



Investing Together. For Good. For Ever.

**Ventura County
Community Foundation**

The Future of Caregiving for an Aging Population:

*Increasing Community and
Economic Vitality in Ventura County*

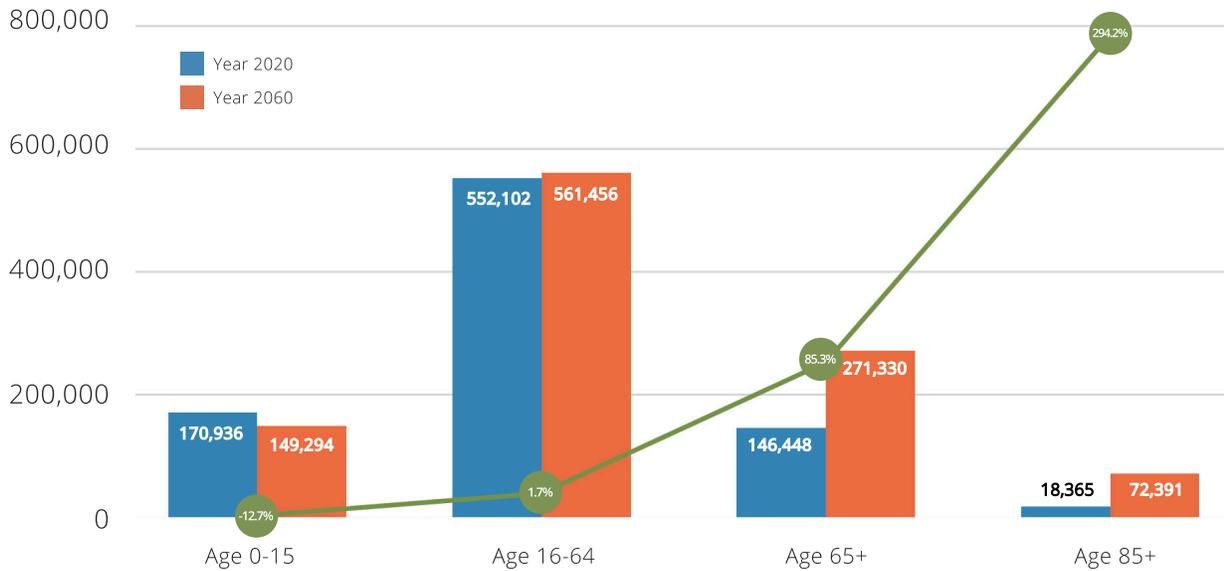
Prepared by
Jamshid Damooei, Ph.D.



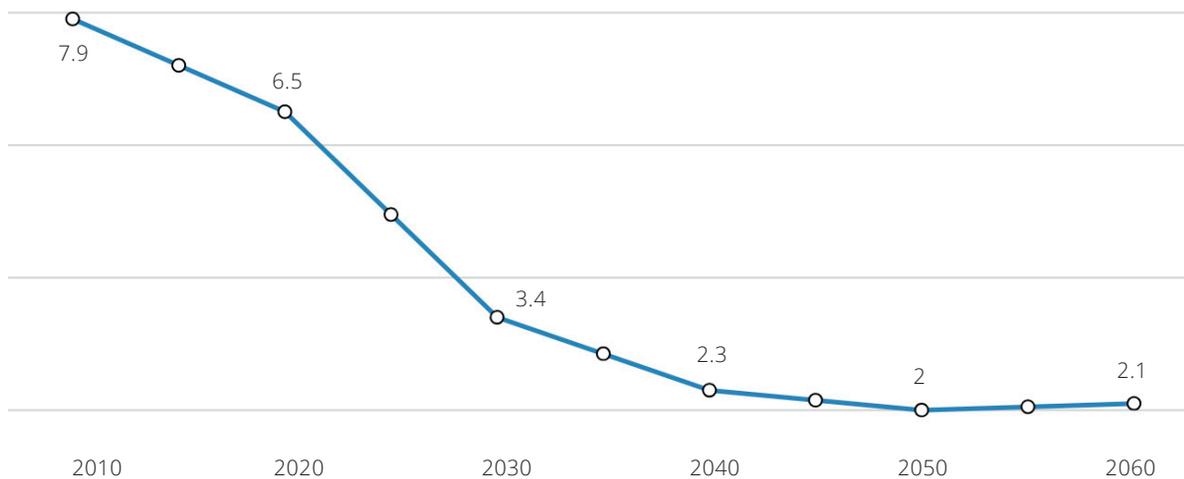
The Future of Caregiving for an Aging Population

Increasing Community and Economic Vitality in Ventura County

A Glance at the Future of Ventura County's Population



Caregiver Support Ratio over Decades (2010 to 2060) in Ventura County



Acknowledgments

I would like to thank Ms. Phylene Wiggins, Vice President of Community Investments & Partnerships of the Ventura County Community Foundation for inviting me to conduct this research and helping me to find a pertinent focus, which will be relevant and positive in regards to the work of partners, stakeholders, advocates and community leaders in the months ahead.

I am grateful for the support and encouragement of Ms. Vanessa Bechtel, President and CEO of the Ventura County Community Foundation in promoting ideas and studies, which aim at making Ventura County a caring and supporting county for all its residents.

I would also like to take this opportunity to express my gratitude to Dr. Jan Vanslyke, Principal Evaluator of Evaluation Specialists for her assistance in further developing this study. I am grateful to the administrators and staff of the Santa Barbara Foundation's Community Caregiving Initiative (CCI) for allowing me to have access to the information and reports provided by the CCI.

Finally, I would like to express our sincere appreciation for the exceptional work and contribution of my colleague and fellow researcher Mr. Ruslan Korchagin, MBA, MSIT in gathering and processing some of the most important information for this study. I am grateful for the contribution of Mr. Adam Erickson, M.Ed., M.A. in editing the manuscript of this study.

Jamshid Damooei, Ph.D.
President of Damooei Global Research
Professor of Economics and Director of Economics Program
Executive Director of Center for Study of Economics of Social Issues (CESI)
California Lutheran University
Tel: (805) 493-3357

Contents

Acknowledgment	3
Table of Figures	5
Executive Summary	8
1. The Challenge of Providing Sustainable Long-Term Care	16
Home Care	19
Community Services	20
Supportive Housing Programs	20
Assisted Living Facilities	21
Continuing Care Retirement Communities (CCRCs)	21
Nursing Homes	21
2. Prevailing Conditions and Demographic Characteristics of Caregivers and Those In Need of Long-Term Care (LTC)	27
Demographics and Living Conditions	29
Size, Areas of Needs for Long-term Care and Preparedness of Caregivers	34
3. Economic and Social Costs of Caregiving	51
Selected Trends Showing Expansion of the Size of the Industry	52
Economic, Social, and Emotional Cost of Care by Caregivers	56
4. Long-term Care in Ventura County and Its Neighboring Region	65
Important Demographic Information about Ventura County	67
Existing and Projected Estimates of People in Need of Long-term Care in Ventura County	70
Information Concerning Demographic and Other Characteristics of Caregivers in Ventura County	75
Focusing on Population of 60 Years of Age and Older in Ventura County	80
Looking into Challenges of Long-term Caregiving in the Region from Santa Barbara Foundation Community Caregiving Initiative (CCI) Surveys in 2017 and 2018	85
Basic Demographics of Respondents	86
Prevailing Conditions for Caregiving and Its Possible Impact on Socio-Economic Environment of Caregiving	89
What Caregivers Are Doing to Take Care of Their Individual Needs	94
What Can Be Done To Help Caregivers to Meet the Needs of Their Care Recipients	102
Evaluating the Effectiveness of the Help and Services Received	106
5. Summary Conclusion, Takeaways and Ideas for Further Consideration	111
Summary of Findings and Takeaways	113
Next Steps Forward	125
Bibliography	126
Appendix	130

Table of Figures

Figure 1: Percent Distribution of Long Term Care Service Providers by Sector, United States	22
Figure 2: Percent Distribution of Long Term Care Services Providers, by Provider Type and Ownership: United States	23
Figure 3: Percentage of Long Term Care Services Providers by Service Provision: United States	24
Figure 4: Percent Distribution of Long-Term Care Services Providers, by Provider Type and Age Group: United States	26
Figure 5: Demographics of Care Recipients, 2015	29
Figure 6: Demographics of Caregivers, 2015	30
Figure 7: Generational Distribution of U.S. Caregivers as of 2017	30
Figure 8: Living Conditions of Care Recipients, 2015	31
Figure 9: General Facts about Caregiving, 2015	32
Figure 10: Locations Where Older Adults Received Long-Term Care in the U.S. 2017	33
Figure 11: Percentage of U.S. People Who Ended Help with Personal Care from Others 1997-2017	34
Figure 12: Elderly Persons with Hospital Stays in the Past Years in the U.S. 1997-2016	35
Figure 13: Services Home Care Aides Should Provide According to Older Adults U.S. 2017	36
Figure 14: Tasks Those Ill Elderly Family Members Needed Assistance with in the U.S. as of 2017	37
Figure 15: Help and Information that Caregiver Needs, 2015	38
Figure 16: U.S. Adult Estimates of Long-Term Elderly Care Needs 2018	39
Figure 17: Opinions on Availability of Support for the Elderly in the U.S. 2017, by Age	40
Figure 18: Rate of Home Health Care Workers per Elderly in the U.S. 2013-2018	41
Figure 19: Number of Alzheimer/Dementia Caregivers in the U.S. 2011-2017	42
Figure 20: Projected Number of Older People with Alzheimer in the U.S. 2011-2050	42
Figure 21: Share of Patients with Alzheimer's Diseases in the U.S. By Age Group 2018	43
Figure 22: Experience with Hospice Among Recently Deceased U.S. Adults 2017, by Location of Care	44
Figure 23: Health Conditions of Care Recipients, 2015	45
Figure 24: Types of Help Provided by Caregivers, 2015	46
Figure 25: Medical/Nursing Task Preparation, 2015	47
Figure 26: Communication with Health Care Providers, 2015	49
Figure 27: Expectations of Future Caregiving Role, 2015	50
Figure 28: Total Employer Firm Revenue of Community Care Facilities for the Elderly 2006-2017	52
Figure 29: Services for the Elderly, Persons with Disabilities Revenue in the U.S. 2010-2022	53
Figure 30: Forecast: Revenue Elderly Homes U.S. 2008-2020	53
Figure 31: Percentage of U.S. Caregivers' Monthly Budget used for Caregivers Costs as of 2017	54
Figure 32: Hours of Unpaid Care per Year in the U.S. 2011-2017	55
Figure 33: Value of Unpaid Care in USD in the U.S. 2011-2017	55
Figure 34: Percentage of U.S. Caregivers Whose Lifestyle was Impacted by Caregivers as of 2017	56
Figure 35: U.S. Caregivers that Felt Select Emotions During Caregiving as of 2016	57
Figure 36: U.S. Caregivers that Felt their Employer was Supportive in 2017	58
Figure 37: Economic and Social Conditions of Caregivers, 2015	59
Figure 38: Economic Cost to Caregivers, 2015	60
Figure 39: Economic, Physical, Emotional, and Other Burden of Being Caregivers, 2015	62
Figure 40: Percentage of U.S. Caregivers Whose Job Has Been Impacted by Caregiving as of 2017	63
Figure 41: Health Conditions of Caregivers, 2015	64
Figure 42: Age Structure of Population in Ventura County from 2018 to 2060	67

Figure 43: Growth in Population of Age Groups in Percentages in Ventura County 2020-2060	68
Figure 44: Caregiver Support Ratio in Ventura County 2010-2060	69
Figure 45: Caregiver Support Ratio over Decades (2010 to 2060) in Ventura County	69
Figure 46: Population of Various Age Groups with Various Disabilities in Ventura County in 2017	70
Figure 47: Proportion of Various Kind of Disabilities across Age Groups in Ventura County in 2017	71
Figure 48: Various Kind of Disabilities by Age Groups in Ventura County 2017-2060	72
Figure 49: People with Disability by Employment Status in Ventura County, 2017	73
Figure 50: People with Disability by Poverty Level in Ventura County, 2017	74
Figure 51: Caregivers by Age in Ventura County, 2009	75
Figure 52: Caregivers by Ethnicity in Ventura County, 2009	75
Figure 53: Caregivers by Employment Status in Ventura County, 2009	75
Figure 54: Caregivers by Poverty Level in Ventura County, 2009	75
Figure 55: Physical and Emotional Stress of Caregivers in Ventura County, 2009	76
Figure 56: Health Related Characteristics of Caregivers in Ventura County, 2009	77
Figure 57: Population of Caregivers by Age in Ventura County, 2009	77
Figure 58: Ethnicity of Caregivers by Age in Ventura County, 2009	78
Figure 59: Population of Caregivers by Gender in Ventura County, 2009	78
Figure 60: Poverty Level of Caregivers by Gender in Ventura County, 2009	79
Figure 61: Population of 60 Years Old and above By Gender in Ventura County, 2017	80
Figure 62: Population of 60 Years Old and above By Race in Ventura County, 2017	81
Figure 63: Population of 60 Years Old and above By Ethnicity in Ventura County, 2017	81
Figure 64: Population of 60 Years Old and above By Educational Attainment in Ventura County, 2017	82
Figure 65: Population of 60 Years Old and above By Disability Status in Ventura County, 2017	82
Figure 66: Population of 60 Years Old and above By Employment Status in Ventura County, 2017	83
Figure 67: Mean Income Status of Population of 60 Years Old and above in Ventura County, 2017	83
Figure 68: Sources of Income of Population 60 Years Old and above in Ventura County, 2017	84
Figure 69: Population 60 Years Old and above by Poverty Status in Ventura County, 2017	84
Figure 70: Preference in Language in Taking the Survey, 2017-2018	86
Figure 71: Which County Do You Live in?, 2017-2018	86
Figure 72: Which County Do You Work in?, 2017-2018	86
Figure 73: What is Your Age?, 2017-2018	86
Figure 74: What is Your Gender?, 2017-2018	86
Figure 75: How Would You Describe Your Racial/Ethnic Background?, 2017-2018	87
Figure 76: Where Does the Person You Care for Live?, 2017-2018	87
Figure 77: What is the Age of the Person You Care For?, 2017-2018	87
Figure 78: What is the Age of the Person You Care For?, 2017-2018	87
Figure 79: Is There Anyone Else Who Helps Care for This Person?, 2017-2018	89
Figure 80: How Long Have You Been Caring for This Person(s)? If You are Caring for More than one Person, Answer for the Person You Have Been Caring for the Longest?, 2017-2018	89
Figure 81: What is Your Current Employment Status?, 2017-2018	89
Figure 82: Employment Status and Age, 2017-2018	90
Figure 83: Employment Status and Gender, 2017-2018	90
Figure 84: Does your Employer Offer Any of the Following Benefits for Caregivers?, 2017-2018	91
Figure 85: Which Employer Benefits Do You Use?, 2017-2018	91
Figure 86: Which Employer Benefits Would You Use if They Were Offered?, 2017-2018	92
Figure 87: Pattern of Benefits Taken by Fulltime and Part-time Working Caregivers, 2017-2018	92
Figure 88: Pattern of Benefits Taken if They Were Offered in the Work Place, 2017-2018	93

Figure 89: Over the Past 6 Months, How Often Have You Felt Stressed Because of Caregiving?, 2017-2018	94
Figure 90: Employment Status and Stress Because of Caregiving, 2017-2018	94
Figure 91: How Regularly Have you Been Able to Take Care of Yourself in These Ways?, 2017-2018	95
Figure 92: How Regularly Has Each of These Needs Been Met for You?, 2017-2018	95
Figure 93: How Regularly Have You Been Able to do the Following to Care for Yourself?, 2017-2018	96
Figure 94: Employment Status and Taking Care of Personal Daily Activities, 2017-2018	96
Figure 95: Employment Status and Attending to Your Own Medical and Financial Needs, 2017-2018	97
Figure 96: Employment Status and Attending to Your Own Emotional Needs, 2017-2018	97
Figure 97: Employment Status and Attending to Your Own Emotional Needs, 2017-2018	98
Figure 98: Employment Status and Eating a Well Balanced Diet, 2017-2018	98
Figure 99: Employment Status and Getting Enough Sleep, 2017-2018	99
Figure 100: Employment Status and Receiving Appropriate Health Care, 2017-2018	99
Figure 101: Employment Status and Having Adequate Shelter, 2017-2018	100
Figure 102: Employment Status and Feeling Good about Yourself, 2017-2018	100
Figure 103: Employment Status and Feeling Secure about Your Financial Future, 2017-2018	101
Figure 104: Have You Needed to Do the Following for the Person You Care For?, 2017-2018	102
Figure 105: How Much Information for Caregivers Have you Received on the Following Topics?, 2017-2018	103
Figure 106: How Much Information for Caregivers Have you Received about the Person You Care for on the Following Topics?, 2017-2018	103
Figure 107: Did You or the Person You Care for Need Any of the Following Services?, 2017-2018	104
Figure 108: How Able Were You to do the Following for the Person You Care for?, 2017-2018	104
Figure 109: Were the Following Services Available, and Did You or the Person You care for Use Them?, 2017-2018	105
Figure 111: How Many Organizations Did You and the Person You Care for Receive Services From?, 2017-2018	106
Figure 112: How Helpful Were Each of the Services Received?, 2017-2018	106
Figure 113: Think about the Services Received. How Much do You Agree with the Following Statements?, 2017-2018	107
Figure 114: What Challenges, if any, Did You or the Person You Care for Have Using These Services?, 2017-2018	107
Figure 115: Employment Status and Challenges to Use Caregiving Services, 2017-2018	108
Figure 116: .How Acceptable Were Services Received, (Thinking about Language, Cultural Background, Religion, Sexual Orientation, and Age)?, 2017-2018	108
Figure 117: How Much do You Agree with the Following Thinking About These Services?, 2017-2018	109
Figure 118: How Helpful Were the Following in Improving Your Caregiving?, 2017-2018	109
Figure 119: How Much Have These Service Experiences Changed Your Opinions about the Following?, 2017-2018	110

Executive Summary

The need for long-term care emanates from a gradual and consistent demographic development that may not come into the purview of many people and policymakers, unless they are presented with the reality of this development based on reliable and scientific data. The number of Americans who need long-term care is expected to increase to 27 million in 2050. By 2050, when the last Baby Boomers turn 85, the number of Americans aged 65 or older is projected to increase to almost 89 million, which will make up 20.2% of the estimated total U.S. population.

Most studies on the cost of Long-Term Service and Support (LTSS) do not explicitly account for the unpaid cost of care, which in turn allows for under-estimation of the growing needs for paid LTSS. A study by AARP, *Caregiving in the US (2015)*, states that some 43.5 million adults in the U.S. (about 18.2% of Americans over age 18) reported that they have provided unpaid care in the previous 12 months.

The cost of caregiving by unpaid family members in its broader definition may include loss of time from work, stress, and emotional suffering which are caused by either taking care of the family members in need or not being assured that they are taken care of through a reliable system and means. This report will attempt to include them for the development of a reliable system that can provide long-term cost savings for a community.

“

Most studies on the cost of Long-Term Service and Support (LTSS) do not explicitly account for the unpaid cost of care, which in turn allows for under-estimation of the growing needs for paid LTSS.



Based on the latest national surveys, a higher proportion of caregivers and care recipients are women. AARP's latest reports put the highest proportion of caregivers between ages of 50 to 64 years of age (34%). There are however, a high proportion of caregivers who are between 18 to 34 years of age (24%) and an equally high proportion who are between 35 to 49 years of age (23%). Some 19% of caregivers are 65 years of age or older (7% are older than 75 years of age).

The option to accept the role of a caregiver was available to about half of those who became caregivers, and in the case of 49% of them, they did not have an option. Areas of support required of caregivers are widely varied, and include many essential needs such as transportation, getting around the house, reminding their charges to take and/or administering medication, shopping, and other elements necessary for the continuation of their charges' daily life.

A majority of caregivers and in particular the younger group, appear to have underestimated the needs for long-term care. Such results from those who are involved in providing care show that the level of awareness among the general population is even less. Some 45% of all ages of Americans interviewed through a survey (randomized selection) believe that there is not enough support for elderly care in the United States and this ratio is even higher among the age range of 30 to 49.

The number of people with Alzheimer's Disease is expected to rise from 4.3 million in 2010 to 5.8 million in 2020 and to a staggering number of 13.8 million by 2050. This shows that we are facing a very steep rate of increase in the number of people with Alzheimer's in the decades ahead. Some 96% of Americans with Alzheimer's are 65 years of age or older. The highest proportion can be found in the age range of 75 years and older. A sharp increase in the number of older people can surely mean a sharp increase in the number of people with such debilitating and grave diseases.

This report provides extensive information taken from multiple national and regional surveys about the needs of caregivers and how they can be assisted effectively.

According the existing information, a third of the caregivers surveyed spent between 1 and 20 percent of their monthly budget on providing care for the people they look after. However, some 40% spent between 20 and 60 percent of their monthly budget. Another 24% said that they spent a portion of their budget for the people under their care but could not provide any estimate for how much they spend.

“

The number of people with Alzheimer's Disease is expected to rise from 4.3 million in 2010 to 5.8 million in 2020 and to a staggering number of 13.8 million by 2050.



“

In 2017, family members and friends provided 18.4 billion hours of unpaid caregiving.

We learned that within the broadest age category of family and friend, 18 years of age and older, only 15% believe that their lifestyle was not impacted by caregiving. However, some 38% stated that their lifestyle was greatly impacted by caregiving. Almost 47% said that their life was moderately impacted by becoming a caregiver. **The impact on the life of caregivers has many dimensions which go far greater than spending time and money. Caregiving impacts their emotions, health, peace of mind, and in general, their level of the happiness and contentment in life. The report provides a detailed account of such incidences in its pertinent sections.**

In 2017, family members and friends provided 18.4 billion hours of unpaid caregiving. Putting a modest value of less than \$13 on each hour of such allocation of time brought the value of unpaid care to a total of \$232.2 billion. It is true that many who accept caring for a loved one take on such tasks often with a profound sense of responsibility, and they love and accept what they must do. In the earlier part of this report, we showed that according to the most recent report from the AARP, some 51% of non-paid caregivers stated that they had a choice in becoming a caregiver.

While giving care can be emotionally uplifting and satisfactory, it can also bring fatigue and at times, negative emotions. The other interesting observation is the gap between feeling positive emotions “often” and “all the time” is narrower than the relatively wide gap between these two values in context of negative emotions. One way to explain such a gap is that negative emotions are not as widespread and pervasive as the positive emotions are or could be.

One of the most important areas of impact, which has far-reaching economic consequences, is the impact of caregiving on the employment, and work environment status of caregivers.

Based on the surveys mentioned in this study, only 41% of employers were very supportive of caregivers as their employees. Some 30% were somewhat supportive. Some 16% were either not supportive at all or not too supportive. These findings can be viewed as somewhat positive if one only focuses on the size of support versus the lack of support. There is however, an important dimension to these findings which should not be lost in such a comparison. That is the additional burden on caregivers when their home responsibilities are combined with a lack of support or even strong disapproval from their employers and their business entities.

Some 60% of caregivers are employed. Out of those who work, 72% work more than 30 hours per week and 56% work 40 hours per week or longer. Some 79% work for others, which usually implies more strict working conditions and a necessity to show up for work under pre-determined and often inflexible conditions. One of the most important responses from the AARP national survey is that some 67% say they have faced discrimination in their work place due to being caregivers.

Ventura County is a community with considerable diversity in its population. The family structures of the county vary in its various population centers and there is a considerable economic diversity which impacts the social dimensions of health, life expectancy, and the ability of the county to support the lives of its population throughout their various stages from childhood, to adulthood, and old age.

As a county, we will be experiencing a negative growth (reduction) in the number of children between ages of 0-15 (-12.7%) while our working population (as known in a demographic sense) will only increase by 1.7% from 2020 to 2060. On the other hand, the population of people age 65 and higher will increase by 85.3% during the same time. The highest population growth rate, 294.2% (almost 300%), will occur in the population of people aged 85 years and older. In other words, the total number of people 85 years old and higher will become nearly half of the population of children ages 0-15 by 2060. This is an important issue to bear in mind and to try to be prepared for over the next 40 years, as this change will surely unfold.

We used the emerging population numbers and calculated the proportion of people with disabilities over the total county population. In 2017, for which we have used the available information, the rate stands at 13%. By 2060, based on our projection, this rate will increase to 31%. Ensuring that Ventura County is ready for such a tremendous increase in the number of people with various needs to accommodate for their disabilities is one of the primary goals of this study.

“

Some 60% of caregivers are employed. some 67% say they have faced discrimination in their work place because of being caregivers.

“

Ventura County will be experiencing a negative growth in the number of children between ages of 0-15 (-12.7%) while our working population will only increase by 1.7% from 2020 to 2060. The population of people age 65 and higher will increase by 85.3% during the same time. The highest population growth rate, 294.2% (almost 300%), will occur in the population of people aged 85 years and older.

Let us put what we have together in order to form a better understanding of the emerging conditions with regard to preparedness for meeting the LTC needs of Ventura County. Here is how we can sum it up:

- **Population of people aged 85 years and older will increase by 294.2% by 2060.**
- **Population of people aged 65 years and older will increase by 85.3% by 2060.**
- **Proportion of people with disabilities will increase from 13% in 2017 to 31% by 2060.**
- **Population of children ages 0-15 will decline by 12.7% by 2060, which is a significant substitution of children with elderly people.**



Adding to this realistic picture is the information about the segment of the older population who are facing poverty. In 2017, some 23,756 people, or 2.8% of the county population, were disabled and living below 200% of the poverty level. A significant proportion of these people were 18 years of age and older. The economic condition of people with low incomes will improve in the decades ahead; otherwise, old age and disability will be added to the poverty concerns for a large number of people in Ventura County. We need to be aware of such a enormous rise in the older population of our county and their emerging needs so that the county is able to provide a variety of help and assistance within the next few decades.

The California Health Interview Survey conducted by the UCLA Center for Health Policy Research in 2009, provided some important information about the prevailing economic and social condition of caregivers in Ventura County.

This study showed that by 2020, the caregiver support ratio will be 6.5 caregivers for every one person. The ratio will decline to 3.4 caregivers per person by 2030, and by 2040 and beyond, this ratio will reach almost two caregivers in the age category of 45 to 64 years for every one person in the age category of 80+ years of age.

The 2009 study shows that caregivers in Ventura County suffer from a variety of stress-related complications. A quarter of caregivers have visited emergency rooms for their problems.

The problem that stands out very clearly is the tendency of caregivers to delay or not pay enough attention to their own physical or emotional needs.

A large percentage of almost 40% of caregivers have been binge drinkers in the past year, and more than 15% had seen mental care providers or had substance abuse issues. An alarming rate of 17.1% have thought about committing suicide.

The study also shows that out of the 158,000 caregivers in Ventura County, some 88,000 are women and the remaining 70,000 are men. This shows a ratio of 55.7% women compared with 44.7% of men. It shows female caregivers are far more likely to be in poverty (below 100% of FPL) than men. Nearly 24% of women caregivers are in poverty compared with just over 7% of men who provide care.

The Community Caregiving Initiative (CCI) develops and supports on-the-ground service networks for the county's 70,000+ unpaid caregivers, who provide 87% of long-term care service. In this study, we use some of the findings from CCI surveys during the last three occasions:

- Caregiver Survey in Spring of 2017 (256 completed)
- Caregiver Survey in Fall of 2017 (165 completed)
- Caregiver Survey in Spring of 2018 (142 completed)

We put together the combined survey, ran frequency tables for each individual survey as well as the combined survey results, and added to this a selected number of cross-tabulations of data regarding the combined pool of data. The findings provided informative volumes of information that shed light on what is going on in regards to elder care in our region. This comes with great potential for extracting more information, leading to additional questions and discussion. The hope is that the findings can be used for the creation of appropriate interventions and cooperation among partners on such important fields of community work in our region.

“

A 2009 study shows that caregivers in Ventura County suffer from a variety of stress-related complications:

- *A quarter of caregivers have visited emergency rooms for their problems.*
- *An alarming rate of 17.1% have thought about committing suicide*

Here is a selected number of important informational findings from a pool of surveys including more than 550 participants (for a complete account, please read the relevant segment of the report):



- About a third of the respondents do not work, and nearly 3/10 of the caregivers are currently working.
- Only 2.2% of caregivers are younger than 30 years of age and 7.2% are 80 years old or older.
- About 75% of caregivers are women.
- More than half of caregivers (51.4%) are looking after their parents. All together, nearly 90% of care is given to family members.
- More than 80% of those who are care recipients are 70 years of age or older. 57.4% of care recipients are 80 years of age or older.
- Almost nine out of ten of them have been caregivers for longer than a year. Some six out of ten of them have been caregivers for more than three years. Some 28.7% of them (almost one out of three) have been caregivers for 5 years or longer.
- Some 60% of the caregivers are currently working and 40% of the 60% or better say some 67% of those who work hold fulltime employment. Only 27.9% are retired. This is a very significant finding and very much along the same findings from the national survey reported on earlier in this study.
- About 90% of caregivers have been under stress because of caregiving. 50% of the respondents have always or often been under stress.

- Coping with emotional stress, feeling secure about their own financial future, feeling good about oneself, getting enough sleep, and receiving appropriate health care appear to emerge as the areas in need of greater attention.
- Fulltime employment is more likely to be missed out on when taking care of someone else's daily activities. Also, the risk of not attending to one's own medical and financial needs is greater among caregivers with full-time employment.
- It appears that all categories of caregivers based on their employment status hardly get enough sleep. However, the plight of caregivers with fulltime employment is far more dire than other categories. Whether or not a caregiver gets enough sleep is an important observation. Getting enough sleep impacts one's overall health by reducing stress, and enabling a person to be more focused and ultimately better able to help persons under their care.
- Insufficient insurance and not having medical coverage appears to be a problem for a significant proportion of respondents.

The summary of findings and some suggestions to remedy the conditions have been placed on a table in the very last section of the study. The following are suggestions identified by the researcher on next steps:

- Address working conditions and work-related issues and provisions of nonpaid caregivers.
- Address work issues and working conditions of paid caregivers.
- Examine health insurance with a focus on coverage as it relates to caregivers and care recipients.
- Provide community-based assistance with a focus on sharing resources and developing greater capacity for offering services to caregivers and care recipients.
- Developing a community focus on underserved families and communities.
- Focus on workforce development and its relationship with skill development and the expansion of knowledge and educational programs to enhance the existing and emerging capacity within the county and the region.
- Advancement of entrepreneurship and innovative thinking and related technology, which can directly impact long-term care with a focus on eldercare.
- Build and strengthen international relations with countries and communities who are ahead of the curve in managing such services.





1

The Challenge of Providing Sustainable Long-Term Care

As a larger proportion of people living in an economy becomes older, the challenge of providing a high-quality care with economic efficiency becomes harder. Individuals experiencing chronic diseases, which reduces or eliminates their capacity to take care of all their needs on their own, need long-term care to survive. These needs are called activities of daily living (ADLs), such as bathing, dressing or eating, or instrumental activities of daily living (IADLs), such as household chores, meal preparation, or managing money. Long-term care often involves the most intimate aspects of people's lives, such as what and when they eat, personal hygiene, getting dressed, using the bathroom, and making sure their medications are taken or administered on time.

Long-term care services are wide-ranging and quite varied, therefore, designing and gathering the data explaining various aspects of such care is complex. This report focuses on the plight of nonpaid caregivers, looks for ways to document, and if possible measure, the scope of the needs and the complexity of their provision by those who provide such services. It also brings to attention that the expression of "non-paid" is meaningless when we consider its economic implications.

Use of any resource brings an inevitable allocation of that resource to meeting what is required and therefore will deprive it from being used elsewhere or for a different purpose. Such reallocation in economics is considered as cost or opportunity cost and it makes an impact on the way that the allocator of the resource makes their decision, which in turn affects the allocation of other resources. A relevant analysis of providing long-term care should include all such arguments into a comprehensive assessment, which can show the way forward and bring about a sustainable method of overall resource allocation for providing long-term care in an economy.

The need for long-term care emanates from a gradual and consistent demographic development that may not come into the purview of many policymakers, unless they are presented with the reality of this development based on reliable and scientific data. The number of Americans who need long-term care is expected to increase from approximately 12 million (as was estimated in year 2012) to 27 million in 2050. Baby Boomers (those born between 1946 and 1964) will turn 65 between 2011 and 2029 and during this time, 10,000 Americans will turn 65 every day. By 2030, when the last Baby Boomers turn 65, the number of Americans aged 65 and older is projected to be about 72 million, or about 19% of the total U.S. population. **By 2050, when the last Baby Boomers turn 85, the number of Americans aged 65 and older is projected to increase to almost 89 million, or about 20.2% of the total U.S. population.**

“

Long-term care often involves the most intimate aspects of people's lives: what and when they eat, personal hygiene, getting dressed, using the bathroom, and making sure their medications are taken or administered on time.

Annually 8,357,100 people in the United States receive support from the five main long-term care services; home health agencies (4,742,500), nursing homes (1,383,700), hospices (1,244,500), residential care communities (713,300), and adult day service centers (273,200). Most but not all persons in need of long-term care are elderly. Approximately 63% are persons aged 65 and older and the remaining 37% are 64 years of age and younger. The existing studies indicate that the lifetime probability of becoming disabled in at least two activities of daily living or of being cognitively impaired is 68% for people aged 65 and older. In 2013, total spending (public, out-of-pocket, and other private spending) for long-term care was \$306.9 billion. This is projected to increase to \$346 billion in 2040.

Long-term care can be provided through several means with a varied degree of substitutability. Providing critical health care services when needed cannot be substituted with any other possible services, which does not include such a high level of care. However, the frequency of using such services may be reduced by increasing the availability of homecare or other possibly available care. We need to draw the big picture in order to be able to calculate the real cost of each alternative among the available options.

Long-term care can be provided through a variety of methods and by a multitude of establishments and institutions. The following list shows a wide spectrum of possibilities for providing people in our communities with long-term care. Not having access to services can also be an occurrence. In order to take a deeper look into LTSS, we listed all such services with their relevant description, allowing us to look into each factor more deeply, with the intension of identifying the availability and the cost of these services.





Home Care

Home care includes help with a range of needed tasks, from daily living activities to nursing care. These services may include the following:



FAMILY CAREGIVING:

This kind of care is provided at home by family members and loved ones. Individuals choose this option because they are either unable to pay for professional care or they prefer to keep the care personal.



HOME HEALTH CARE:

This includes a range of health care services that provide assistance during an illness or injury. These include caring for wounds, prescription management, at-home physical therapy, and other related services.



HOMEMAKER SERVICES:

This type of care assists individuals who cannot perform day-to-day household duties.



HOME TELEHEALTH:

This includes a wide variety of technologies that help in delivering virtual medical, health, and education services or advice. This type of care incorporates various technological devices to assist in care.

Community Services

These services allow care recipients to live in a safe, friendly, and comfortable community while family caregivers attend to their other responsibilities or to get their much-needed break from caregiving. These may include:



ADULT DAY CARE CENTERS:

This caters to the needs of elderly individuals during the day. These facilities help families care for their loved ones without sacrificing their day-to-day responsibilities.



HOME CARE AGENCIES:

They provide either scheduled caregiver visits or assistance with household chores such as meal preparations, housekeeping, or other labor-heavy activities.



CONTINUING CARE RETIREMENT COMMUNITIES:

They are clusters of homes and apartments in which elderly individuals can enjoy independent living while still receiving basic care.



TRANSPORTATION SERVICES:

They allow elderly individuals a way to move around the community when they can no longer drive for themselves.



RESPIRE CARE:

They work towards relieving caregivers from providing care temporarily. In these situations, other caregivers take over the duties for a short duration of time.



MEAL PROGRAMS:

Volunteers ensure seniors have complete meals prepared for them.



VILLAGES:

Volunteers in the area help the growing older population remain in their homes longer through various neighbor-helping-neighbor systems.

Supportive Housing Programs

The Federal Department of Housing and Urban Development (HUD) developed these programs, which offer low-cost housing to seniors with low to moderate income. Most of these facilities provide help with meals and carrying out daily living activities such as housekeeping, shopping, and laundry.

Assisted Living Facilities

These facilities allow for relative independence among their residents. These facilities provide 24-hour supervision, assistance in personalized care and medication management, and homemaker services such as laundry and housekeeping services in a home-like setting. Assisted living facilities also provide social and recreational activities.

Continuing Care Retirement Communities (CCRCs)

These allow seniors to move into independent living units or private apartments, which provide social and housing-related services.

