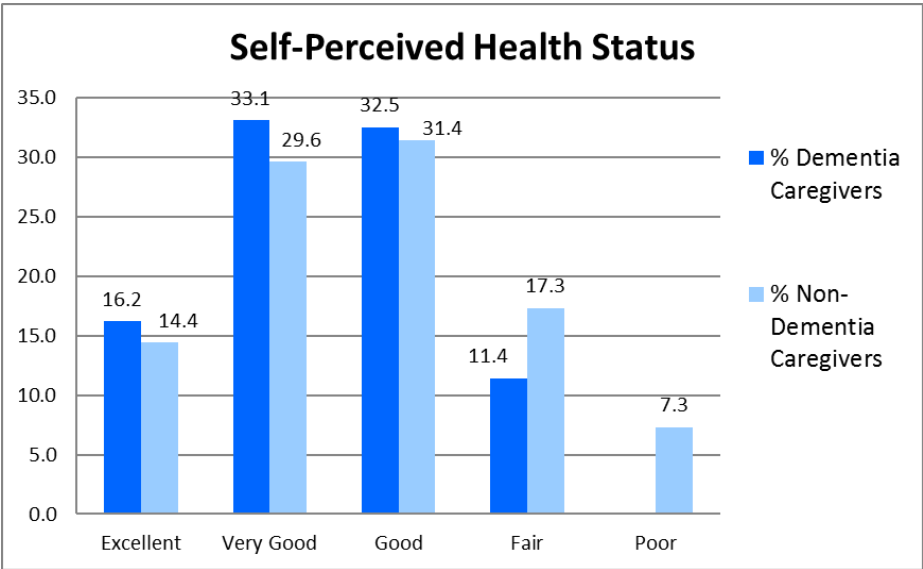
Income varies across the two groups above \$25,000 per year. A higher percentage of the dementia caregivers earn between \$25,000 and \$49,000 while non-dementia caregivers have a higher percentage in the \$50,000 plus category.



Note: Data excluded when sample size was insufficient to generate a valid estimate

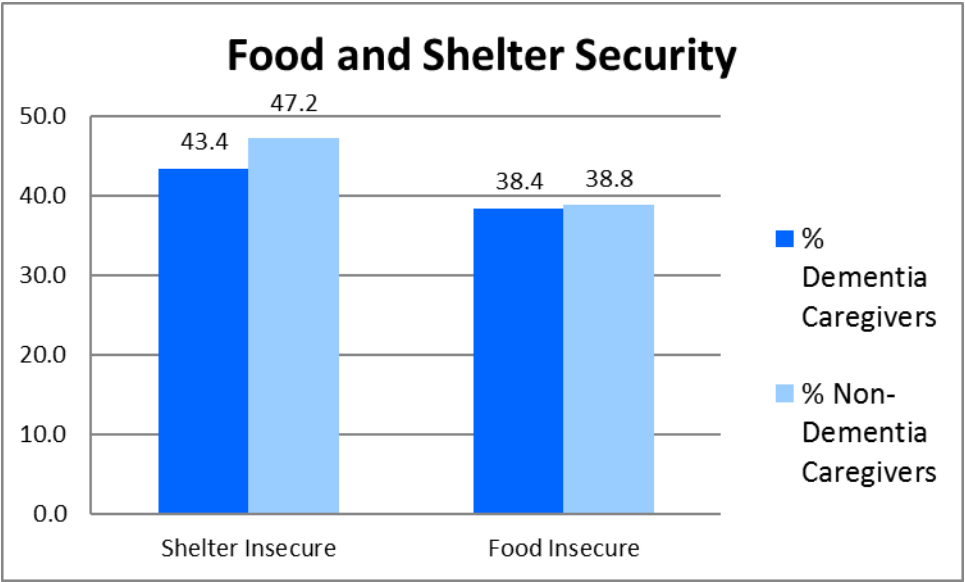
Quality of Life

When asked to describe their general health, both caregiver groups were in general agreement with slightly more of the dementia caregivers reporting excellent to good health and slightly more non-dementia caregivers reporting fair to poor health.

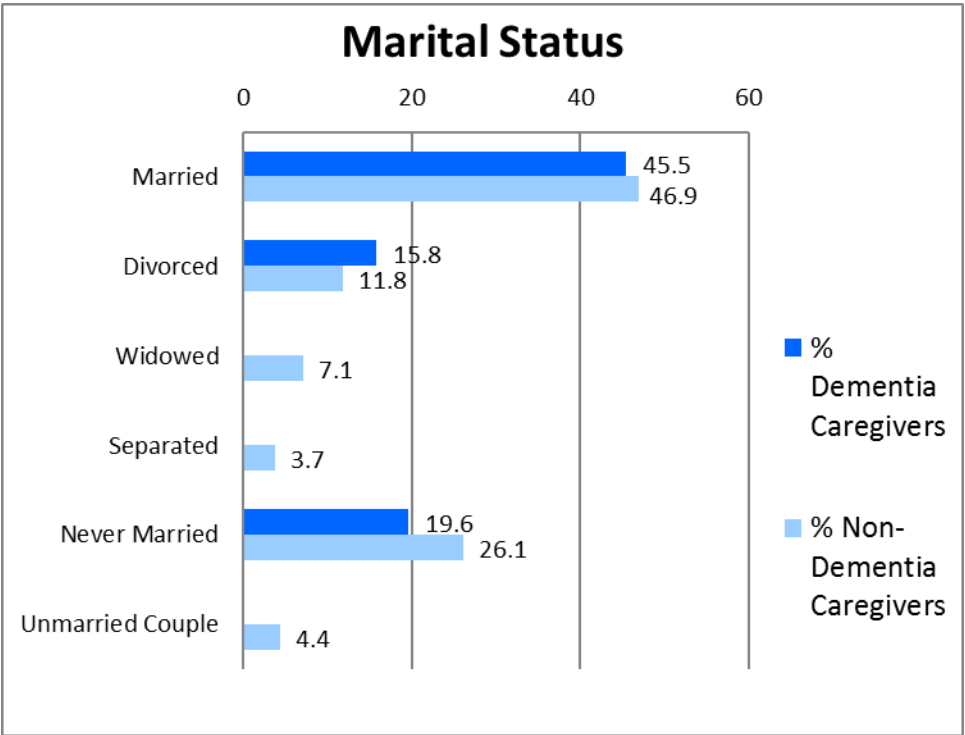


Note: Data excluded when sample size was insufficient to generate a valid estimate

Food and shelter insecurity is very similar across the two caregiver groups. 43.4% to 47.2% percent report shelter insecurity (always, usually or sometimes being worried about paying rent) and 38.6% report food insecurity (always, usually or sometimes worried about having enough money to buy nutritious meals).

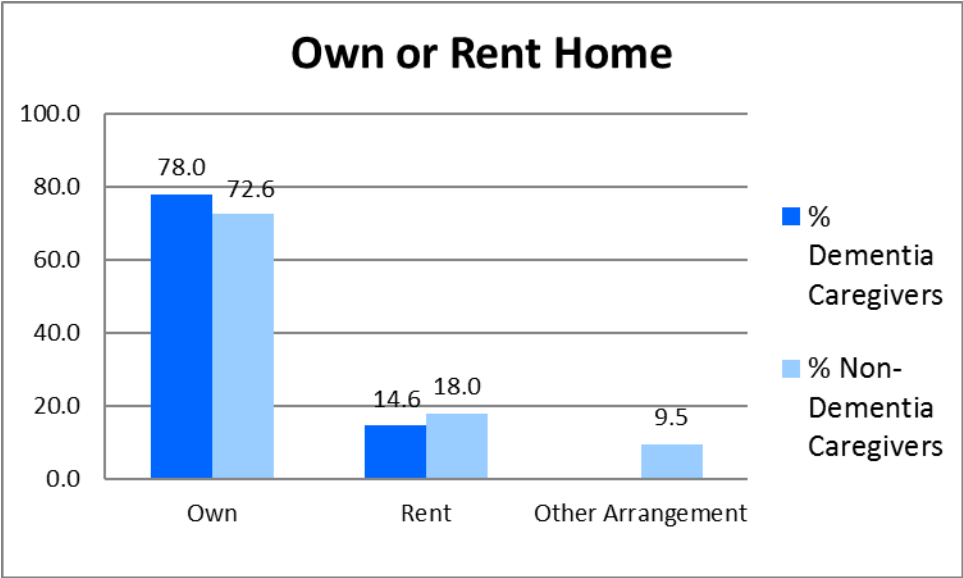


Marital status for both caregiver groups is very similar. The majority (45.5% to 46.9%) are married. 19.6% to 26.1% are never married and 11.8% to 15.8% are divorced.



Note: Data excluded when sample size was insufficient to generate a valid estimate

Most Caregivers own their home (72.6% to 78.0%) with 14.6% to 18.0% renting. 9.5% of non-dementia caregivers have other arrangements for housing.

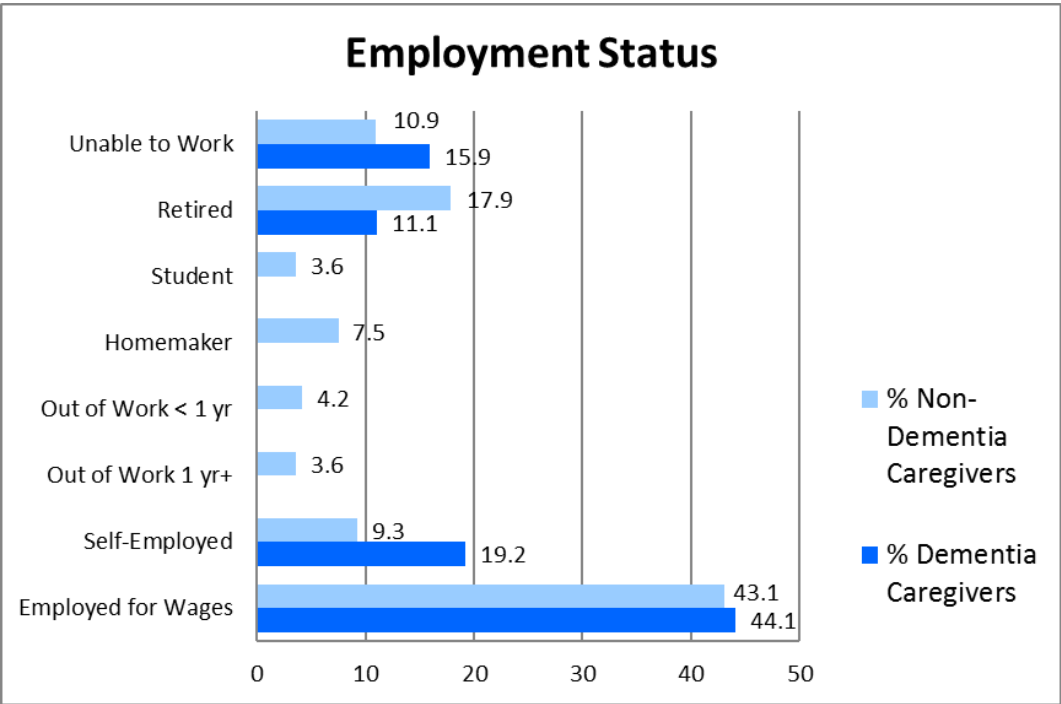


Note: Data excluded when sample size was insufficient to generate a valid estimate

Sample size was insufficient to compare number of children in the households, but 69.3% of dementia caregivers have no children in the house compared to 64.2% of non-dementia households.

Employment

Most caregivers are employed for wages. 9.9% more dementia caregivers are self-employed compared to non-dementia caregivers, and 15.9% are unable to work compared to 10.9% of non-dementia caregivers. At 17.9%, more non-dementia caregivers are retired compared to 11.1% of dementia caregivers.

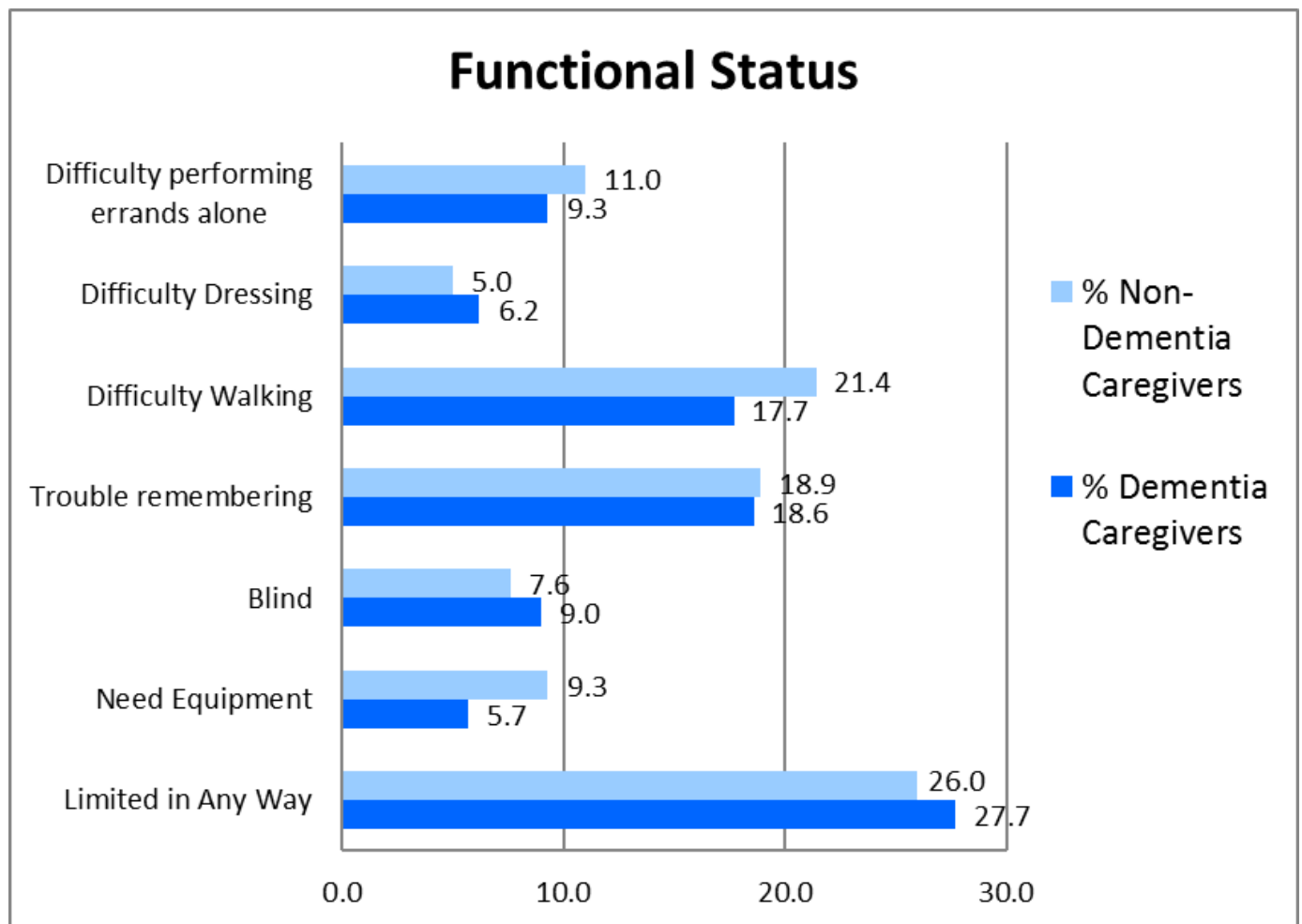


Note: Data excluded when sample size was insufficient to generate a valid estimate

Functional Status

BRFSS tracks several types of functional status. The responses to the following questions are charted below:

- Are you limited in any way in any activities because of physical, mental or emotional problems?
- Do you now have any health problem that requires you to use special equipment such as a cane, a wheelchair, a special bed, or special telephone?
- Are you blind or do you have a serious difficulty seeing, even when wearing glasses?
- Because of a physical, mental, or emotional condition, do you have serious difficulty concentrating, remembering or making decisions?
- Do you have serious difficulty walking or climbing stairs?
- Do you have difficulty dressing or bathing?
- Because of a physical, mental, or emotional condition, do you have difficulty doing errands alone such as visiting a doctor's office or shopping?