Nursing Homes

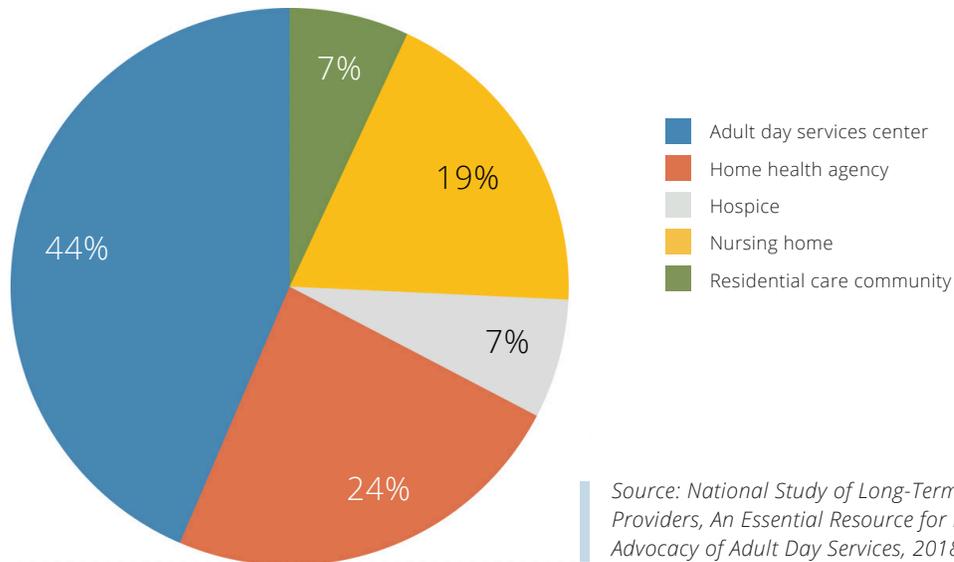
These are licensed facilities, which provide 24-hour supervision. They have the most comprehensive range of long-term care services for chronically ill residents and to people who cannot receive care at home or in a community. It should also be mentioned that Nursing Homes are the most expensive type of long-term care facility. Although there are some options for helping to pay for them, for the overwhelming majority of older Americans in need of access to nursing homes, they are not financially possible.

The decision to select or opt for one or a combination of services provided largely depends on the socio-economic status and preferences of care receivers. It should also be mentioned that although preference plays a role, having any option at all largely depends on the economic circumstances of care receivers. The cost of care plays the most important role, and the role of government becomes crucial when such choice is reduced due to the economic ability of the impacted population.

It is important to have a meaningful way of allocating the available resources to various options, which exist for long-term care. Furthermore, how we use each source may impact the overall picture of such allocation, and more importantly, we need to be clear about the way any allocation is made in direct relation to the quality of care and its overall economic efficiency. These reasons may change from variations in demographics, budgetary allocation, and preferences of the care recipients. At the same time, cost of services and abilities of the care industries, particularly in the areas of home and community-based services, may have affected this change. We need to explore the reasons further, and at the same time, look into the existing capacity of the industry to serve the existing and the emerging population requiring care.

FIGURE 1

Percent Distribution of Long-Term Care Service Providers, by Sector, United States



The above chart provides the existing pattern and distribution of long-term care service providers by sector in the years 2015 and 2016 (the latest available information). The chart shows a significant proportion of long-term care services are provided by residential care communities.

Residential care community refers to long-term care given to adults or children who stay in a residential setting rather than in their own home or family home. There are various residential care options available, depending on the needs of the individual. The latest data provided by the CDC indicates that there are some 28,000 of them in the United States and some 78.9% of them are for profit and they provide some 996,610 licensed beds. Residents of residential care communities are persons who cannot live independently but generally do not require the skilled care provided by nursing homes. This shows a very specialized type of long-term care service that can be provided without specialized care provisions outside their own place of residence. The issue here is the scope of the need, its cost, and the possibility of having a viable substitution which could provide the same service with greater cost effectiveness.

The second highest proportion is the share of nursing homes and their relative cost. We can explore the possibility of finding any effective substitute for all or part of the services. **One of the viable arguments for changing the cost of long-term care is to prolong the segment of the care, which is available at relatively lower cost without compromising on the quality of care.**

The third biggest share of long-term care providers belongs to home health agencies. Home health agencies give care in the home, as their name implies. People with medical conditions or disabilities sometimes get home health care services from these agencies, as an alternative to nursing home

care. Services offered depend on the agency, but it might include services such as skilled nursing care, physical therapy, or home health aide services. Some agencies may also teach the recipient of care to care for themselves, or teach their relatives and friends how to care for the person.

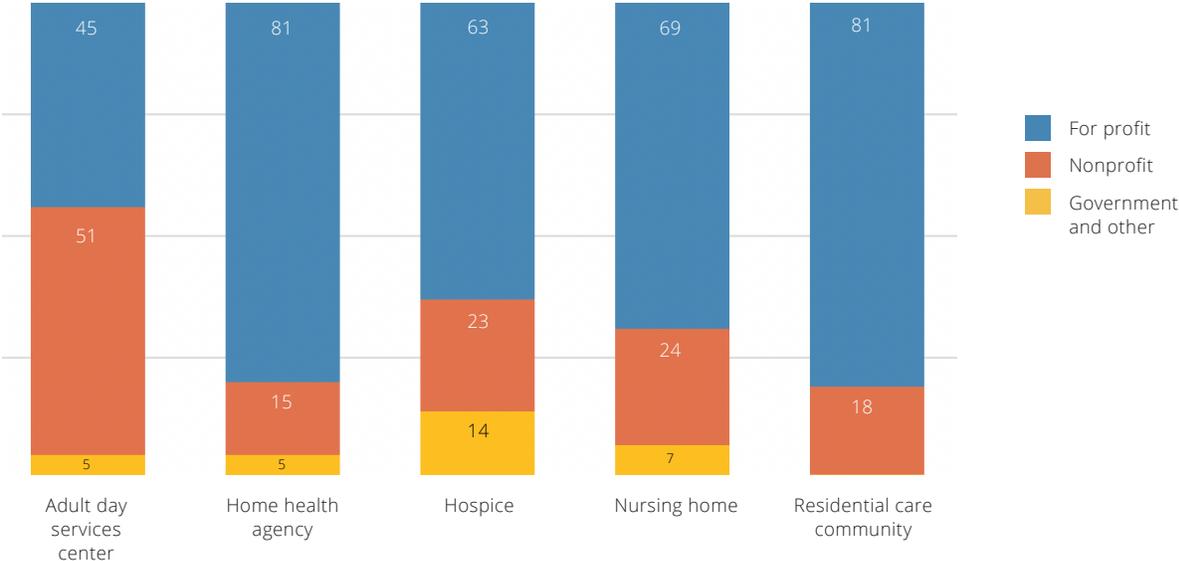
An increasing number of people are finding themselves in the position of caregivers for family members or friends. Caregivers may take care of one’s parents, spouses, relatives, friends, or children with special needs. They might help with food shopping and cooking; house cleaning; paying bills; administering medicine; bathing, dressing, and other personal care; and provide company and emotional support.

There are other alternatives to home health agencies besides caregivers. For older people with low to moderate incomes, some federal and state-subsidized senior housing programs may assist residents who need help with certain tasks, such as shopping and laundry. There are also “assisted living” arrangements offering some services to residents who live in an assisted living facility. Such services may include cooking, laundry, or reminders to take medications. Assisted living facilities can cost thousands of dollars per month, which is generally not covered by Medicare.

People who cannot live independently but do not require nursing home services can opt for board and care homes. These homes are set up as group living arrangements to meet the needs of the residents. The staff usually provides help with certain daily living activities, such as eating, bathing, walking, and toileting. The important issue in here is that such facilities can be provided by insurance and medical assistance. Medicare does not cover them.

FIGURE 2

Percent Distribution of Long-Term Care Services Providers, by Provider Type and Ownership: United States



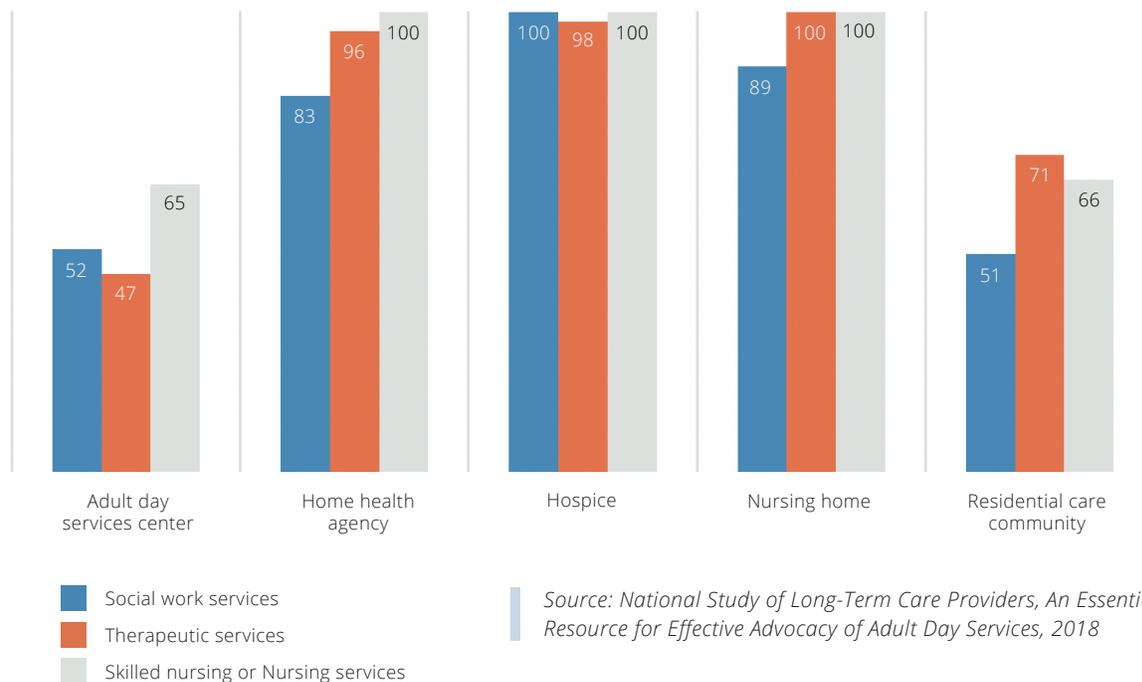
Source: National Study of Long-Term Care Providers, An Essential Resource for Effective Advocacy of Adult Day Services, 2018

The prior chart presents an interesting picture of the ownership of the long-term care service providers in the United States. The for-profit sector has the highest share of service providers in all areas, with exception of adult day services. The biggest share of for-profits are in residential care communities and home agencies. The government owns a very small share of service providers. **Ownership should not be confused with provisions of funds for offering of such services.**

In looking further into the workings and contributions of various service providers, we took a look at the following information, which includes the latest national study of long-term care providers and the services offered. This is depicted in the following graph.

FIGURE 3

Percentage of Long-Term Care Services Providers by Service Provision: United States



There are several ways to explain the information presented in the above diagram. The most relevant for our discussion in this study is the level of contribution of skilled nursing services, therapeutic services, and service social work services. The information shows that nursing homes, hospices, and home health agencies use skilled nursing services in 100% of their facilities. However, this information does not present any information concerning the level of their use within any specific facility. This information will be provided through staffing ratios later in this research.

The provision of therapeutic services are also used almost 100% in nursing homes, hospices and home health agencies. There is, however, a significant amount of skilled nursing services present in adult day services centers and residential care communities. Finally, social worker services have

a distinct place in all types of long-term care services. **The above discussion may be used to argue that both adult day services centers and residential care communities may be able to develop a greater capacity to offer their services by replacing some of the duties of a more highly skilled or trained professional with others with some training, which can bring a higher level of cost effectiveness into the system.**

A close examination of the proportion of staffing hours of members for each of the three set of establishments offering services for long-term caregiving presents interesting results. It shows that the largest proportion of staff in every set of establishments for long-term caregiving are aides. The smallest proportion of staffing hours are registered nurses. Social workers have much higher proportional staffing hours in adult day services. Licensed practical and vocational nurses are used more than registered licensed nurses. Activities directors and staff have a significant role in adult day services. A close examination of the level of skills and special educational requirements in various types of facilities for long-term caregiving with the exception of nursing homes indicate that these skills are relatively basic and attainable through training and skill development programs. This provides a healthy level of upward mobility within the industry and greater cost effectiveness through such investments.

Some seven out of ten of Americans 65 years old and above will need some form of long-term care. However, long-term care is not just for the aging population. Around 41% of working adults below 65 years old will also need long-term care because of a chronic illness, a mental condition, or an injury from an accident. According to the 2010 Investment Guide of the National Investment Center (NIC), the average length of stay of residents in an assisted living facility is 29 months, or approximately 2.5 to 3 years. According to Centers for Disease Control and Prevention (CDC), the average length of stay in a nursing home is 835 days, or more than two years. However, circumstances may be different if the care recipient has a cognitive condition.

Those who are suffering from dementia or Alzheimer's may stay in a nursing home for five years or more.

The age distribution of recipients of long-term care is an important issue in making sense of the structure and cost of long-term care.

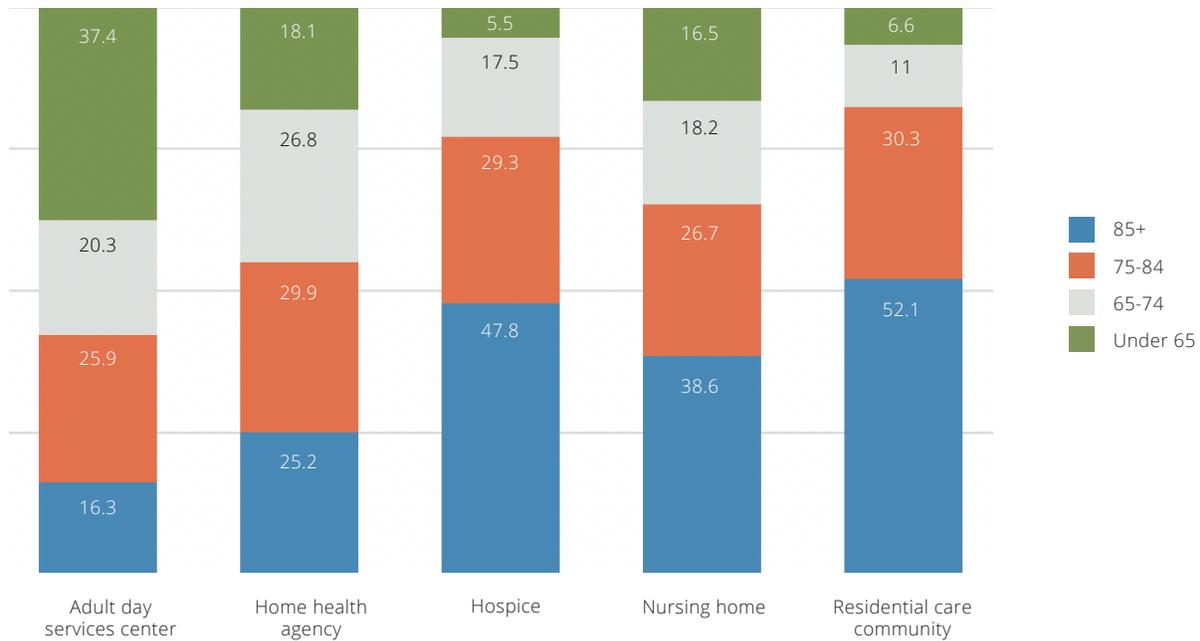


“

Some 7 out of 10 of Americans 65 years old and above will need some form of long-term care. Around 41% of working adults below 65 years old will also need long-term care because of a chronic illness, a mental condition, or an injury from an accident.

FIGURE 4

Percent Distribution of Long-Term Care Services Providers, by Provider Type and Age Group: United States



Source: National Study of Long-Term Care Providers, An Essential Resource for Effective Advocacy of Adult Day Services, 2018

Being in need of long-term care largely is a function of old age. However, there is a significant proportion of people under 65 years of age who are in need of such care and receive the care they need through the five categories of service providers depicted in the above graph. The plight of the oldest category of 85 years of age and older highlights the pivotal contribution of residential care communities. By examining further, we find that the age of more than 80% (82.4%) of their service recipients is 75 years and older. Combining the information of the last two charts together, we observe that more than 80% of recipients of long-term care in residential care communities are 75 years of age and older and 76% of their staffing needs are met by aides. This shows that the quality of care for the oldest proportion of our population in need of long-term care depends on the skill set of the aides.

Receiving care through residential care communities largely depends on the financial ability of the population being served. The bigger question is: who pays for the cost of long-term care of Americans?

“ Middle income and affluent families buy long-term care insurance to pay for home care, nursing homes, assisted living, and other long-term care services. Low-income families rely on Medicaid, which provides long-term care coverage to people who meet its eligibility requirements.



2

Prevailing Conditions and
Demographic Characteristics of
Caregivers and Those In Need
of Long-Term Care (LTC)

Most studies on the cost of long-term service and support (LTSS) do not explicitly account for unpaid costs of care, which in turn allows for an under-estimation of the growing needs for paid LTSS. A recent study by AARP, *Caregiving in the US (2015)*, states that some 43.5 million adults in the U.S. (about 18.2% of Americans over age 18) reported that they have provided unpaid care in the previous 12 months.

Family caregivers are the spouses, partners, adult children, other relatives, friends, or neighbors who provide care and support to adults with disabilities and/or older adults. The definition of “family caregivers” includes “families of choice,” not just the families people are born into. It is expected that the ranks of family caregivers will grow due to the population aging, increasing longevity, and the growing number of individuals with chronic conditions associated with an aging population, such as Alzheimer’s disease and related dementias (ADRDs), and the increasing cost of LTSS.

The cost of caregiving by unpaid family members in its broader definition may include loss of time from work, and the stress and emotional suffering which are caused by either taking care of the family members in need or not being assured that they are taken care of through a reliable system and means. This report will attempt to include them in the development of a reliable system that can provide long-term cost savings for a community.

This section is divided into two parts. In the first part, we look at the caregivers and learn about the prevailing circumstances in their lives from a number of sources, which explored this area of inquiry at the national level. The second part puts the spotlight on the prevailing living and working environment of the care recipients. The purpose of this part of the study is to consider the facts as they are and to the extent possible as they may evolve and develop over time.

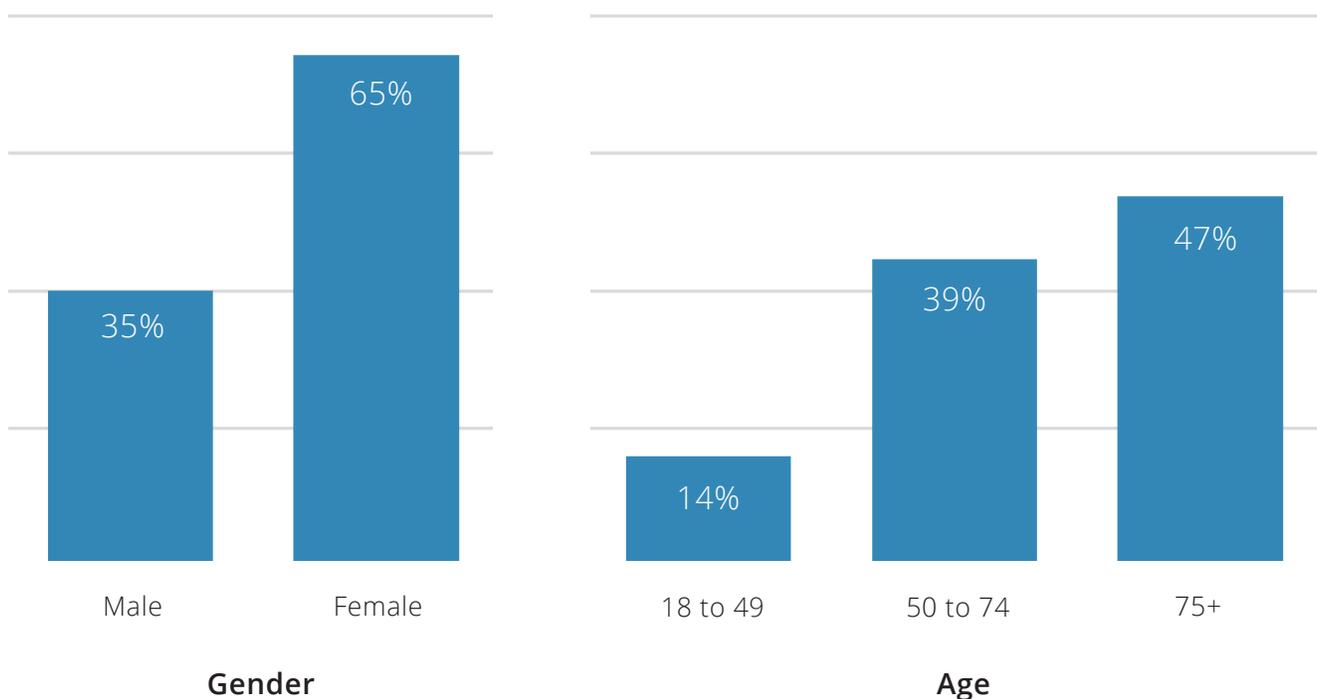


Demographics and Living Conditions

Through the study of these groups, we learned about the shortcomings and problems that exist in providing the needed care in the best possible way. The best possible way in large measure contains various elements of economic efficiency, which means keeping the quality up while reaching the least costly way of providing such services. In all such cases, costs include both explicit and implicit costs (often referred to as the opportunity or resource cost).

FIGURE 5

Demographics of Care Recipients, 2015

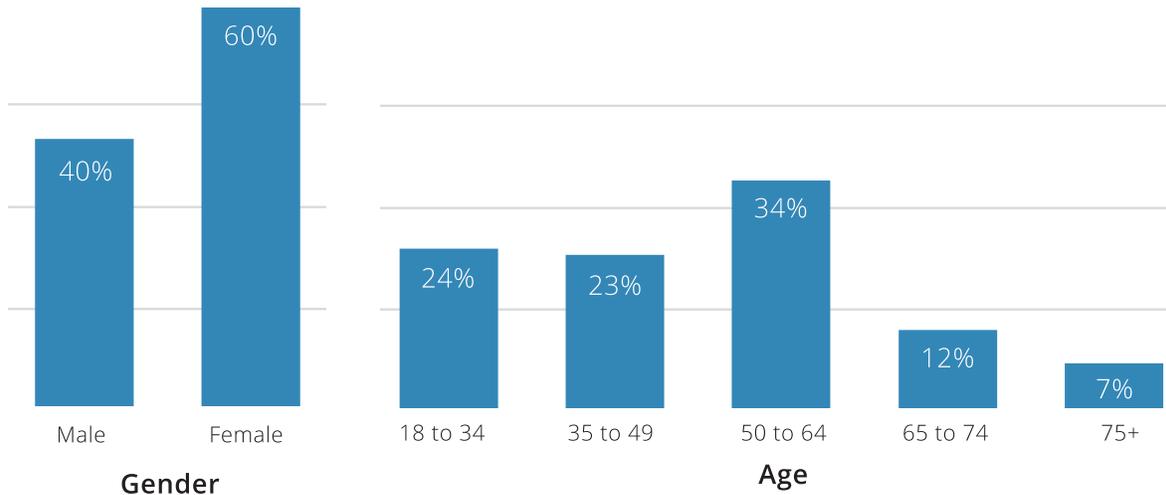


Source: AARP, *Caregiving in the U.S., 2015*

65% of care recipients are female. This is in part based on the longer life expectancy of women compared to men. The second part of the above chart that breaks up the age categories of care recipients sheds more light on the uneven breakdown of men and women in making up the total proportion of care recipients. Based on an AARP survey, some 47% of care recipients were 75 years old or older.

FIGURE 6

Demographics of Caregivers, 2015



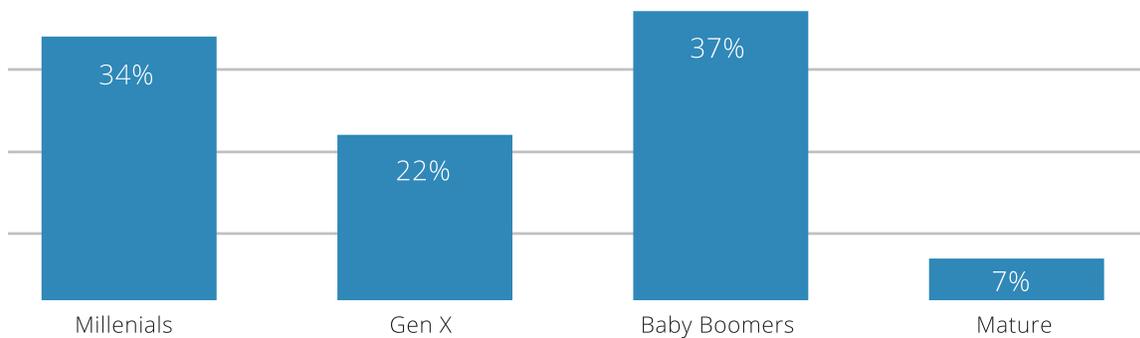
Source: AARP, *Caregiving in the U.S., 2015*

A higher proportion of caregivers are women. The highest proportion of caregivers are between the ages of 50 and 64 years (34%). There is, however, a high proportion of caregivers who are between 18 and 34 years of age (24%) and an equally high proportion who are between 35 and 49 years of age (23%). Some 19% of caregivers are 65 years of age or older (7% are older than 75 years of age).

The age breakdown presented in the above chart shows that caregivers come from all ages and age groups. The burden of caregiving may have a greater impact in terms of its cost and social impacts across various age groups.

FIGURE 7

Generational Distribution of U.S. Caregivers as of 2017



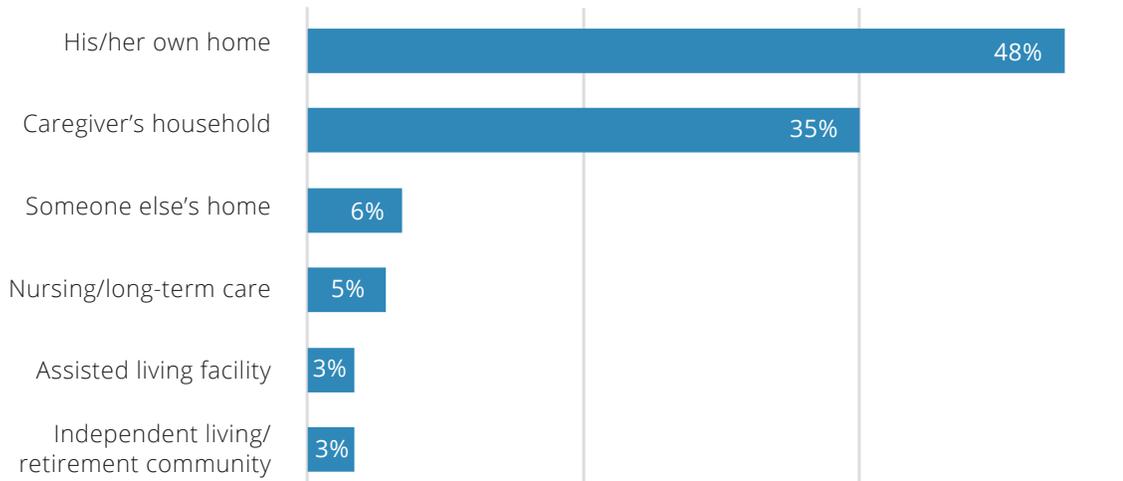
Source: TCHS; Harris Poll, March 13 to April 21, 2017, Online survey

The share of Millennials and Gen-Xers together is larger than Baby Boomers and more mature generations. They provide 56% of the care needed at present time.

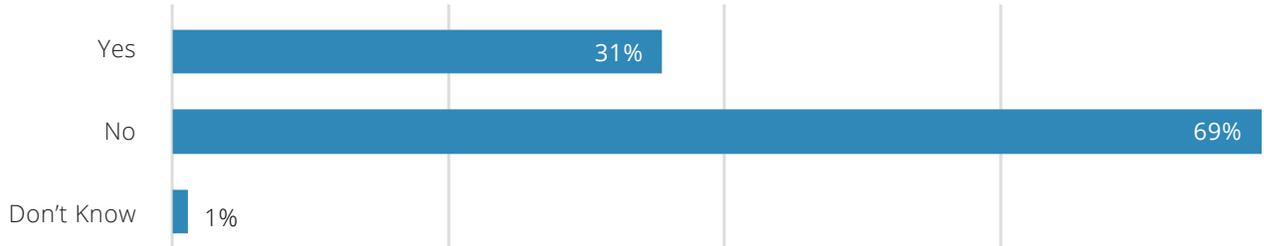
FIGURE 8

Living Conditions of Care Recipients, 2015

PLACE OF LIVING:



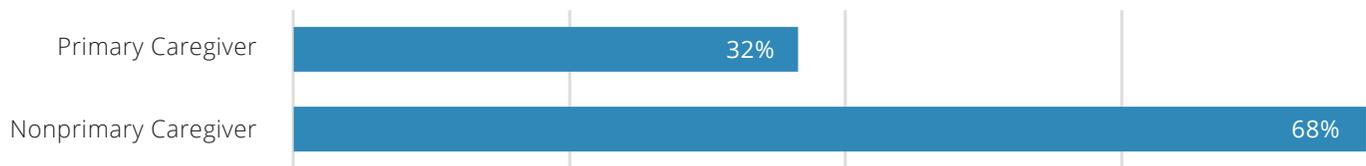
LIVING ALONE:



UNPAID CAREGIVING:



PAID CAREGIVING:



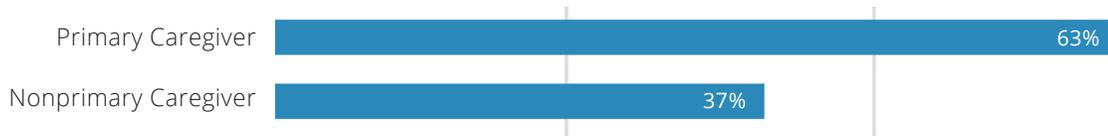
Source: AARP, *Caregiving in the U.S., 2015*

Slightly less than half of care recipients (48%) live in their own home. Out of the remaining 52%, some 35% of the total respondents live in their caregivers' homes and 6% live in someone else's home. The remaining 11% live in nursing homes, assisted living, or independent living /retirement communities. The information presented in the above chart also shows that only 31% of care recipients live alone. Out of the total number of respondents, some 68% received care from nonprimary caregivers and only 32% received care from primary caregivers in the last 12 months. Some 53% of the help received in the last 12 months were from unpaid caregivers.

FIGURE 9

General Facts about Caregiving, 2015

PRIMARY CAREGIVER STATUS:



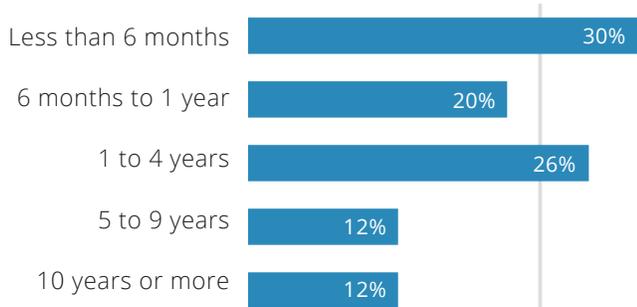
ADULT CARE RECIPIENTS:



CURRENT VS. PAST CARE:



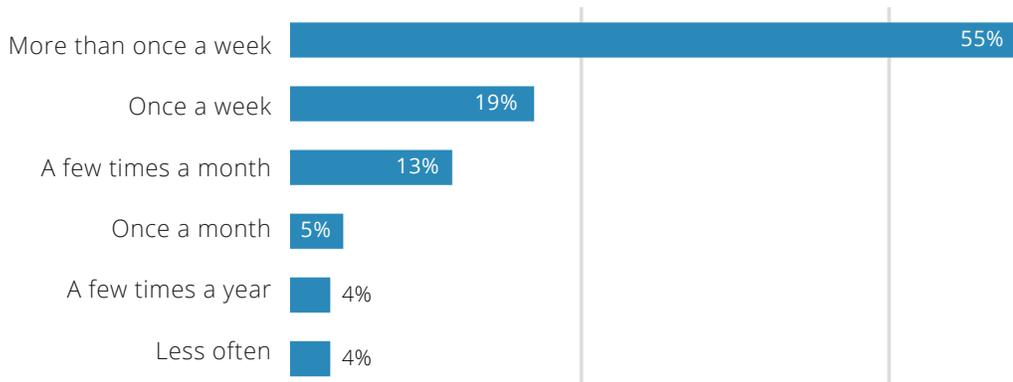
DURATION OF CARE:



CHOICE IN TAKING ON CAREGIVING ROLE:



FREQUENCY OF VISITS:



Source: AARP, *Caregiving in the U.S., 2015*

The findings tabulated in the above chart provide some important information from the latest survey conducted by the AARP in 2015. It shows that about half of those who became caregivers had the option to accept the role of a caregiver, and the remaining 49% of them did not have an option.

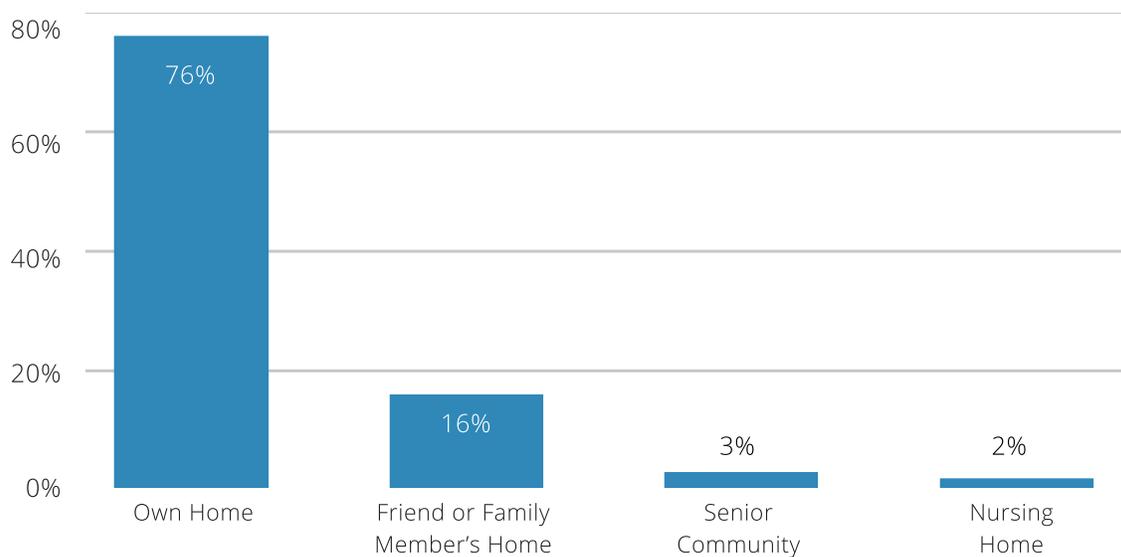
The chart shows that the majority of respondents, some 63% of them, are primary caretakers. The majority care only for one person (82%). Some 44% have given care before and only 56% are doing it for the first time. Some 50% have been caregivers for less than a year and the remaining 50% have been engaged in such tasks for more than a year. Some 12% have been caregivers for more than ten years. With regard to the frequency of visits, some 55% have been doing it more than once a week.

“

In 2015, half of those who became caregivers had the option to accept the role, and the remaining 49% of them did not have an option.

FIGURE 10

Locations Where Older Adults Received Long-Term Care in the U.S. 2017



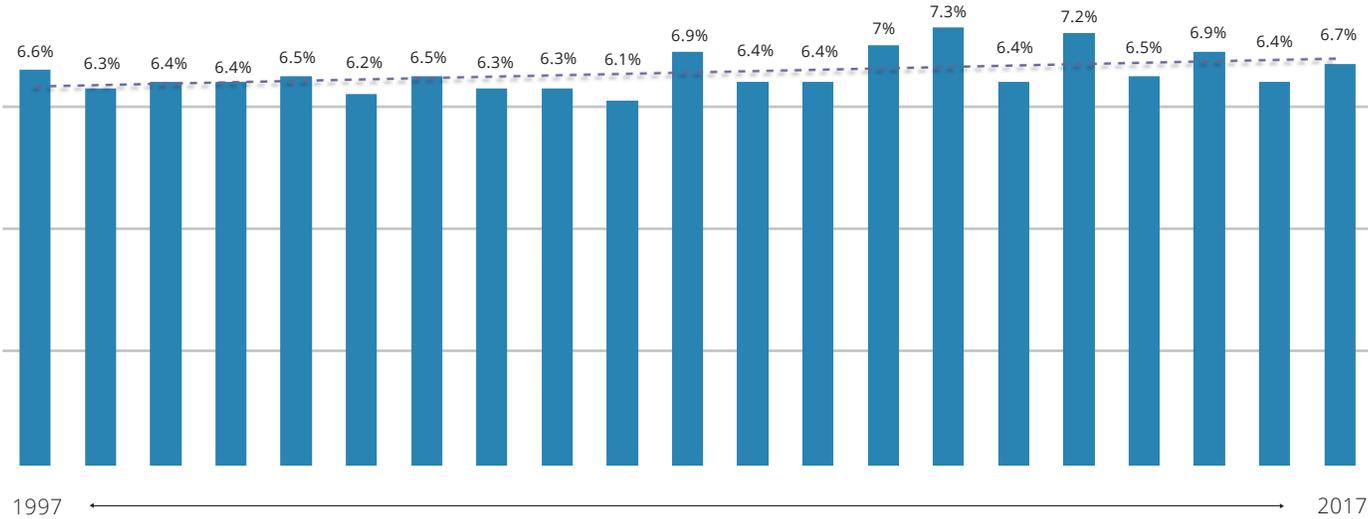
Source: AP-NORC; Scan Foundation, Telephone interviews and online survey, March 2 to 26 of 2017, with 1341 respondents of age 40 and higher.

A majority of those who received care had such services in their own home, as surveyed and presumed by the Associated Press National Opinion Research Center of the University of Chicago (AP-NORC).

Size, Areas of Needs for Long-Term Care and Preparedness of Caregivers

Long-term care is provided for a variety of reasons, which strongly relate to aging. There are however, other areas of need which relate to disabilities alongside and unrelated to becoming old. In this section of the study, we look into areas of care in relation to care recipients as well as the conditions and circumstances of caregivers.