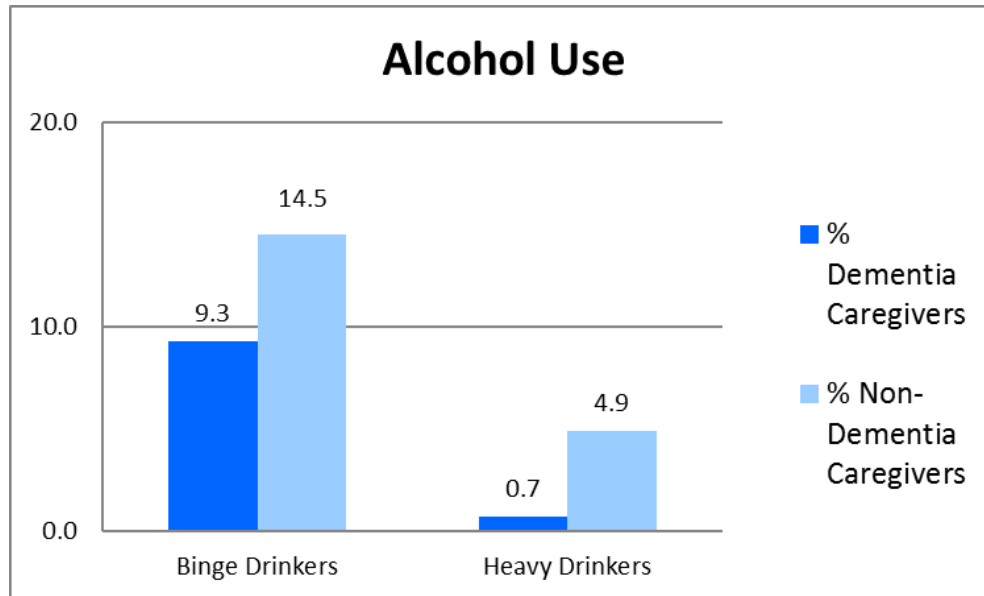
The two caregiver groups have similar distributions across the functional status categories. Chi square analysis showed no significant difference between the two caregiver groups for any of the categories.

Alcohol and Tobacco Use

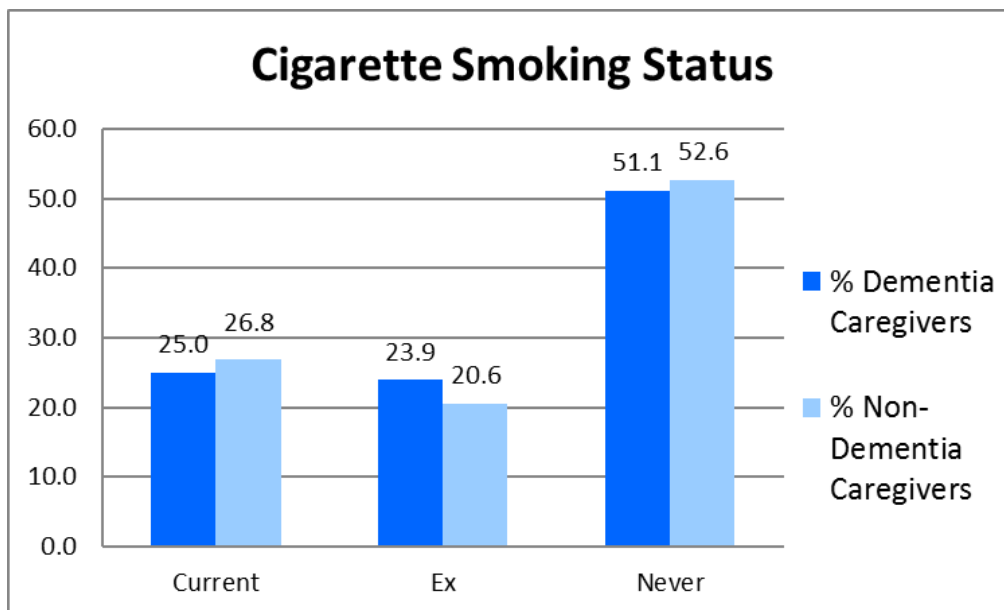
BRFSS has developed definitions for binge drinking and heavy drinking based upon the total number of alcoholic beverages consumed on a given occasion or per week:

- Binge Drinker: males having five or more drinks on one occasion, females having four or more drinks on one occasion
- Heavy Drinker: adult men having more than 14 drinks per week and adult women having more than 7 drinks per week

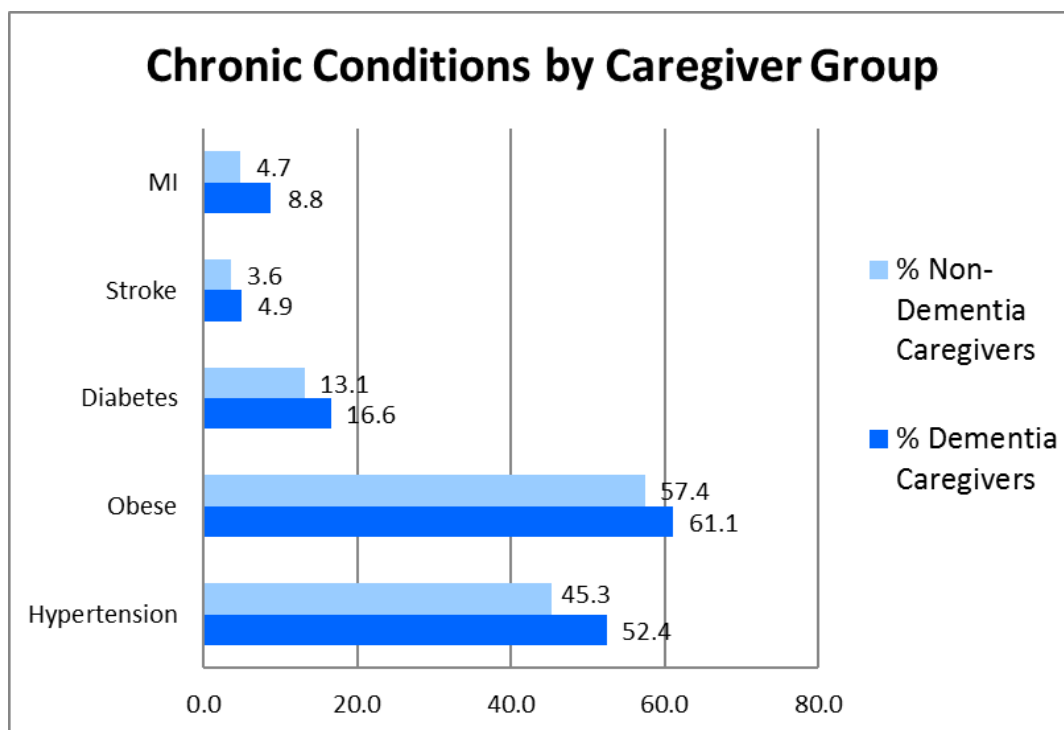
Non-dementia caregivers are more likely to be binge drinkers (14.5% vs 9.3%) and heavy drinkers (4.9% vs 0.7%) based upon these definitions.



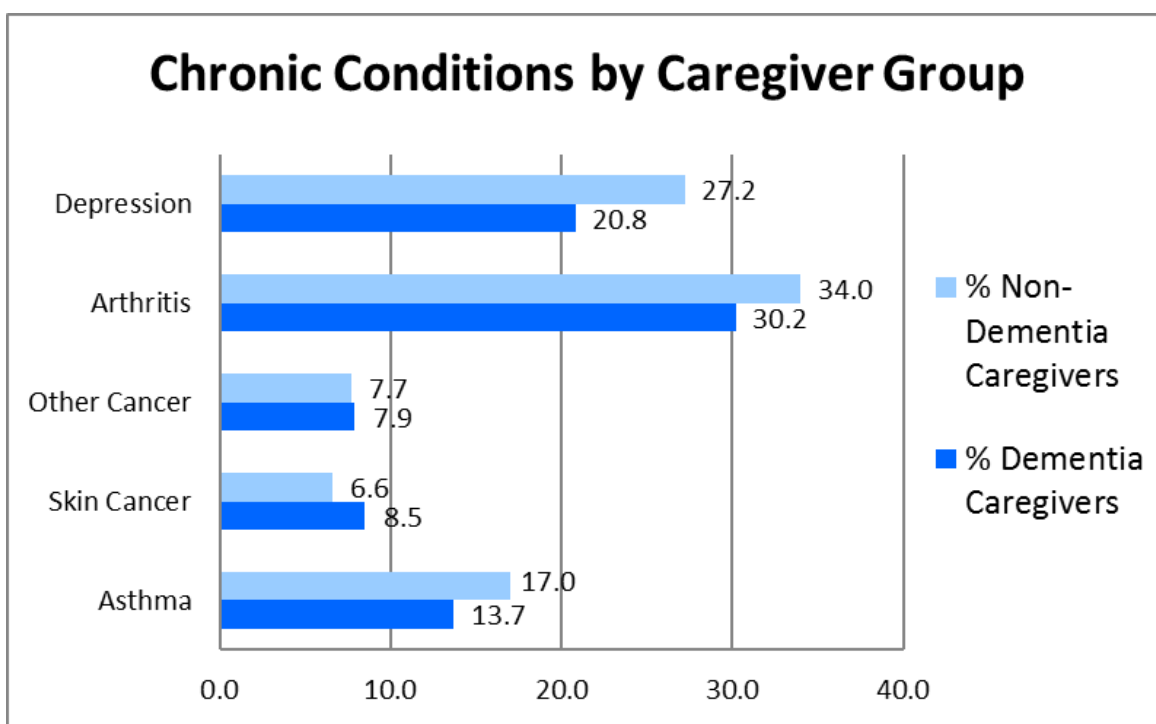
The two caregiver groups have similar distributions across current, ex and never smoking status.



Chronic Conditions



Chi square analysis was done to compare the dementia caregivers to the non-dementia caregivers for the chronic conditions that are tracked annually by BRFSS. There was never a statistically significant difference between the two groups for any of the conditions or for obesity. The dementia group consistently had slightly higher prevalence for hypertension, obesity, diabetes, stroke and MI and slightly lower prevalence for depression, arthritis and asthma.

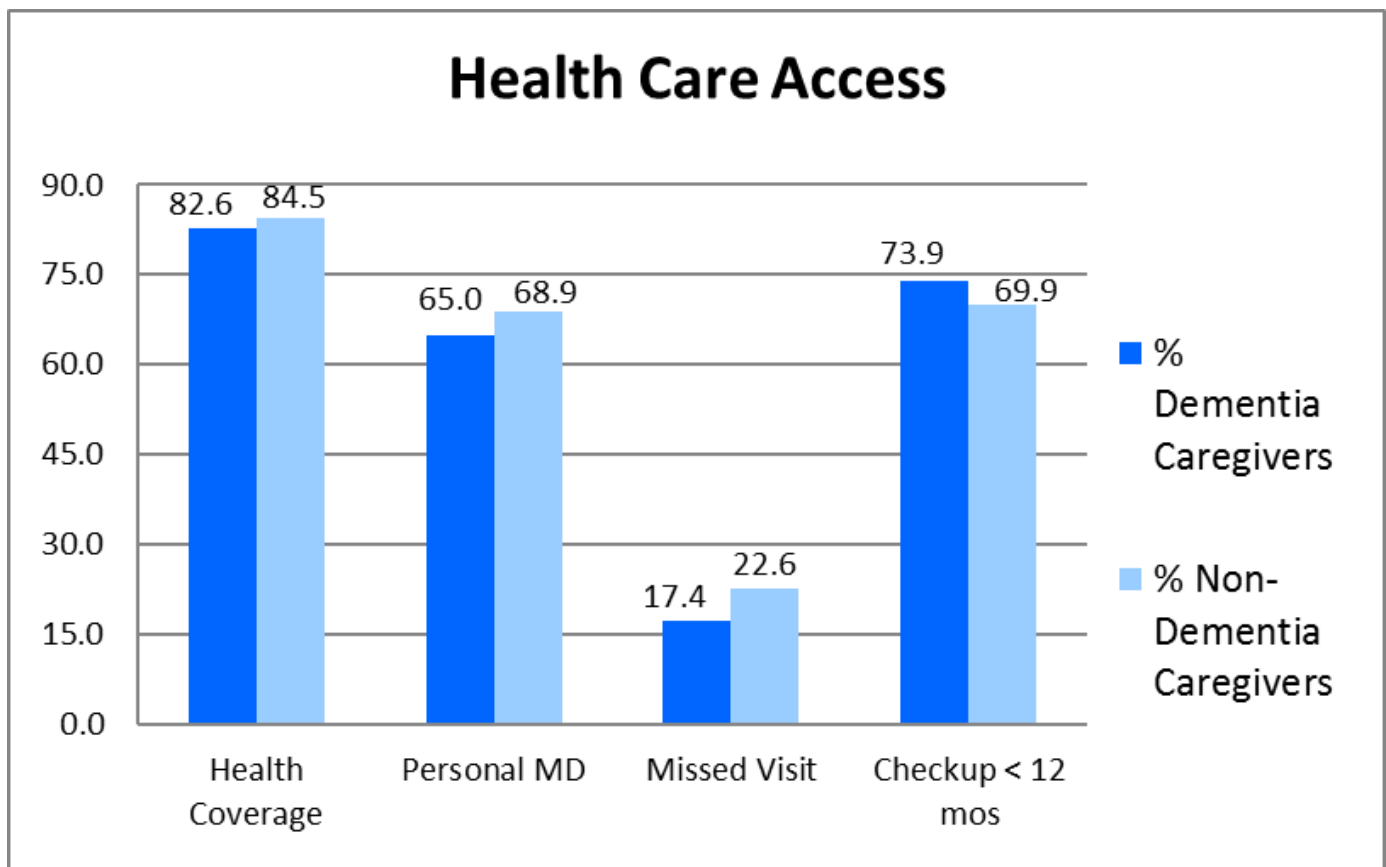


Health Care Access

Health care access is measured with the following questions:

- Do you have any kind of health care coverage, including health insurance, prepaid plans such as HMO's or government plans such as Medicare, or Indian Health Service?
- Do you have one person you think of as your personal doctor or health care provider?
- Was there a time in the past 12 months when you needed to see a doctor but could not because of cost?
- About how long has it been since you last visited a doctor for a routine checkup?