FIGURE 11
Percentage of U.S. People Who Ended Help with Personal Care from Others 1997-2017

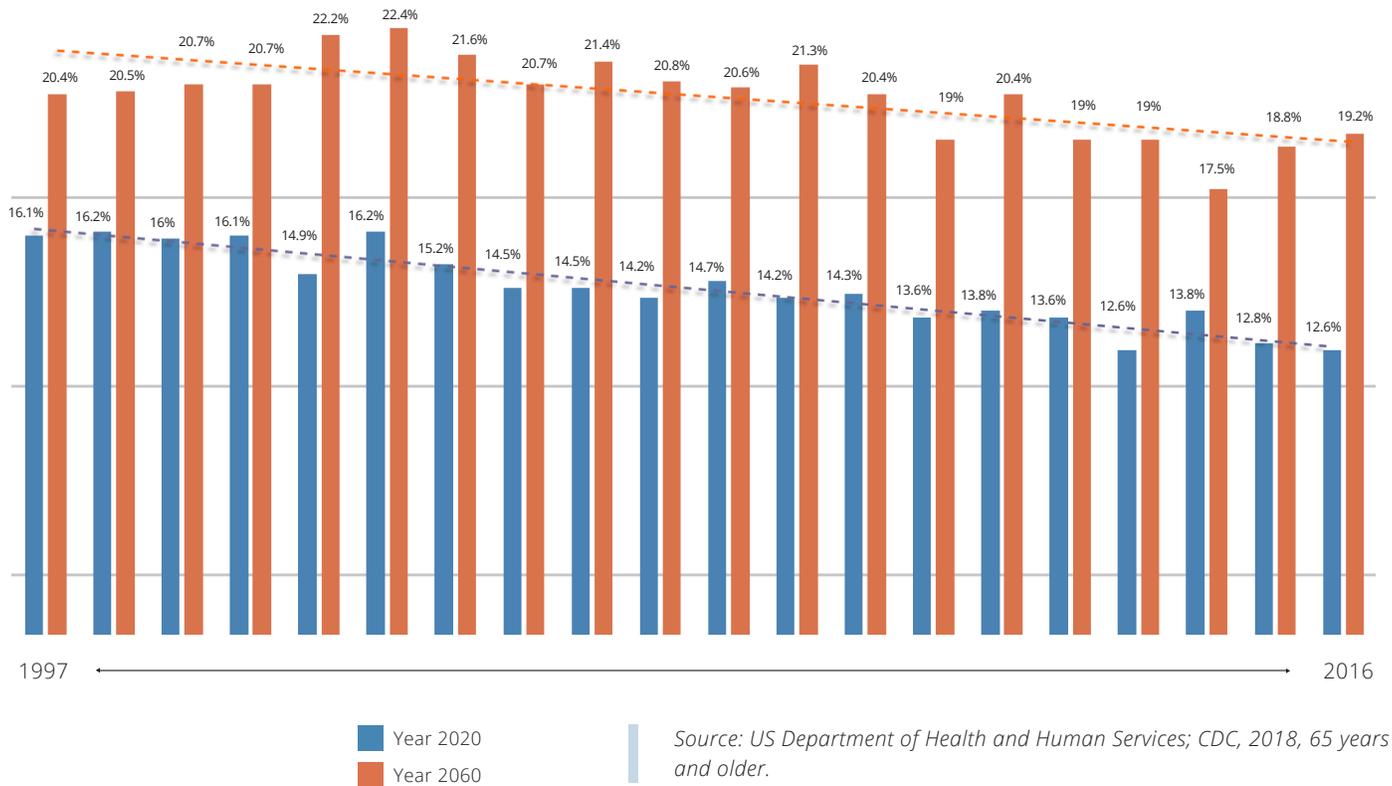


Source: CDC, NCHS (National Health Interview Survey), Face-to-face interview, around 35,000 households, 65 years and older, Figures from 1997 to 2005 were taken from the previous year's report.

The rate of needs fluctuated within a relatively narrow range of 6 to 7 percent over the period studied.

FIGURE 12

Elderly Persons with Hospital Stays in the Past Years in the U.S. 1997-2016

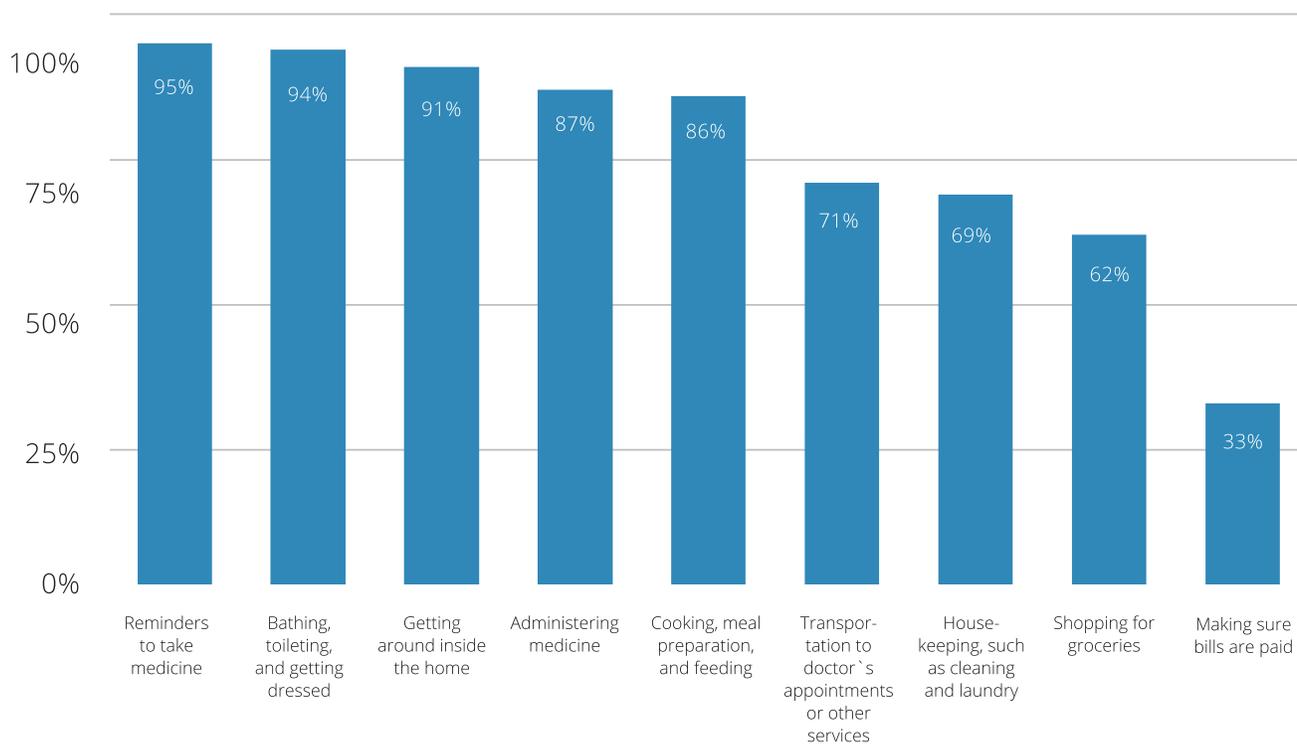


Note: These estimates exclude hospitalizations for institutionalized persons and those who died while hospitalized. Estimates are for persons 65 years of age and over and are age-adjusted to the year 2000 standard population using two age groups: 65-74 years and 75 years and over.

One hopeful deduction from the above chart is that the rate of hospitalization fell over the past two decades. The fall may be due to better care and the ability to reduce the needs for hospitalization. This conclusion is premature and cannot be proven without additional evidence. There is, however, a possible conclusion that increasing the quality of care can be an important element of the rate reduction for hospitalization and the existing numbers suggest that this may have been one of the reasons for the reduction in hospitalization of older people during the last two decades.

FIGURE 13

Services Home Care Aides Should Provide According to Older Adults U.S. 2017



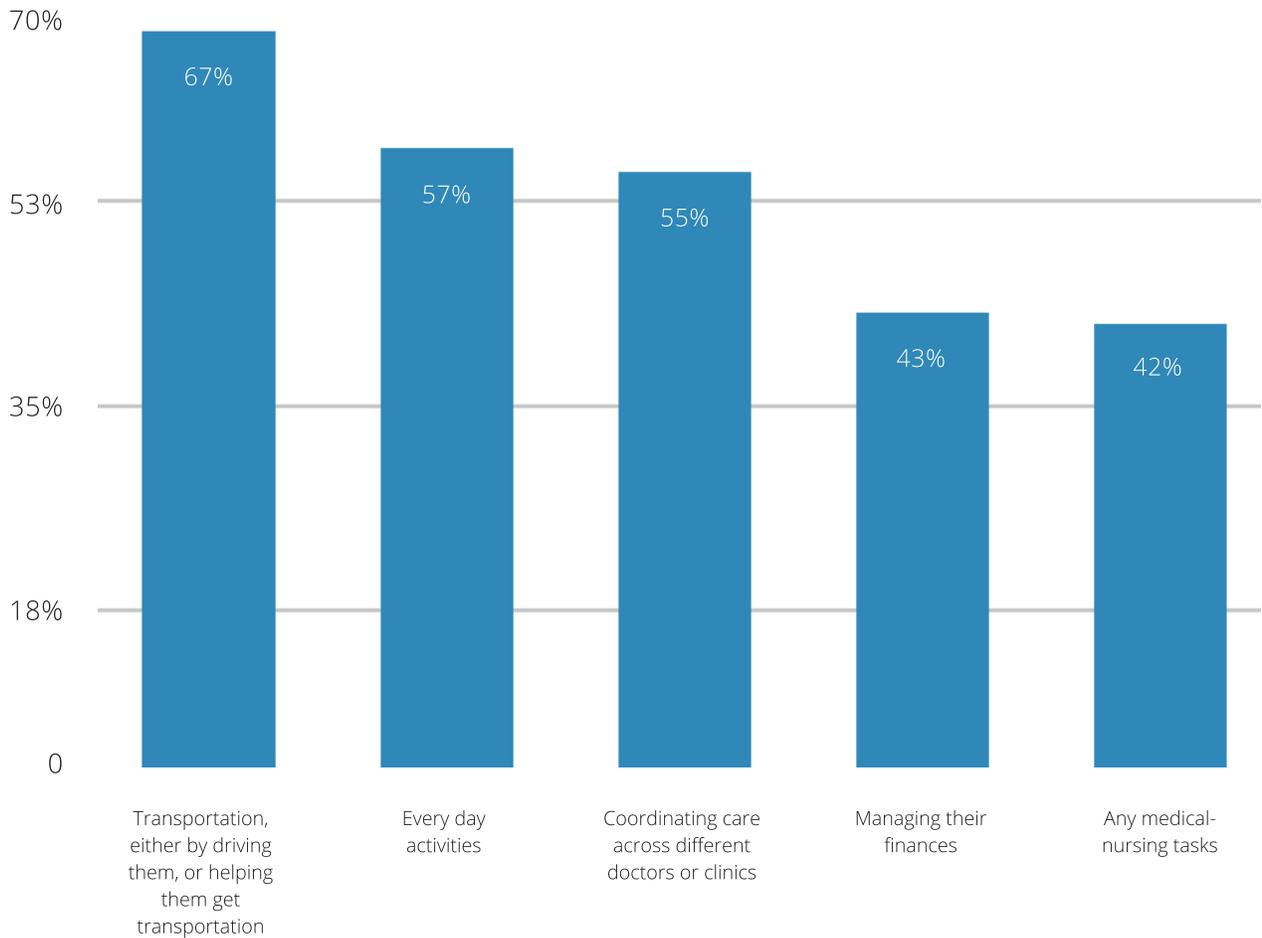
Source: AP-NORC; Scan Foundation, Telephone interviews and online survey, March 2 to 26 of 2017, with 1341 respondents of age 40 and higher.

Note: Original question: "Thinking about home health care aides for people who require ongoing living assistance, do you think the typical home health care aide should provide each of the following as part of their care, or should this not be a service they provide?"

The extent of the needs of care recipients are broad. Reminding to take medication and very personal care are on top of the list. This represents a high degree of dependency of older adults to the range of the assistance they require for the orderly continuation of their daily needs.

FIGURE 14

Tasks Those Ill Elderly Family Members Needed Assistance with in the U.S. as of 2017



Source: *Serious Illness Late in Life: The Public's Views and Experiences*, Kaiser Family Foundation, Computer-assisted telephone interviews (CATI), 2040 18 years and older, May 4 to July 12, 2017

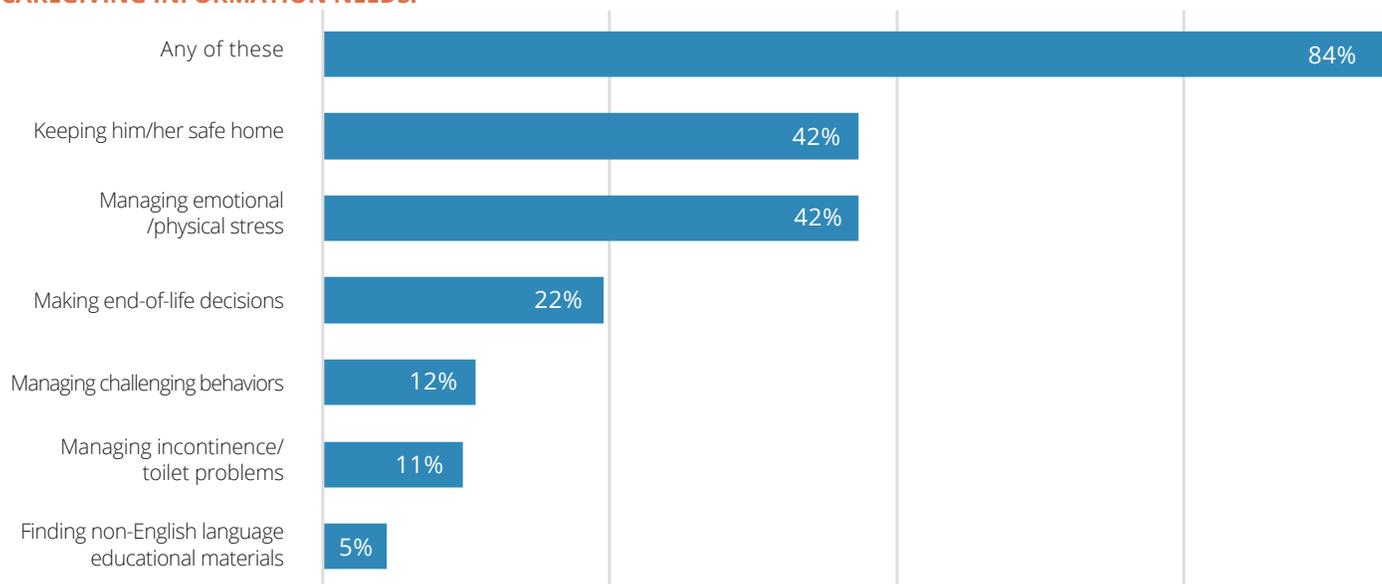
Looking into areas of needs of ill and elderly family members possesses an important urgency, which requires special attention. **Transportation is one of the major areas of need.** Everyday activities and coordination of care were also among the high areas of need. Older Americans need help with medical nursing tasks and management of their finances.

Knowing the general areas of needs is essential for providing the required assistance in the most effective way. This can be understood from the latest survey from the AARP in 2015.

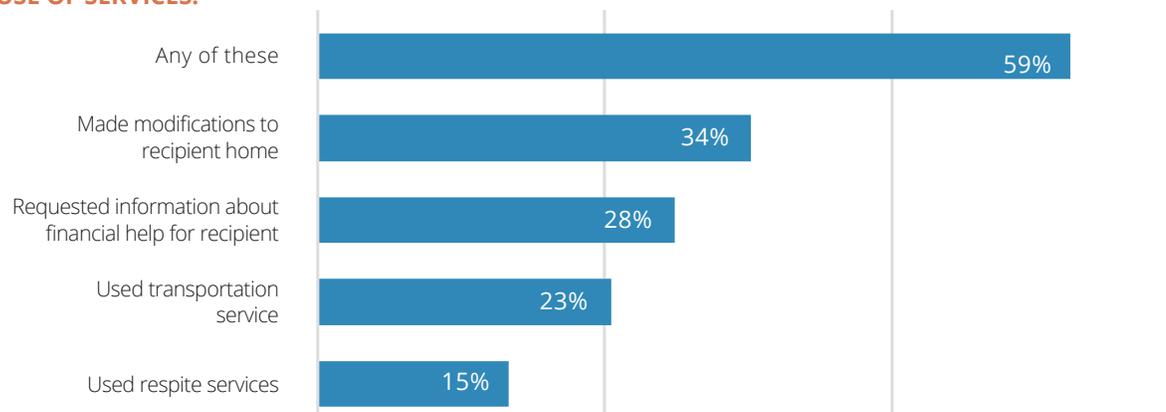
FIGURE 15

Help and Information that Caregiver Needs, 2015

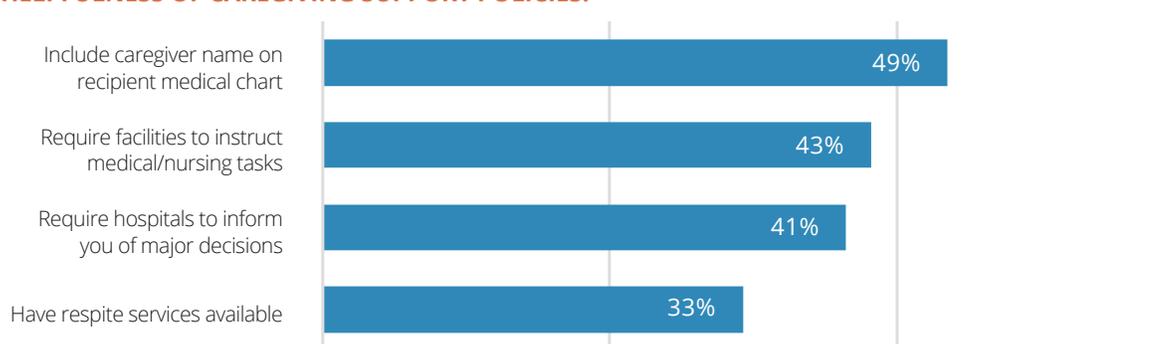
CAREGIVING INFORMATION NEEDS:



USE OF SERVICES:



HELPFULNESS OF CAREGIVING SUPPORT POLICIES:

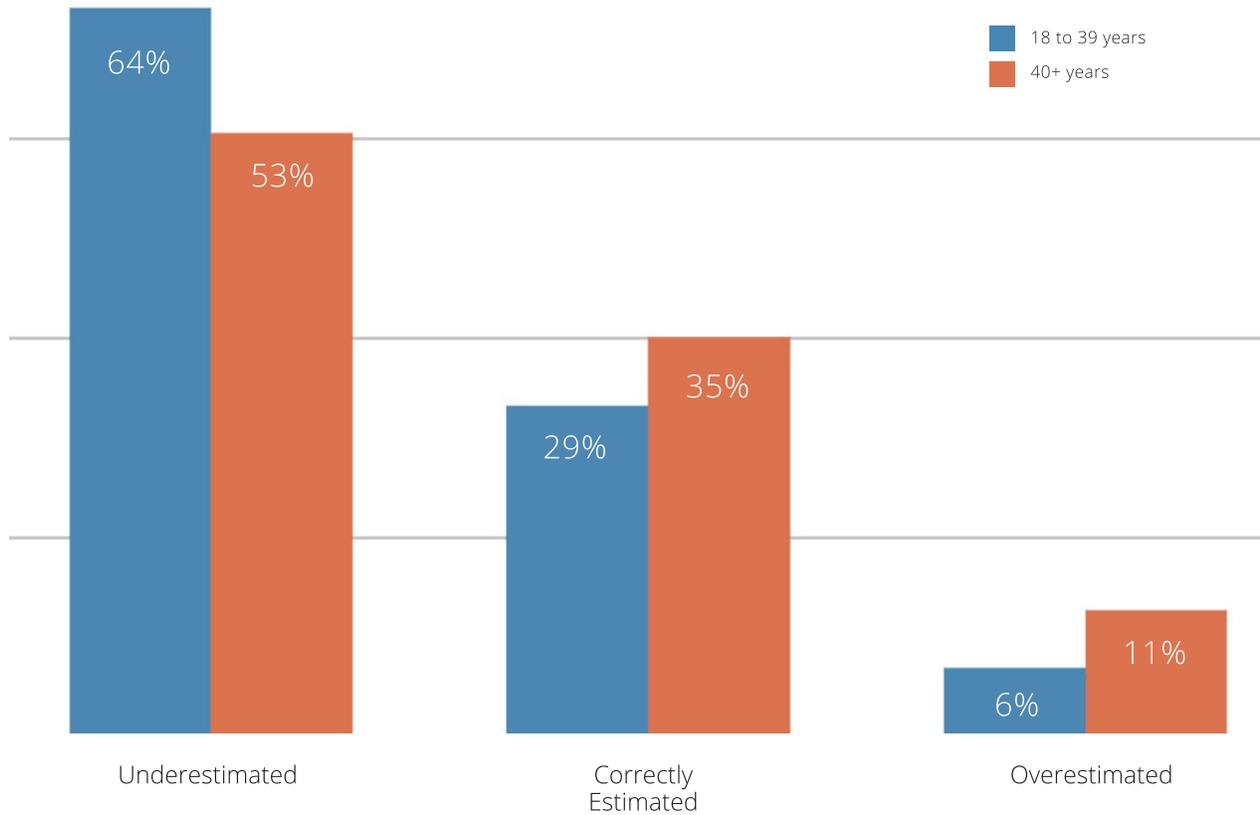


Source: AARP, *Caregiving in the U.S., 2015*

Safety and helping to better manage the emotional needs of those in their care are among the most important areas of assistance needed for caregivers to better accomplish their tasks of providing the care that have to offer. The above chart provides many practical and highly important areas of assistance to caregivers.

FIGURE 16

U.S. Adult Estimates of Long-Term Elderly Care Needs 2018



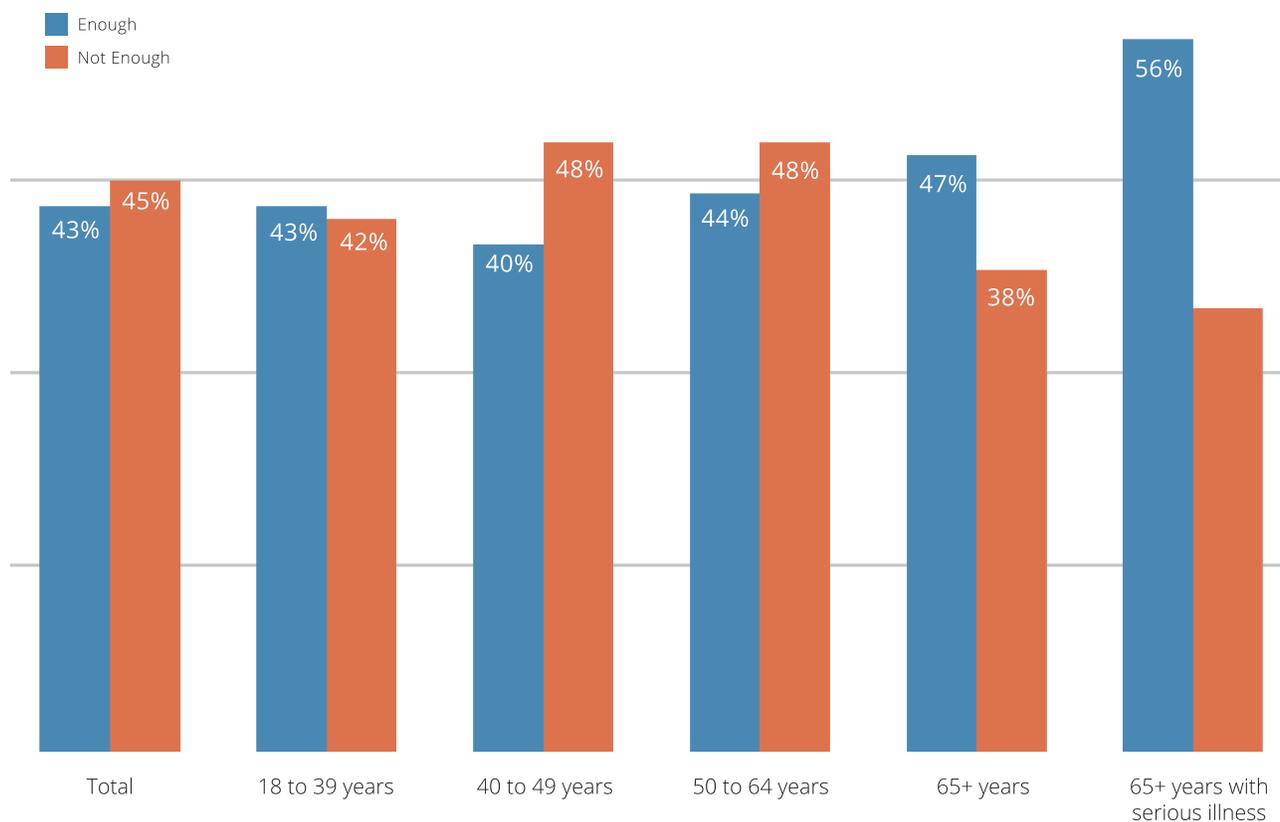
Source: AP-NORC; Scan Foundation, Telephone interviews and online survey, March 13 to April 5, 2018, 1945 respondents of age 18 and higher.

Note: Original question: "Just a guess, what is your best estimate of the percentage of Americans over the age of 65 who will need some form of ongoing living assistance in their lifetime?"

The above chart underscores the high rate of inaccurate estimation of the need for some form of ongoing living assistance in elderly patients' lifetime. The other important finding is the large rate of underestimation for such assistance between both categories of respondents, and in particular, the younger group of respondents. The implication of this finding is a lack of preparation among people who will need it sometime in their life and apparently are unaware of such needs.

FIGURE 17

Opinions on Availability of Support for the Elderly in the U.S. 2017, by Age



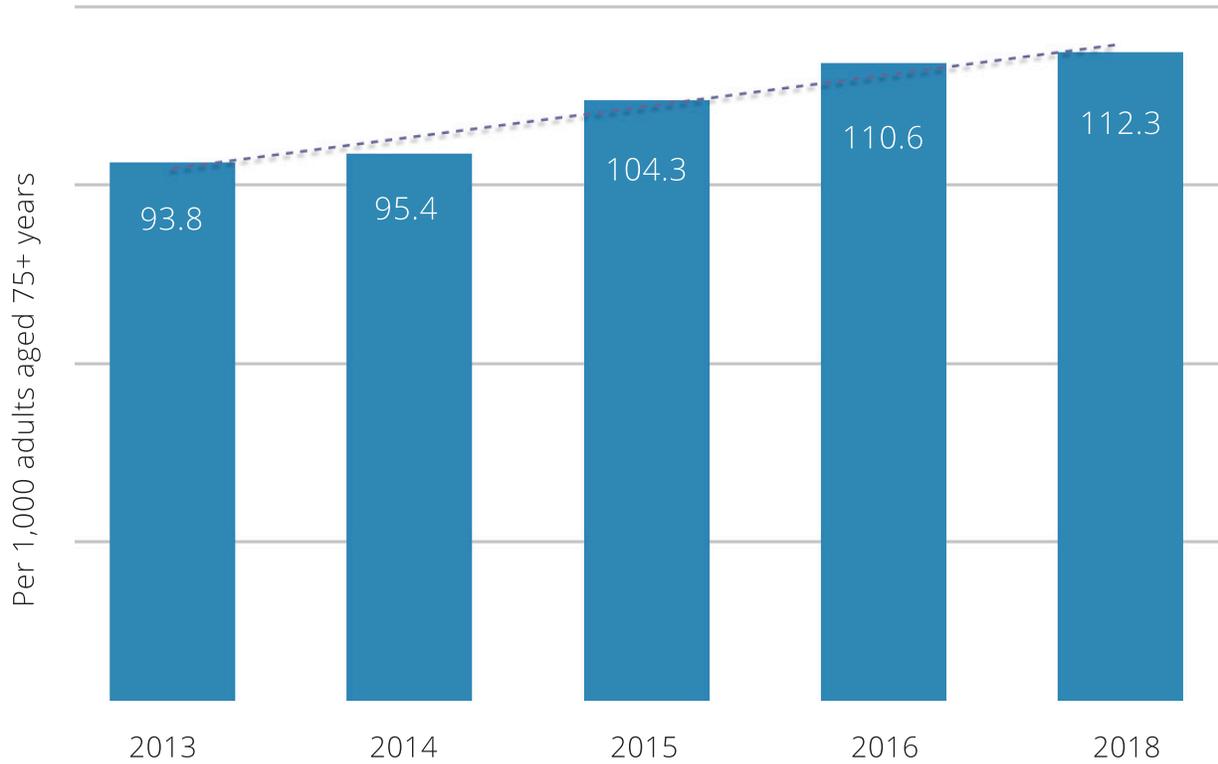
Source: Kaiser Family Foundation, May 4 to July 12, 2017, Computer-assisted telephone interviews (CATI), number of people surveyed 2040 who were 18 years and older

Note: Original question: “Do you think there is enough or not enough support available in your community for older people with serious health needs?”

The above percentages echo a familiar message that overall, the opinion is almost equally divided among all respondents on whether or not there is enough support. However, a higher proportion of older people over age 50 believe that the availability of support is enough than those who believe it is not enough. The ratio of those believing that the availability of support is enough appears to be highest among the oldest group of respondents, which is 64 years and older. The generational difference of opinion regarding the availability of support is very important and, in part, may have been influenced by their own generational experiences or optimism.

FIGURE 18

Rate of Home Health Care Workers per Elderly in the U.S. 2013-2018

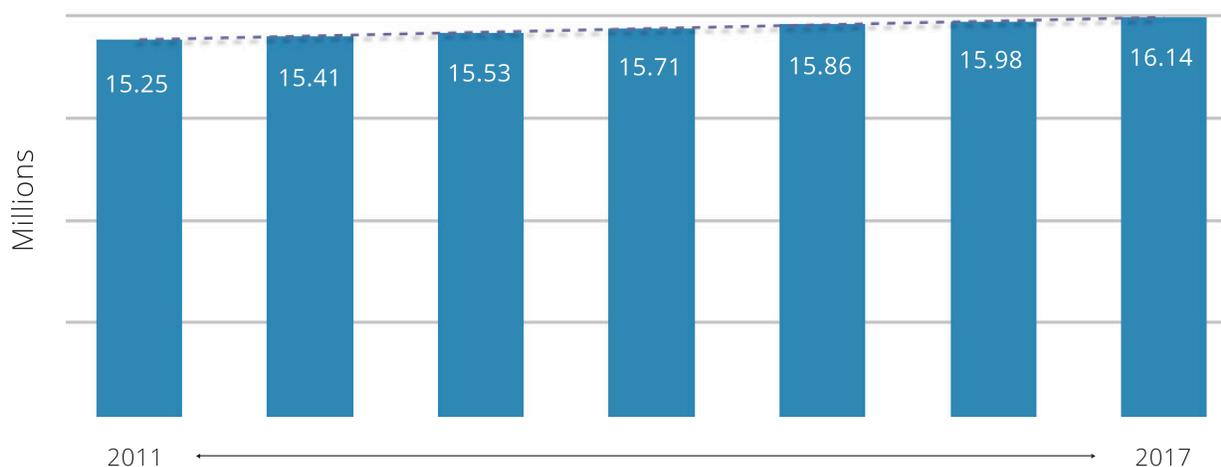


Source: CDC, United Health Foundation, *America's Health Rankings: Senior Report 2018*, from 2013 to 2018, Figures from 2013 to 2016 were taken from the previous year's report, Figures for 2017 were not available.

The rate of homecare workers per 1,000 adults aged 75 and older is increasing continually. Bearing in mind that the population count of older people aged 75 and older will increase rapidly in the decades ahead, we can conclude that as stands, **there seems to be an emerging reduction in the proportion of caretakers per group of older adults in need.**

FIGURE 19

Number of Alzheimer/Dementia Caregivers in the U.S. 2011-2017

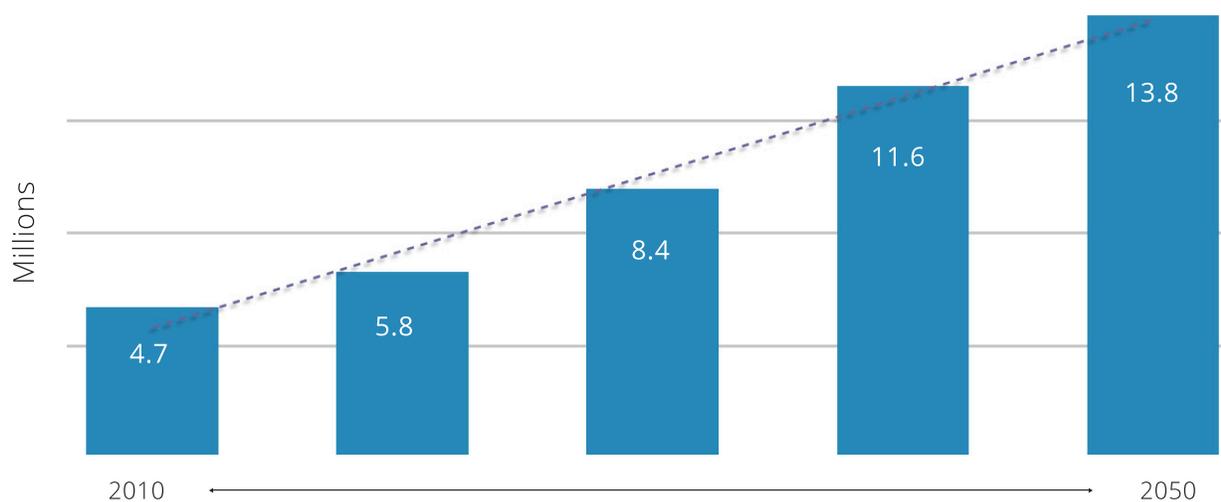


Source: 2018 Alzheimer's Disease Facts and Figures, Alzheimer's Association, US Census Bureau; CMS; National Alliance for Caregiving; AARP; US Department of Labor, 2018

The trend shows a near-stagnation in the number of Alzheimer's caregivers in the United States from 2011 to 2017, despite the increase in the number of patients, which becomes evident in the following graph.

FIGURE 20

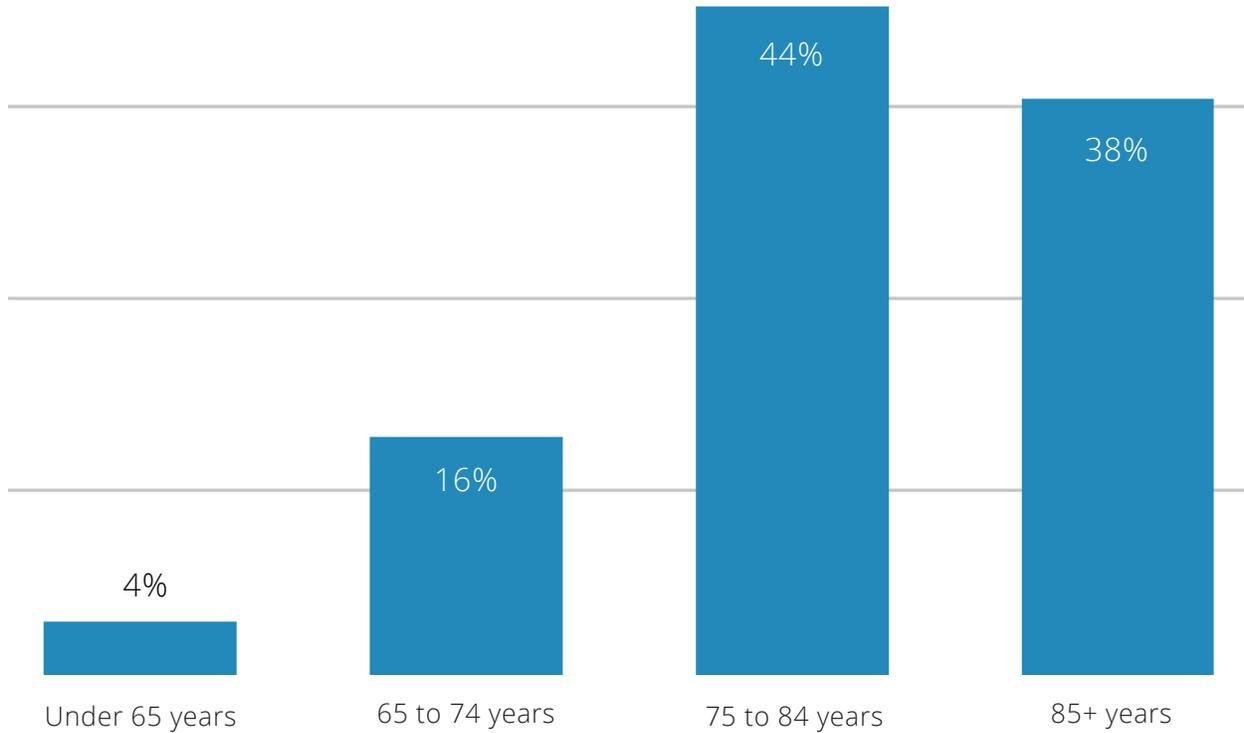
Projected Number of Older People with Alzheimer in the U.S. 2011-2050



Source: US Census Bureau; Expert(s) (Hebert et al.), Alzheimer's Association

FIGURE 21

Share of Patients with Alzheimer's Diseases in the U.S. by Age Group 2018



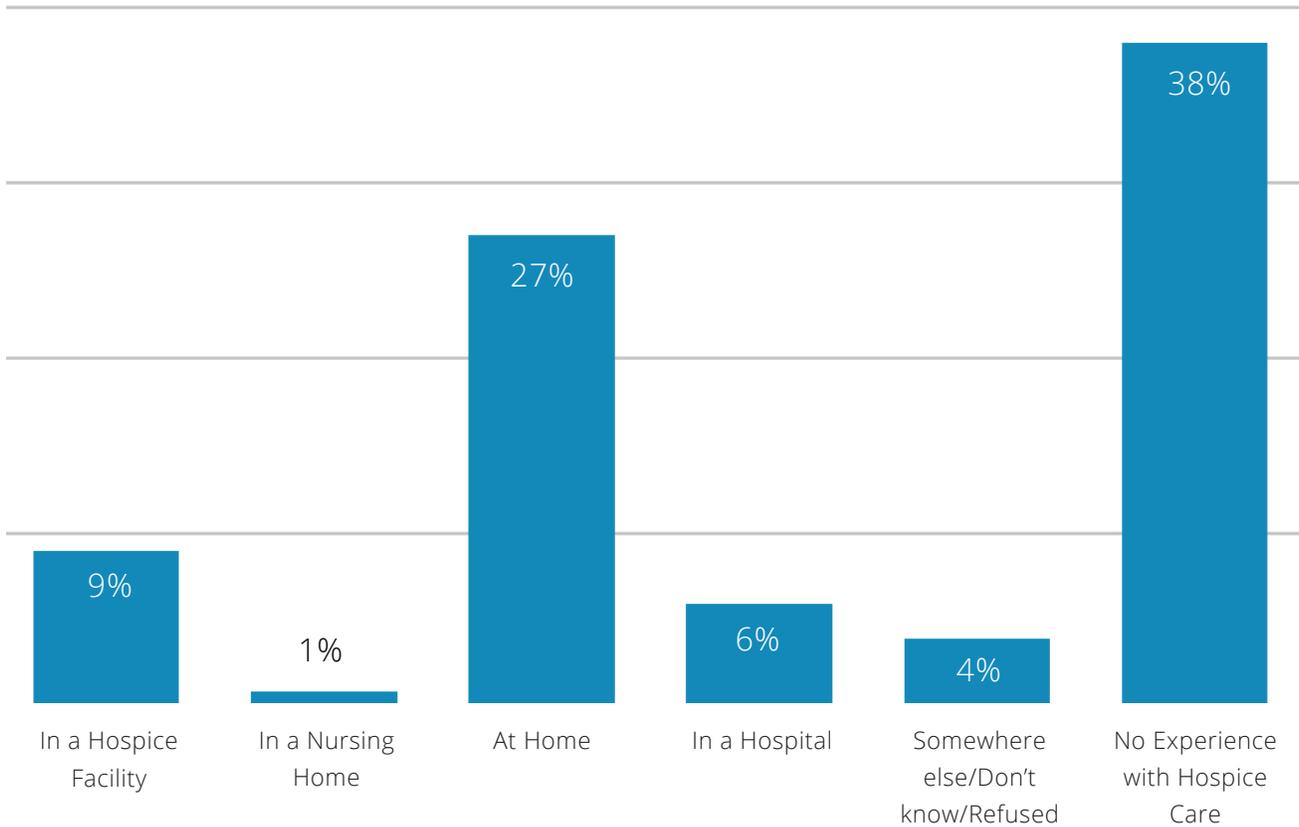
Source: US Census Bureau; Expert(s) (Hebert et al.), Alzheimer's Association

The above chart explains why we are facing a very steep rate of increase in the number of people with Alzheimer's in the decades ahead. Some 96% of Americans with Alzheimer's are 65 years of age or older. The highest proportion can be found in people aged 75 years and older. The population prediction for the next thirty years shows the highest rates of increase in the older population, and this is the very reason for expecting to face a much higher number of people with this very debilitating disease. Knowing this fact should bring every community around to doing everything possible in order to meet such challenges in the not-to-distant future.

End of life experience is an important area of care, which unfortunately everyone has to face with regard to oneself, and with regard to family and friends. Hospice has emerged as an important area that fulfills such needs. The following chart shows that for an overwhelming majority of Americans, the experience of dealing with such institutions is quite small.

FIGURE 22

Experience with Hospice Among Recently Deceased U.S. Adults 2017, by Location of Care



Source: Kaiser Family Foundation, Computer-assisted telephone interviews (CATI), May 4 to July 12, 2017 with 2040 people age 18 years and older.

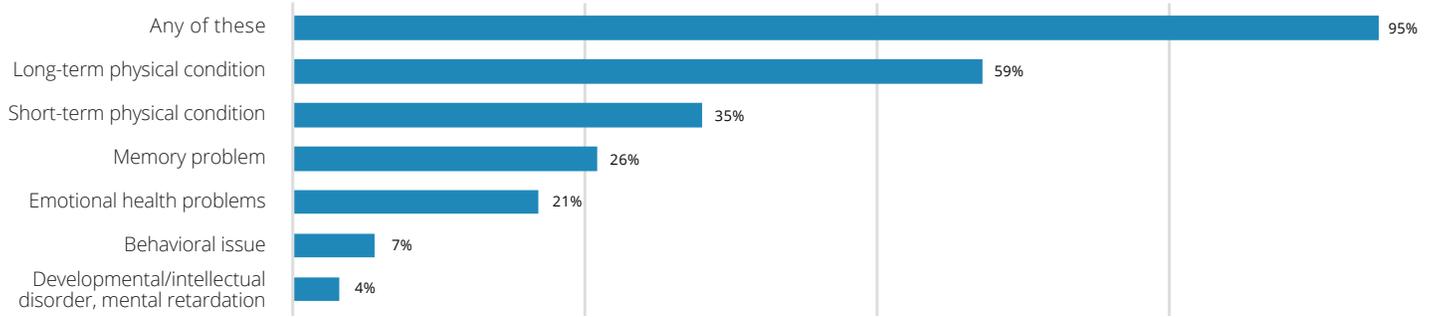
Note: Original question: "Did your loved one have experience with hospice care in the year before they died? Was this hospice care at home, in a hospice facility, in a hospital, in a nursing home, or somewhere else?"

The above table shows that home is the most prevalent place in which people pass away. Only 9% passed away in hospice care facility and 38% of respondents have not had any experience with hospice care. Knowing the overall health conditions of care recipients can help to focus on the area of needs, and more importantly, what is needed to have a correct and timely response.

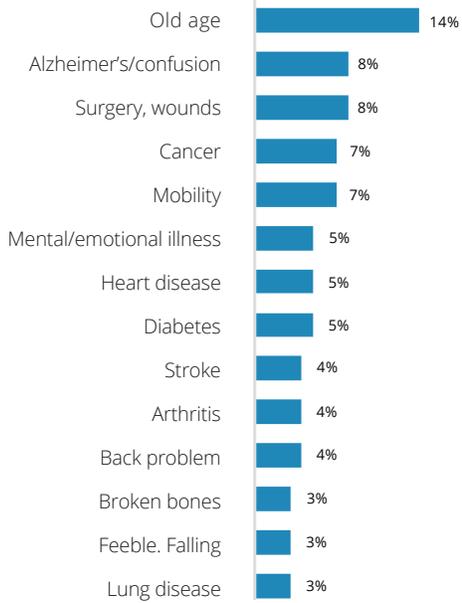
FIGURE 23

Health Conditions of Care Recipients, 2015

CARE RECIPIENT CONDITIONS:



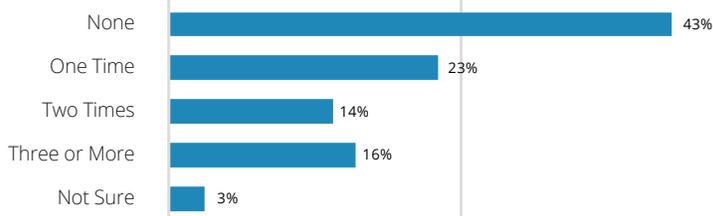
PROBLEMS OF ILLNESS:



ALZHEIMER'S, DEMENTIA, OR OTHER MENTAL CONFUSION:



HOSPITALIZATIONS IN THE PAST YEAR:



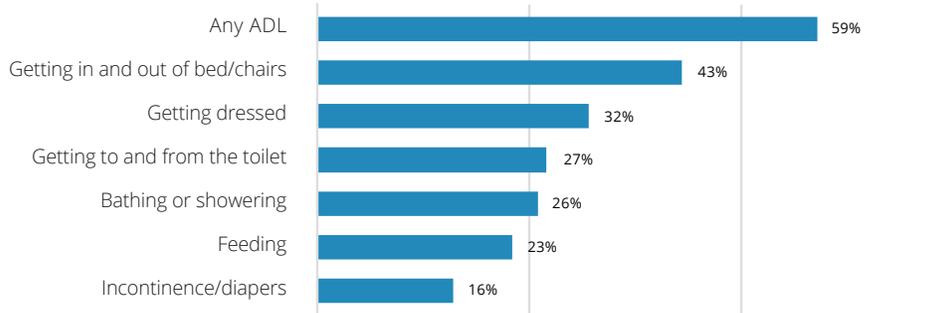
Source: AARP, *Caregiving in the U.S., 2015*

Physical condition and loss of memory are among the most likely areas of need for a large proportion of care recipients. More than 50% of care recipients needed hospitalization during the year in question, and 30% needed it twice or more.

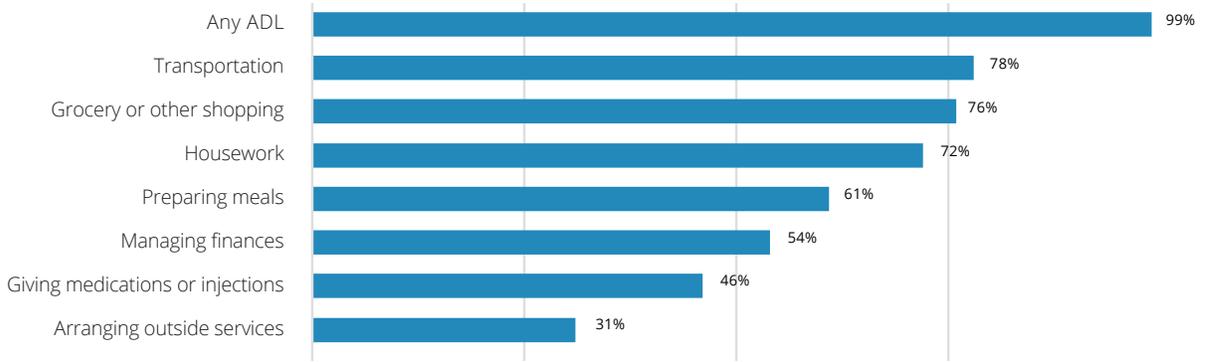
FIGURE 24

Types of Help Provided by Caregivers, 2015

HELP WITH ACTIVITIES OF DAILY LIVING:



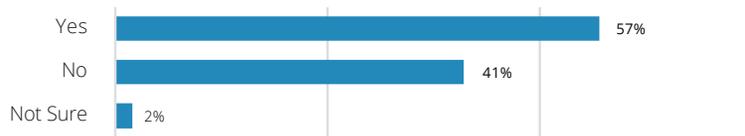
HELP WITH INSTRUMENTAL ACTIVITIES OF DAILY LIVING:



HELP WITH OTHER KEY ACTIVITIES:



HELP WITH MEDICAL/NURSING TASKS:



Source: AARP, *Caregiving in the U.S., 2015*

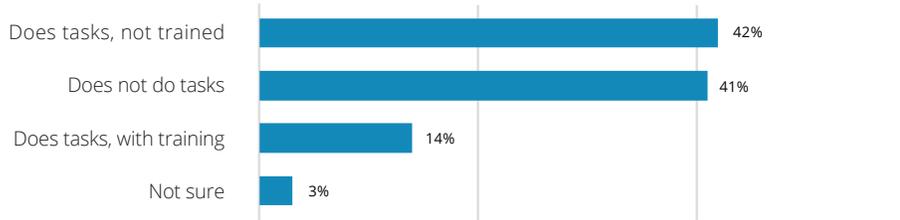
The above table includes a wide variety of medical and other types of assistance that caregivers need to provide. Transportation and other duties to keep a house running are among the most likely responsibilities needed to be taken care of for the overwhelming majority of care recipients.

While for most, keeping a house in order may not require much training and preparedness, the same cannot be said about fulfilling certain tasks, which require a great deal of familiarity with how they are done medically and in the correct way. Indeed, 57% of respondents have stated that they need help with medical/nursing tasks.

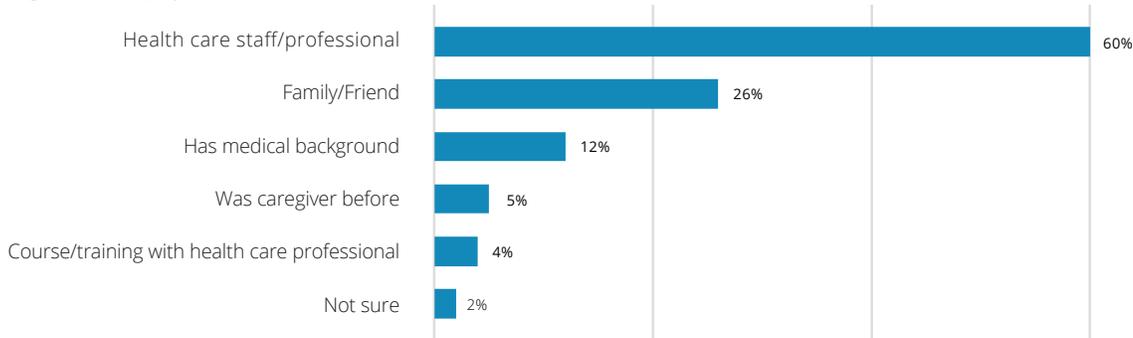
FIGURE 25

Medical/Nursing Task Preparation, 2015

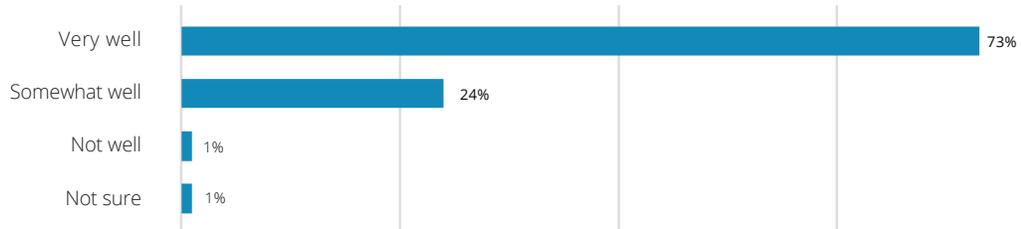
MEDICAL/NURSING TASK PREPARATION:



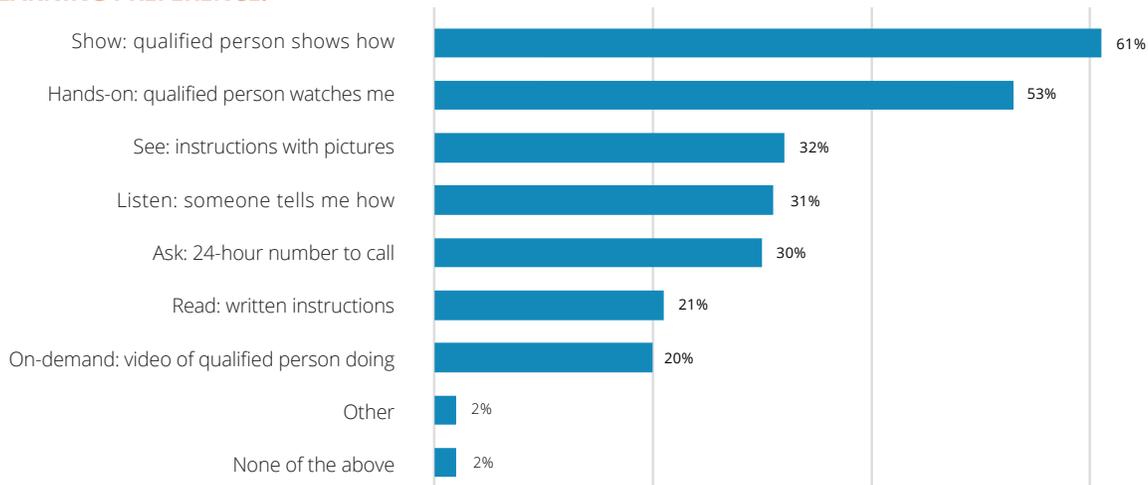
WHO PREPARED:



EVALUATION:



LEARNING PREFERENCE:



Source: AARP, *Caregiving in the U.S., 2015*

The previous chart shows that some 57% of respondents need to perform some medical/nursing tasks. Some 42% of respondents are not trained for such tasks. If we apply this proportion to those who need to perform such tasks, the proportion of those who perform the task but are not trained for it will reach 76%. In other words, 76% of those who perform medical or nursing tasks are not trained for such tasks. Overall, only 14% of respondents said that they take on such tasks and have been trained for them. Again, taking the ratio of 55% as those who have to perform medical or nursing tasks, the percentage of those who perform the tasks and have adequate 25%.

Finally, the last area of inquiry reported in the above chart shows that an overwhelming majority of respondents, some 60%, would like to have a qualified person show them how the work is done. In response to a similar question, some 53% said that they would like this training to be hands-on. There are other options that were chosen by other caregivers, and looking at the pattern of responses, some expressed an interest in having such training in multiple ways.

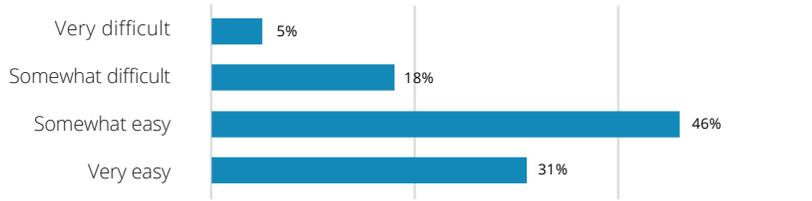
The important overall deduction from the above chart is that **performing medical and nursing tasks are required from the majority of caregivers, and only a small proportion of them have received some training for such tasks.** In addition, they certainly need and are asking for such training.



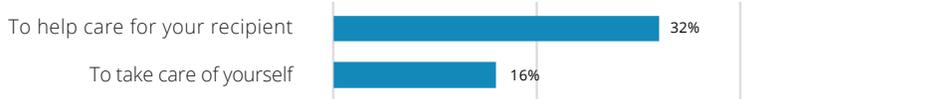
FIGURE 26

Communication with Health Care Providers, 2015

COORDINATION OF CARE BETWEEN PROVIDERS:



CONVERSATION WITH HEALTH CARE PROVIDER:



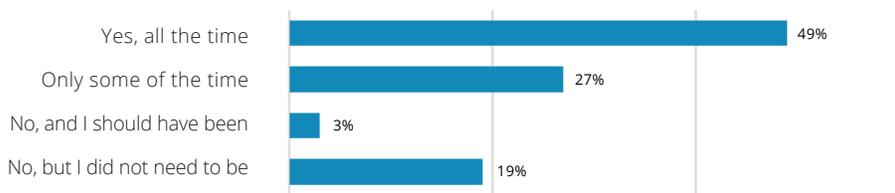
HELPFULNESS OF CONVERSATION WITH HEALTH CARE PROVIDER:



HOSPITAL INSTRUCTIONS TO CAREGIVER:



CARE DISCUSSION INCLUSION:



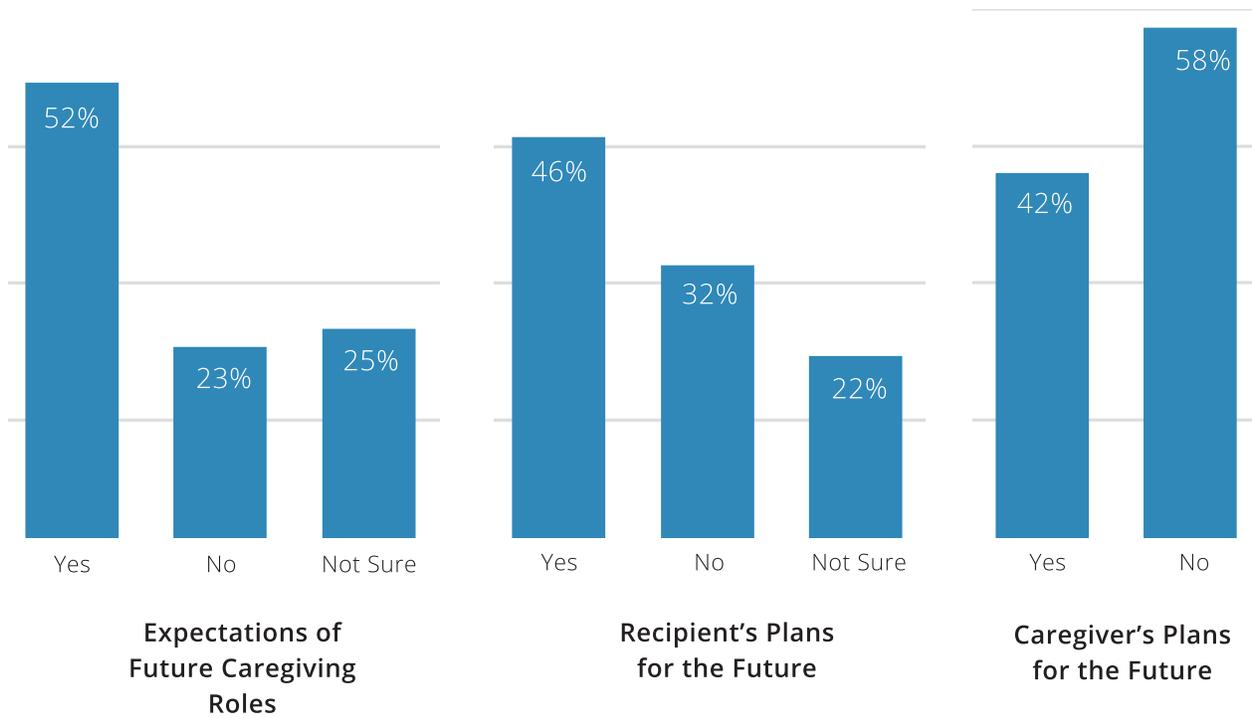
Source: AARP, *Caregiving in the U.S., 2015*

According to the above table, the majority of respondents said that communicating with health care providers is very easy or somewhat easy (77%). There are, however, some 23% which believed such communication was somewhat difficult (18%) or very difficult (5%). Having almost a quarter of respondents seeing difficulty in communicating with health providers is critical enough to further explore the issue and find solutions for it.

Caregivers have had conversations with care providers with regard to the care of recipients and care of themselves (caregivers). In both cases, the percentage of usefulness of the conversations was somewhat less than expected (38% rated usefulness for care recipients and 26% for their own).

FIGURE 27

Expectations of Future Caregiving Role, 2015



Source: AARP, *Caregiving in the U.S., 2015*

More than half (52%) expect to be caregivers in the future. Only 21% said that they do not expect to be caregivers in the future, and 25% did not know. In response to the question of if they have any plans for the future or whether their care recipients have plans, the gap was very small. Some 42% of respondents have plans for their own future and 46% of the care recipients have plans for their future care needs. This shows that a majority of people do not have any plans for their future care, and being a caregiver may not have any decisive impact on putting a plan of care together.

“

A majority of people do not have any plans for their future care, and being a caregiver may not have any decisive impact on putting a plan of care together..



3

Economic and Social Costs of Caregiving

Selected Trends Showing Expansion of the Size of the Industry

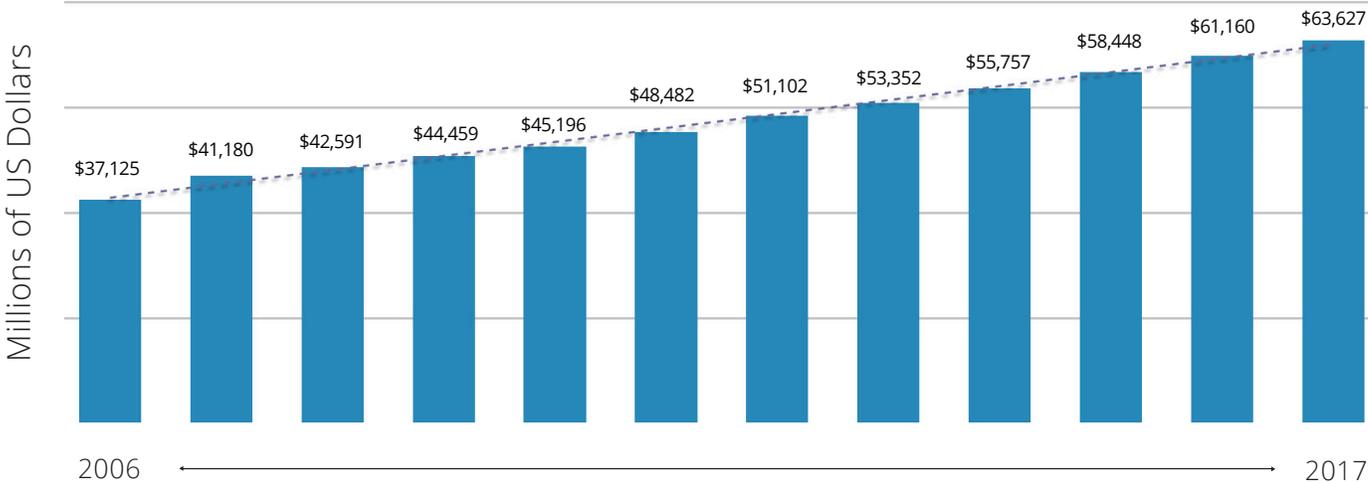
As indicated at the outset of this report, cost in economics refers to the use of resources for producing a good or offering a service and it can occur explicitly or implicitly. The explicit cost often shows as a payment from the good or service, whereas an implicit cost can present itself in a number of ways, such as giving up an opportunity, or being forced to bear an adverse consequence. Cost in economics includes every item or occasion, which can result in giving up an opportunity or enduring a negative impact or payoff.

The cost of caregiving by unpaid caregivers provides a variety of possibilities which can be regarded as economic cost, the following information from various sources provides the necessary data for establishing the economic cost of caregiving in the United States.

This study focuses on the impact of caregiving by non-paid caregivers. It also offers information on the provision of care through organizations and individuals who are employed in long-term care (LTC).

FIGURE 28

Total Employer Firm Revenue of Community Care Facilities for the Elderly 2006-2017

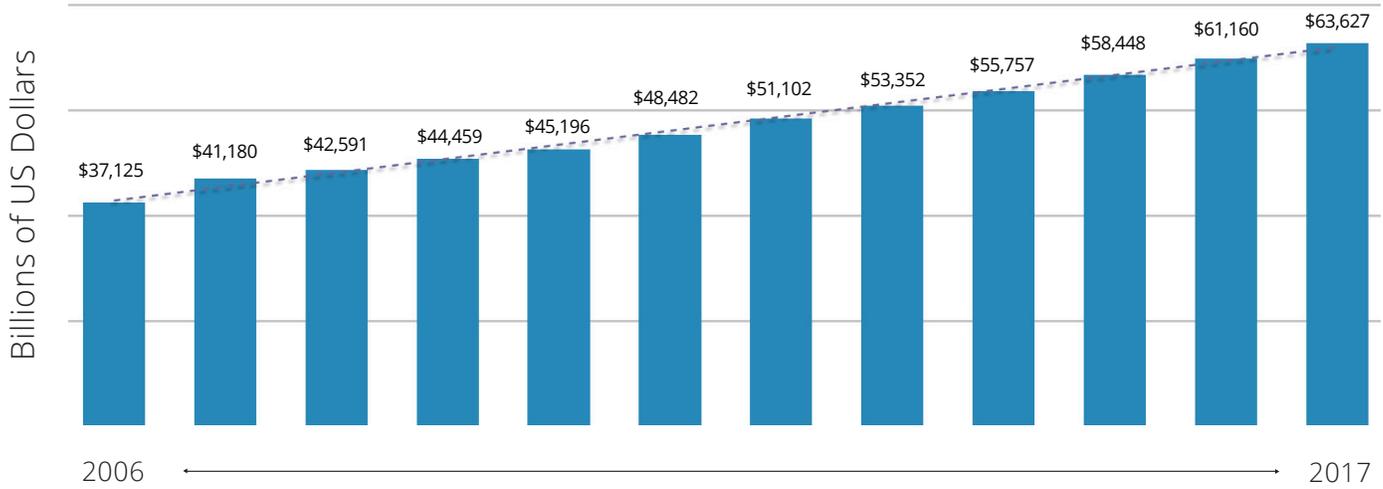


Source: US Census Bureau, 2006 to 2017

This chart shows that the industry has experienced considerable growth over last decade, resulting in an overall increase of 71% from 2006 to 2017.

FIGURE 29

Services for the Elderly, Persons with Disabilities Revenue in the U.S. 2010-2022

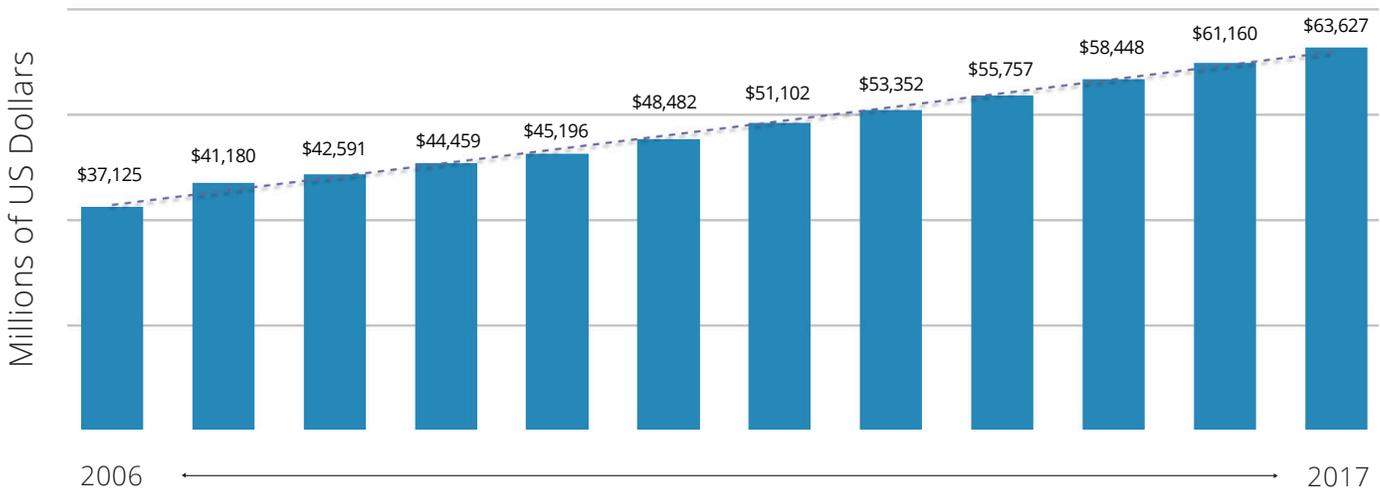


Source: US Census Bureau, 2006 to 2017

Similar to what has been stated earlier with regard to the size of industry offering eldercare, services to the elderly with disabilities have also experienced significant growth, such growth is expected to continue at an increasing rate in the years ahead.

FIGURE 30

Forecast: Revenue Elderly Homes US 2008-2020

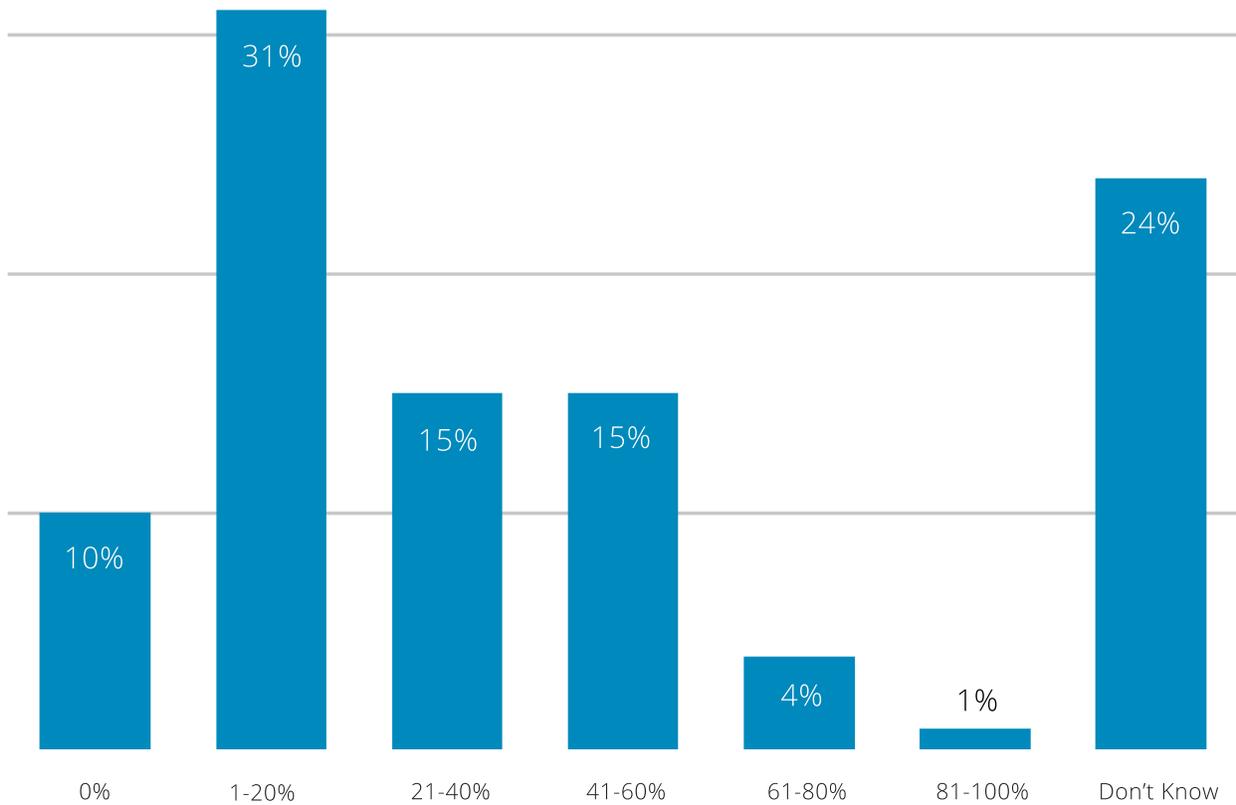


Source: US Census Bureau, 2006 to 2017

Revenue of elderly homes is also expected to increase by a combined rate of 91% between 2008 to 2020. Caregivers spend a sizeable proportion of their income to provide care in an explicit manner. This can be seen in the following chart.

FIGURE 31

Percentage of U.S. Caregivers' Monthly Budget Used for Caregiving Costs as of 2017



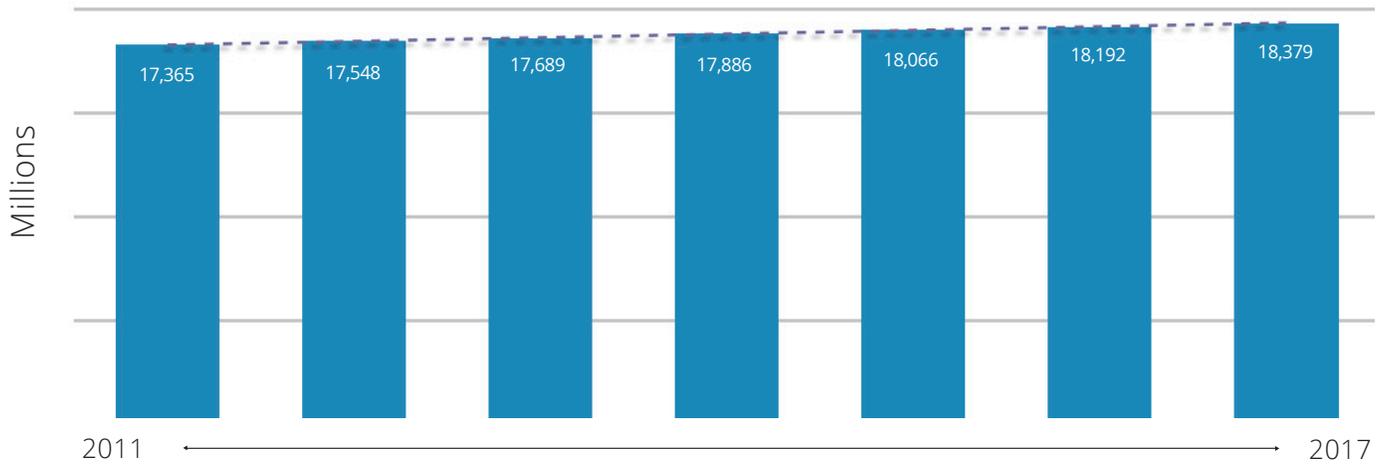
Source: Northwestern Mutual (Statista), online survey, November 29 to December 7, 2017, 405 respondents of 18 years of age and older of qualified caregivers

Note: Original question: "Approximately what percentage of your current monthly budget goes to providing care for aging family members or friends? This may include costs to hire a caregiver and/or costs you incur for caregiving you do yourself."