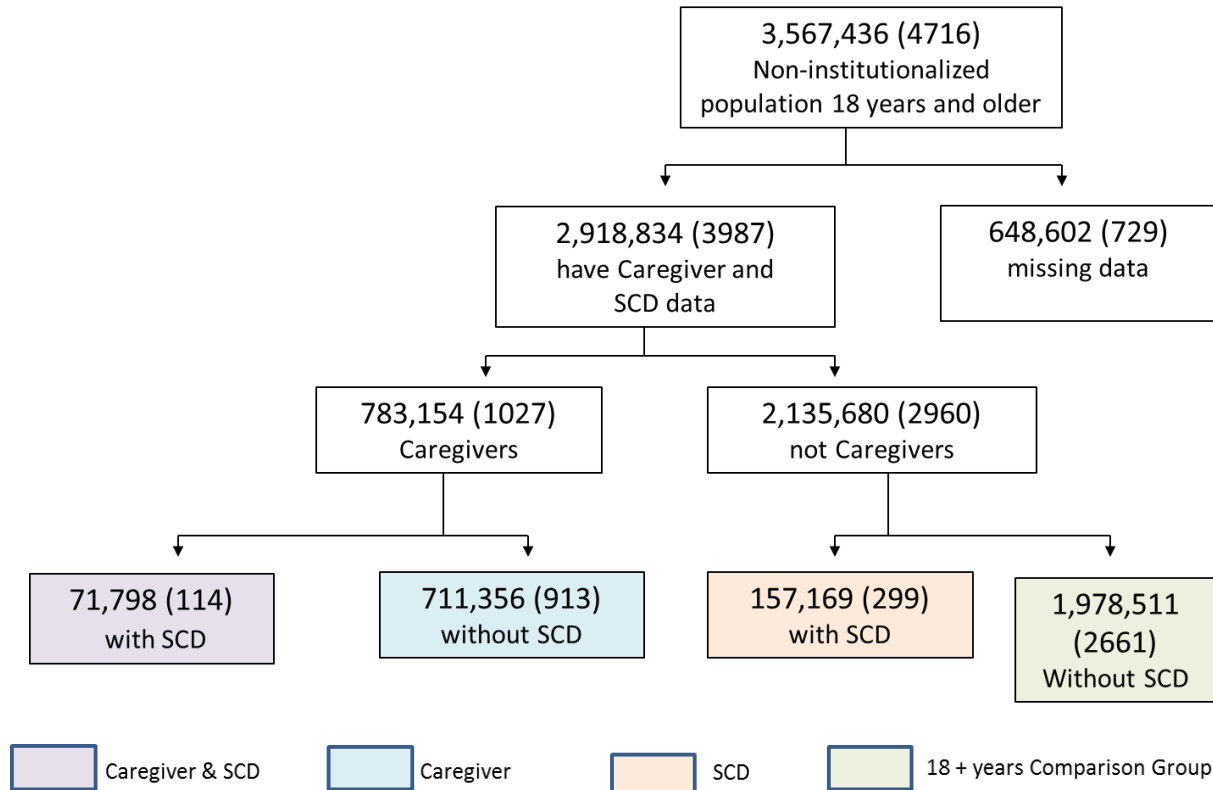
Both caregiver groups report similar access to health care. Over 80% have some health coverage and approximately 70% have had a routine checkup sometime in the last 12 months. 17.4% to 22.6% have missed a visit due to cost.



III. COMPARISON OF CAREGIVER AND SCD POPULATIONS TO POPULATION REPORTING NEITHER CAREGIVER STATUS NOR SCD

Methods

In 2015, Louisiana BRFSS administered the Caregiver Module to all respondents focusing on the status of those who said they provide regular care or assistance to a friend or family member who has a health problem or disability (Caregiver). In addition, the Cognitive Impairment Module was administered to respondents aged 45 years and older who said that during the last 12 months they had experienced confusion or memory loss that is happening more often or is getting worse (Subjective Cognitive Decline or SCD). The following chart describes the population breakdown with weighted N and (unweighted number of respondents).



9.4 percent of all Caregivers also claimed SCD. 31.4 percent of those with SCD are Caregivers.

The population with caregiver and/or SCD data was categorized into four mutually exclusive groups: Caregivers, Caregivers with SCD, those with SCD only and a comparison group that did not claim to be caregivers or to have SCD.

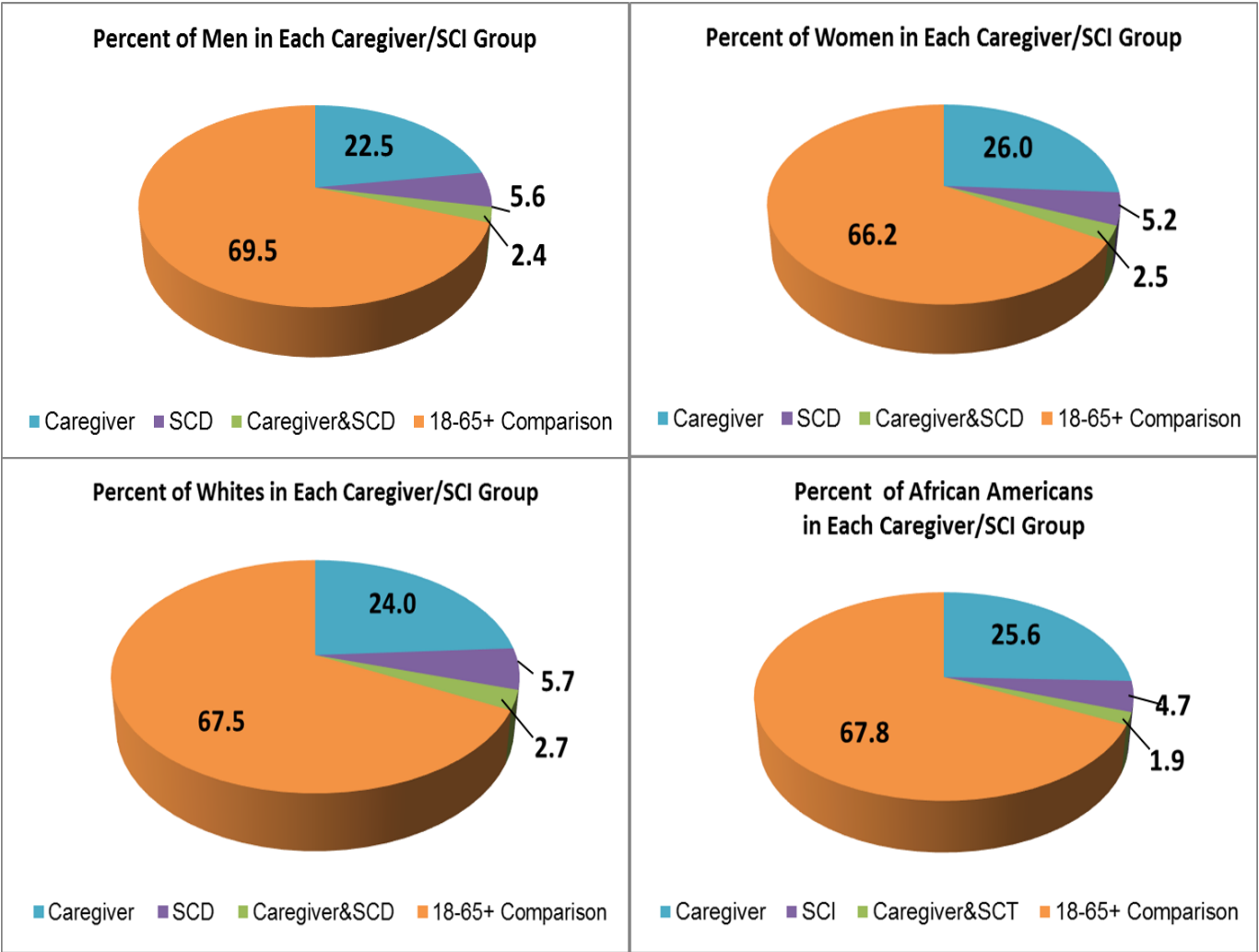
Analysis Groups	Percent of Total Population	Percent of Those 45 and Older
Caregiver	24.4	22.5
SCD	5.4	9.9
Caregiver & SCD	2.5	4.5
Comparison 45 – 65+	28.0	63.0
Comparison 18 – 65+	67.8	----

The entire comparison group was used when analyzing the Caregiver group (aged 18 years and older) while only those 45 years and older from the comparison group were used when analyzing the Caregivers with SCD and the SCD only groups.

Analysis focused on demographics, education, income, quality of life, health care access, chronic conditions and functional status. Caregivers are described in terms of recipient health, type of care performed, duration of care and recipient relationship to caregiver. Those with SCD are described in terms of type of care needed.

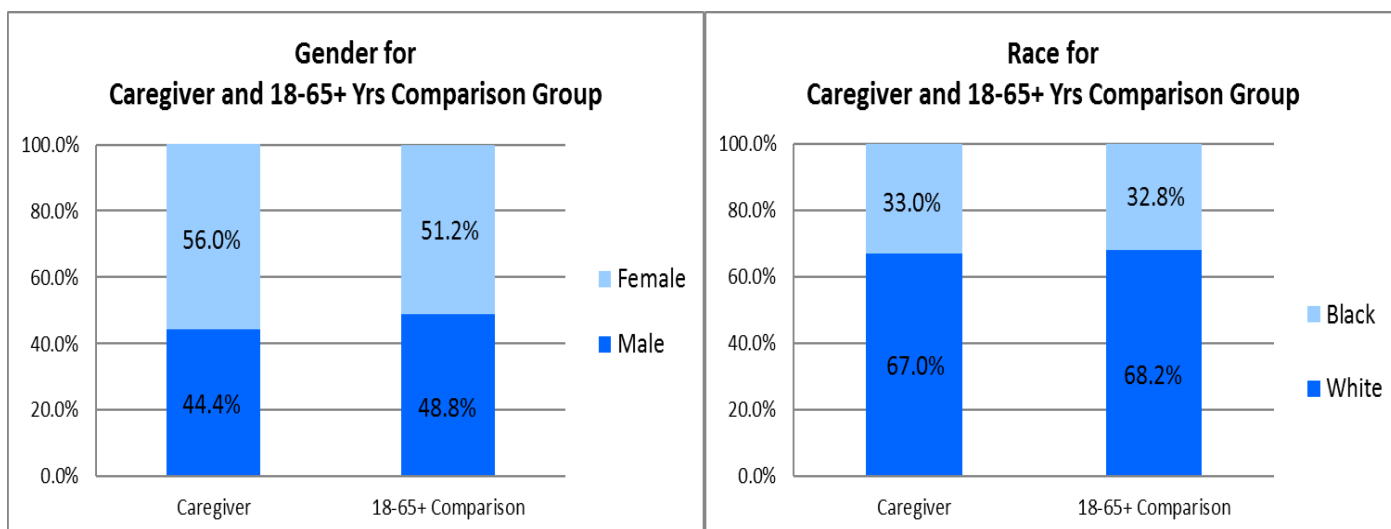
Results

Gender and Race

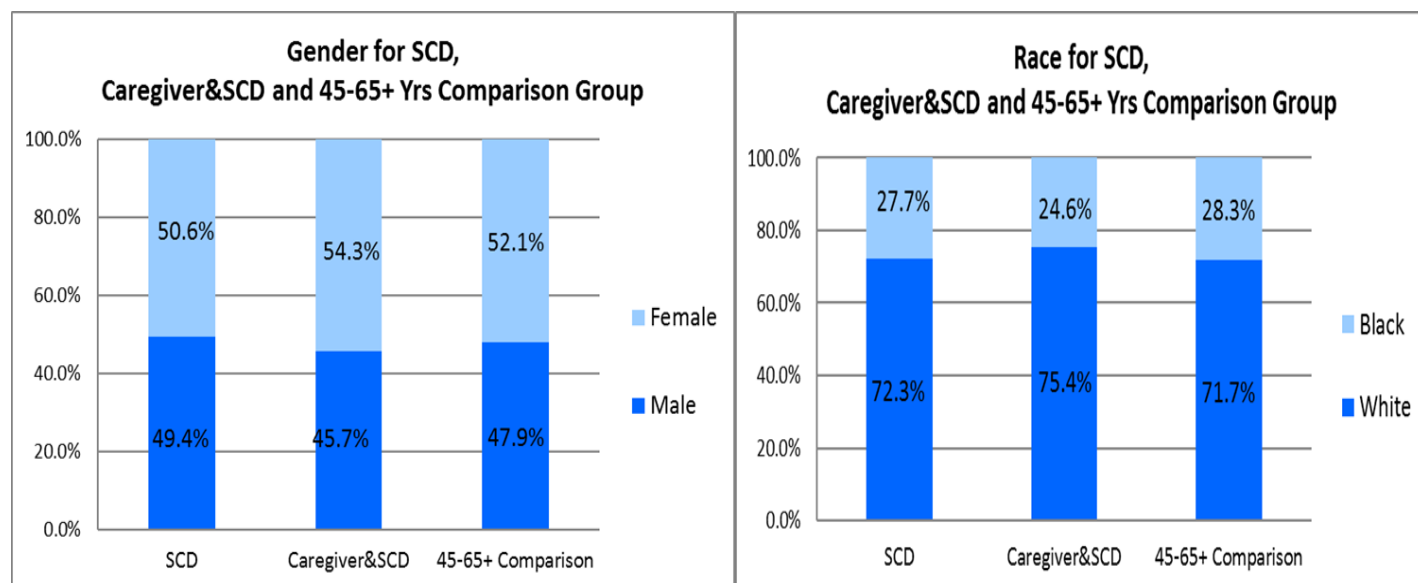


At 26.0 percent, slightly more women are Caregivers compared to men at 22.5 percent. Both populations, however, have very similar proportions in the SCD category (5.2% for women vs 5.6% for men) and in the Caregiver & SCD category (2.5% for women and 2.4% for men).