This chart shows that almost one third of the caregivers surveyed spent between one and 20 percent of their monthly budget on providing care for the people they look after. Some 40% spent between 20 and 60 percent of their monthly budget. Some 24% could not provide any estimate for how much they spend on people under their care.

FIGURE 32

Hours of Unpaid Care per Year in the U.S. 2011-2017

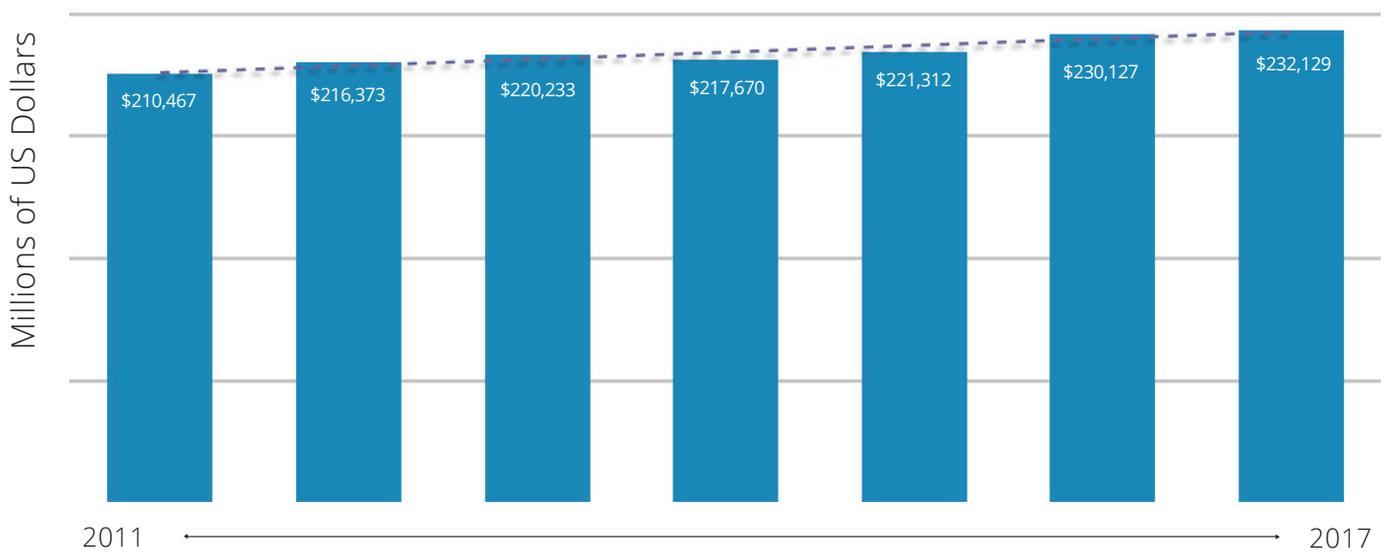


Source: US Census Bureau; CMS; National Alliance for Caregiving; AARP; US Department of Labor

The above chart shows that in 2017, nearly 18.4 billion hours have been dedicated to unpaid caregiving. Putting a modest value on each hour of such allocated time brought the value of unpaid care to a total of \$232.2 billion as shown in the following chart

FIGURE 33

Value of Unpaid Care in USD in the U.S. 2011-2017



Source: US Census Bureau; CMS; National Alliance for Caregiving; AARP; US Department of Labor

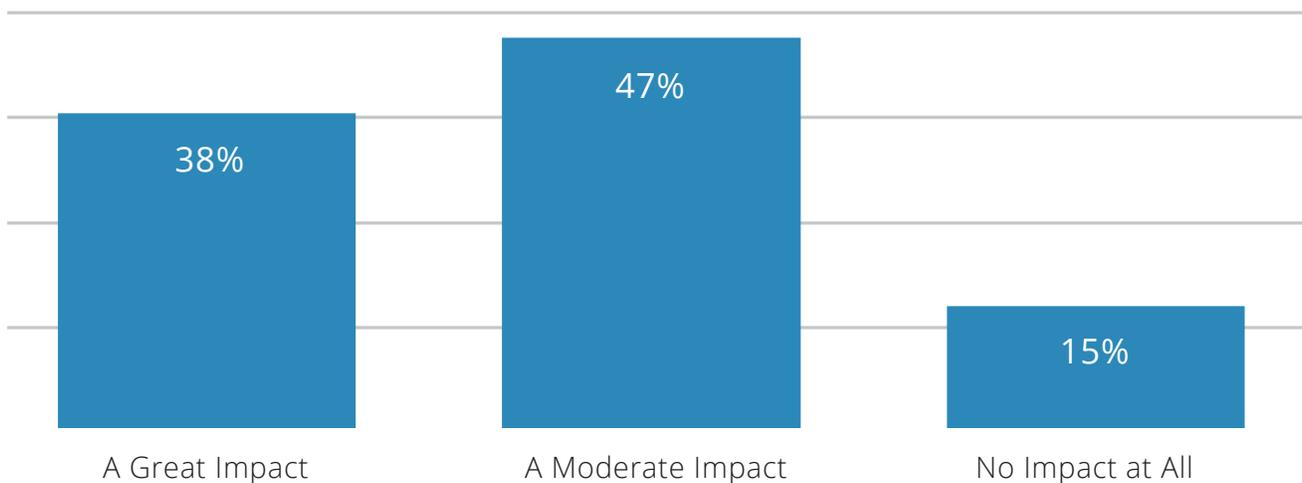
Economic, Social, and Emotional Cost of Care by Family and Friend Caregivers

This section of the study provides a comprehensive account of the opportunity cost of care by non-paid caregivers. It includes a variety of such costs gathered by a number of organizations and research centers within the country.

It is true to say that many who accept to care for a loved one take the charge often with a profound sense of responsibility and love for what they do. In the earlier part of this report, we showed that according to the most recent report from the AARP, some 51% of non-paid caregivers stated that they had a choice in becoming a caregiver. The important issue to realize is having an option or taking the responsibility of caregiving has no relationship with its cost. The following information gathered from a number of most recent studies shows various dimensions of such cost.

FIGURE 34

Percentage of U.S. Caregivers Who's Lifestyle Was Impacted by Caregiving as of 2017

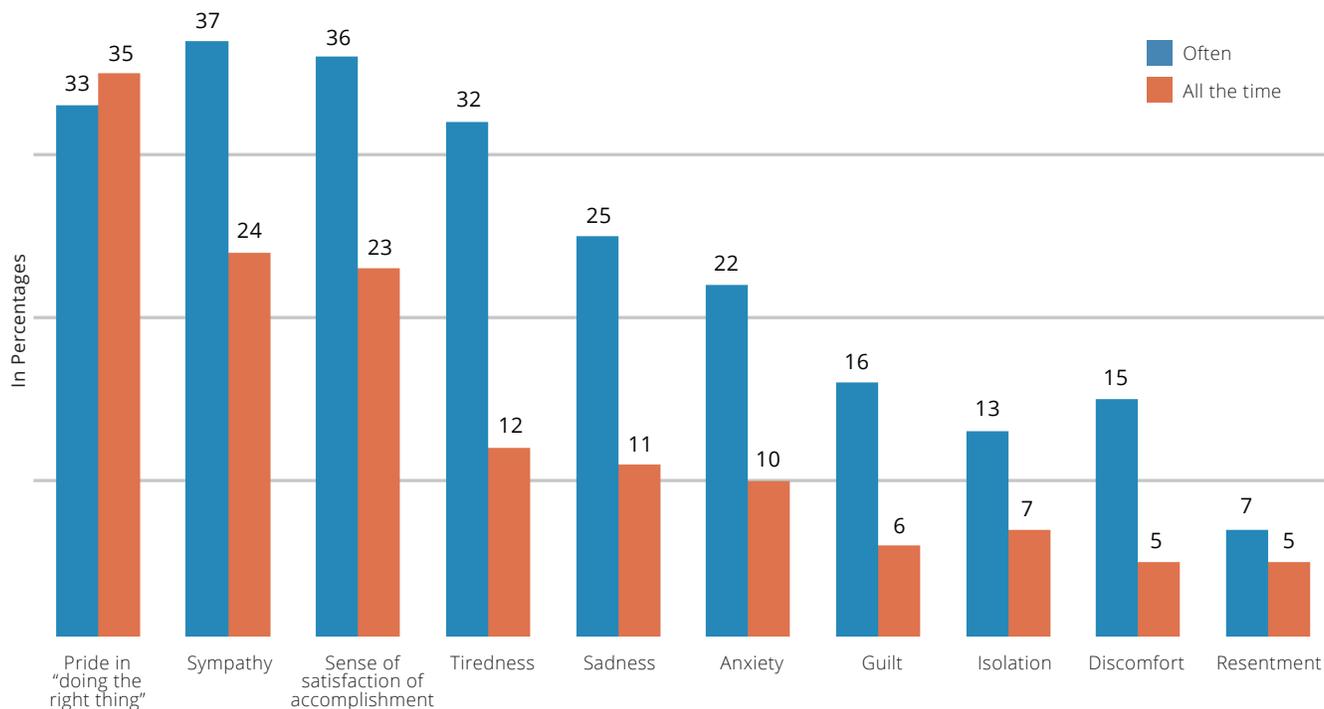


Source: 2018 Alzheimer's Disease Facts and Figures, Alzheimer's Association, US Census Bureau; CMS; National Alliance for Caregiving; AARP; US Department of Labor, 2018

The above chart shows that within the broadest age category of 18 years of age and older, only 15% said that their lifestyle was not impacted by caregiving. Some 38% stated that their lifestyle was greatly impacted by caregiving. Almost 47% said that their life was moderately impacted by becoming a caregiver.

FIGURE 35

U.S. Caregivers that Felt Select Emotions During Caregiving as of 2016



Source: Northwestern Mutual, Online survey, 1014 respondents 18 years and older, November 11 to 28, 2016

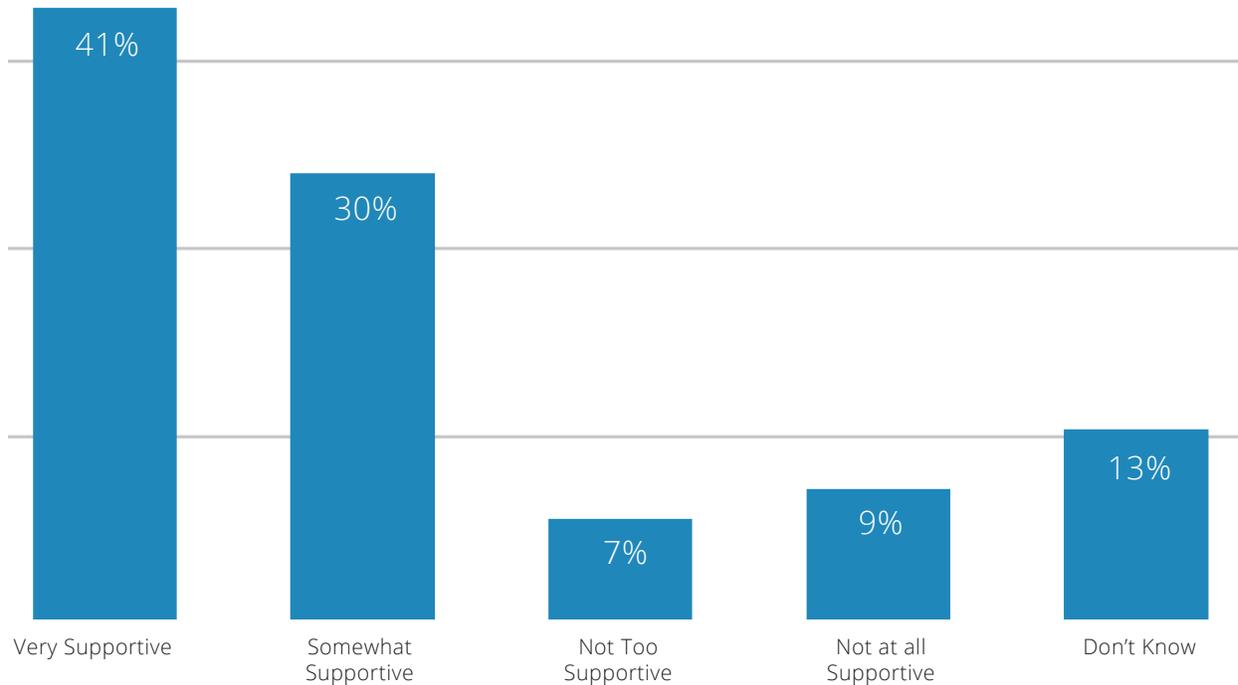
Note: Original question: "Below is a list of emotions you may experience as a caregiver. Please rate how often you've felt each of these emotions in your personal caregiving experiences."

The above chart shows that while caregiving is emotionally uplifting and satisfactory, it brings fatigue and at times, negative emotions. The other interesting observation is that the gap between the rates of "often" and "all the time" is narrower when it comes to feeling positive emotions, whereas the gap is wider when it comes to feeling negative emotions. One way to explain such a gap is that negative emotions are not as widespread and pervasive as the positive emotions are or could be.

One of the most important areas of impact, which has far-reaching economic consequences, is the impact of caregiving on employment, work environment, and the status of caregivers. The following information sheds light on these important issues from various recent available sources.

FIGURE 36

U.S. Caregivers that Felt Their Employer was Supportive in 2017



Source: TCHS; Harris Poll, 3074 18 years and older online survey, March 13 to April 21, 2017

Note: Original question: "How supportive is your employer of your caregiving responsibilities?" Only asked of those employed full-time or part-time.

The above chart shows that only 41% of employers were very supportive of caregivers as their employees. Some 30% were somewhat supportive. Some 16% were either not supportive at all or not too supportive. These findings can be viewed as somewhat positive if one only focuses on the size of support versus the lack of support. There is, however, an important dimension which should not get lost in such a comparison, and that is the additional burden on caregivers that results from a lack of support or strong disapproval of employers or their business entities. This calls for a clear intervention in the work environment with rules and regulations that support employees legally and institutionally. In other words, support for working caregivers should not be left to the whims of the employers or corporate policies, which do not pay the needed attention to this matter.

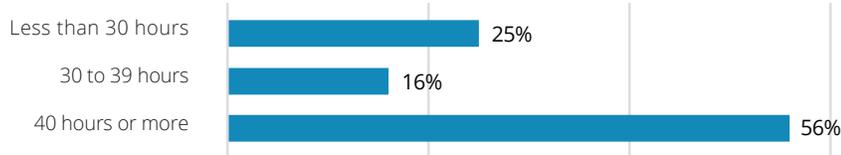
FIGURE 37

Economic and Social Conditions of Caregivers, 2015

EMPLOYMENT:



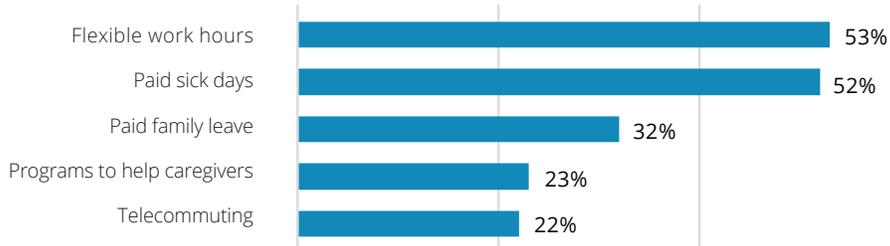
NUMBER OF HOURS WORKED:



SELF-EMPLOYMENT:



WORKPLACE BENEFITS:



MOST PREFERRED FINANCIAL SUPPORT:



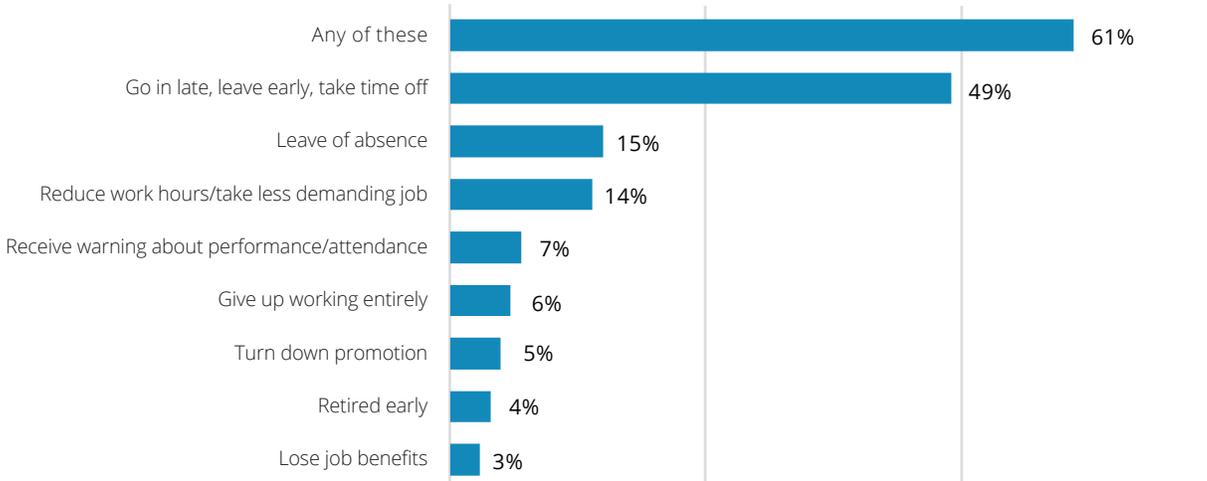
Source: AARP, *Caregiving in the U.S., 2015*

The above study shows that 60% of caregivers are employed. Out of those who work, 72% work more than 30 hours per week, and 56% work 40 hours per week or more. Some 79% work for others, which usually implies stricter working conditions and the necessity of showing up for and leaving work under pre-determined and often less flexible conditions. However, when the data is pooled together, the survey shows that in total, 53% benefit from flexible working hours. In total, 52% enjoy paid sick days, and only 32% have paid family leave. Only 23% have programs to help caregivers with information and referrals and EAP (Employment Assistance Program). Only 22% can benefit from telecommuting. Finally, some 30% have programs that allow caregivers to be paid for some hours of caregiving. Only 30% have income tax credits and no more than 11% have partially paid leave. The other important finding is that a large proportion of respondents, some 29%, do not know what kind of support programs their working institutions have for caregivers, which shows an information vacuum in many of our workplaces when it comes to the prevailing working conditions of caregivers.

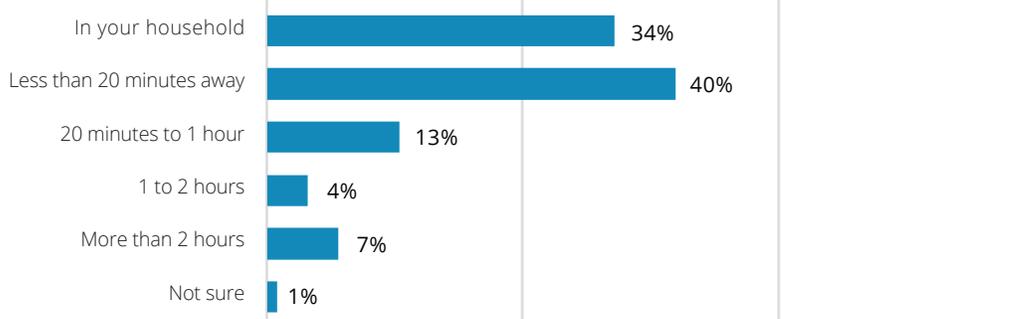
FIGURE 38

Economic Cost to Caregivers, 2015

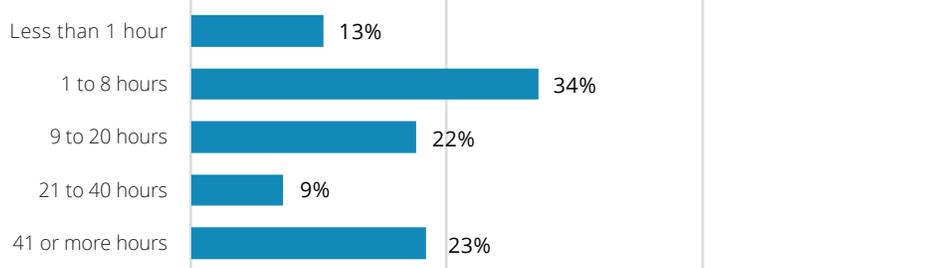
WORK IMPACTS:



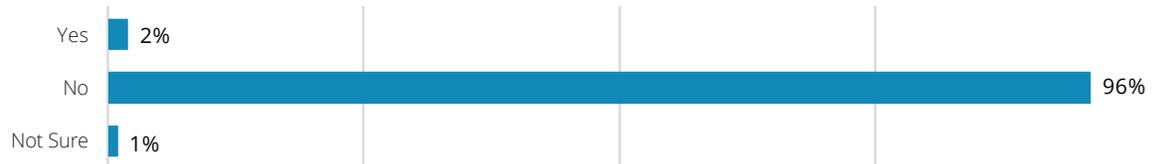
DISTANCE:



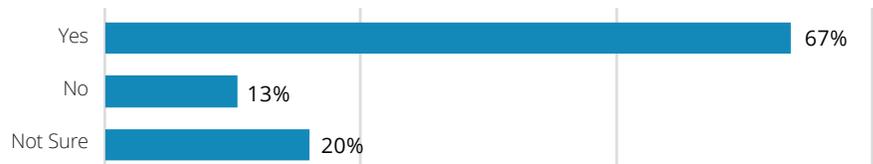
HOURS OF CARE:



CAREGIVING AS A REASON FOR BEING TERMINATED:



WORKPLACE CAREGIVING DISCRIMINATION:



Source: AARP, *Caregiving in the U.S., 2015*

The previous chart provide important insights into working and living conditions of employed caregivers. These questions are important as they shed light on the daily problems associated with caregivers meeting the challenge of keeping their jobs.

In the first part of the graph, we find important impacts that being caregivers can bring about on their working conditions. Some 61% of respondents said that one or more of the listed developments have impacted them. Almost half of the respondents (49%) said that they have had to leave early, go in late, or take leave at times in order to keep up their duties as caregivers. Some 14% had to reduce work or take less demanding jobs because of being a caregiver. Some 15% had to take a leave of absence. Some 7% received warnings for the impact on their job performance, and 6% gave up working altogether.

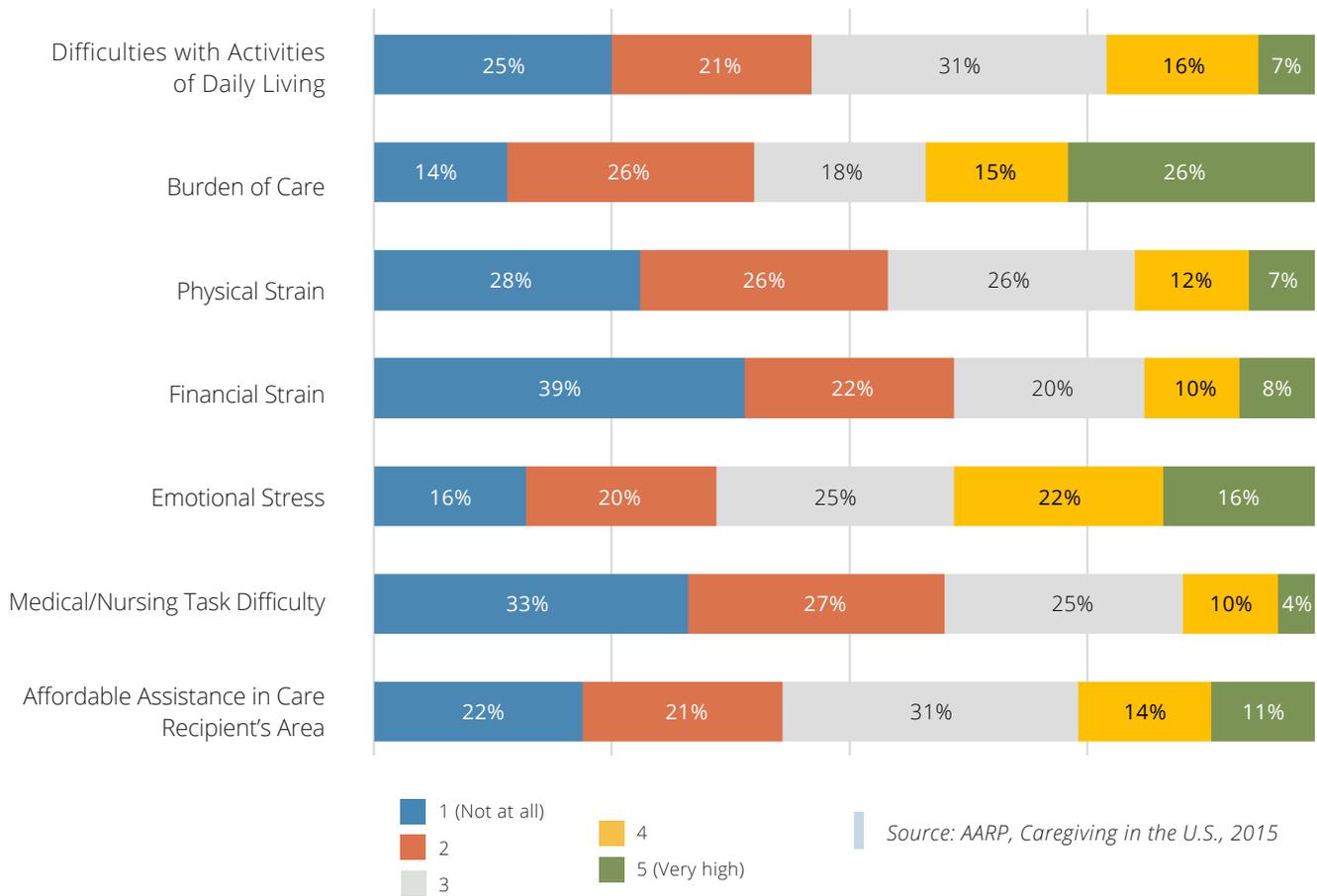
The distance needed to attend to their duties as caregivers appears as a challenge as well. Some 40% have to travel less than 20 minutes. Some 13% had to travel between 20 minutes to an hour, and some 11% travel for an hour or more to fulfill their roles as caregivers. Some two percent of the respondents mentioned being a caregiver as a reason for being terminated from their employment. One of the most important responses from this survey is that some 67% reported that they have faced discrimination in their work place because of being caregivers.

AARP survey findings in 2015 suggest that "we need to focus on what can be done to make working and caregiving for millions of Americans a possibility that can go hand-in-hand," and not be a source of conflict in workplace and an added economic, emotional, and social burden for working caregivers.



FIGURE 39

Economic, Physical, Emotional, and Other Burden of Being Caregivers, 2015



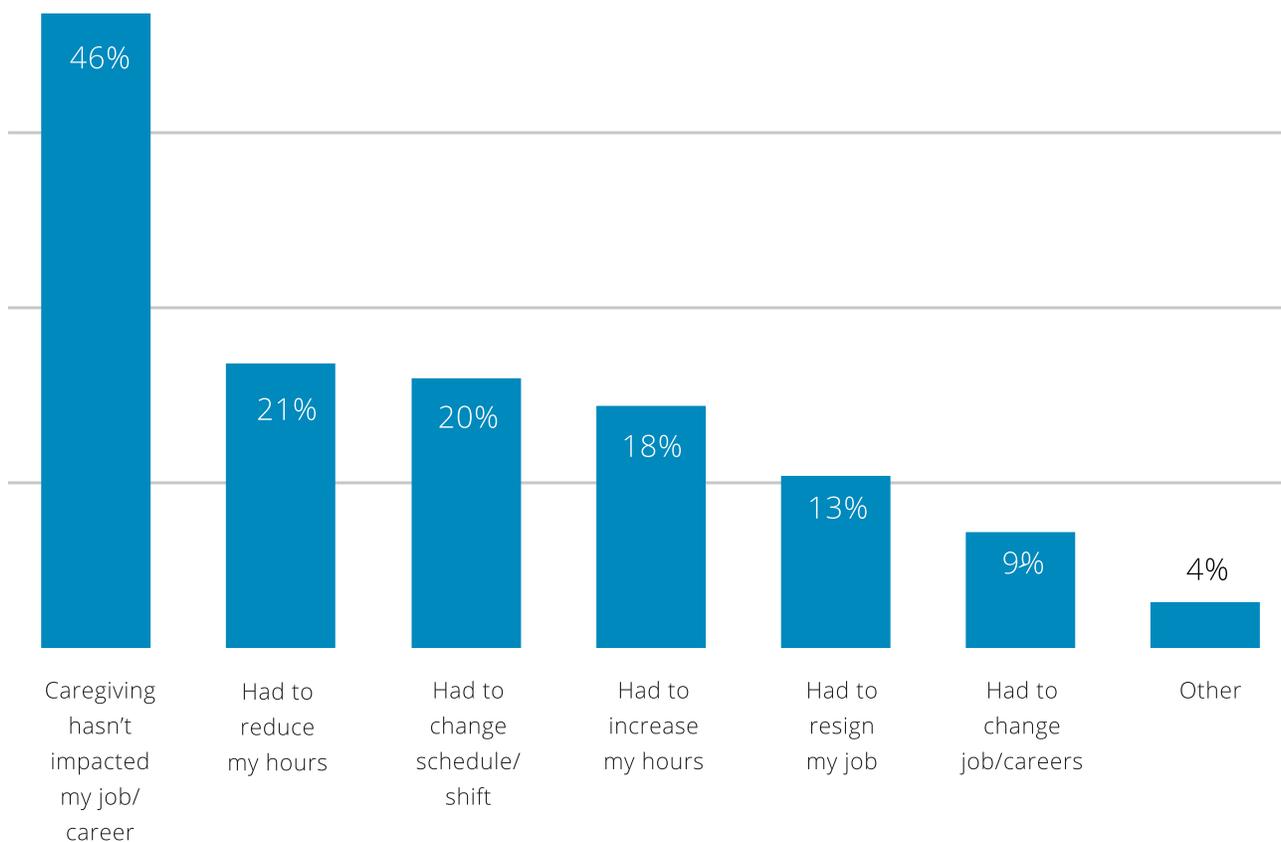
The above chart provides a detailed account of a variety of problems and complications related to being caregivers in the United States. For a quick review of such problems, we only reported on the Levels 4 and 5 difficulties, also referred to as “very high” or “somewhat high,” as we glanced through the list.

Some 41% of caregivers are faced with very high or somewhat high levels of burden of care on day-to-day basis. Some 38% face severe or somewhat severe levels of emotional stress. Some 25% have very high or somewhat high levels of problems with affordable assistance with their care recipients. Some 19% have high or somewhat high levels of difficulties with daily living activities. Some 18% feel a very high or high level of physical strain in providing care as a caregiver.

The following chart provides more evidence and support for the findings taken from the AARP survey. The importance of the following chart is that it includes a much wider age range of caregivers, from 18 years of age to older.

FIGURE 40

Percentage of U.S. Caregivers Whose Job has Been Impacted by Caregiving as of 2017



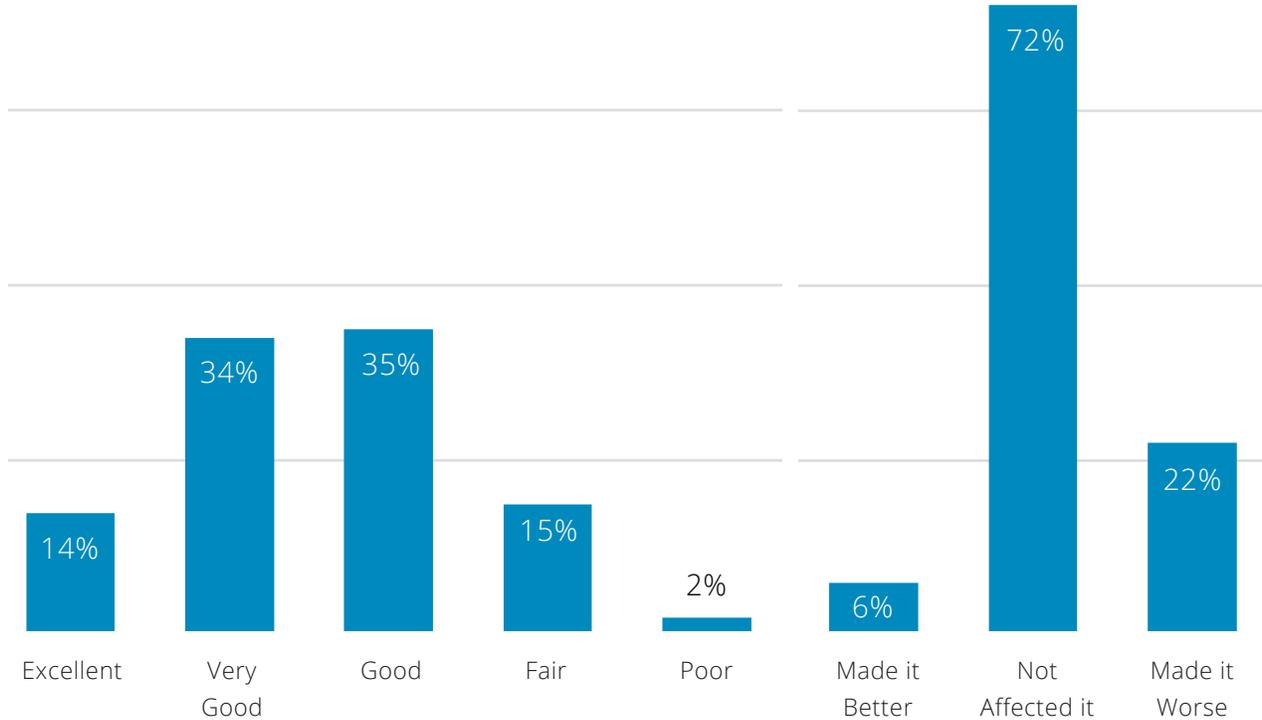
Source: Northwestern Mutual (Statista), online survey, November 29 to December 7, 2017, 405 respondents of 18 years of age and older of qualified caregivers

The following chart provides an interesting picture of a number of difficulties and burdens that caregivers have to endure and need to be understood and resolved as we move towards an escalating level of LTC in the country and every community within it.

Some 54% of respondents have stated that being a caretaker affected their job or career in some way. Some 21% had to reduce their working hours, while 20% had to change their work schedule. Another 18% had to increase their working hours. Some 13% had to resign from their work and 9% of respondents had to change jobs or their career.

FIGURE 41

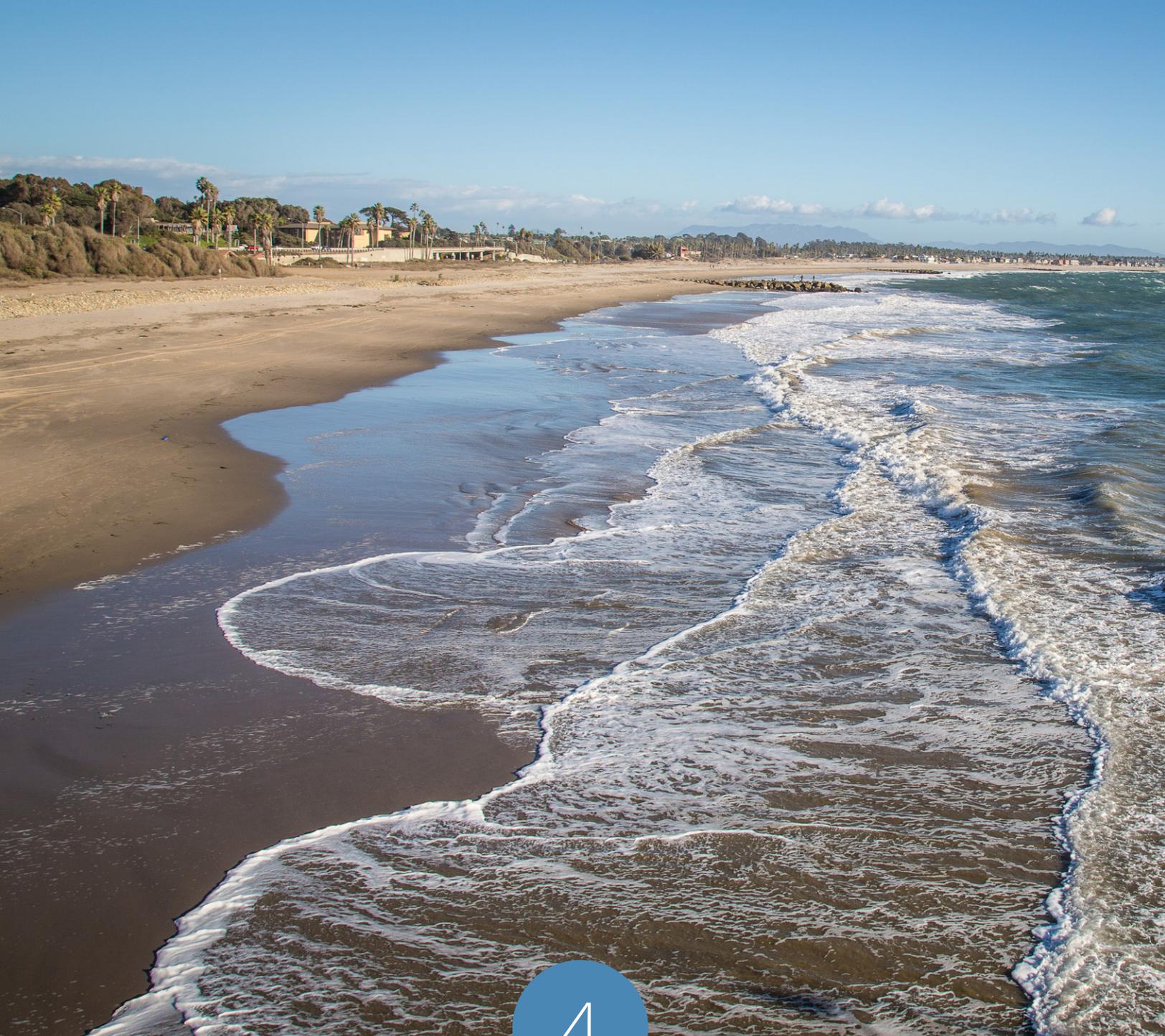
Health Conditions of Caregivers, 2015



Source: AARP, *Caregiving in the U.S., 2015*

The above chart provides an interesting insight into the health conditions of caregivers and how being caregivers may affect their health. Only 14% of caregivers consider their health to be excellent. However, a considerable proportion (69%) consider it to be very good or good. Finally, some 17% consider their health to be fair or poor.