Blacks and Whites have very similar proportions of their populations in each Caregiver/SCD group, with Blacks slightly higher for the Caregiver group (25.6% vs 24.0%) and slightly lower for Caregiver with SCD and SCD.

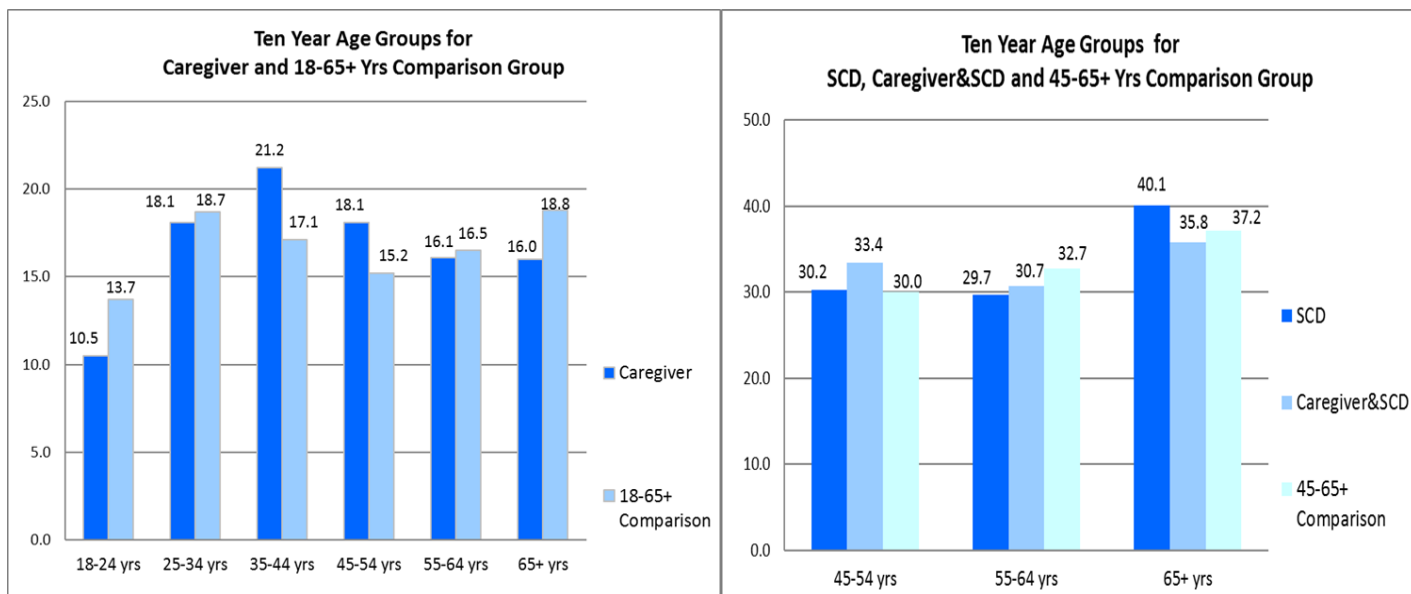


The gender and race distributions for the Caregiver, SCD or Caregiver & SCD groups compared to the Comparison groups were very similar. The only comparison that was close to being significantly different was gender for the Caregiver group compared to the 18-65+ Comparison group ($p=0.0631$).

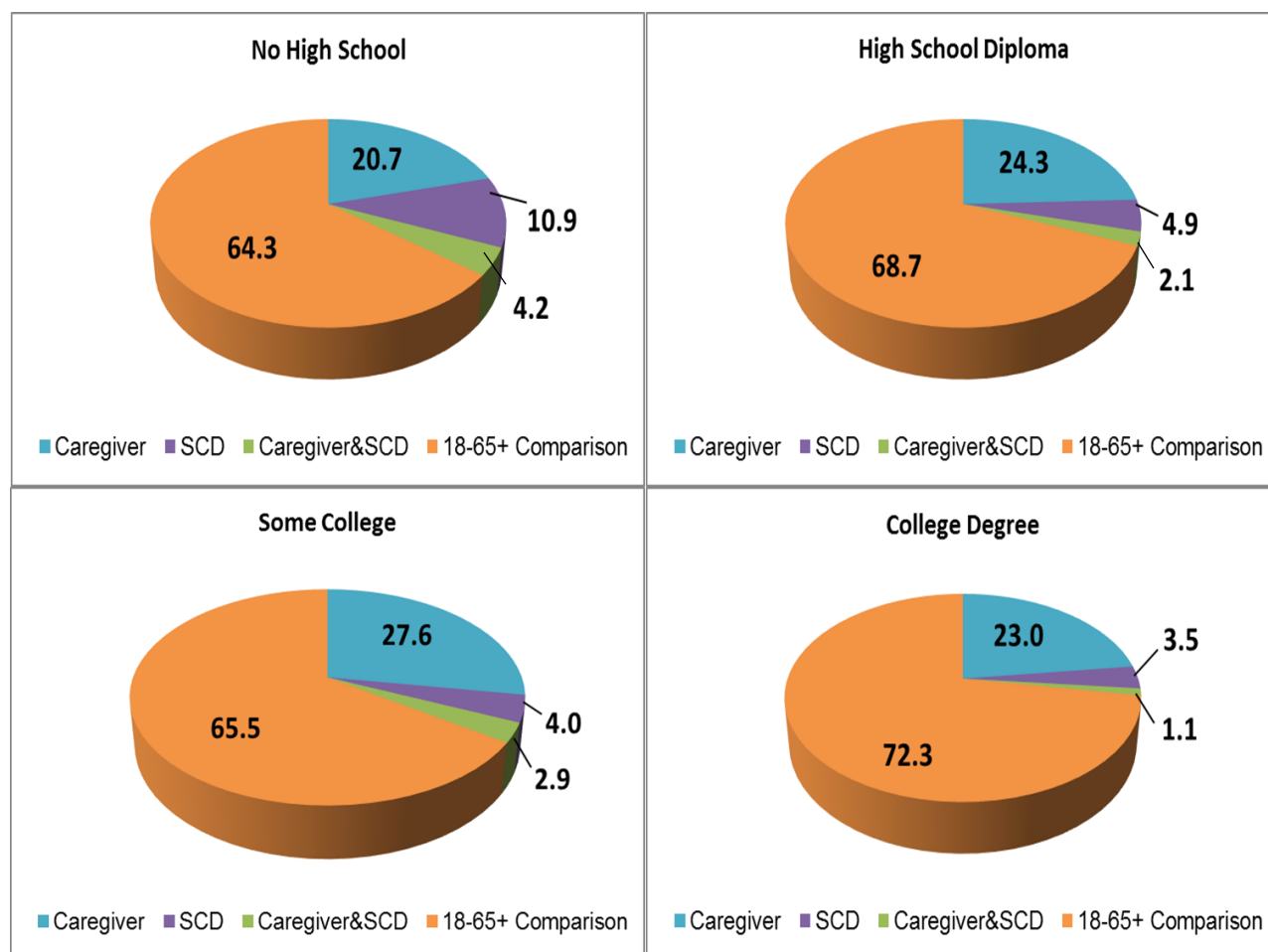


AGE

A breakout by ten-year age groups shows the Caregiver population peaks with the 35-44 years group at 21.2% while the 18-65+ years Comparison population appears bi-modal with peaks of 18.7% and 18.8% for the 25-34 years and the 65+ year age groups, respectively. The SCD, Caregiver & SCD and the 45-65+ years comparison groups have similar distributions across the age groups with the SCD group having the largest proportion in the 65+ year category.



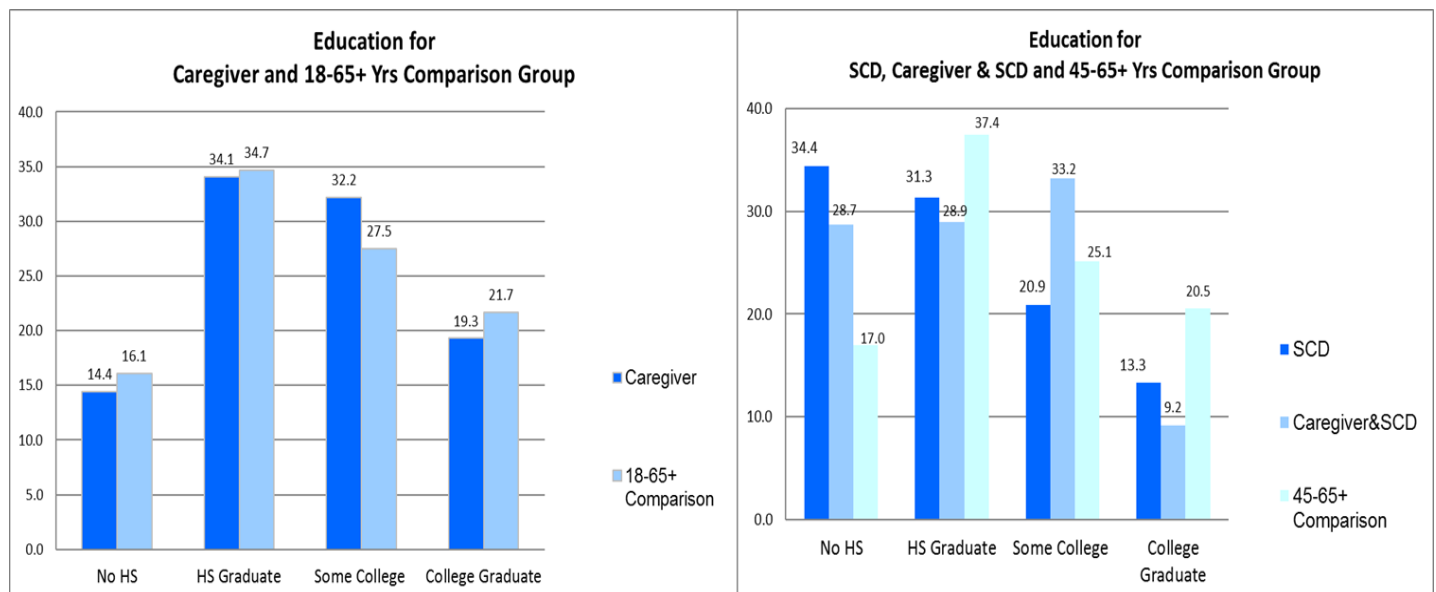
Education



Education level and percentage of the population reporting SCD are inversely correlated.

Education Level	Percent with Subjective Cognitive Decline
No High School Diploma	15.1%
High School Diploma	7.0%
Some College or technical School	6.9%
College Degree or Technical Certificate	4.6%

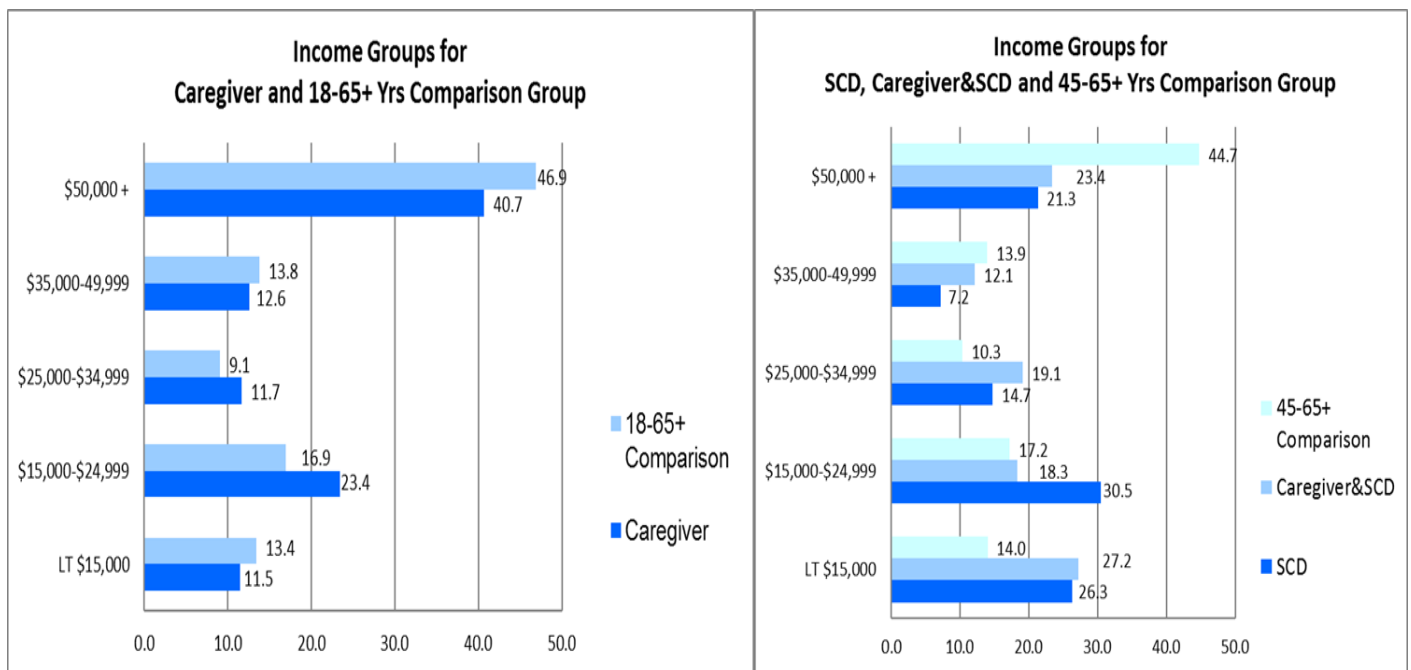
The Caregiver portion of each population ranges from a low of 20.7% for no high school diploma to a high of 27.6% of the some college population.



Both comparison groups have their largest proportion in the high school graduate category, followed by some college, college graduate and no high school. Caregivers follow the same pattern. Caregiver & SCD has a majority of respondents in the high school graduate and some college categories, while the majority of the SCD group is in the no high school and high school graduate categories.

Income

The comparison groups have a greater proportion of their populations reporting annual income greater than \$35,000 when compared to any of the Caregiver/SCD groups.



Annual Income	SCD (%)	Caregiver & SCD (%)	45-65+ Year Comparison (%)	Caregiver (%)	18-65+ Year Comparison (%)
< \$35,000	71.5	64.6	41.5	46.6	39.4
\$35,000 +	28.5	35.5	58.6	53.3	60.7

In general, relative annual income for these groups is:

SCD < Caregiver & SCD < Caregiver < 45-65+ year Comparison < 18-65+ year Comparison

Breaking each Caregiver/SCD category into ten-year age groups shows statistically significant differences in income between the comparison groups and the Caregivers, Caregivers with SCD and those with SCD only. The significant differences begin with the 35-44 year age group and extend into the 65+ years group for the SCD group.

Age	Caregivers			18 – 65+ Years Comparison Population		
	% Employed	Income LT \$35,000	Income GE \$35,000	% Employed	Income LT \$35,000	Income GE \$35,000
18-24 yrs	61.4	41.7	58.3	53.6	46.3	53.7
25-34 yrs	64.7	50.9	49.1	79.4	38.8	61.2
35-44 yrs	77.3	48.6*	51.4	79.0	30.4*	69.6
45-54 yrs	63.3	39.0**	61.0	69.1	28.8**	71.2
55-64 yrs	48.6	41.6	58.4	53.4	35.6	64.4
65 + yrs	13.5	55.7	44.3	11.7	58.2	41.8

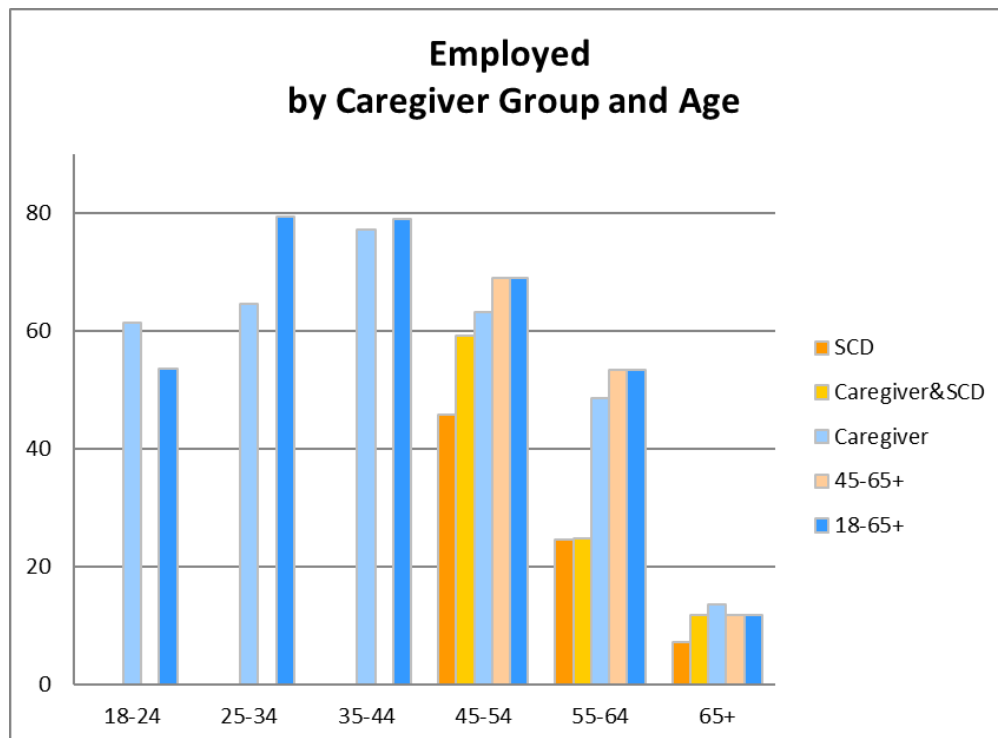
*chi sq p=0.0032, **p=0.0688

	Caregiver with SCD			45 – 65+ Years Comparison Population		
Age	% Employed	Income LT \$35,000	Income GE \$35,000	% Employed	Income LT \$35,000	Income GE \$35,000
45-54 yrs	59.3	75.1*	25.0	69.1	28.8*	71.2
55-64 yrs	24.8	64.0**	36.0	53.4	35.6**	64.4
65 + yrs	11.7	55.3	44.7	11.7	58.2	41.8

*chi sq p=<0.0001, ** p=0.0059

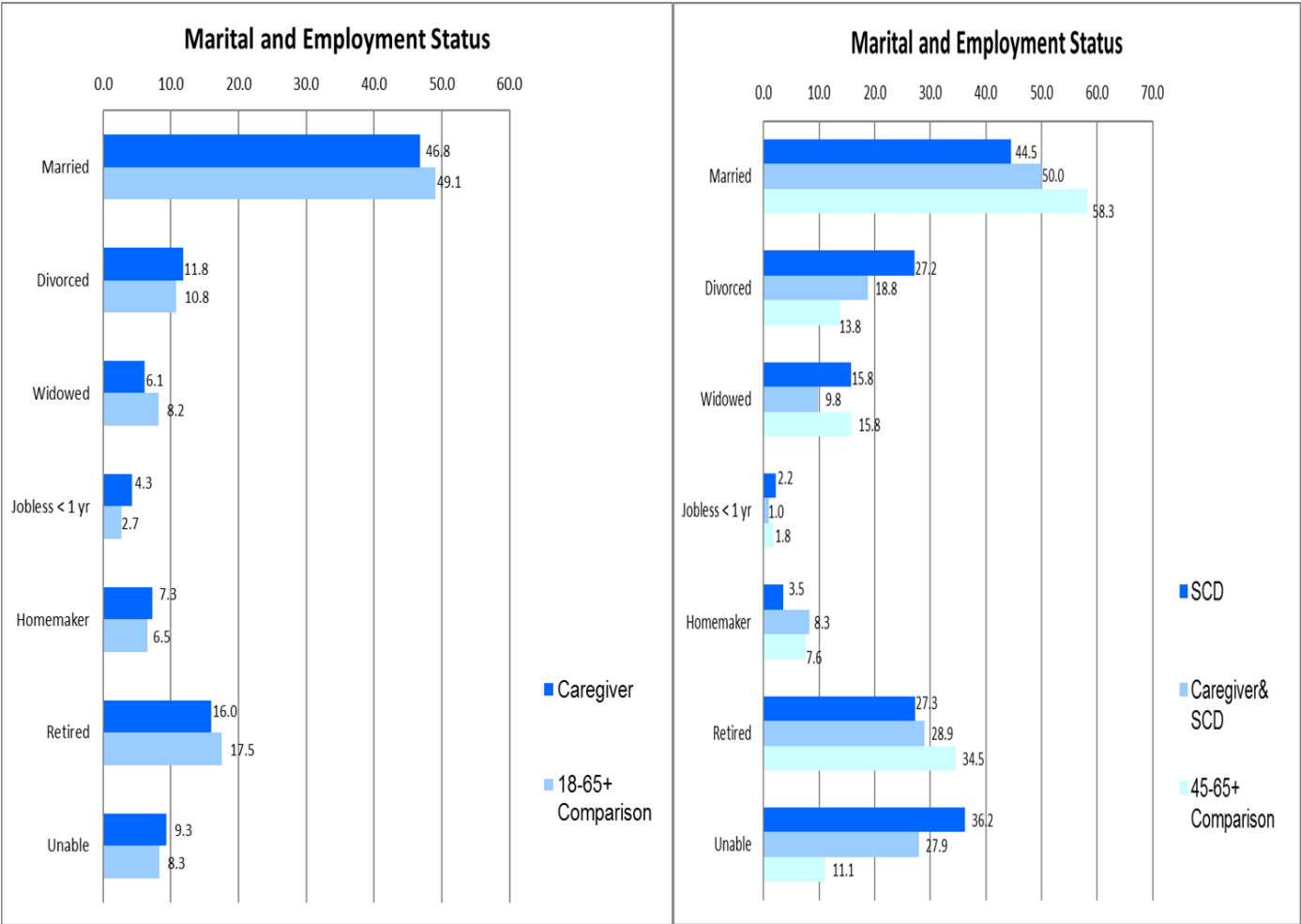
	SCD			45 – 65+ Years Comparison Population		
Age	% Employed	Income LT \$35,000	Income GE \$35,000	% Employed	Income LT \$35,000	Income GE \$35,000
45-54 yrs	45.8	59.1*	40.9	69.1	28.8*	71.2
55-64 yrs	24.5	78.5**	21.5	53.4	35.6**	64.4
65 + yrs	7.1	75.3***	24.7	11.7	58.2***	41.8

*chi sq p=0.0021, ** p < 0.0001, *** p=0.0017

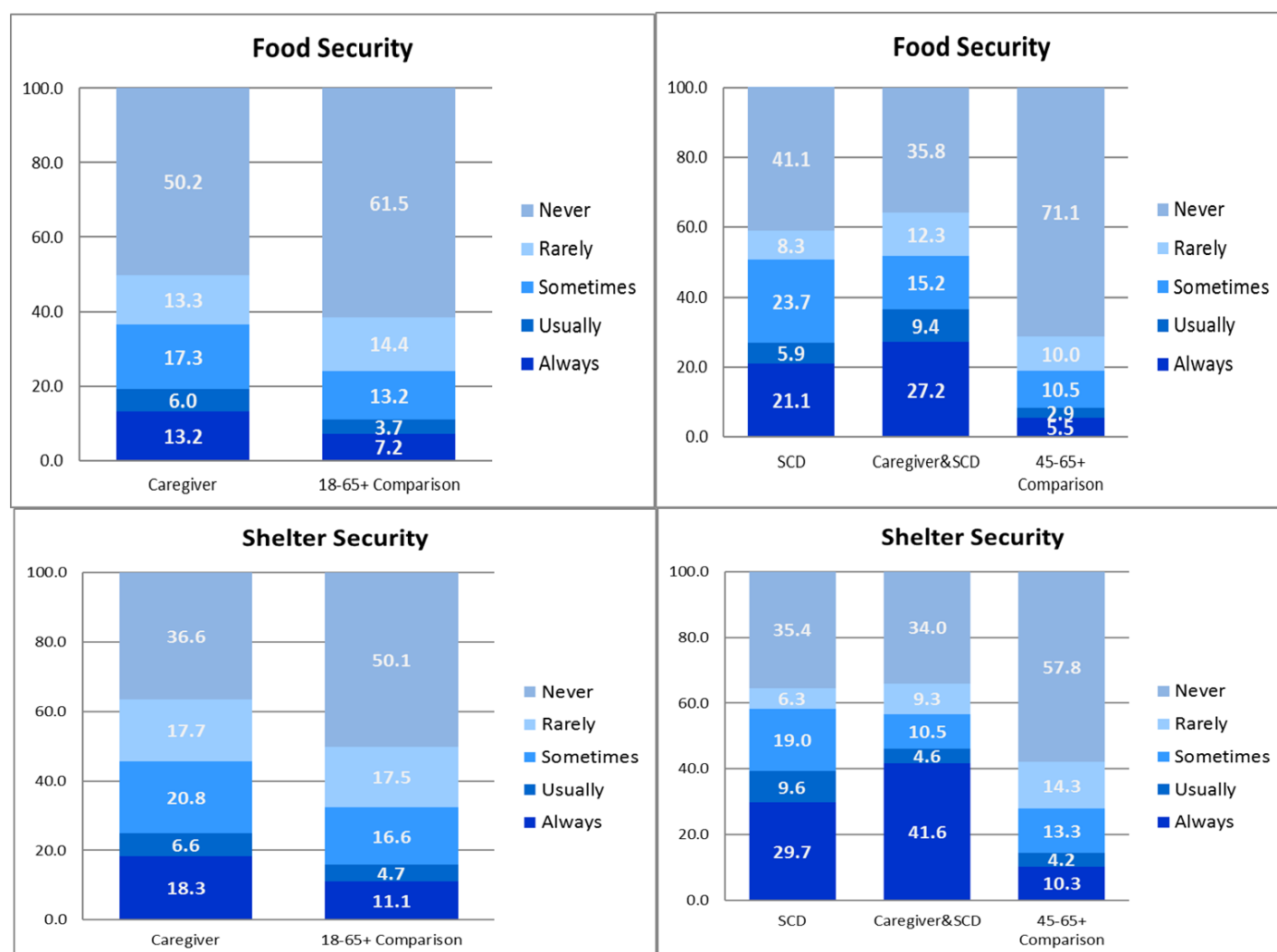


The comparison groups generally have the highest proportion with employed status. More Caregivers in the youngest (18-24 years) and in the oldest (65+ years) age categories have employed status compared to the 18 to 65+ years Comparison group. The SCD and Caregiver with SCD groups have the lowest employment rate in the 45 to 64 years age range.

Caregivers and the 18 to 65+ Comparison group have very similar marital and work status. Caregivers are more likely to be married than divorced or widowed. Sixteen percent are retired and 9.3% are unable to work. The SCD group is least likely to be married and more likely to be divorced than either the Caregiver with SCD or the 45 to 65+ Comparison groups. SCD are less likely to be homemakers or retired than either the Caregiver with SCD or 45 to 65+ Comparison group and are 3.3 times as likely to be unable to work vs the 45 to 65+ Comparison group.



Food and Shelter Security

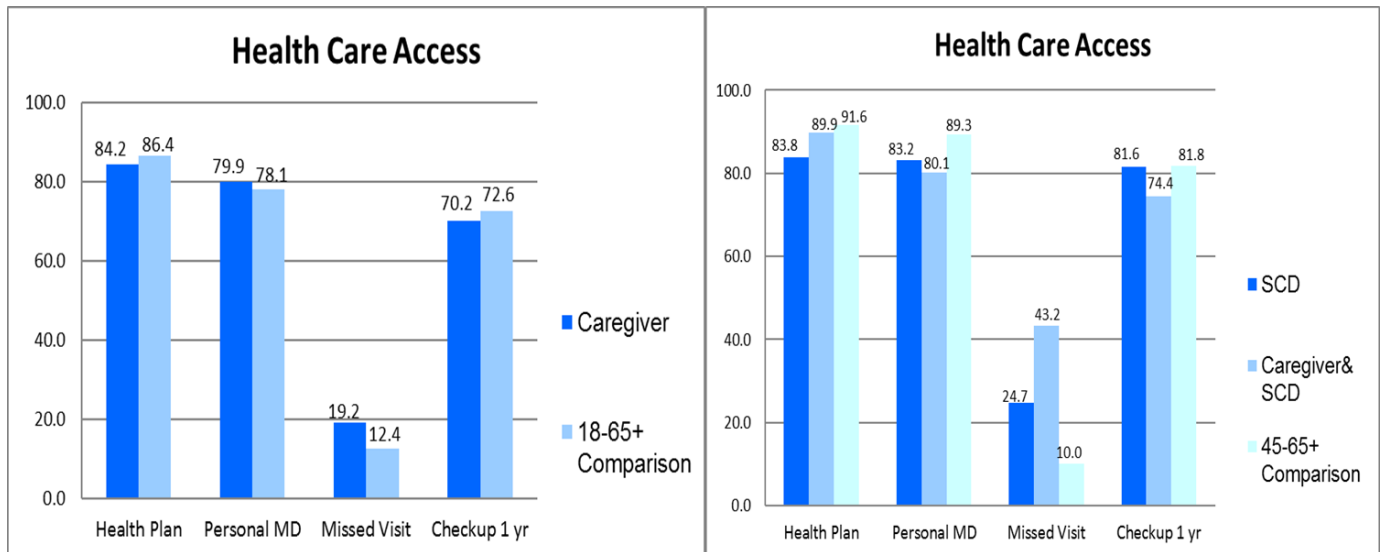


Shelter security was measured on a five point response scale of always, usually, sometimes, rarely and never to the question: How often in the past 12 months would you say you were worried or stressed about having enough money to pay your rent/mortgage? Food security was measured using the same response scale to the question: How often in the past 12 months would you say you were worried or stressed about having enough money to buy nutritious meals?