The second panel presented in the above chart indicates that the overwhelming majority of respondents, some 72%, do not believe that being a caregiver influenced their health. However, a considerable proportion, some 22%, believe that being a caregiver made their health worse. On the other hand, a smaller proportion (6%) believe that being caregiver affected their health positively.



4

Long-term Care in Ventura
County and Its Neighboring
Region

In this section of our study, we focus on Ventura County and its surrounding regions.

This is to present a picture of the current situation and predict the near future to the extent possible. Our findings with regard to the United States as a whole provide reliable findings, which can be applied to the county. There is, however, additional information that we received from the Santa Barbara County Community Caregiving Initiative (CCI). The findings from CCI come from their three recent surveys during the Fall and Spring of 2017 and in the Fall of 2018. Two of the surveys had the same question, and with a few exceptions, the questions of all three were the same.

We processed each survey separately and integrated them together by cleaning the information and eliminating a few questions. The pooled sample allowed us to run the frequency tables as well as a number of cross-tabulations of the responses, which therefore allowed us to go further and make more sense of the responses for relevant and appropriate conclusions and policy implications.



Important Demographic Information about Ventura County

Ventura County is a community with a considerably diverse population. Family structures of the county vary in its various population centers and there is a considerable economic diversity which impacts social dimensions of health, life expectancy, and the ability of the county to support the lives of its population throughout their various stages of living, from childhood to adulthood and old age.

FIGURE 4.2

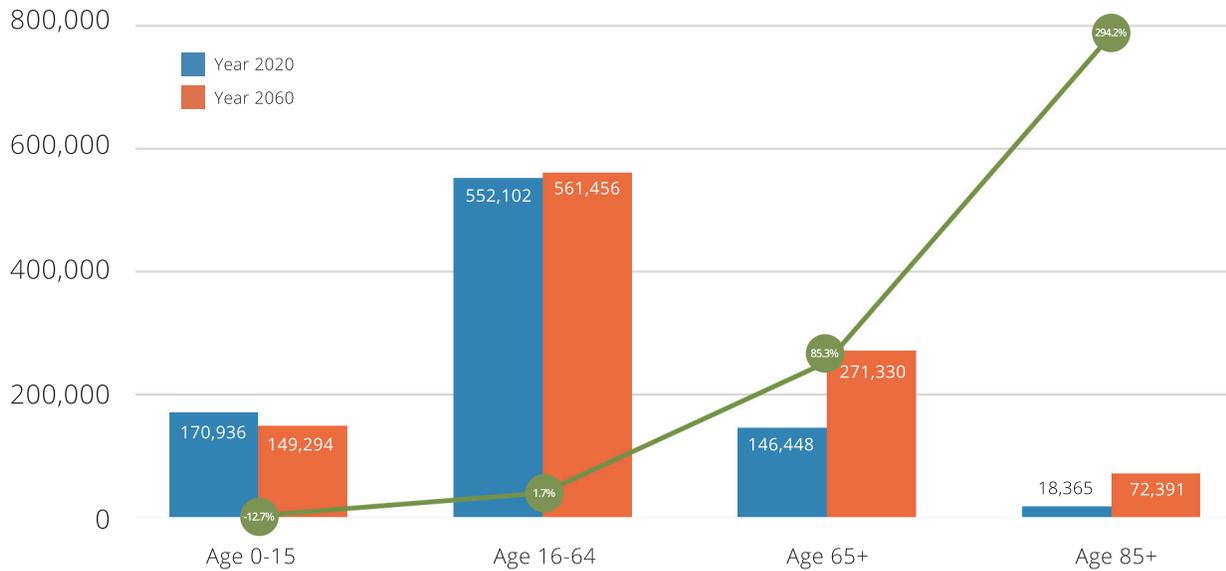
Age Structure of Population in Ventura County from 2018-2060



The above chart provides clear information about the size of the population in various age categories. The needs of the population change through the passage of time and represent different economic and social needs. The focus of this study is on older age categories of the population, and this becomes the focus of our attention when we look at the sheer number of people in various age groups. A cursory look indicates that that the county is becoming older in terms of the age of its population over time, and this will become self-evident in the next several decades. On the other hand, the number of children and younger people will not be rising at the same rate. These changes are captured in the following chart.

FIGURE 43

Growth in Population of Age Groups in Percentages in Ventura County from 2020-2060



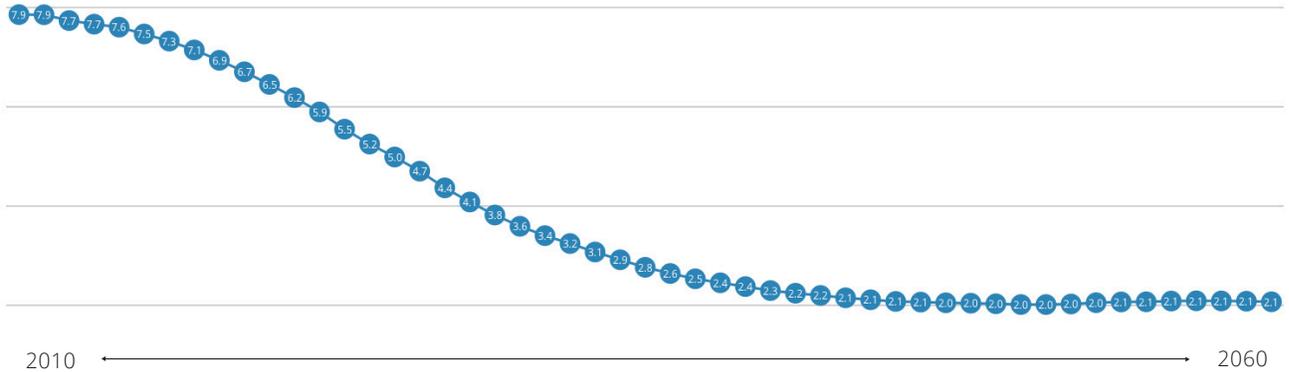
Source: California Department of Finance

The above picture is very clear and indicates that Ventura County will experience a negative growth (reduction) in the number of children between the ages of 0-15 (-12.7%) while our working population (ages 16-64) will only increase by 1.7% from 2020 to 2060. On the other hand, the population of people aged 65 and older will increase by 85.3% within the same duration. The highest population growth at the rate of 294.2% (almost 300%) will occur in the population of people aged 85+. In other words, the total number of people 85 years old and older will become nearly half of the population of children ages 0-15 by 2060. This is an important issue to bear in mind and try to be prepared for over the next 40 years, as this will gradually and surely unfold.

Change in demography has important consequences on the emerging wellbeing of any community. One of such issue, which is a direct derivative of demographic change, is the change in the caregiving support ratio. This ratio is calculated by dividing the total number of the population between the ages of 45 to 64 over the total population of 80 years of age and older. We have used the existing information and calculated this ratio for six decades, starting from 2010 to 2060. The following chart presents this decreasing trend, which is the direct outcome of having an older population over time.

FIGURE 44

Caregiver Support Ratio in Ventura County 2010-2060

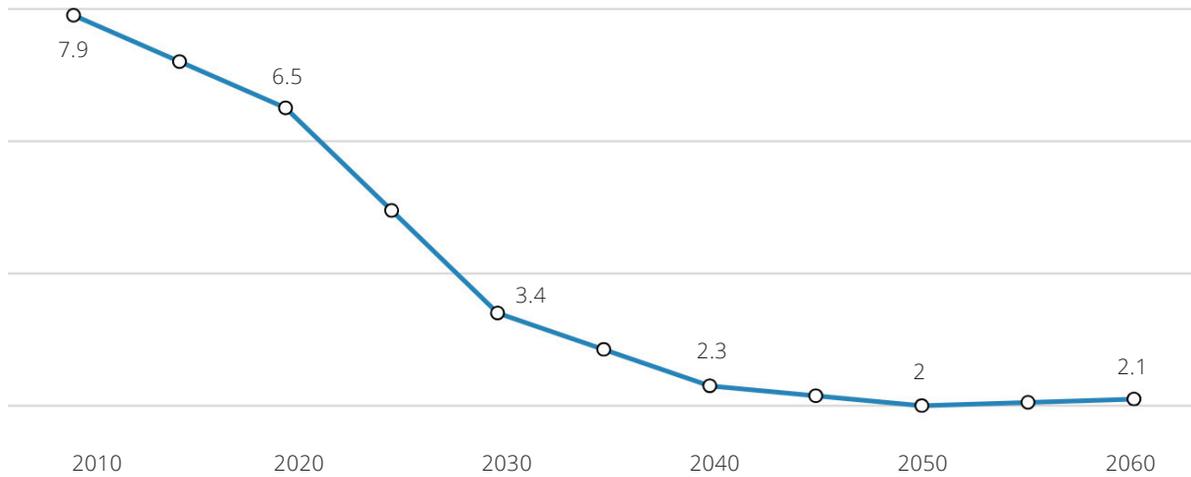


Source: California Department of Finance and Author's calculation

This chart shows an alarming trend which will take place in Ventura County over time. In order to focus on decades-long changes, we reproduced the following chart from the above set of data.

FIGURE 45

Caregiver Support Ratio over Decades (2010 to 2060) in Ventura County



Source: California Department of Finance and Author's calculation

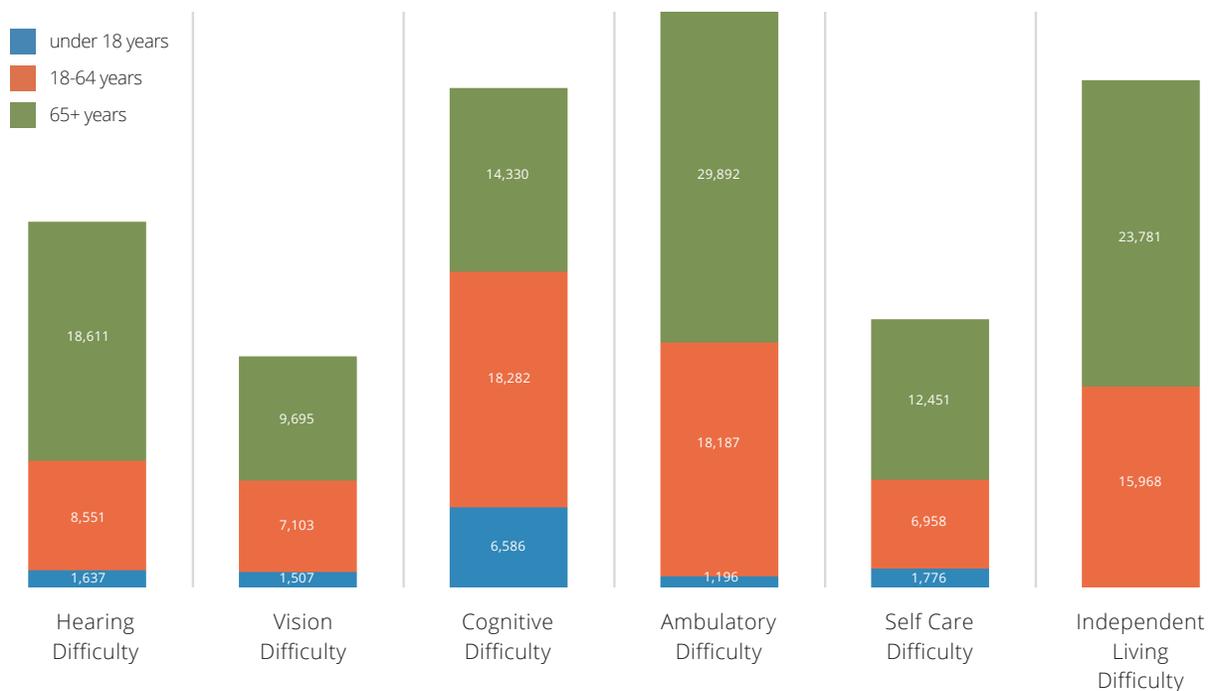
By 2020, the ratio of support will be 6.5 caregivers for every one care recipient. The ratio will decline to 3.4 per person by 2030, and by 2040 and beyond, this ratio will reach almost approximately two caregivers aged 45 to 65 for each care recipient over 80+ years of age.

Existing and Projected Estimates of People in Need of Long-term Care in Ventura County

Long-term care is primarily for people at an old age, but it also includes people with disabilities. It is also true that disability is largely a function of old age, but it also includes people of other ages, such as children and working adults. The following sets of information show the existing and the emerging number of people with various kinds of disabilities in Ventura County.

FIGURE 46

Population of Various Age Groups with Various Disabilities in Ventura County in 2017

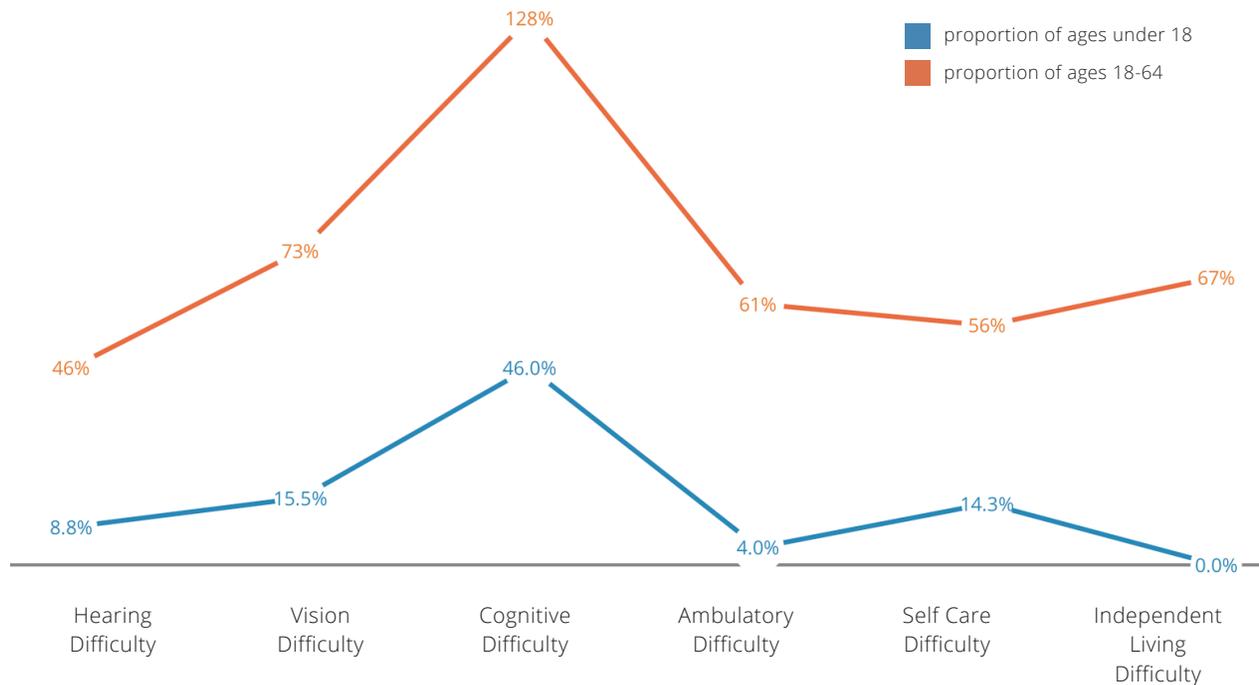


Source: U.S. Census, American Community Survey, FactFinder, S1810, 2018

The above chart shows the breakdown of disabilities within various age groups. The population of children under age 18 have some disabilities, as is the case with any age group. However, the chart clearly indicates that the likelihood of contracting a disability increases as people become older over time and eventually reach old age. Among such common disabilities are hearing loss, limited independence, and ambulatory difficulties. The proportions are illustrated in the following chart.

FIGURE 47

Proportion of Various Kind of Disabilities across Age Groups in Ventura County in 2017



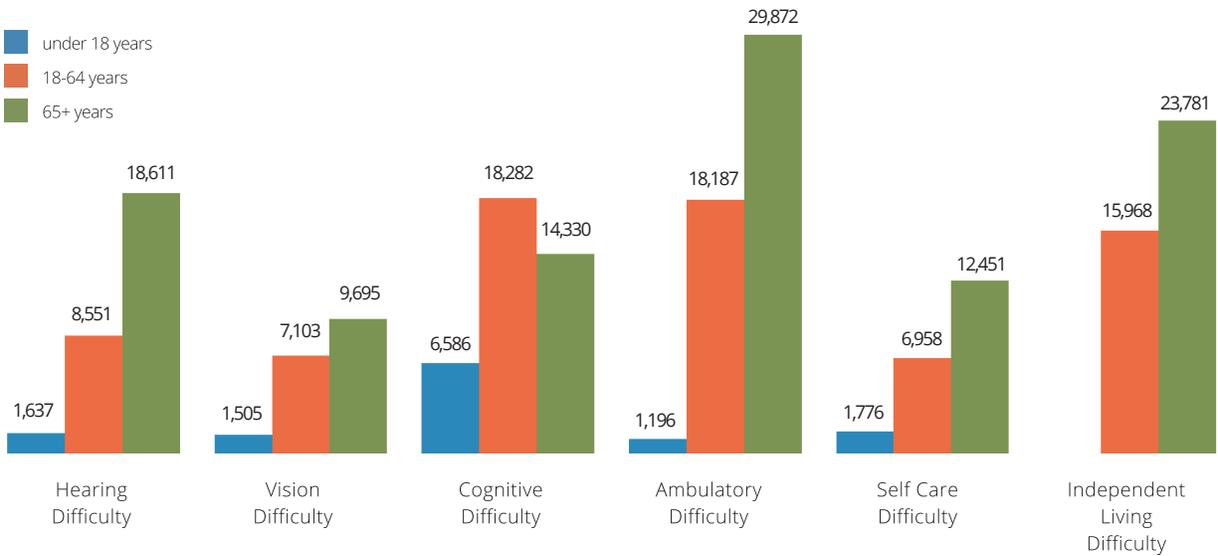
Source: U.S. Census, American Community Survey, FactFinder, S1810, 2018 and author's calculation

The above chart presents the proportions of various disabilities as a ratio of children over the older population of people aged 65 and over and as proportion of the adult group of the population (working population from 18 to 64 years of age) over the population of people aged 65 years and older. This chart confirms the validity of the discussion presented around the previous chart.

We also used the predicted population structure put forward by the California Department of Finance to predict the emerging number of people with disabilities in the next few decades. The result of our projection is illustrated in the following chart.

FIGURE 48

Various Kind of Disabilities by Age Groups in Ventura County 2017-2060



Source: U.S. Census, California Department of Finance and author's projection

The above chart presents an alarming picture about the future needs of Ventura County. It shows that all categories of long-term care for the disabled population we will experience an increase of need, and in some areas, a very steep rate of increase. Among these, four areas stand out, 1) the portions of the population with hearing loss, 2) ambulatory difficulties 3) self-care problems, and 4) independent living difficulties.

We used these emerging numbers and calculated the proportion of people with disabilities over the total county population. In 2017, for which we have available information, the rate stands at 13%. By 2060, based on our projection, this rate will increase to 31%. Ensuring that we are prepared for such a tremendous increase in the population with a multitude of disability requirements is one of the primary goals of this study.

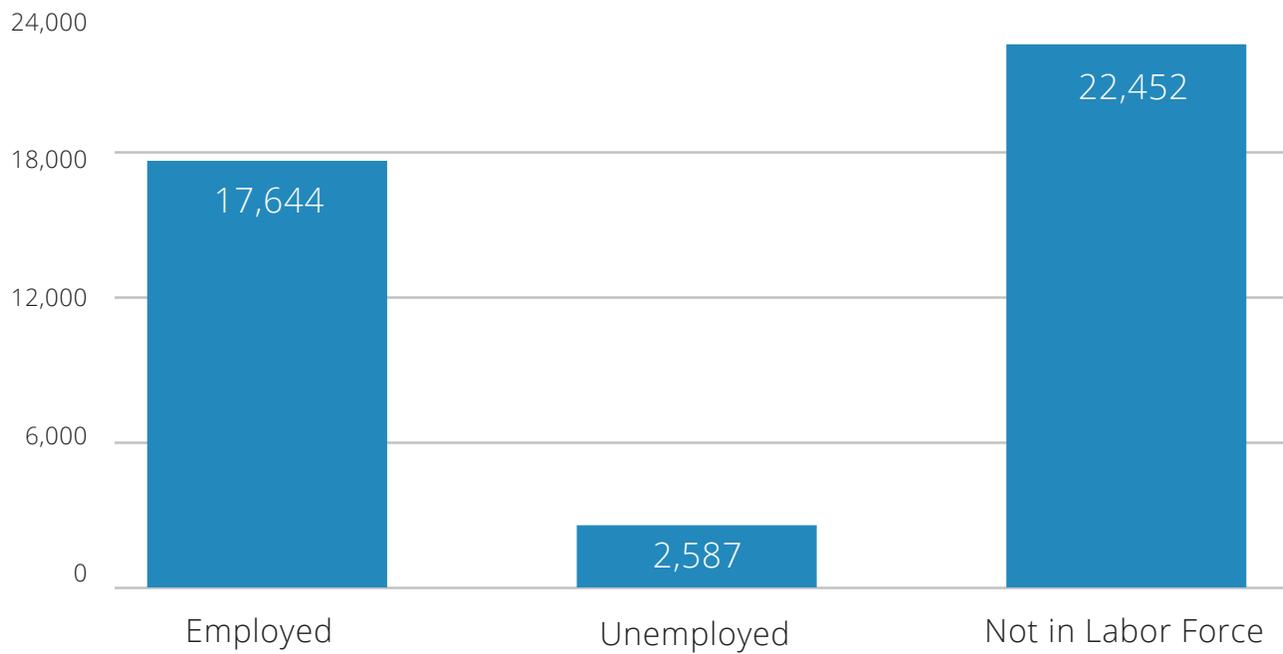
The findings identified below allow for a better understanding of the emerging conditions with regard to preparedness for catering to the LTC needs of Ventura County.

- Population of people 85 years of age and older will increase by 294.2% by 2060.
- Population of people 65 years and older will increase by 85.3% by 2060.
- Proportion of people with disabilities will increase from 13% in 2017 to 31% by 2060.

There is a need to bring awareness to the enormous rise in care needs for the population of our county and have our institutions and families prepared for the impactful surge in the few decades ahead of us.

FIGURE 49

People With Disability by Employment Status in Ventura County, 2017



Source: U.S. Census, American Community Survey (ACS), American Factfinder, B18120, 2018

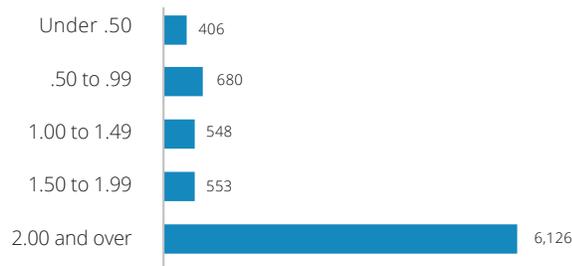
The above chart shows that a significant proportion of people with disabilities participate in the labor market and are employed. Being disabled often does not result in an immediate inability to work. However, the work place must be a suitable environment and, to the extent possible, suitable for the needs of people with disabilities. Laws within the country and the state include special provisions for allowing the disabled to work and not be impeded because of their disability. There are, however, ample opportunities to add other considerations on regional and local bases.

People with Disability by Poverty Level in Ventura County, 2017

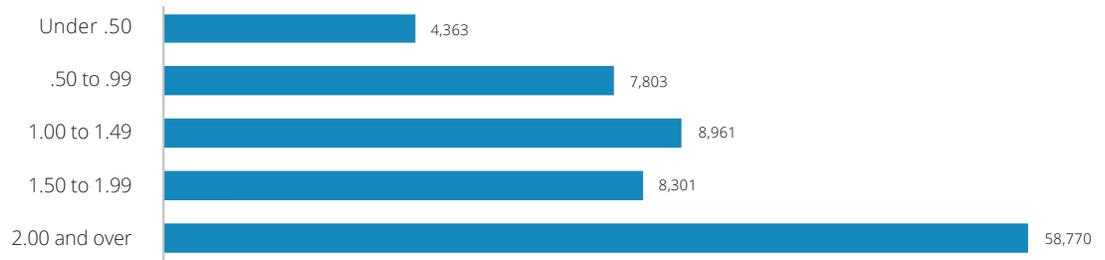
UNDER 5 YEARS:



5 TO 17 YEARS:



18 YEARS AND OVER:



Source: U.S. Census, American Community Survey (ACS), American Factfinder, B18131 2018

Finally, the above chart brings to light another very important piece of information about the disabilities of people in different age groups who are in various level of poverty. Poverty and disability are a very complicated mix and may have far-reaching negative consequences. According to the data presented in the above chart, poverty is prevalent among children with disabilities in all age groups.

The data suggest that in 2017, some 23,756 people, or 2.8% of county population, were disabled and living below 200% of the poverty level. A significant proportion of these people were aged 18 years and older.

Information Concerning Demographic and Other Characteristics of Caregivers in Ventura County

The latest efforts to gather information on various characteristics of caregivers were gathered in 2009 by the UCLA Center for Health Policy Research. We have selected some of the most important items of this inquiry and presented it through the following charts.

FIGURE 51

Caregivers by Age in Ventura County, 2009

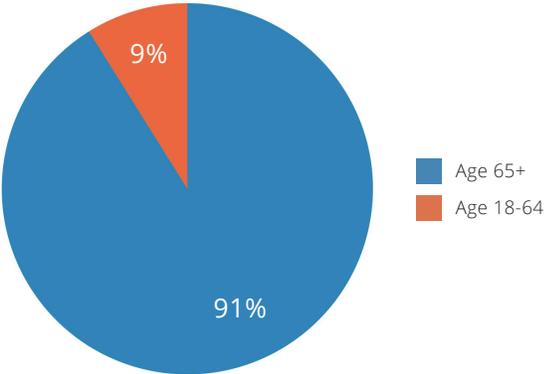


FIGURE 52

Caregivers by Ethnicity in Ventura County, 2009

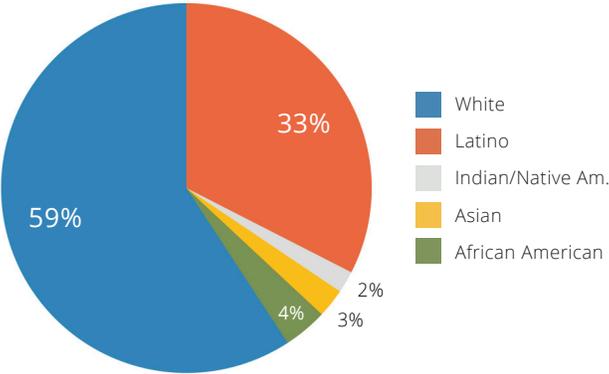


FIGURE 53

Caregivers by Employment Status in Ventura County, 2009

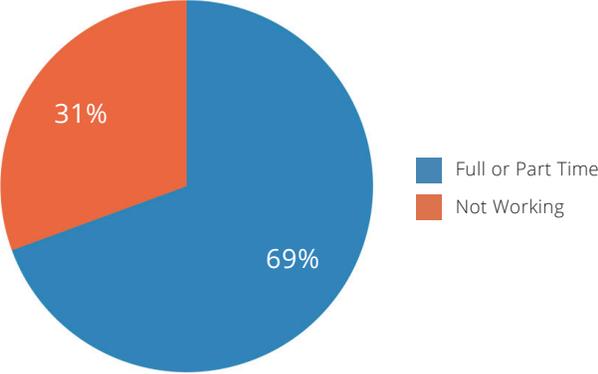
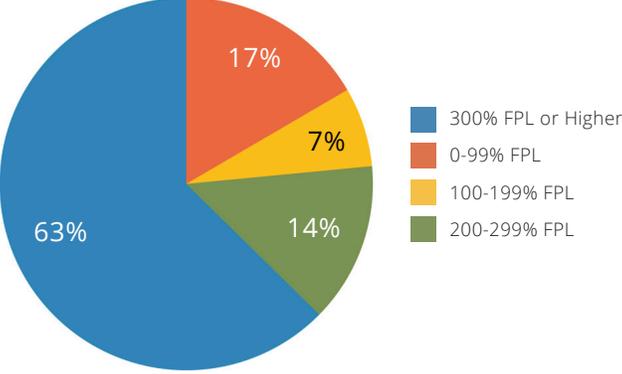


FIGURE 54

Caregivers by Poverty Level in Ventura County, 2009



Source: UCLA Center for Health Policy Research, AskCHIS 2009, <http://ask.chis.ucla>

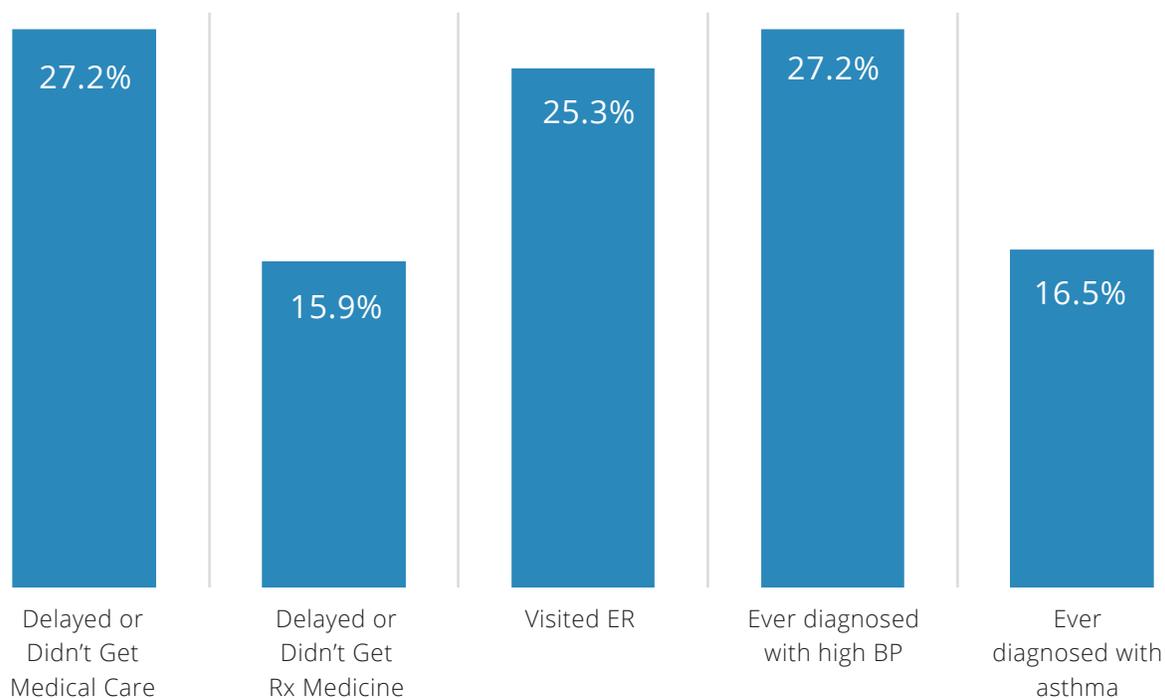
The data above shows that:

- More than 91% of caregivers in Ventura County are within the ages of 18 to 64 years.
- Some 59% of them are White and 33% are Latino. This is because white at this point of time represents the largest share of older people. The proportion is likely to change with the passage of time, and the Latino group will increase in number.
- Some 69% of caregivers work fulltime.
- Some 16% of caregivers are below 100% of the poverty line. Seven percent of them are between 100% to 199% of the poverty line, and 14% are between 200% and 299% of the FPL. This shows that a considerable proportion of caregivers are below the poverty line or designated low income.

The following chart looks at the physical and emotional stress on caregivers in Ventura County. Physical and emotional stress is one of the important costs of caregiving, which is often understated or ignored in assessing the true cost of caregiving in a society.

FIGURE 55

Physical and Emotional Stress of Caregivers in Ventura County, 2009

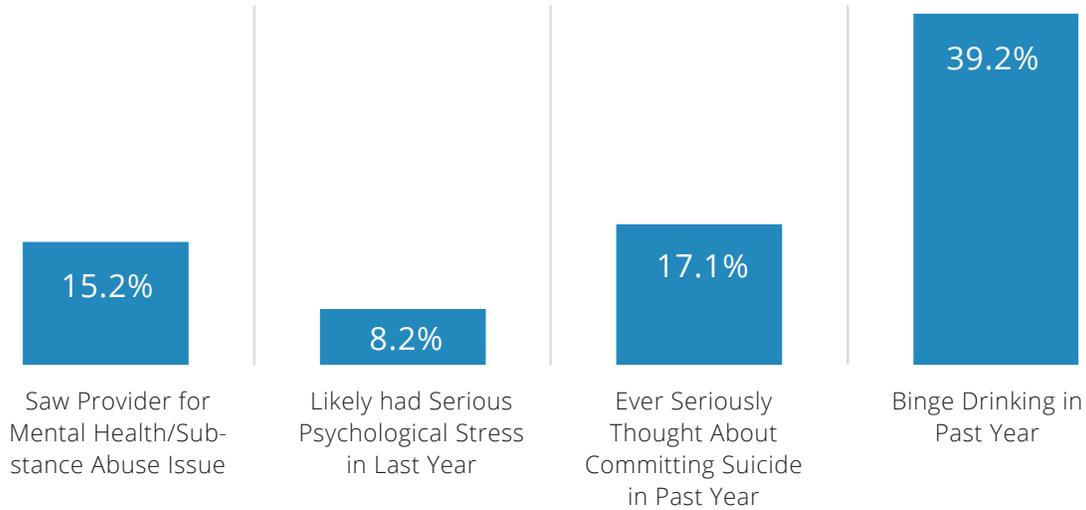


UCLA Center for Health Policy Research, AskCHIS 2009, <http://ask.chis.ucla>

Caregivers suffer from a variety of health and stress-related complications. A quarter of caregivers have visited emergency rooms for their problems. The problem that stands out very clearly is the tendency of caregivers to delay or not pay enough attention to their own physical or emotional needs.

FIGURE 56

Health Related Characteristics of Caregivers in Ventura County, 2009

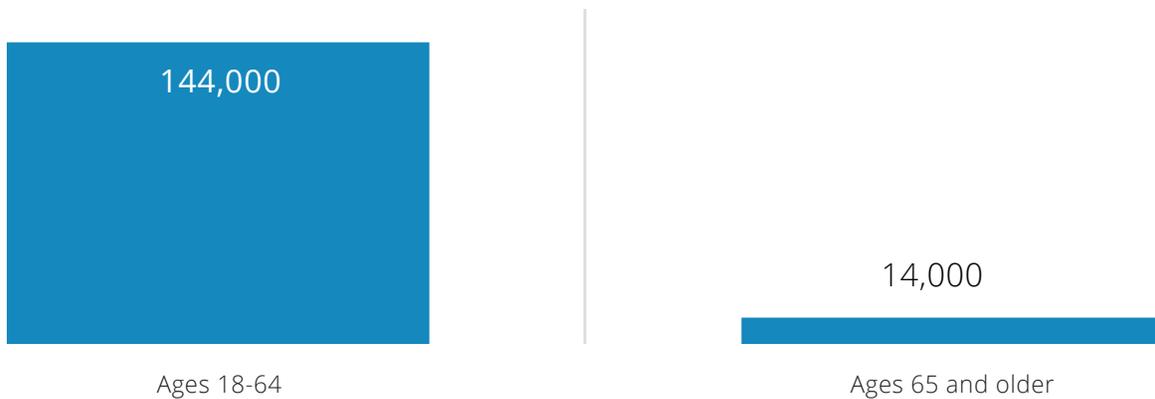


Source: UCLA Center for Health Policy Research, AskCHIS 2009, <http://ask.chis.ucla>

The above chart explores the health-related issues of caregivers in Ventura County. A large percentage of almost 40% have been binge drinkers in the past year, and more than 15% had seen mental care providers or had substance abuse issues. An alarming rate of 17.1% have thought about committing suicide.