All three of the Caregiver/SCD groups have significantly greater proportions ($p < 0.001$ in all cases) of their populations in the Always-Usually Food and Shelter Security categories than their respective comparison groups. Caregivers with SCD have the highest food and shelter insecurity at 36.6% and 46.2%, respectively.

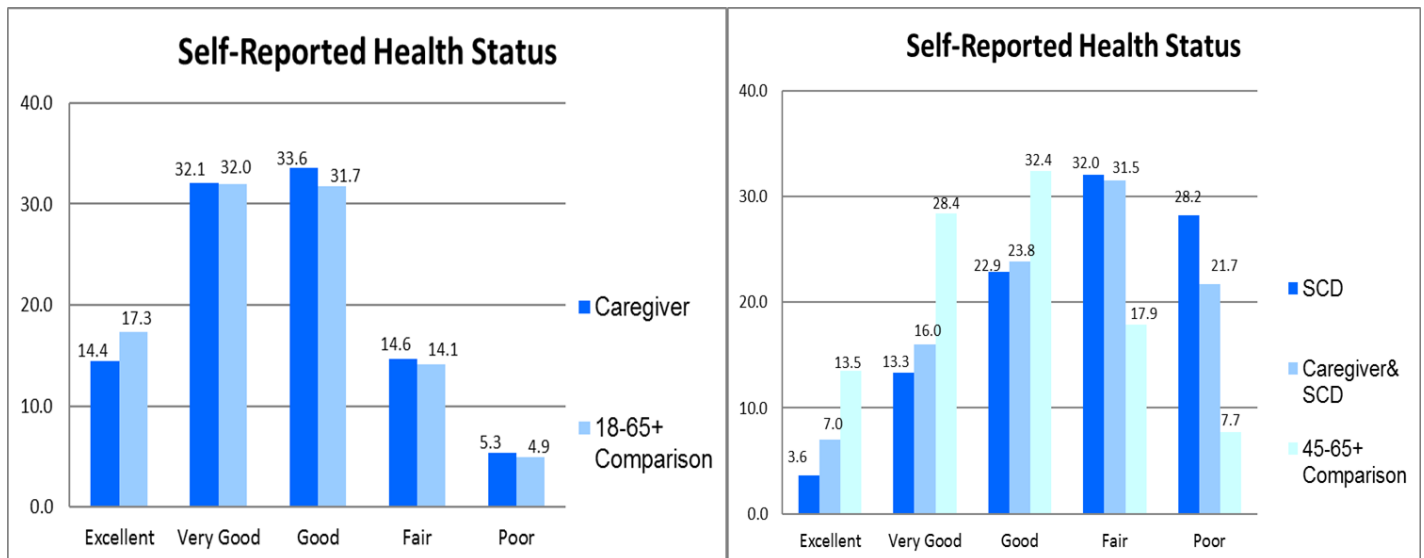
	Caregiver	18 – 65+ Comparison	p value	SCD	45-65+ Comparison	p value	Caregiver & SCD	45-65+ Comparison	p value
Food Insecure	19.2	10.9	< 0.0001	27.0	8.4	< 0.0001	36.6	8.4	< 0.0001
Shelter Insecure	24.9	15.8	< 0.0001	39.3	14.5	< 0.0001	46.2	14.5	< 0.0001

Health Care Access



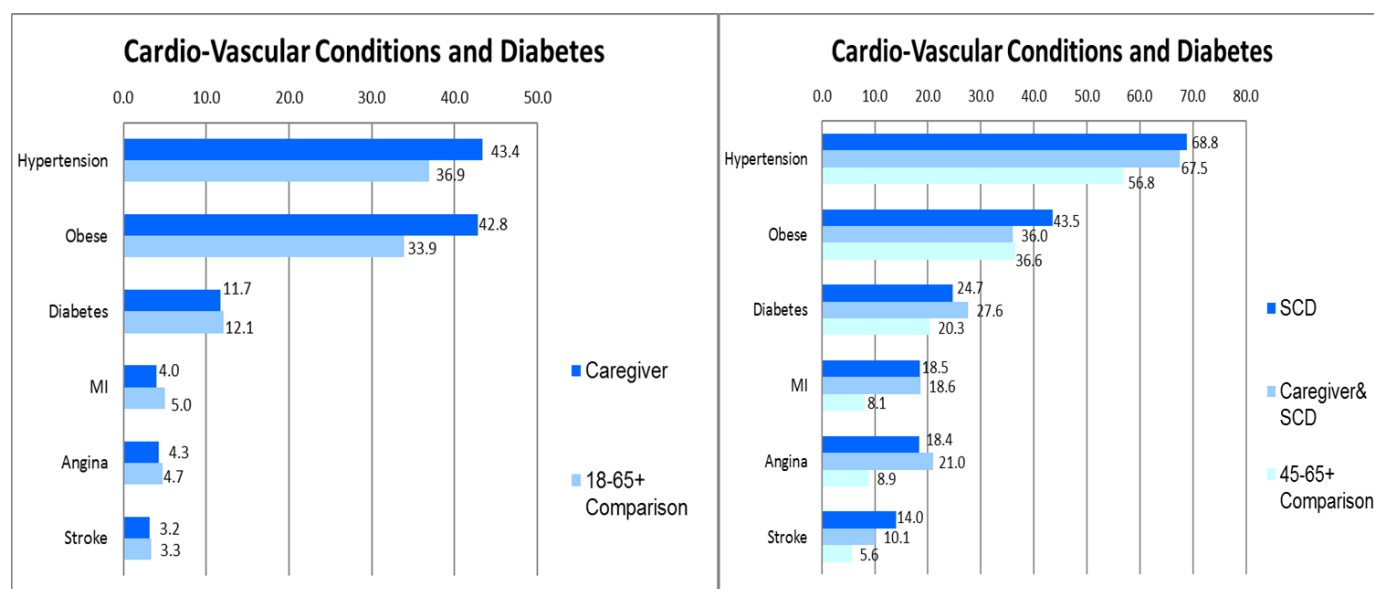
Similar proportions of all groups report having a health plan. Only the SCD group at 83.8% was significantly lower than the 45-65+ comparison group at 91.6%. Only 80.1% of Caregivers with SDI report having a personal physician compared with 89.3% of the 45-65+ comparison group. Caregivers were 6.8% more likely to have missed a visit due to cost than the 18-65+ comparison group. Caregivers with SCD were 33.2% more likely and those with SCD only were 14.7% more likely to miss a visit due to cost compared to those in the 45-65+ comparison group.

Self- Reported Health Status



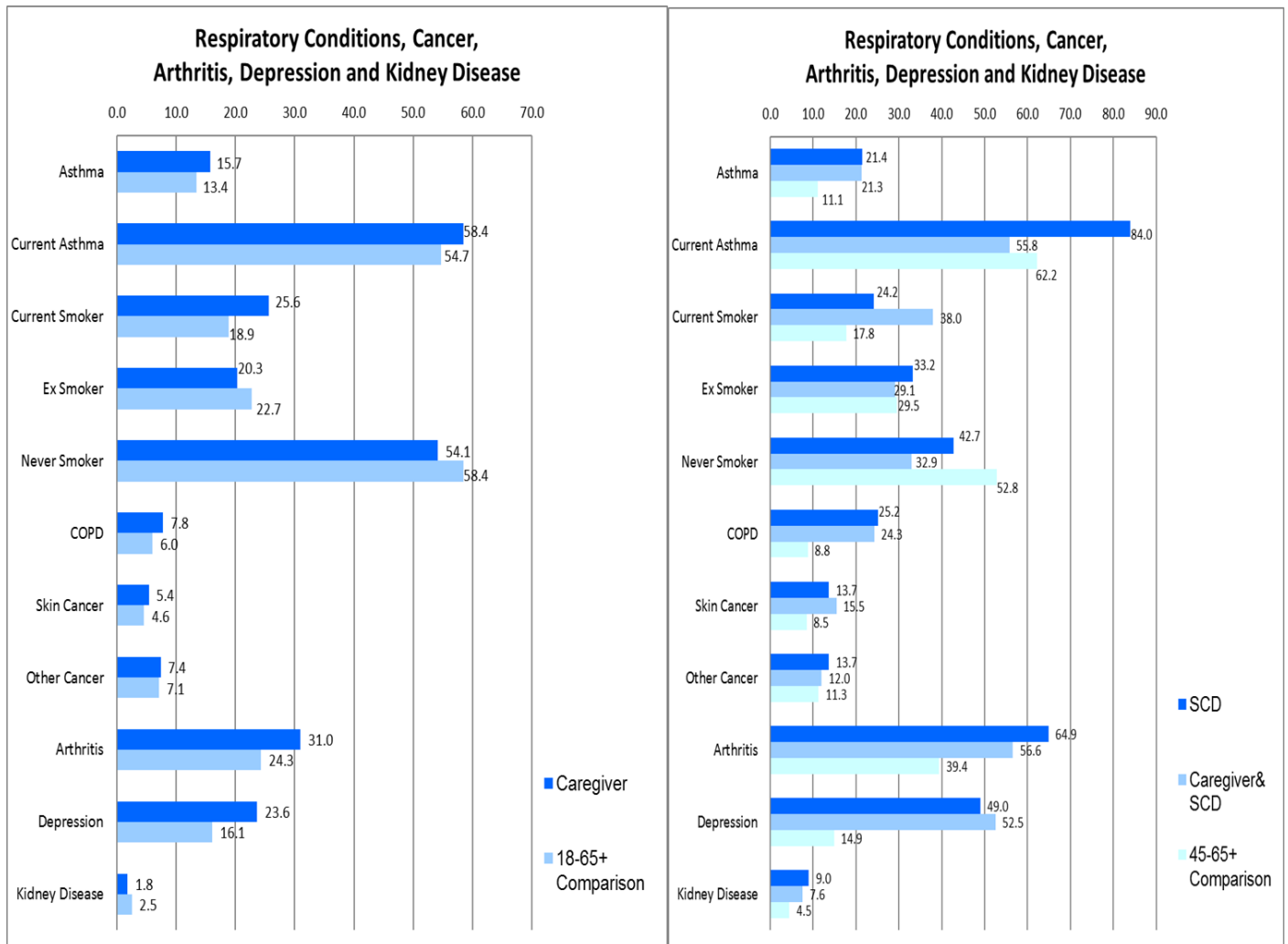
The Caregiver group reports very similar self-reported health status as the 18-65+ comparison group. 2.9% more of the comparison group reported excellent health compared to the Caregivers. The SCD only and the Caregiver with SCD groups consistently report higher levels of Fair and Poor health and lower levels of Excellent, Very Good or Good health than the 45-65+ comparison group. The greatest discrepancy is between the SCD only group with 28.2% Poor health compared to 7.7% of the 45-65+ comparison group.

Chronic Conditions



The Caregiver group has higher prevalence of both hypertension and obesity than the 18-65+ Comparison group, but has slightly less diabetes, heart attack, angina or stroke. The SCD Only and Caregiver with SCD report equal or higher prevalence for all these conditions compared to the 45-65+ Comparison group. The following table shows the chisq p value obtained when comparing the prevalence of each condition in a given Caregiver/SCD group to the proper Comparison group. Significant differences are bolded.

Caregiver/SCD Group	Chronic Condition	P Value
Caregiver	Hypertension	0.0080
	Obesity	0.0004
	Diabetes	0.8369
	Heart Attack	0.3249
	Angina	0.7097
	Stroke	0.8631
SCD	Hypertension	0.0047
	Obesity	0.0989
	Diabetes	0.1628
	Heart Attack	< 0.0001
	Angina	< 0.0001
	Stroke	< 0.0001
Caregiver with SCD	Hypertension	0.0835
	Obesity	0.9192
	Diabetes	0.1243
	Heart Attack	0.0012
	Angina	0.0003
	Stroke	0.0580

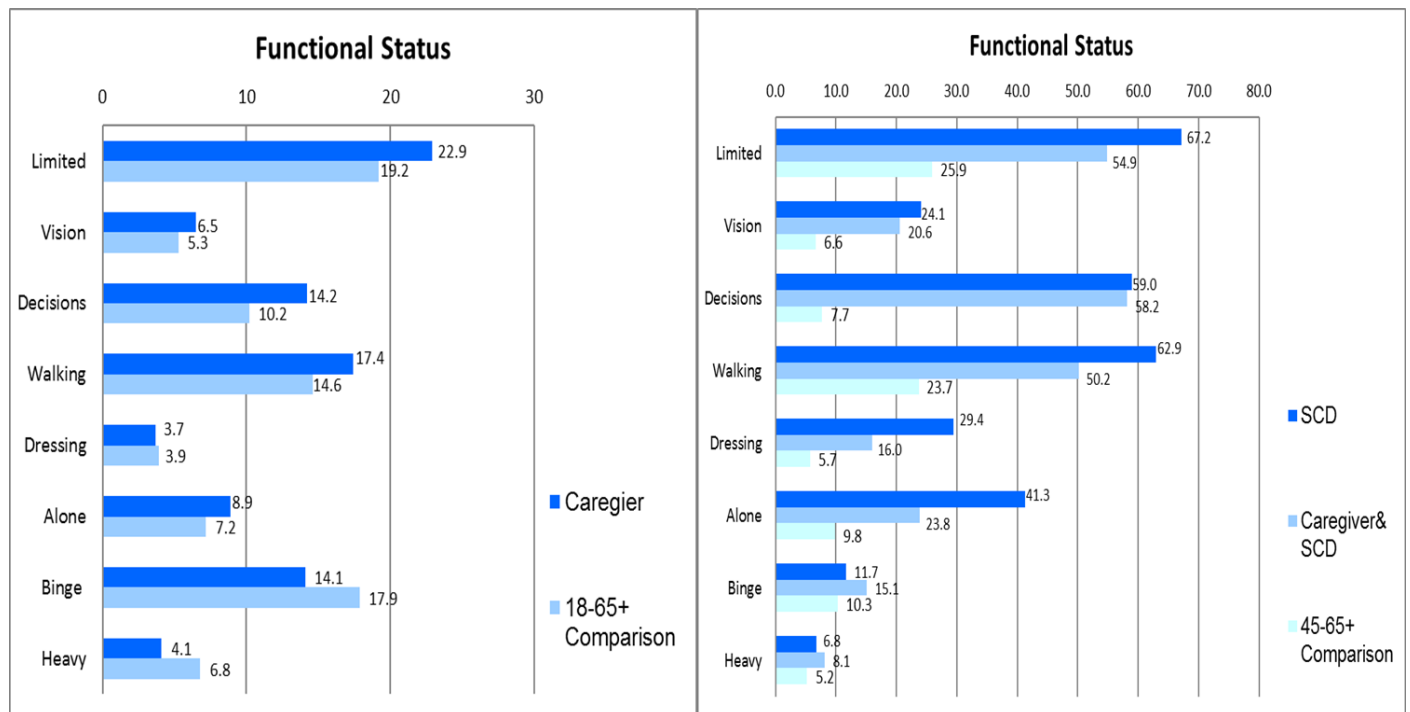


The Caregiver group has slightly elevated prevalence of asthma, current asthma, COPD, skin cancer, other cancers, arthritis and depression than the 18-65+ Comparison group. The difference in prevalence between the Caregiver with SCD and the SCD only groups vs the 45-65+ Comparison group is much greater for these conditions. SCD has 21.8% higher prevalence of current asthma and 34.1% higher prevalence of depression than the comparison group. SCD has twice the prevalence of kidney disease. All three caregiver/SCD groups have higher current smoker and lower never smoker prevalence than the comparison groups.

The following table shows the chisq p value obtained when comparing the prevalence of each condition in a given Caregiver/SCD group to the proper Comparison group. Significant differences are bolded.

Caregiver/SCD Group	Chronic Condition	p Value
Caregiver	Asthma	0.2528
	Current Asthma	0.6345
	COPD	0.0932
	Skin Cancer	0.9031
	Other Cancer	0.8186
	Arthritis	0.0015
	Depression	< 0.0001
	Kidney Disease	0.2951
	Current Smoker	0.0022
	Ex Smoker	0.2087
	Never Smoker	0.0869
SCD	Asthma	< 0.0001
	Current Asthma	0.0050
	COPD	< 0.0001
	Skin Cancer	0.0243
	Other Cancer	0.2990
	Arthritis	< 0.0001
	Depression	< 0.0001
	Kidney Disease	0.0084
	Current Smoker	0.0767
	Ex Smoker	0.3240
	Never Smoker	0.0146
Caregiver with SCD	Asthma	0.0043
	Current Asthma	0.5944
	COPD	< 0.0001
	Skin Cancer	0.0302
	Other Cancer	0.0454
	Arthritis	0.0039
	Depression	< 0.0001
	Kidney Disease	0.1612
	Current Smoker	<0.0001
	Ex Smoker	0.9489
	Never Smoker	0.0009

Functional Status



Functional Status is measured using the following questions:

- Are you limited in any way in any activities because of physical, mental or emotional problems? (LIMITED)
- Are you blind or do you have serious difficulty seeing, even when wearing glasses? (BLIND)
- Because of a physical, mental or emotional condition do you have serious difficulty concentrating, remembering, or making decisions? (DECISIONS)
- Do you have serious difficulty walking or climbing stairs? (WALKING)
- Do you have difficulty dressing or bathing? (DRESSING)
- Because of a physical, mental or emotional condition, do you have difficulty doing errands alone such as visiting a doctor's office or shopping? (ALONE)
- Binge drinking: males having five or more drinks on one occasion, females having four or more drinks on one occasion (BINGE)
- Heavy drinking: men having more than 14 drinks per week and women having more than 7 drinks per week (HEAVY)

Caregivers report higher levels of being limited, having vision difficulties, difficult decision making, problems walking and completing errands alone than the 18 to 65+ years comparison group. They report lower prevalence of binge and significantly lower prevalence of heaving drinking.

The SCD and Caregiver with SCD groups also report higher levels of all the non-alcohol related functional indicators than the 45 to 65+ years comparison group. When compared to the 45 to 65+ years group, the SCD group is:

- 2.6 times as likely to report being limited,
- 3.7 times as likely to have vision problems,
- 7.7 times as likely to have difficulty making decisions,
- 2.7 times as likely to have difficulty walking,

- 5.2 times as likely to have difficulty dressing and
- 4.2 times as likely to have problems finishing errands alone.

The Caregiver with SCD group reported higher prevalence for both binge and heavy drinking.

The following table shows the chisq p value obtained when comparing the prevalence of each functional status indicator in a given Caregiver/SCD group to the proper Comparison group. Significant differences are bolded.

Caregiver/SCD Group	Chronic Condition	P Value
Caregiver	Limited	0.0615
	Blind	0.2721
	Decisions	0.0162
	Walking	0.0955
	Dressing	0.8491
	Alone	0.2063
	Binge	0.0724
	Heavy	0.0216
SCD	Limited	< 0.0001
	Blind	< 0.0001
	Decisions	< 0.0001
	Walking	< 0.0001
	Dressing	< 0.0001
	Alone	< 0.0001
	Binge	0.6353
	Heavy	0.4120
Caregiver with SCD	Limited	< 0.0001
	Blind	< 0.0001
	Decisions	< 0.0001
	Walking	< 0.0001
	Dressing	0.0002
	Alone	< 0.0001
	Binge	0.2157
	Heavy	0.2790

Discussion

Note: For this discussion, the 18 to 65+ years and the 45 to 65+ years comparison groups will be referred to as the standard population(s).

The distribution of Caregivers, Caregiver with SCD and SCD only groups is very similar across gender and race. Slightly more women than men are caregivers, a difference of only 3.5%. When comparing the Caregiver/SCD groups to their appropriate standard populations, only the Caregivers were close to being significantly different (4.8% more females, $p=0.0631$).

The caregiver population is generally younger than the standard population while the SCD and Caregiver with SCD groups are slightly older. SCD status and education level are inversely correlated, with STD status at a high

of 15.1% for the no High School diploma category to a low of 4.6% for those with a college degree or a technical certificate.

Caregivers and both standard populations have the largest proportion of their population in the High School and some college categories, while the Caregiver with SCD are concentrated in the High School graduate and some college categories. The majority of the SCD group are in the no High School and High School graduate categories.

In general, relative annual income for these groups is:

SCD < Caregiver & SCD < Caregiver < 45-65+ year Comparison < 18-65+ year Comparison

The majority of both the SCD and the Caregiver with SCD groups earn less than \$35,000 per year, while the standard groups and the Caregiver group have their majorities in the greater than \$35,00 per annum category.

Annual Income	SCD (%)	Caregiver & SCD (%)	45-65+ Year Comparison (%)	Caregiver (%)	18-65+ Year Comparison (%)
< \$35,000	71.5	64.6	41.5	46.6	39.4
\$35,000 +	28.5	35.5	58.6	53.3	60.7

More Caregivers in the 18 to 24 year and 65 plus years categories are currently employed compared to the standard group. The Caregiver with SCD and the SCD groups have the lowest currently employed status for each of the 45 to 54 years, 55 to 64 years and the 65 plus years categories.

Caregivers, Caregivers with SCD and those with SCD are less likely to be married, widowed or retired and more likely to be divorced or unable to work compared to their respective standard populations. They also claim significantly more food and shelter insecurity than their standard populations.

More than 80% of all five groups have some kind of a health plan. SCD had the lowest coverage at 83.8% compared to the standard at 91.6%. 43.2% of Caregivers with SCD missed an appointment due to cost followed by those with SCD at 24.7% and Caregivers at 19.2%. The standard populations had the lowest missed visit rate at 12.4% for the 18 to 65+ group and 10.0% for the 45 to 65+ group.

The Caregiver and 18 to 65 plus standard group have very similar response to self reported health status. The majority of both populations falls into the Very Good to Good status range (65.7% for Caregivers and 63.7% for the standard population). Caregivers with SCD and those with SCD consistently report higher levels of Fair and Poor health and lower levels of Excellent, Very Good or Good health than the standard group. The SCD only group reports 28.2% with Poor health compared to 7.7% for the standard population.

All three Caregiver/SCD groups report significantly higher prevalence ($p < 0.0005$) for chronic conditions when compared to the standard populations, ranging from four out of fourteen for Caregivers to ten out of fourteen

for those with SCD. All three groups had higher prevalence for Arthritis and Depression. None of the three groups had a higher prevalence for Diabetes or Kidney Disease.

**Shaded Cells Significantly Higher Rate (p < 0.0005)
of Chronic Condition Compared to Standard Population**

	Caregiver	Caregiver & SCD	SCD
Hypertension			
Obesity			
Diabetes			
Heart Attack			
Angina			
Stroke			
Asthma			
Current			
COPD			
Skin Cancer			
Other Cancer			
Arthritis			
Depression			
Kidney			

All three groups reported significantly higher prevalence of functional limitations, with Caregivers claiming problems concentrating, remembering or making decisions and both Caregiver with SCD and SCD claiming problems with all measures with the exception of binge drinking and heavy drinking. Caregivers were significantly lower than the standard population for binge drinking.

**Significantly Higher Rate (p < 0.0005)
of Decreased Functional Status Compared to Standard Population**

	Caregiver	Caregiver & SCD	SCD
Limited			
Vision			
Decisions			
Walking			
Dressing			
Alone			
Binge			
Heavy			

In general, Caregivers differ slightly from their standard population. They earn less, they experience more food and shelter insecurity and they report higher prevalence for four out of fourteen chronic conditions and one out of eight functional limitations. They also have similar marital and job status, access to health care, self-perceptions of health and more of their population has some college.

When compared to their standard populations, those with SCD report lower educational attainment, much lower annual income, three to four times the food and shelter insecurity, twice as many missed doctor visits due to cost and twice as much of their population reports fair to poor health. They report significantly higher prevalence for ten out of fourteen chronic conditions and six out of eight functional limitations. In addition, thirty-one percent of those with SCD are providing regular care to a friend or family member who has a health problem or disability.

The SCD group reported that they had 'confusion or memory loss that is happening more often or is getting worse'. Are they in the very early stages of Alzheimer's Disease or are they overly burdened with chronic conditions, disabilities and social/economic insecurity? The literature varies on the proportion of SCD populations that progress to AD, but there is agreement that the only way to definitively answer the question is to follow those who report SCD over time to determine their outcome. Regardless of their eventual AD status, this group is most likely to need caregiving as they age.

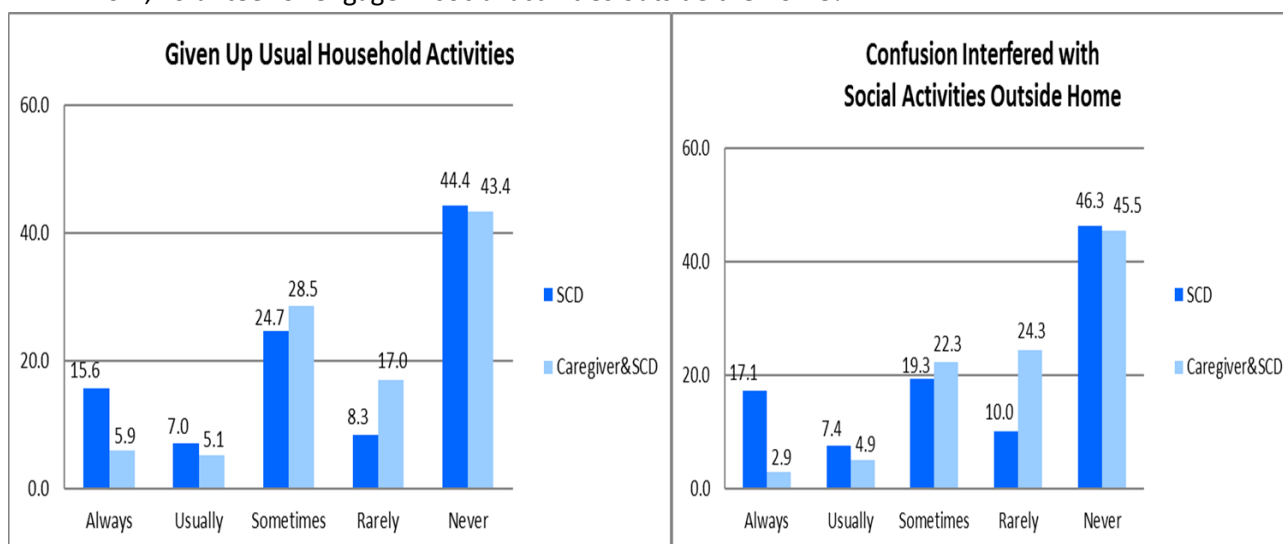
Note: The BRFSS survey did not include questions to determine if any in the SCD group were currently receiving care or if any of the caregivers were employed to provide care.

IV. FACTORS SPECIFIC TO CAREGIVERS, CARE RECIPIENTS AND TO THOSE WITH SCD

Limitations due to Confusion for Caregiver with SCD and those with SCD only

To measure the effect that confusion or memory loss has had on daily life, respondents that claimed SCD were asked two questions:

- During the past 12 months, how often have you given up day-to-day household activities or chores you used to do such as cooking, cleaning, taking medications, driving or paying bills?
- During the past 12 months, how often has confusion or memory loss interfered with your ability to work, volunteer or engage in social activities outside the home?