FIGURE 57

Population of Caregivers by Age in Ventura County, 2009

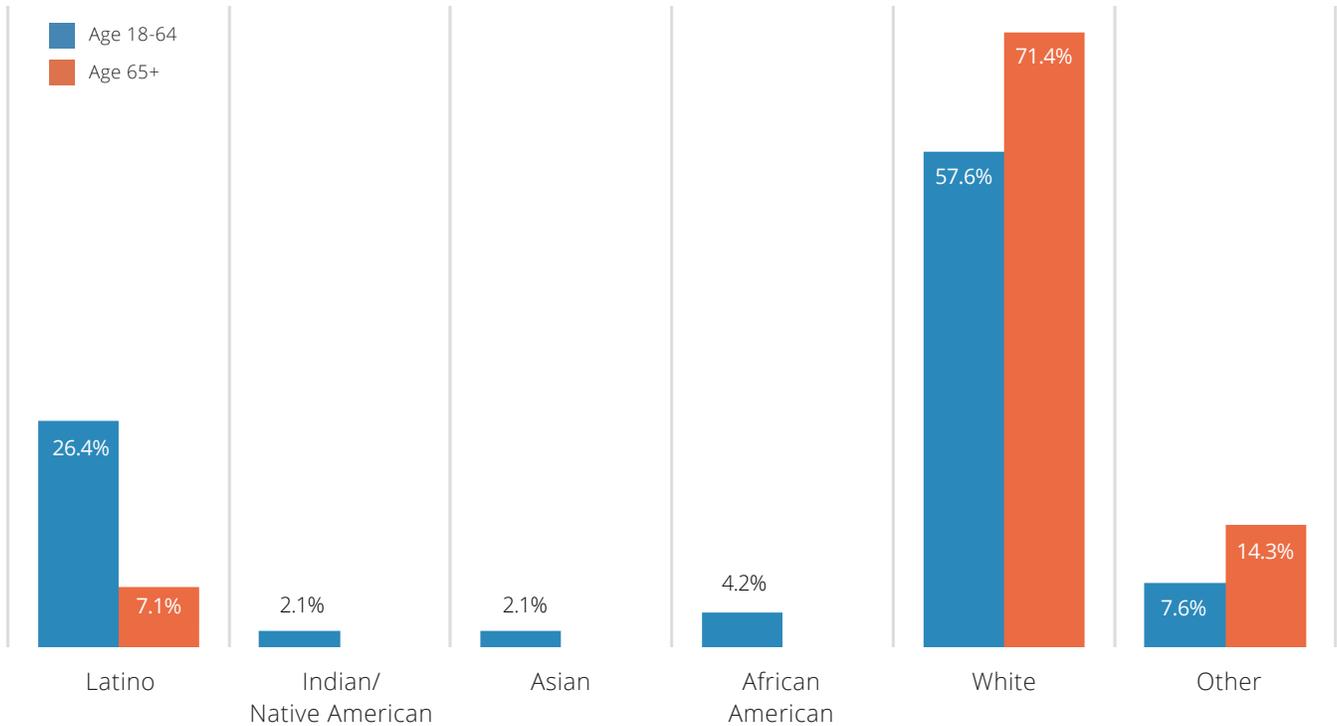


Source: UCLA Center for Health Policy Research, AskCHIS 2009, <http://ask.chis.ucla>

The above chart gives information about the size of the caregiver population and their age in Ventura County. As it can be seen, a large group of 158,000 people provide care for their loved ones, and among them, some 144,000 are within the ages of 18 to 64 years.

FIGURE 58

Ethnicity of Caregivers by Age in Ventura County, 2009

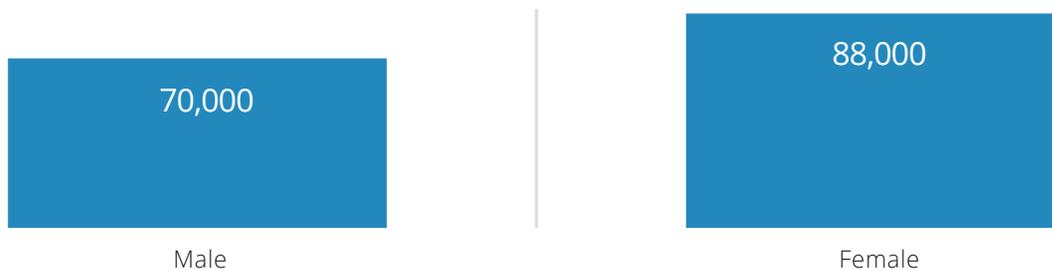


Source: UCLA Center for Health Policy Research, AskCHIS 2009, <http://ask.chis.ucla>

As mentioned before, Whites comprise the largest proportion of caregivers in Ventura County. However, the above chart provides additional information about the age breakdown of caregivers across ethnicities. The interesting issue that can be a takeaway from the above chart is that proportionally, the age category of 18 to 64 years provides more caregiving than the age group of 65 years and older among Latinos. This is not the case with regard to the population of caregivers among Whites. One explanation is the smaller number of older Latinos compared to their younger age group within the county.

FIGURE 59

Population of Caregivers by Gender in Ventura County, 2009



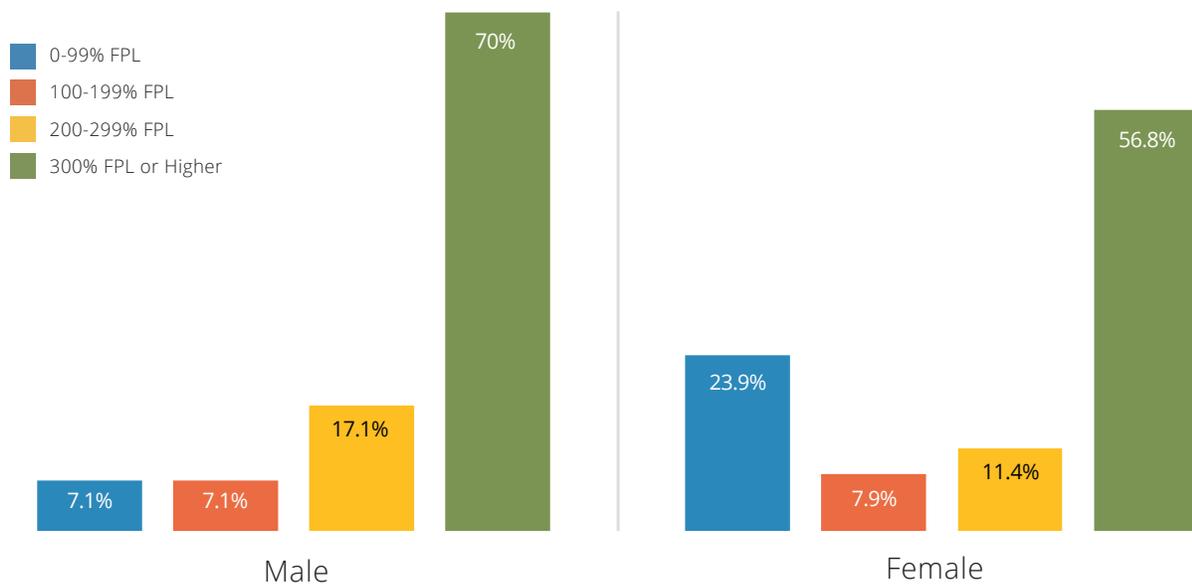
Source: UCLA Center for Health Policy Research, AskCHIS 2009, <http://ask.chis.ucla>

The above chart shows that out of the 158,000 caregivers in Ventura County, some 88,000 are women and the remaining 70,000 are men. This shows a ratio of 55.7% women compared with 44.3% men. The gender breakdown of women and men in Ventura County is different than other surveys of caregivers nationally. In all such studies, the proportion of women is higher than men, which is the case in Ventura County too. However, the percentage of men appears to be higher than the percentage nationwide.

Finally, the following chart provides the breakdown of poverty status of caregivers by gender. Gender is an important issue in measuring the impact of poverty on people within every community. A lack of sufficient attention to the plight of women may be an important source of feminizing poverty. Feminization of poverty has a devastating impact on lives of young children, and we may extend the same argument to the wellbeing of the older proportion of our population and issues related to providing long-term care in our communities.

FIGURE 60

Poverty Level of Caregivers by Gender in Ventura County, 2009



Source: UCLA Center for Health Policy Research, AskCHIS 2009, <http://ask.chis.ucla>

As the above chart shows, women caregivers are far more likely to be in poverty (below 100% FPL) than men.

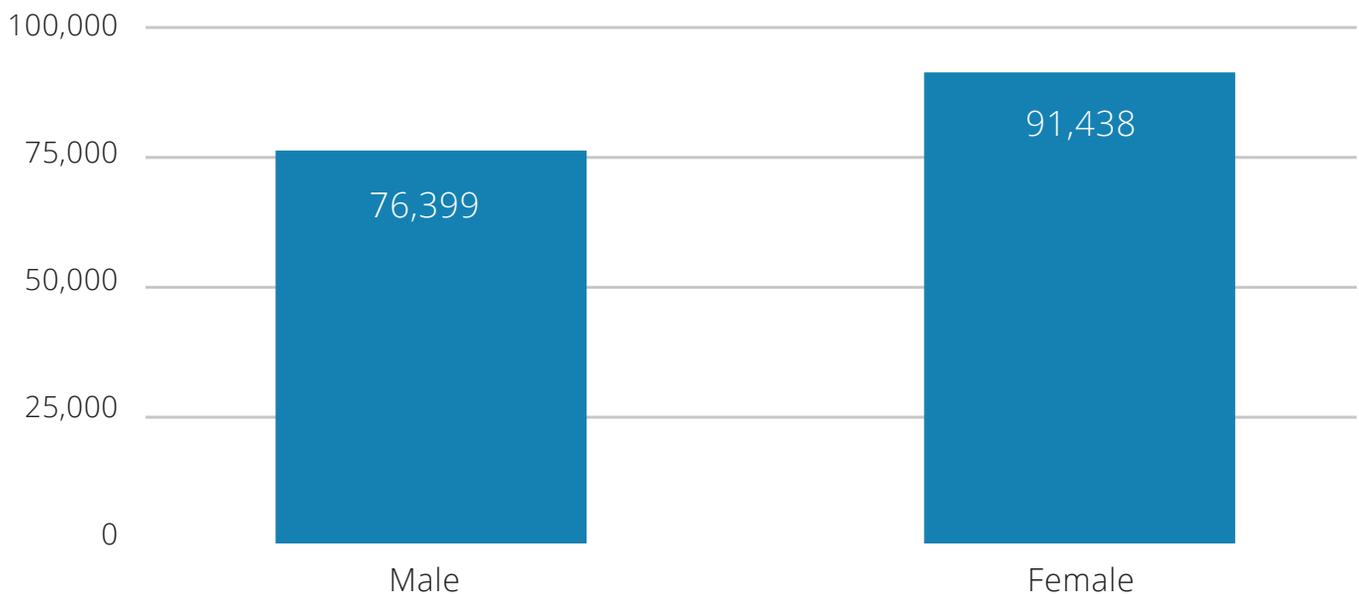
Nearly 24% of women caregivers are in poverty compared with just over 7% among men who provide care.

Focusing on Population of 60 Years of Age and Older in Ventura County

The population of people 60 years of age and older has an important impact on the existing and emerging needs for long-term care in Ventura County. We therefore gathered and put together a number of important statistics that can shed light on the wellbeing of this group of Ventura County residents.

FIGURE 61

Population of 60 Years Old and above By Gender in Ventura County, 2017

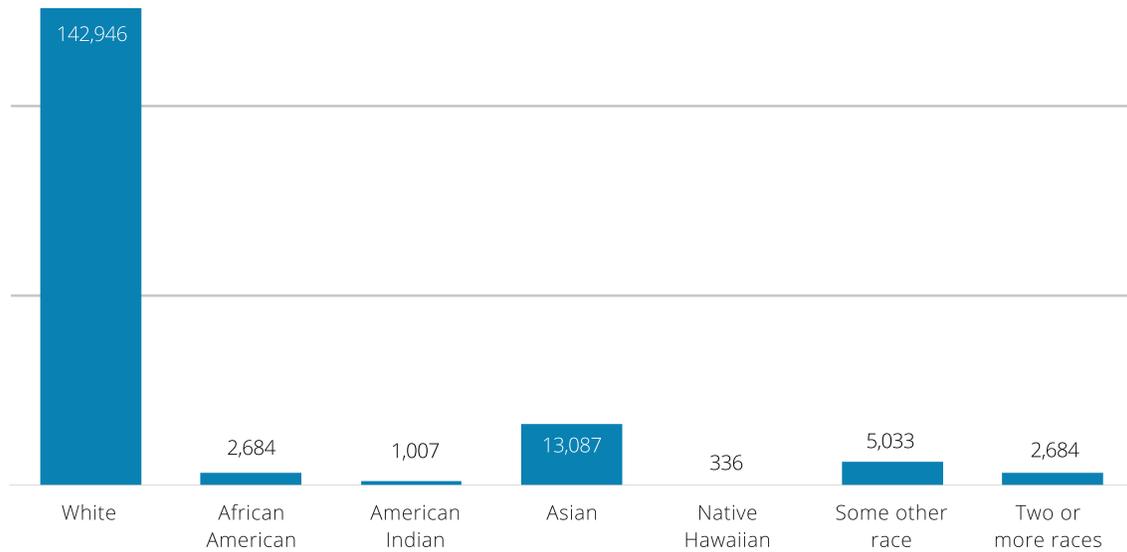


U.S. Census, American Community Survey, American Factfinder, S0102

The imbalance in the number of people at age 60 and above comes as no surprise. It is a demographic fact and universal knowledge that the life expectancy of women at birth is longer than men. It should be born in mind that life expectancy is also highly correlated with income and education.

FIGURE 62

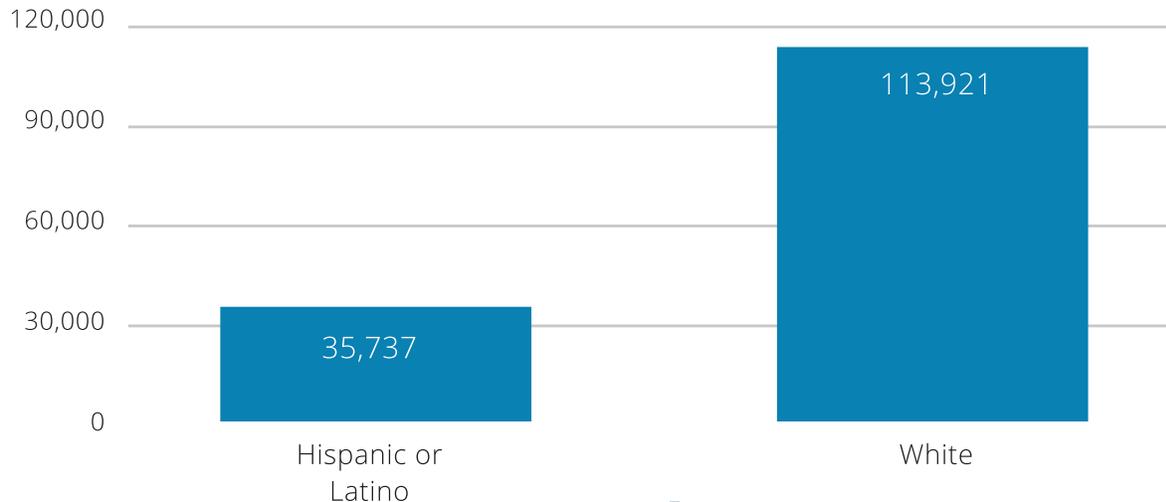
Population of 60 Years Old and Above By Race in Ventura County, 2017



U.S. Census, American Community Survey, American Factfinder, S0102

FIGURE 63

Population of 60 Years Old and Above By Ethnicity in Ventura County, 2017

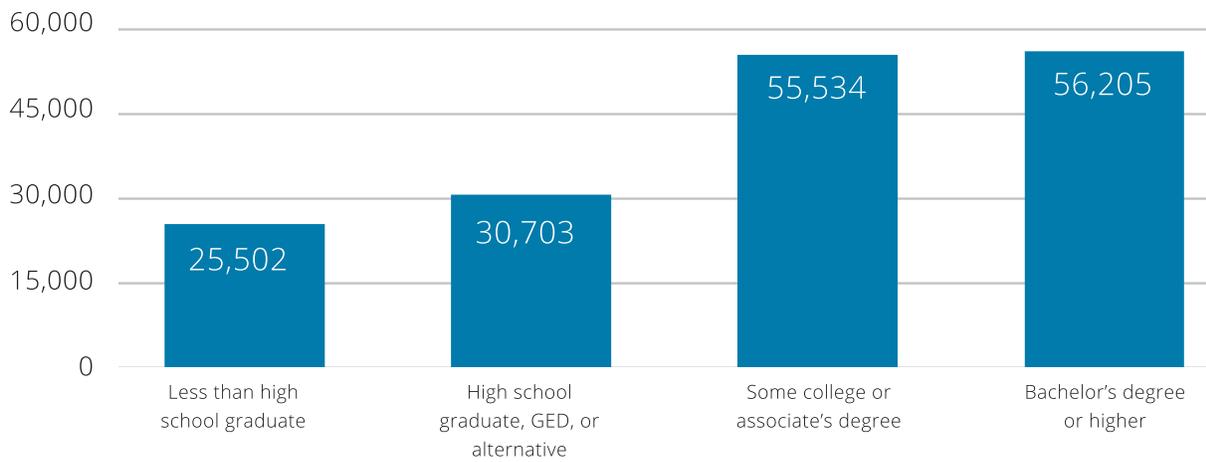


U.S. Census, American Community Survey, American Factfinder, S0102

The above two charts show that at the present time, the overwhelming majority of the older population in Ventura County is White. There are, however, a sizable population of older Hispanics and Asians .

FIGURE 64

Population of 60 Years Old and Above By Educational Attainment in Ventura County, 2017

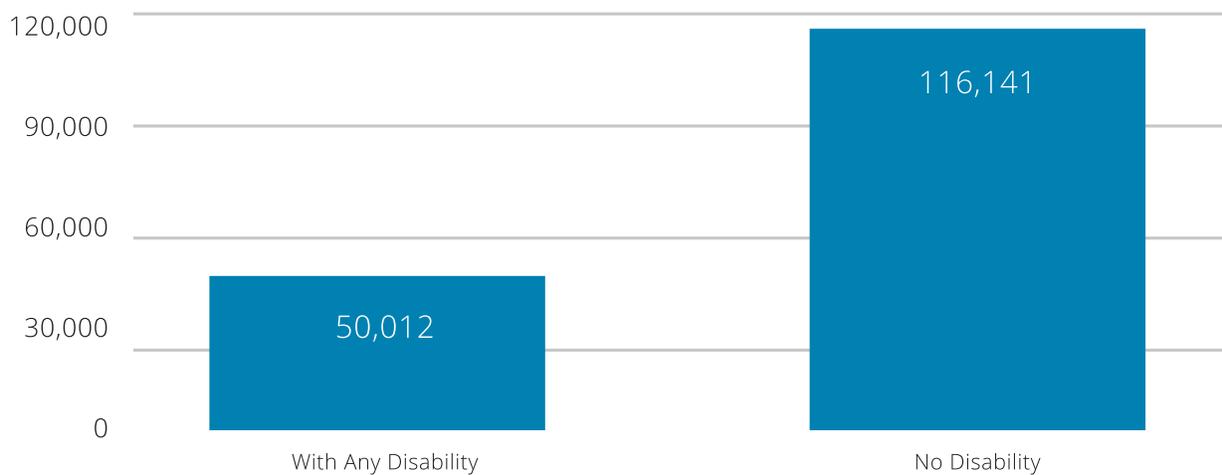


Source: U.S. Census, American Community Survey, American Factfinder, S0102

The older population in Ventura County is generally well-educated. However, there is a considerable number of this population whose educational attainment is below a high school diploma GED.

FIGURE 65

Population of 60 Years Old and Above By Disability Status in Ventura County, 2017

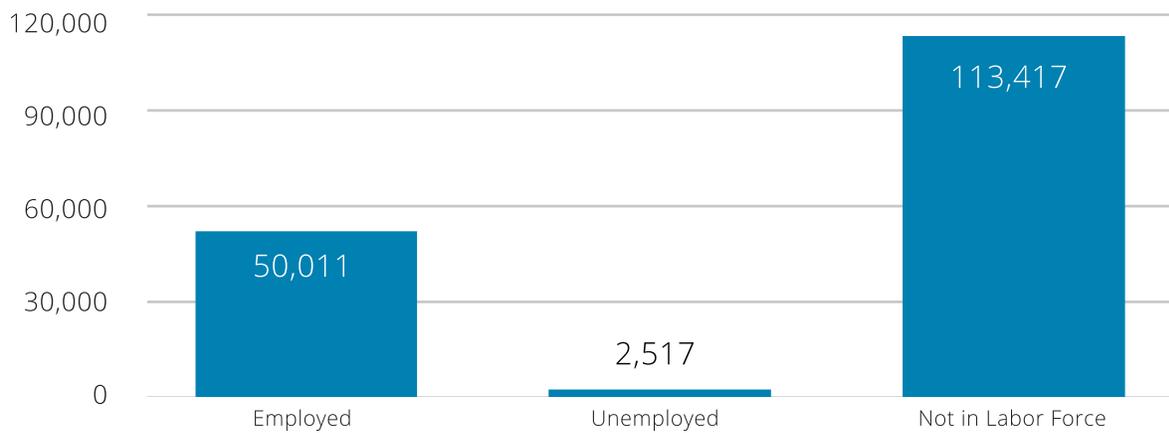


Source: U.S. Census, American Community Survey, American Factfinder, S0102

There are over 50,000 people in the older population in Ventura County who have one or more disabilities.

FIGURE 66

Population of 60 Years Old and Above By Employment Status in Ventura County, 2017



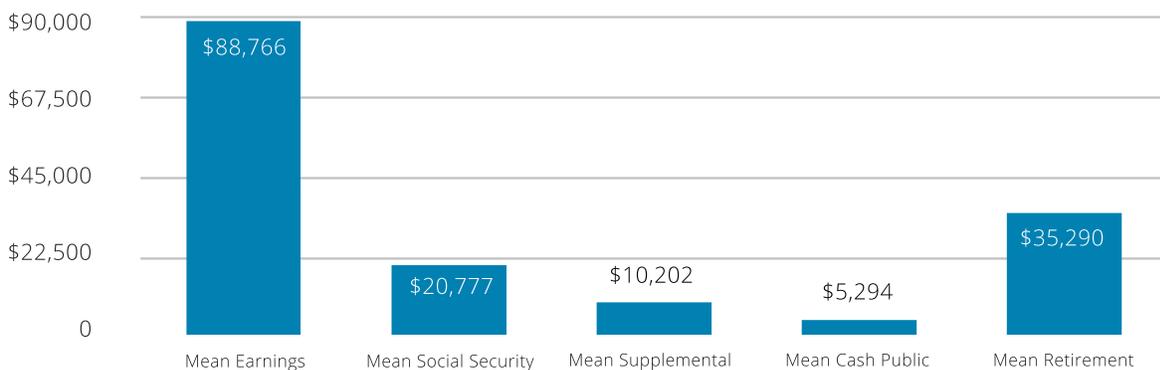
Source: U.S. Census, American Community Survey, American Factfinder, S0102

Some 31% of people aged 60 and over are employed. There are more than 2,500 people 60 years old and older who are looking for a job and could not find one in 2017.

The following chart shows the mean income of the older population (60 years of age and older) within the county. Mean earnings of the age group is \$88,766, which does not come as a surprise bearing in mind their higher level of educational attainment in general. However, the mean retirement income is very modest given the cost of living in Ventura County.

FIGURE 67

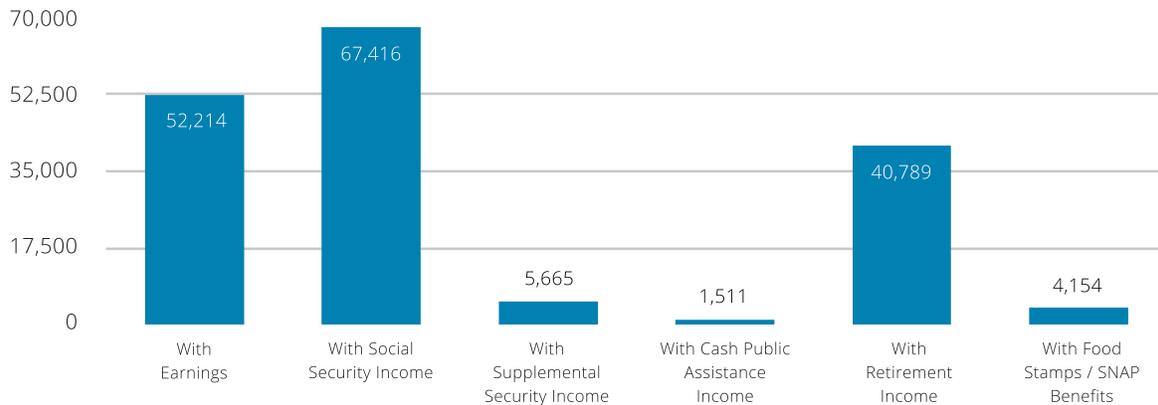
Mean Income Status of Population of 60 Years Old and Above in Ventura County, 2017



Source: U.S. Census, American Community Survey, American Factfinder, S0102

FIGURE 68

Sources of Income of Population 60 Years Old and Above in Ventura County, 2017

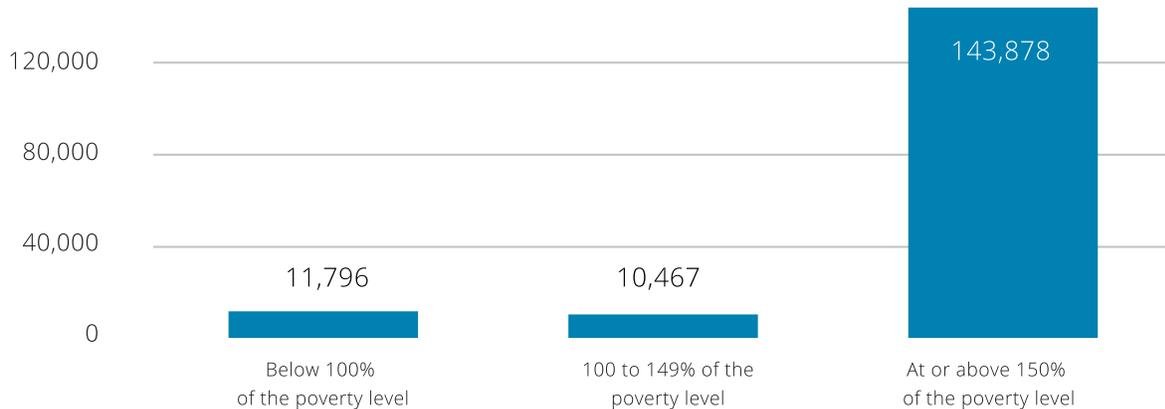


Source: U.S. Census, American Community Survey, American Factfinder, S0102

The above chart shows that a significant number of the older population in Ventura County have income earnings. A large number of the older population receive social security income. Some 5,665 receive supplemental security income. Some 1,511 of them receive cash public assistance, and 40,789 receive retirement income. Some 4,154 of them receive food stamps or SNAP benefits.

FIGURE 69

Population 60 Years Old and Above by Poverty Status in Ventura County, 2017



Source: U.S. Census, American Community Survey, American Factfinder, S0102

Finally, the above chart shows that some 11,796 people 60 years of age and above live below 100% of the poverty line. Some 22,263 of this segment of Ventura County's population live with an income below 150% of the poverty level. This shows a proportion of 13.4% of this group who live below 150% of the poverty line.

Looking into Challenges of Long-term Caregiving in the Region from the Santa Barbara Foundation Community Caregiving Initiative (CCI) Surveys in 2017 and 2018

The Community Caregiving Initiative (CCI) develops and supports on-the-ground service networks for the Santa Barbara County's 70,000+ unpaid caregivers, who provide 87% of the county's long-term care.

In this segment of this study, we use some of the findings from CCI surveys during the last three occasions:

- Caregiver Survey in Spring of 2017 (256 completed)
- Caregiver Survey in Fall of 2017 (165 completed)
- Caregiver Survey in Spring of 2018 (142 completed)

In order to prepare the completed surveys for processing we took the following steps:

- *Eliminated the surveys of those who were not eligible to participate in the survey, such as people who are not caregivers. We also decided to take a few who said they have taken the survey before (during the last six months).*
- *We ran frequency distributions for each survey separately and then combined the three.*
- *In combining the three surveys, we combined the second and the third survey, because they had exactly the same structure.*
- *The surveys had almost the same questions, but in different orders. We therefore created a combined survey based on the pattern of questions in the second and third survey. There were some additional questions in the last two surveys, which we kept in the combined survey. Thus, the total responses to these additional questions only include the responses from the second and third surveys.*
- *Having a combined survey is important for our analyses since this will allow us to run cross-tabulations of some of the responses across a variety of patterns which can be statistically significant.*
- *Due to a very large volume of results, we only reported on a selected number of findings and only from the combined survey file in this report. All other frequency tables and clean data for each survey is available if needed.*
- *Finally, we have combined the frequency tables with selected cross-tabulations in areas where there is a need to identify group behaviors and actions. For example, when we talk about handling the health or emotional needs of caregivers, we may learn more about them if we can also identify how various groups responded to this question based on their employment status. We should add that we have the ability to run more such deep experiments, if needed.*

Basic Demographics of Respondents

The following charts provide information about the respondents. Having such information provides some context as to who they are in demographic terms and how their challenges, hopes and expectations can be translated to an average caregiver in our region.

FIGURE 70

Preference in Language in Taking the Survey, 2017-2018

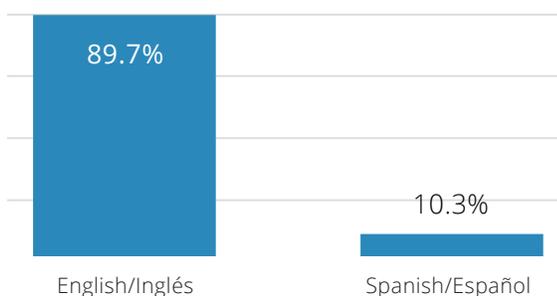


FIGURE 71

Which County Do You Live in?, 2017-2018

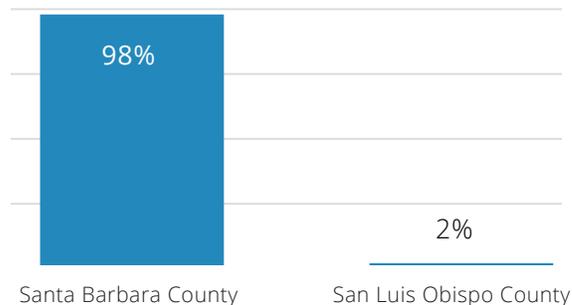


FIGURE 72

Which County Do You Work in?, 2017-2018

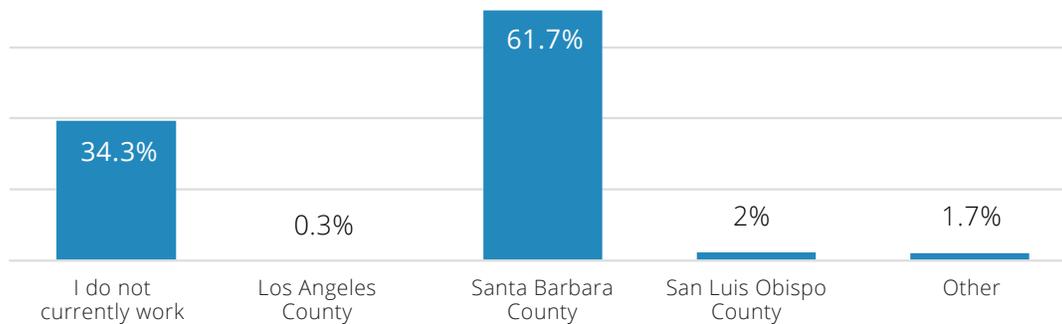


FIGURE 73

What is Your Age?, 2017-2018

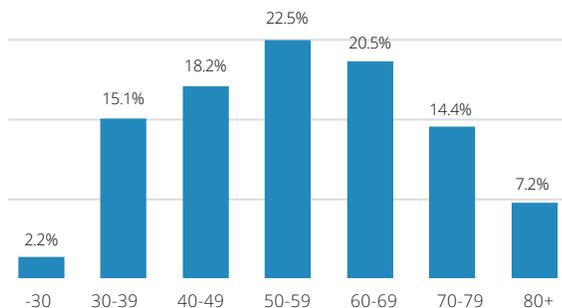


FIGURE 74

What is Your Gender?, 2017-2018

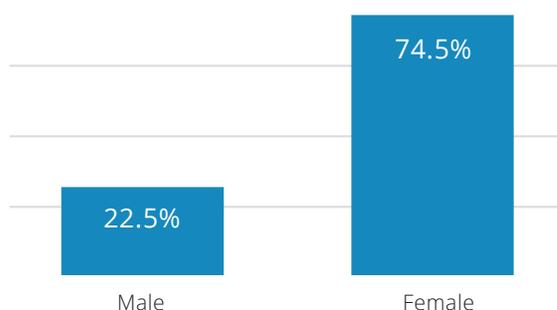


FIGURE 75

How Would You Describe Your Racial/Ethnic Background?, 2017-2018

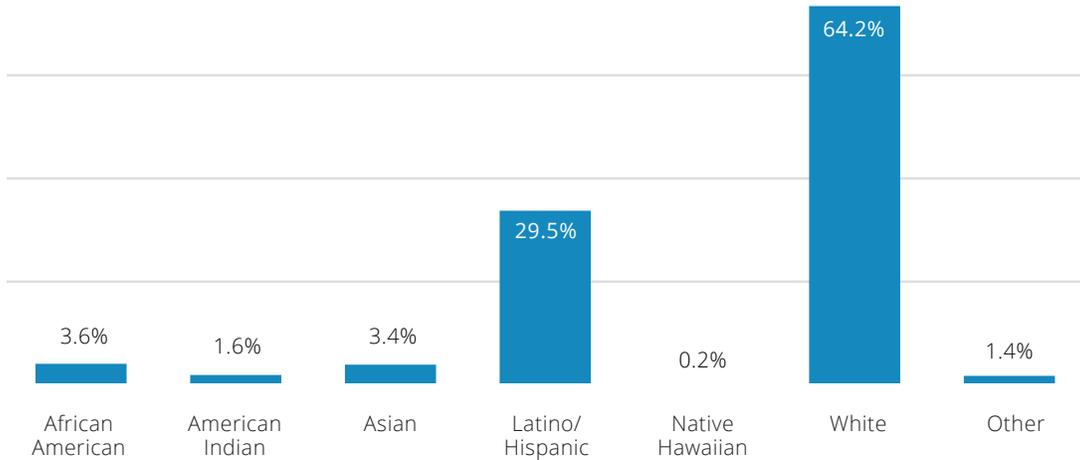


FIGURE 76

Where Does the Person You Care for Live?, 2017-2018

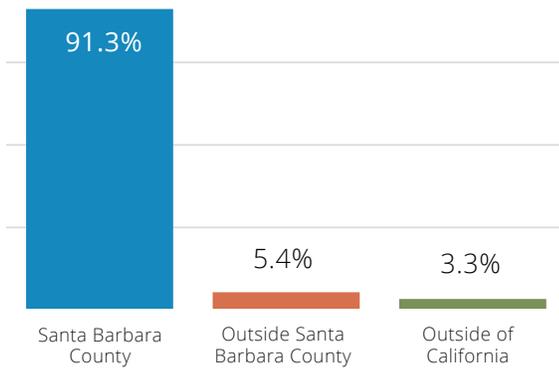


FIGURE 77

What is the Age of the Person You Care For?, 2017-2018

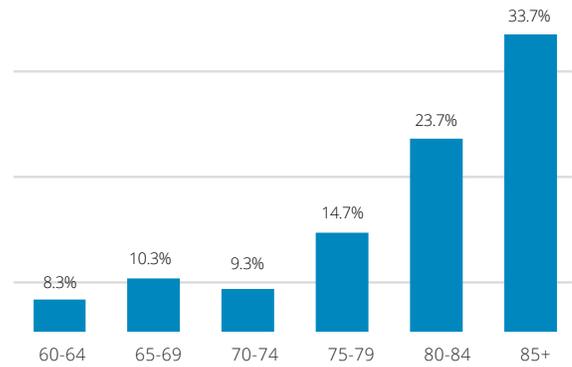
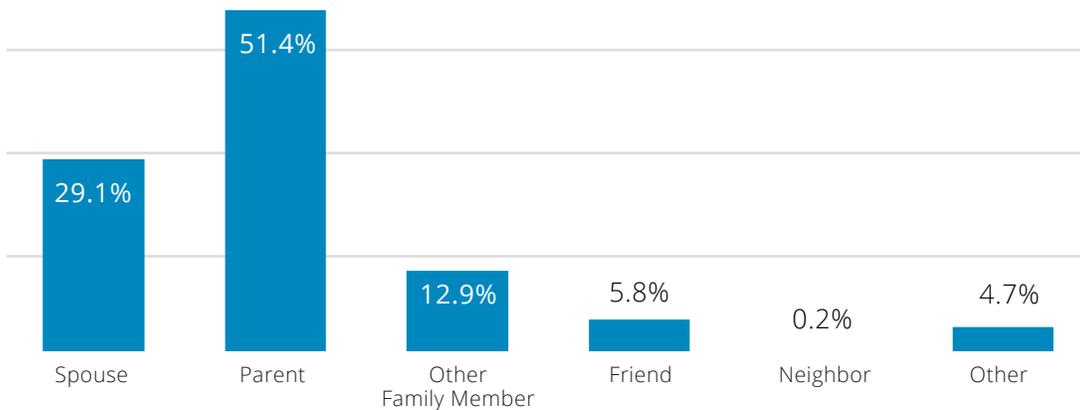


FIGURE 78

For Whom are You a Caregiver?, 2017-2018



Demographics Summary:

- An overwhelming majority of caregivers and the people they care for live in **Santa Barbara County**.
- About one third of the respondents do not work, and nearly three quarters of the caregivers are **currently working**.
- Only 2.2% of caregivers are younger than 30 years of age and 7.2% are 80 years old or older.
- About 75% of caregivers are **women**.
- More than half of caregivers (51.4%) are looking after their parents. All together, nearly 90% of care is given to **family members**.
- More than 80% of those who are care recipients are **70 years of age or older**. In addition, 57.4% of care recipients are 80 years of age or older.