Those with SCD only were more likely to Always or Usually give up household chores or experience difficulty when participating in social activities outside the home than Caregivers with SCD. Combining the two SCD groups, for those who always or usually give up household chores due to confusion or memory:

- 47.1% say they always or usually need help with these chores
- 55.0% say they always or usually get the help they need

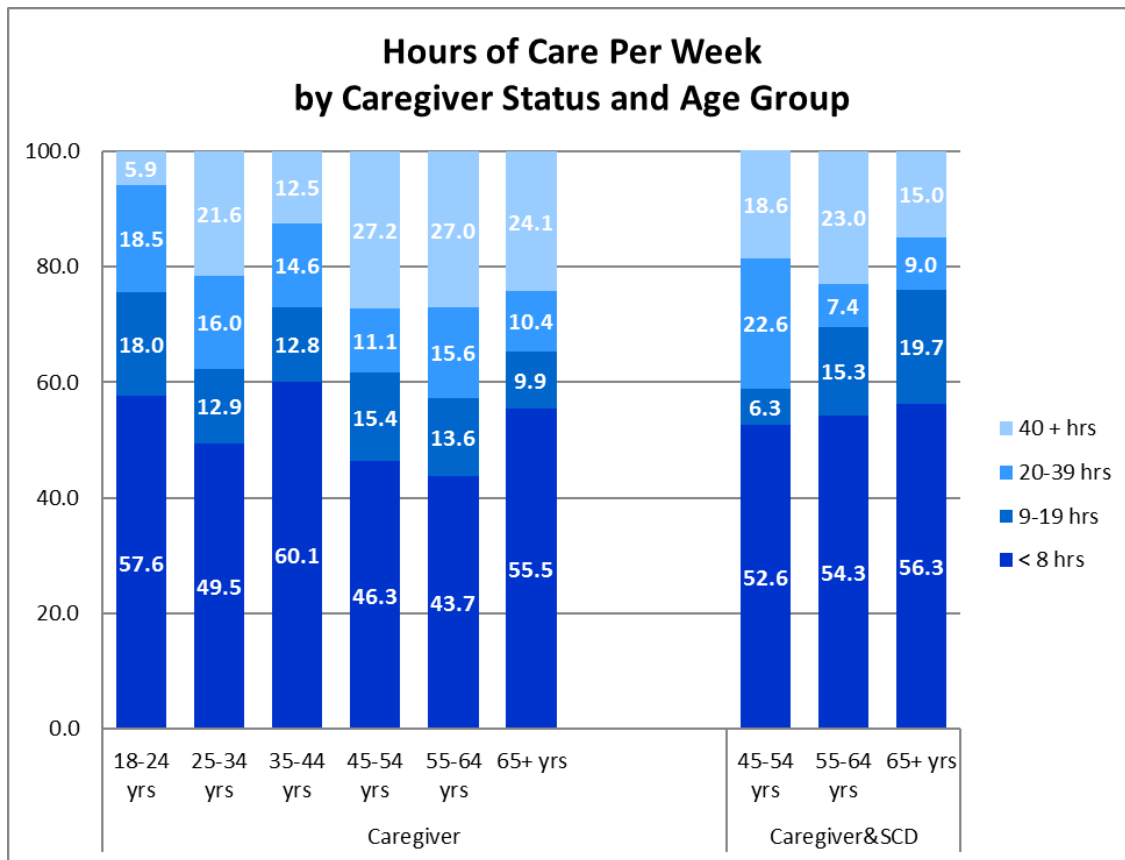
Overall, 38.3% of the combined SCD group have talked to a health care professional about their confusion/memory concerns. For those who always or usually give up household chores, 53.0% have consulted with a medical professional.

Care Recipient Characteristics and Time Spent in Caregiving

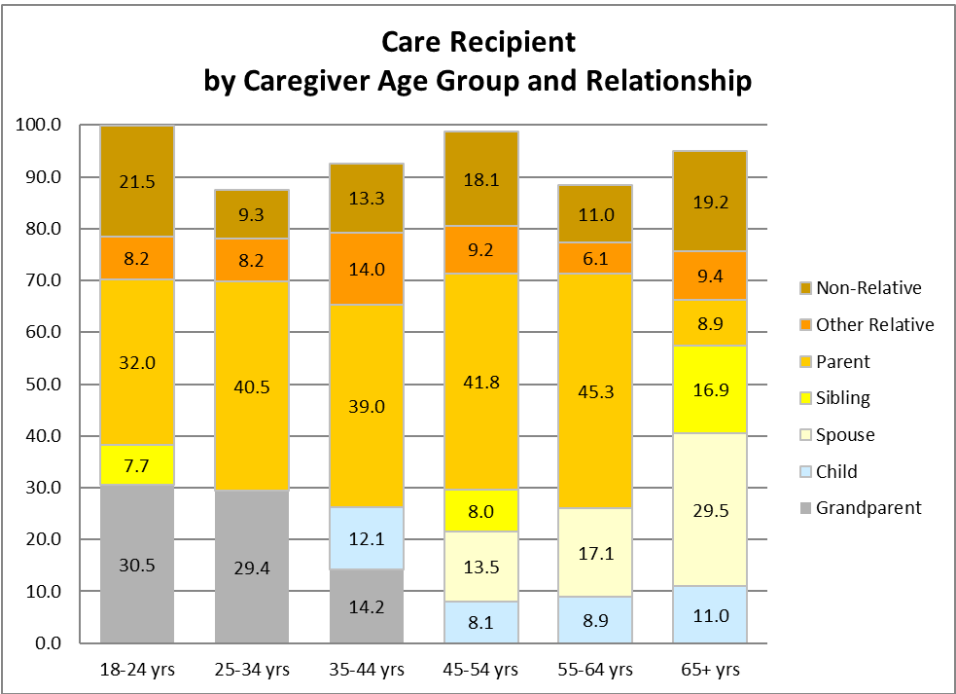
More than half of all Caregivers (52.3%, 48.4%-56.5%) spend up to eight hours a week providing care, but one fifth (20.2%, 16.9% - 23.5%) spend 40 hours or more in caregiving activities.

	Up to Eight Hours per Week	40 Hours or More per Week
Caregiver	52.1	20.3
Caregiver with SCD	54.4	18.8
All Caregivers	52.3	20.2

The table below shows the number of hours of care per week by the age group of the caregiver for both Caregivers only and Caregivers with SCD. Caregivers with SCD have fewer forty-hour weeks than Caregivers. The 45 to 64 years age group for Caregivers has the highest percentage of forty-hour weeks.

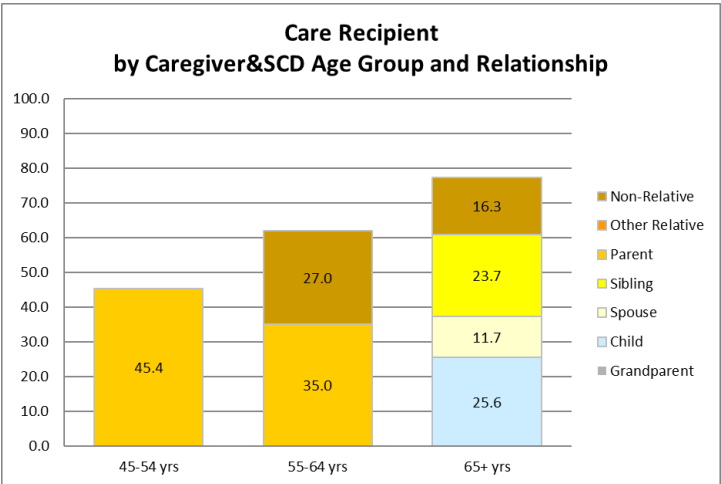


The relationship of the recipient to the caregiver also fluctuates with the age group of the caregiver.



For the younger age groups, grandparents and parents make up the largest share of recipients. Siblings, other relatives and non-relatives make up the balance. At 35 to 44 years, children become part of the recipient population, the proportion of grandparents decreases and the proportion of parents increases. Other relatives and non-relatives are still part of the recipient population. Grandparents are replaced by spouses by age 45 to 64 years, children and parents remain steady and siblings enter the population. By the 65 and older age group, spouses make up the largest proportion of recipients followed by non-relatives, siblings and children. Other relatives and parents make up the remainder.

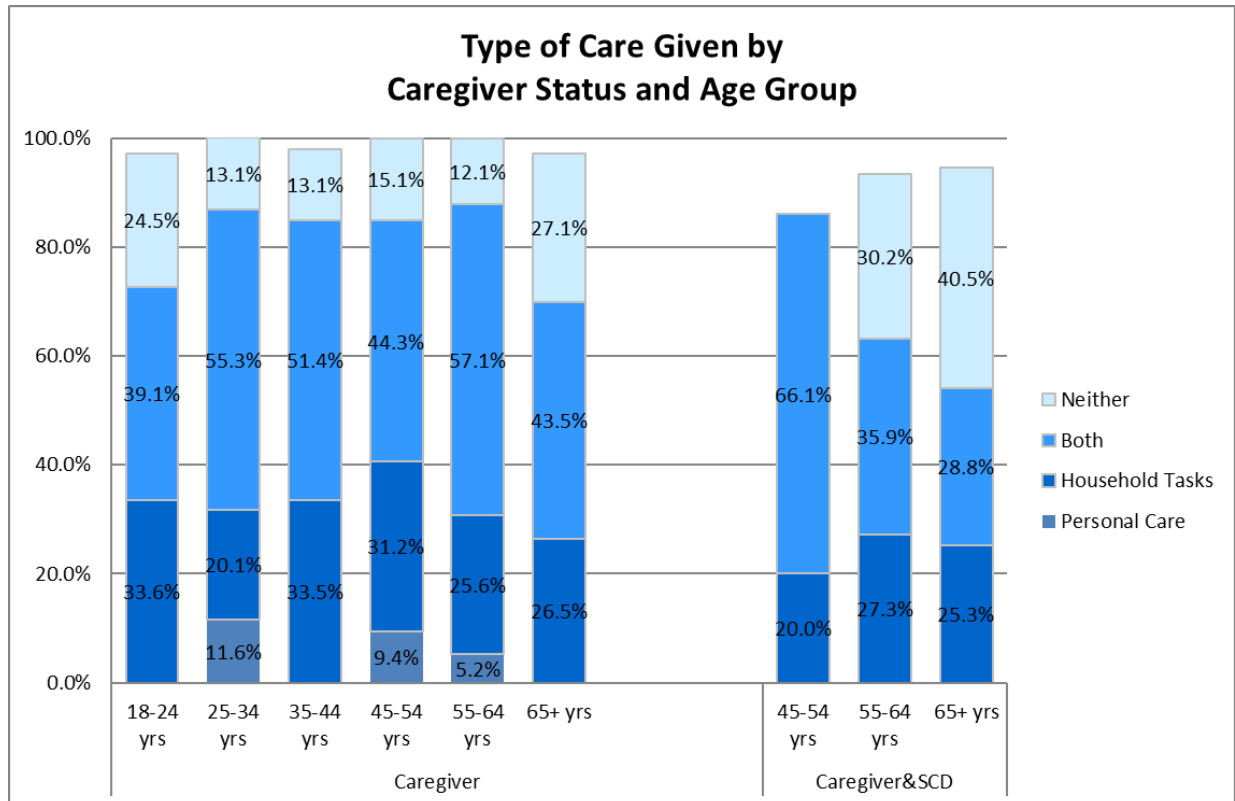
Data for the Caregivers with SCD is insufficient to provide the same level of detail as the Caregivers, but for the 45-54 years age group, the major recipient was parents; non-relatives are part of the recipient population for the 55 to 64 year olds; and children and siblings become recipients at the 65 and older group.



Type of Care Provided

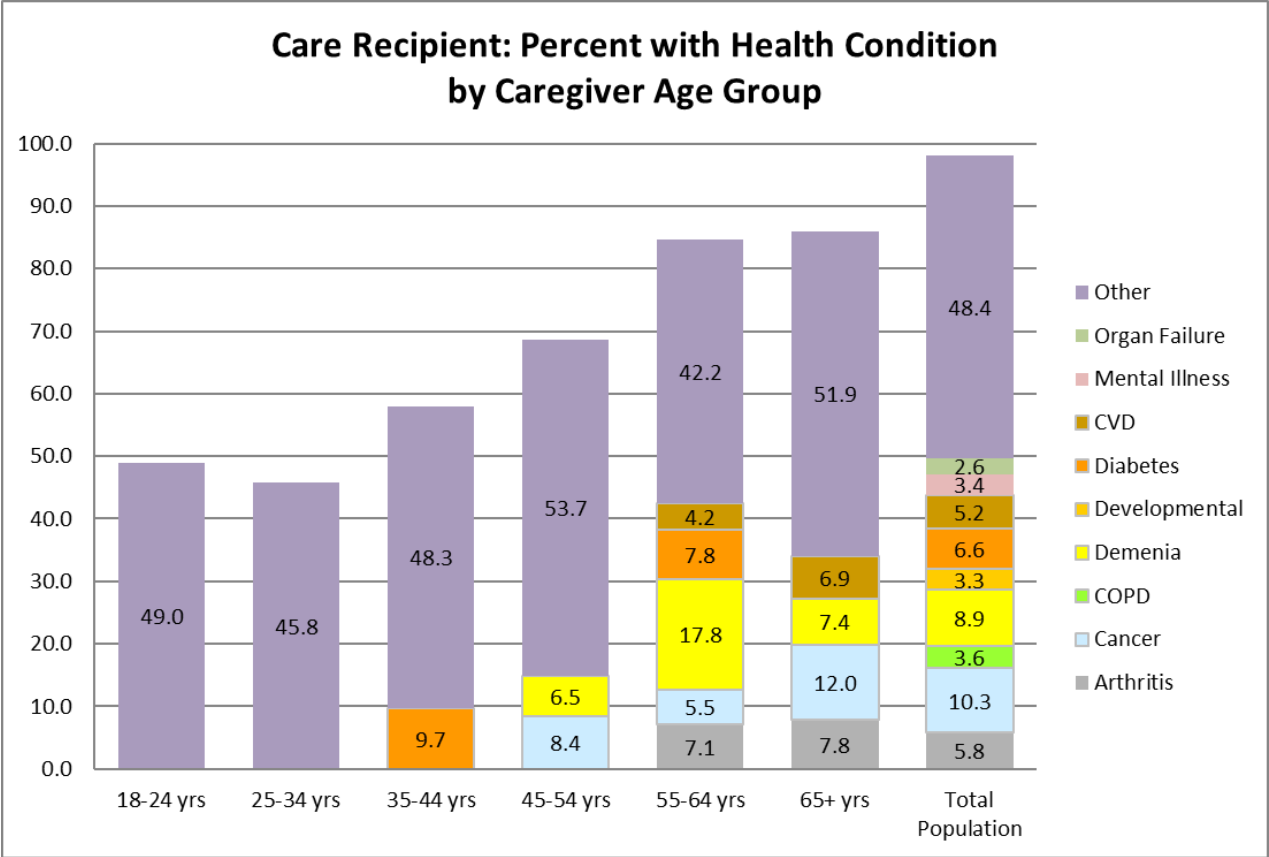
The type of care provided to recipients has been categorized into:

- Personal Care: giving medications, feeding dressing or bathing or
- Household tasks: cleaning, managing money or preparing meals



Overall, most caregivers provide both types of service to recipients (48.6%), followed by household care only (27.9%), with a small proportion of caregivers providing only personal care (5.7%). 17.8% of self-reported Caregivers provide neither personal nor household care.

Health Condition of the Care Recipient



The number of health conditions increases with the age of the Caregiver with the major categories being cancer, dementia, diabetes and cardiovascular disease. Data was insufficient to characterize the recipients of the Caregivers with SCD by age group, but overall 42.2% fell into the other category, 15.0% had dementia, 13.2% had cardiovascular disease and 8.0% had arthritis.

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