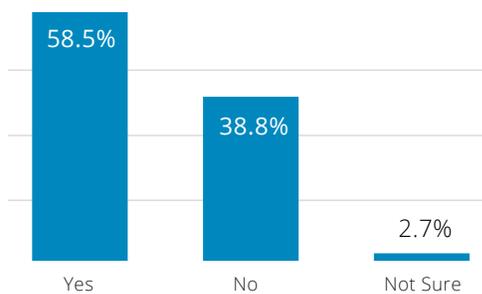


Prevailing Conditions for Caregiving and Its Possible Impact on Socio-Economic Environment of Caregiving

In this segment of the report, we present some of the findings that show the environment of caregiving and some of the impacts it has on caregivers and care recipients.

FIGURE 79

Is There Anyone Else Who Helps You Care for This Person?, 2017-2018

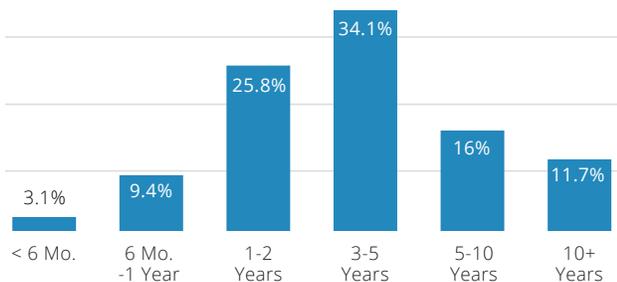


A majority of care recipients receive care for someone else in addition to the respondents.

However, for every two out of five people who are receiving care, the respondent caregiver was the only person to care for them.

FIGURE 80

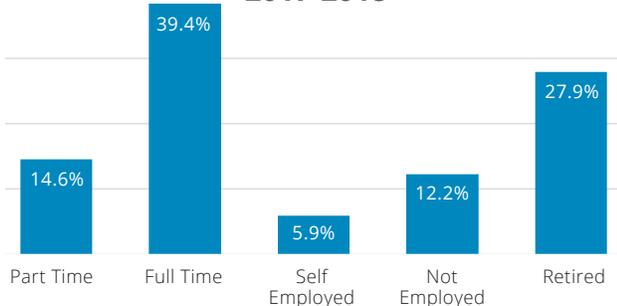
How Long Have You Been Caring for This Person?, 2017-2018



An overwhelming majority of the respondents have been caregivers for a number of years. Almost nine out of 10 of them have been caregivers for longer than a year. Some six out of ten of them have been caregivers for more than three years. Some 28.7% of them (almost one out of three) have been caregivers for five years or longer.

FIGURE 81

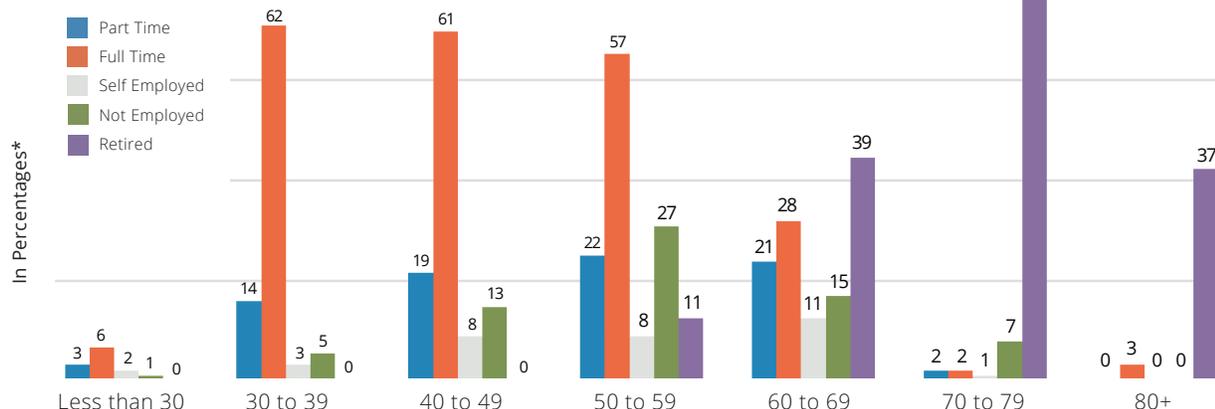
What is Your Current Employment Status?, 2017-2018



Some 60% of the caregivers are currently working and 40% of the 60% or better say some 67% of those who work hold fulltime employment. Only 27.9% are retired. This is a very significant finding and very much aligned with the findings from the national survey reported on earlier in this study. Employment status of caregivers and their age groups can provide more information, from which we can learn how they can be helped more effectively. We therefore provided the following cross-tabulations of the information.

FIGURE 82

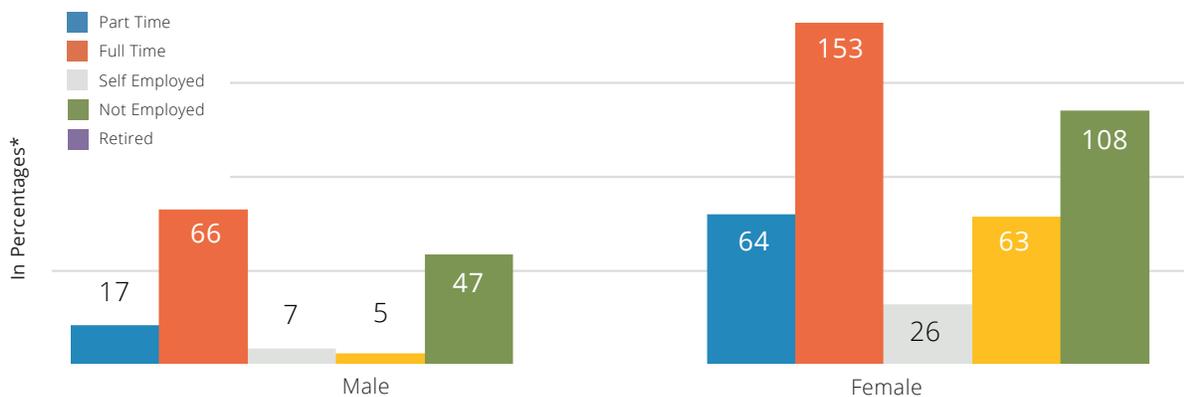
Employment Status and Age, 2017-2018



As the chart of the cross-tabulation of employment status versus age shows, the largest group of caregivers who are working fulltime or part-time are in the ages of 30 to 59 years of age. The number of working caretakers who are also in the labor market and work in the age range of 60 to 69 years is noteworthy.

FIGURE 83

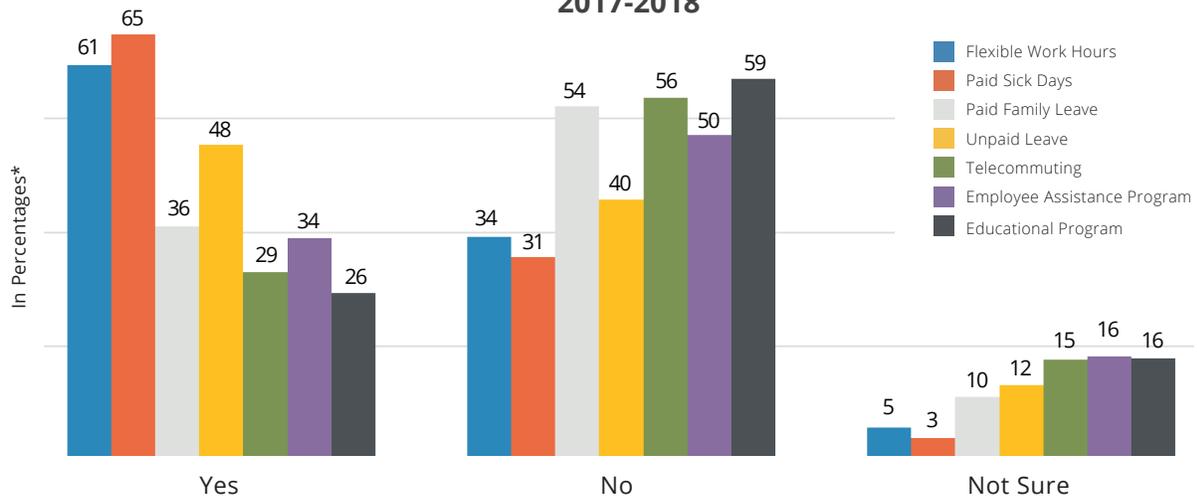
Employment Status and Gender, 2017-2018



Bearing in mind that 75% of caregivers responding to this survey are women, the proportion of men and women who are caregivers and have fulltime employment are compatible with a ratio of one to three. However, the number of women who are not employed when compared to men is somewhat disproportionate. This could be an outcome of lesser participation of women in labor market or the decision not to work while they are providing care. On the other hand, the proportion of women taking part-time jobs compared to men is also proportionate. These differences do not come as an exception to the labor force status related to caregivers and can be found when the employment status of men and women in areas such as Santa Barbara, or a good proportion of Ventura County, is analyzed. The importance of highlighting them in this study is to indicate how they are doing and this may help us to find better ways to assist the population of caregivers in their lives and in relation to their tasks.

FIGURE 84

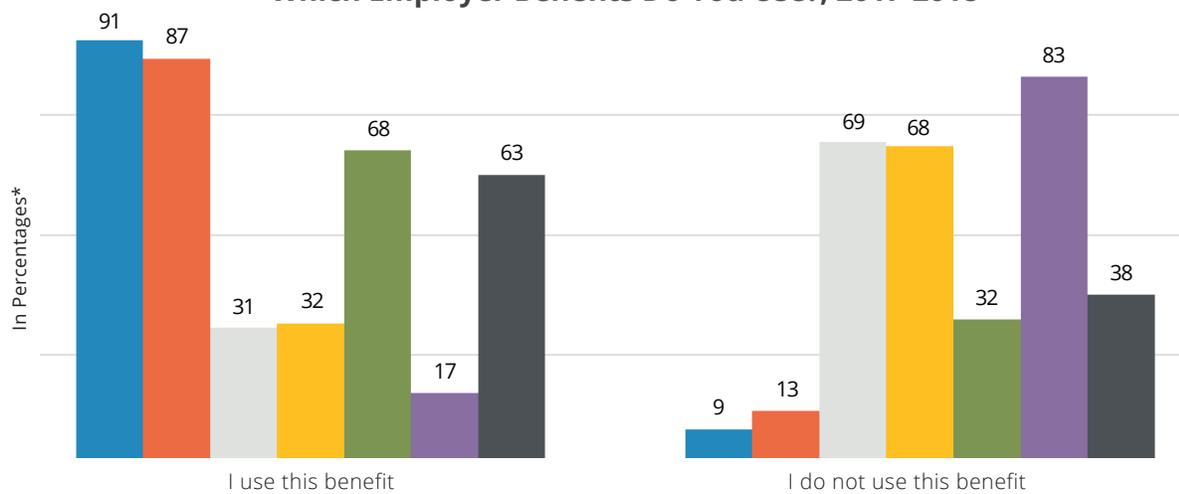
Does Your Employer Offer the Following Benefits for Caregivers?, 2017-2018



This provides an important insight into the working environment of caregivers who need to work, and at the same time, take care of the person or people for whom they provide care. Any of the listed benefits can be of great value to caregivers. A larger proportion of employers do not offer many of the services that support caregiving. It is hard to evaluate the work environment with any significant level of deficiency in any of the listed benefits. A more ideal situation calls for improvements in all the areas pointed out. However, there seems to be a great lack of benefits such as: telecommunication, educational programs for caregivers, employees' assistance, and paid leave which may affect caregivers more directly.

FIGURE 85

Which Employer Benefits Do You Use?, 2017-2018

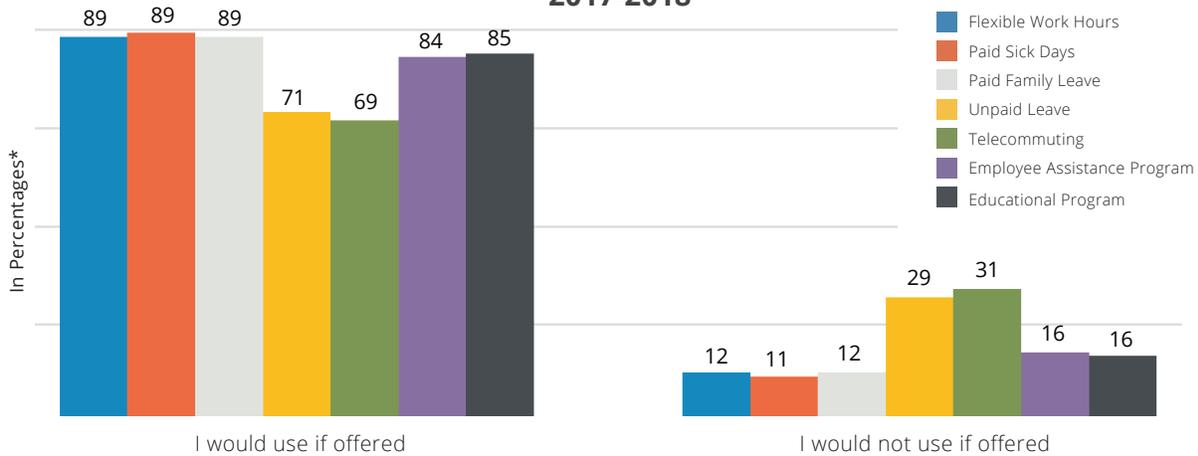


An overwhelming majority of respondents who work where these benefits are offered use flexible work hours and paid sick days. Telecommuting and educational programs for caregivers are also used largely by caregivers where they are offered.

*Values have been rounded to the nearest whole number.

FIGURE 86

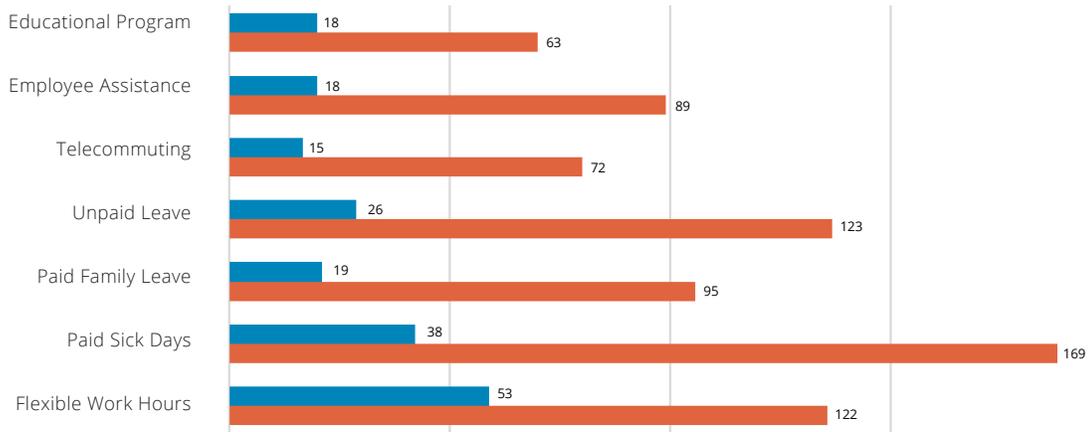
Which Employer Benefits Would You Use if They Were Offered?, 2017-2018



An overwhelming majority of workers would use the services listed, if their employers offered them. Among them, flexible work hours, paid sick days, paid family leave, and employee assistance programs are very popular, if they were offered. Over 70% stated that they would take unpaid leave, if the employers offered it.

FIGURE 87

Pattern of Benefits Taken by Fulltime and Part-time Working Caregivers, 2017-2018

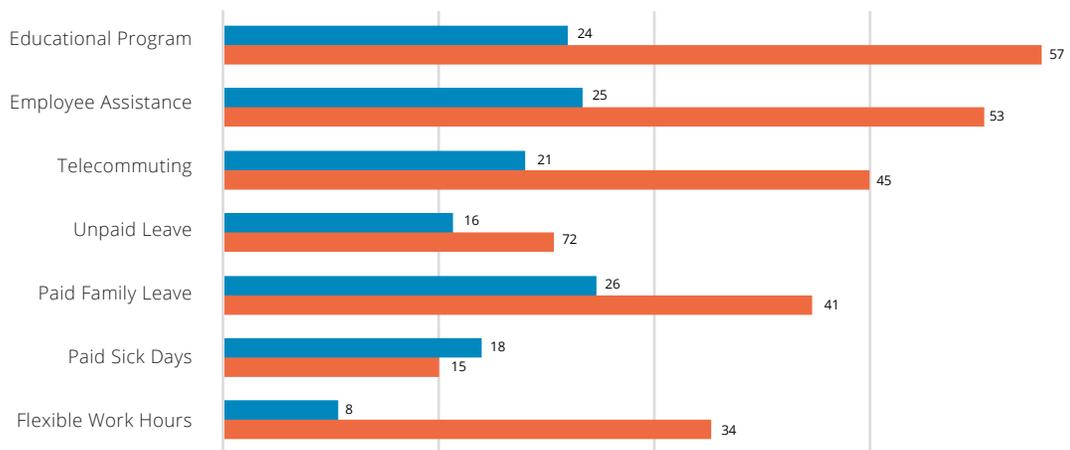


Paid sick days are the most frequent benefit taken by working caregivers. By comparing and contrasting the results of the cross-tabulation against the benefits offered that are taken or would be taken if they were offered, we could learn what can be helpful for working caregivers. There is no doubt that **telecommunication** has a great attraction to caregivers, and there is good potential for having a larger number of working caregivers using this benefit if it is offered in most institutions. **Employee assistance** is another area, which is very attractive, and if offered in more places, it would be used by working caregivers. The same can be said about **flexible working hours**.

*Values have been rounded to the nearest whole number.

FIGURE 88

Pattern of Benefits if They Were Offered in the Workplace, 2017-2018



The above chart underscores the attraction of educational programs, employee assistance, telecommunication, and flexible working hours.

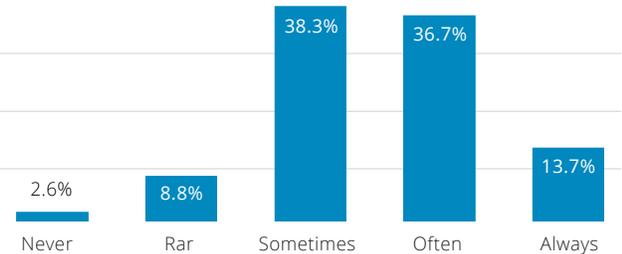


What Caregivers Are Doing to Take Care of Their Individual Needs

In this section of the report, we report the findings that can help us to find the areas of need of caregivers in order to be able to help themselves to the extent that they can as individuals with certain social, emotional, and health needs. The idea of looking into one's needs is crucial, as one cannot be helpful to others if one is in financial trouble, or cannot manage one's own life, health and emotions adequately. The other side of looking into such queries is to find what can be done within the community to help caregivers be content with their own life and able to help others in their care effectively.

FIGURE 89

How Often Have You Felt Stressed Because of Caregiving?

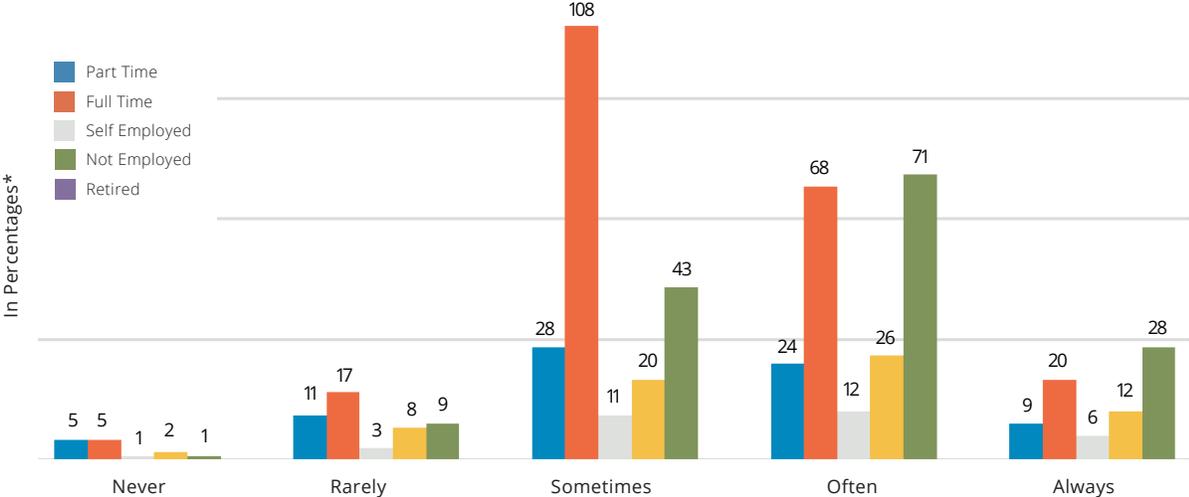


About 90% of caregivers have been under stress because of caregiving. Some 50% of the respondents have always or often been under stress.

In order to explore the issue of feeling stressed further, we cross-tabulated the feeling of been stressed against the employment status of respondents.

FIGURE 90

Employment Status and Stress Because of Caregiving, 2017-2018

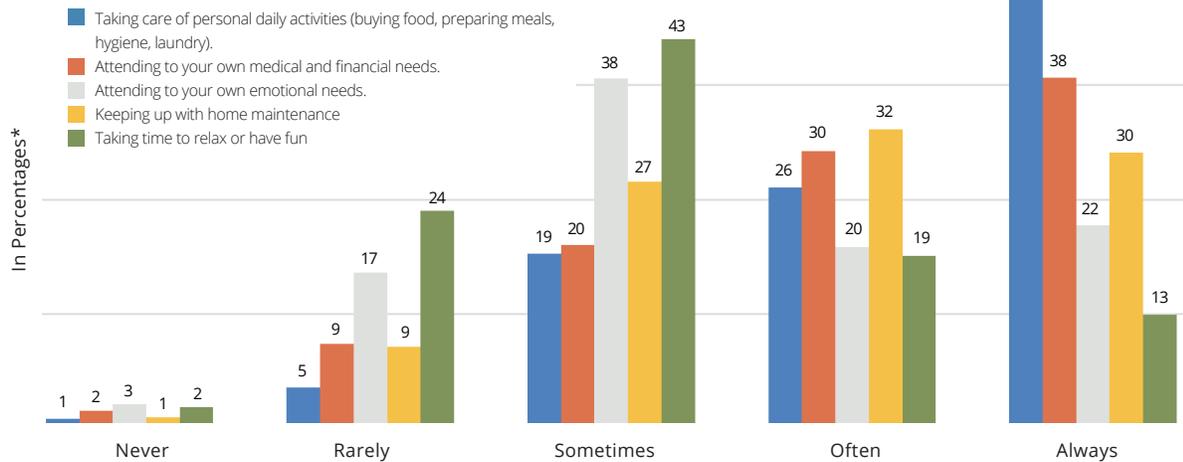


Proportionally, those who are retired feel stressed always or often as compared to other categories of respondents. The following chart shows the extent of the care that caregivers allow themselves to take advantage of as caregivers who may be in great need of care themselves.

*Values have been rounded to the nearest whole number.

FIGURE 91

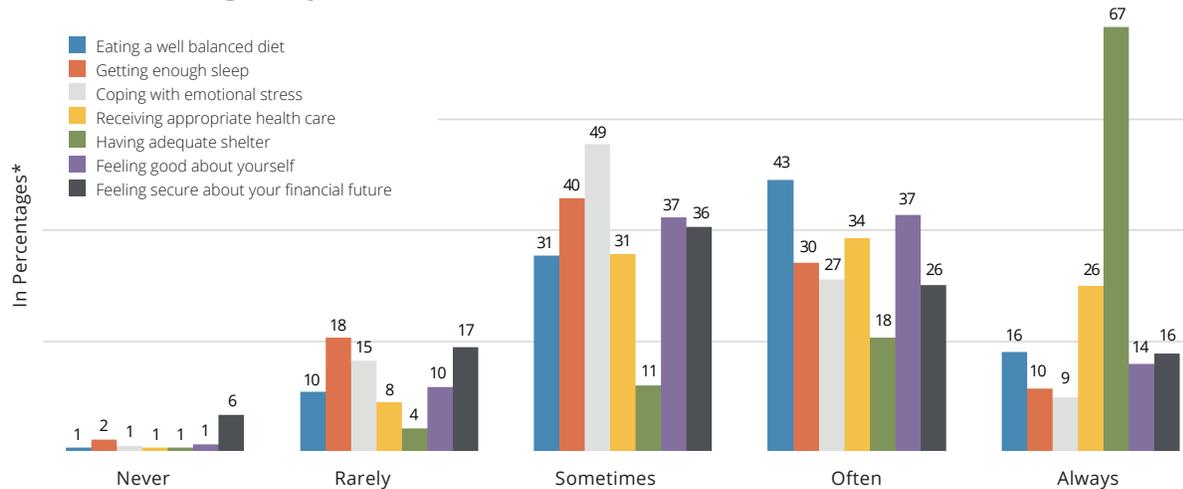
How Regularly Have You Been Able to Take Care of Yourself in These Ways?, 2017-2018



Examining the pattern in which respondents do take care of themselves and look after their needs is crucial. This leaves the sum of the never or rarely categories as the explored area, to which caregivers and families or employers of caregivers should be encouraged to pay attention. These categories of need are: taking time to relax, and attending to one's emotional needs.

FIGURE 92

How Regularly Has Each of These Needs Been Met for You?, 2017-2018

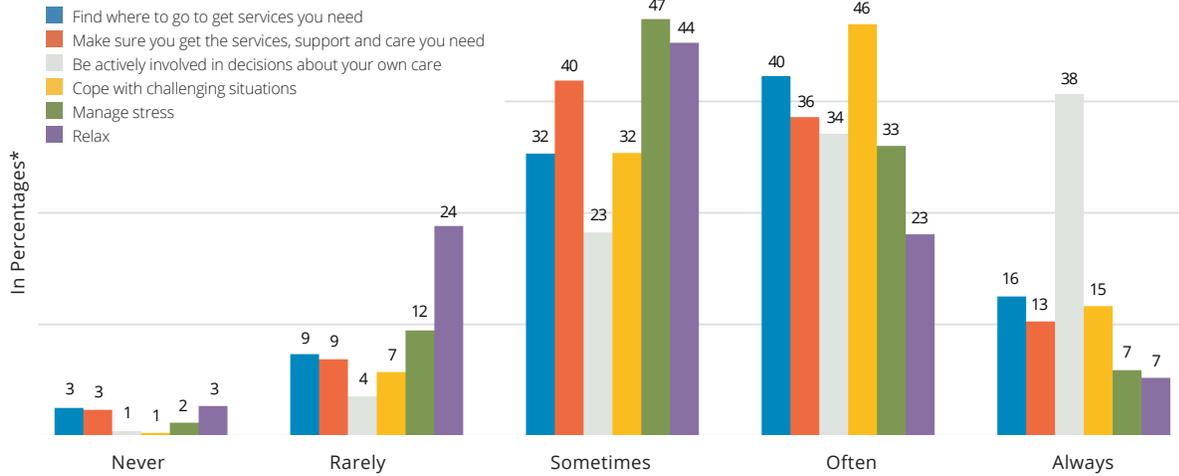


The above chart opens other areas of individual needs that caregivers should pay attention to in their daily life, and many of them are measures that can help them be better prepared as caregivers and individuals with their own needs. Once again, adding the percentages of the always and often categories depicts the area, which can show a comfort zone, and the rarely and never categories together represent the weight of forgetting one's own needs. In order to bring greater emphasis on the importance of meeting one's own needs, we added together the three areas of sometimes, rarely and never in order to find where the critical area of neglecting oneself emerges.

*Values have been rounded to the nearest whole number.

FIGURE 93

How Regularly Have You Been Able to Take Care of Yourself in These Ways?, 2017-2018

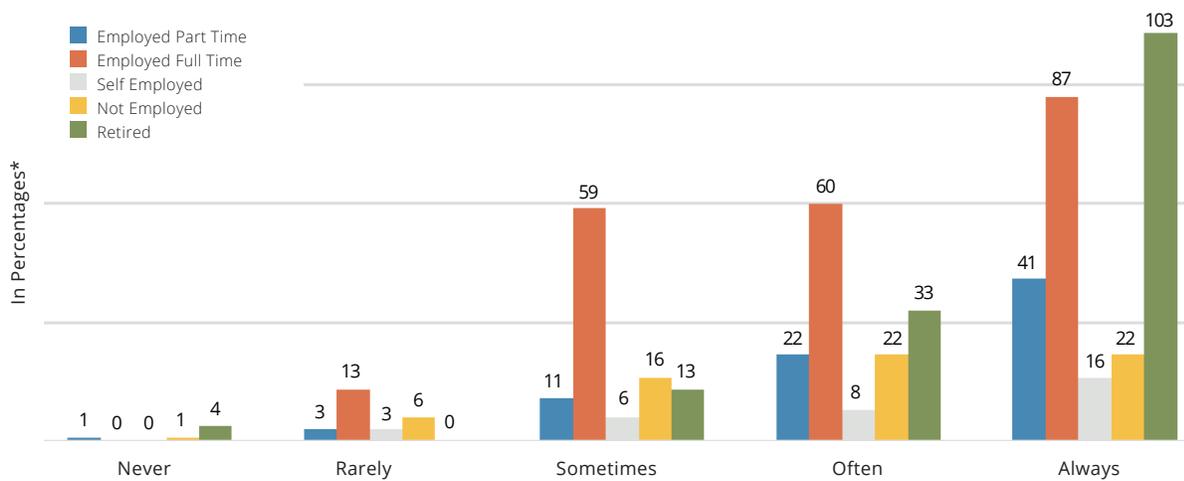


Using the same method of analyzing the findings in the above graph, we realize that relaxing, managing stress, making sure one gets the service and support one needs, and coping with the challenging situation appear to be in need of more attention.

In order to look further into the steps taken by the caregivers to help themselves to better withstand the pressure of caregiving with or without employment, we compiled the following information from the cross-tabulation of the available data.

FIGURE 94

Employment Status and Taking Care of Personal Daily Activities, 2017-2018

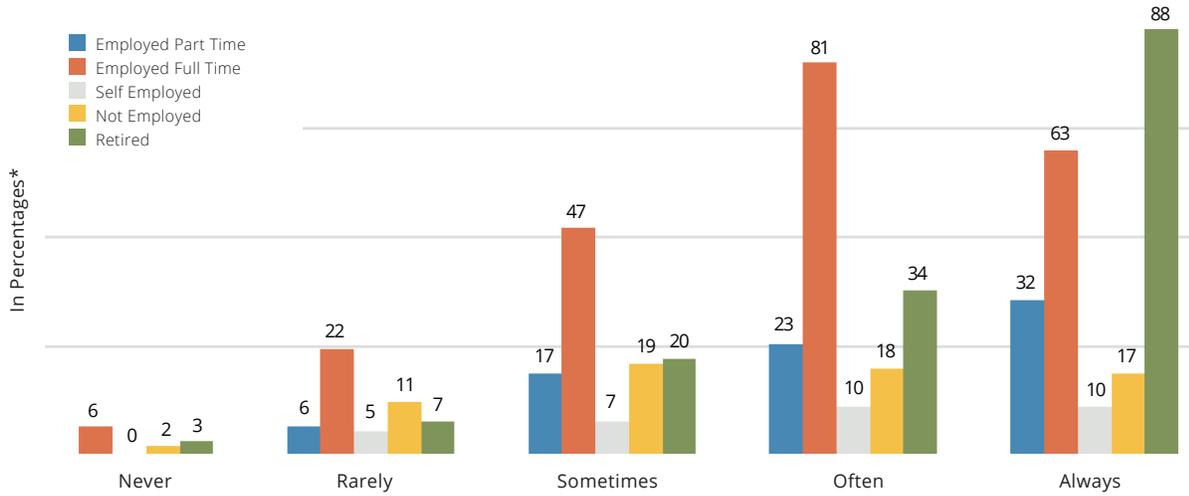


The chart clearly shows that **people with fulltime employment are more likely to be neglecting taking care of their daily activities.**

*Values have been rounded to the nearest whole number.

FIGURE 95

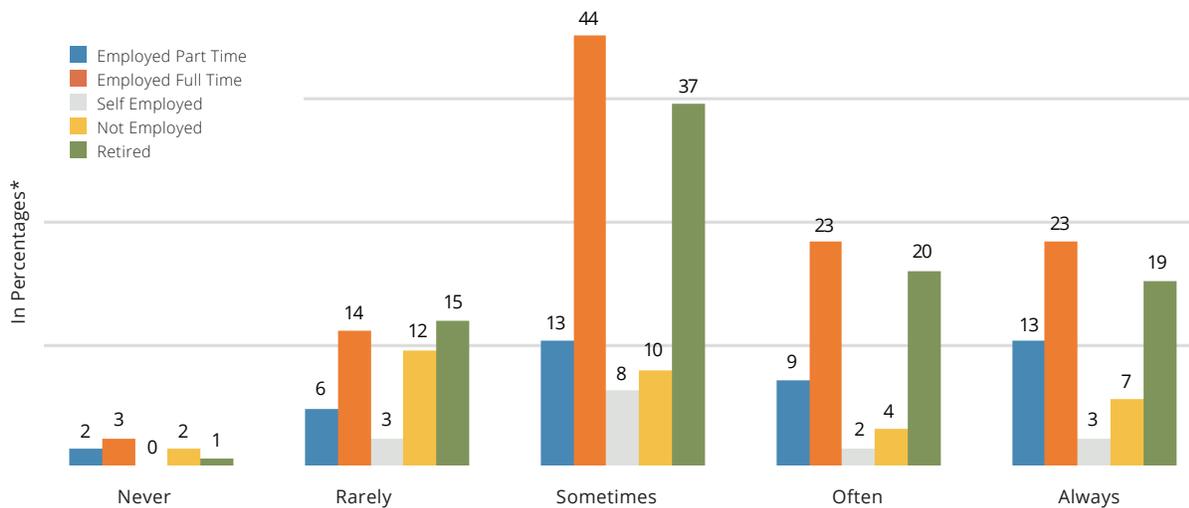
Employment Status and Attending to Your Own Medical and Financial Needs, 2017-2018



Once again, caregivers working full-time are less likely to attend to their own medical and financial needs.

FIGURE 96

Employment Status and Attending to Your Own Emotional Needs, 2017-2018

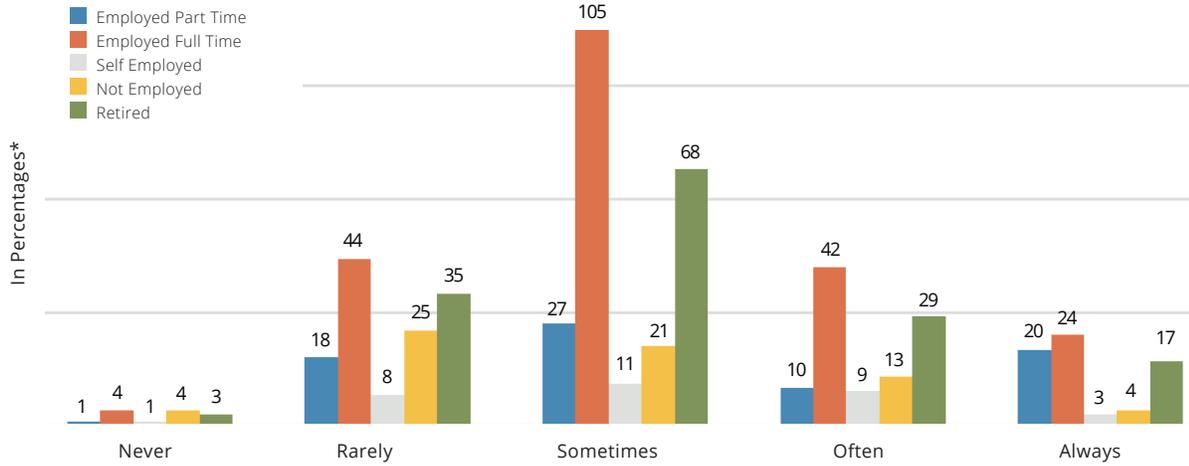


Attending to caregivers' emotional needs seem to be less impacted by employment status. A relatively higher proportion of caregivers in all categories of employment seem to be less attentive to their own emotional needs if we add up the status of sometimes, rarely and never together.

*Values have been rounded to the nearest whole number.

FIGURE 97

Employment Status and Attending to Your Own Emotional Needs, 2017-2018

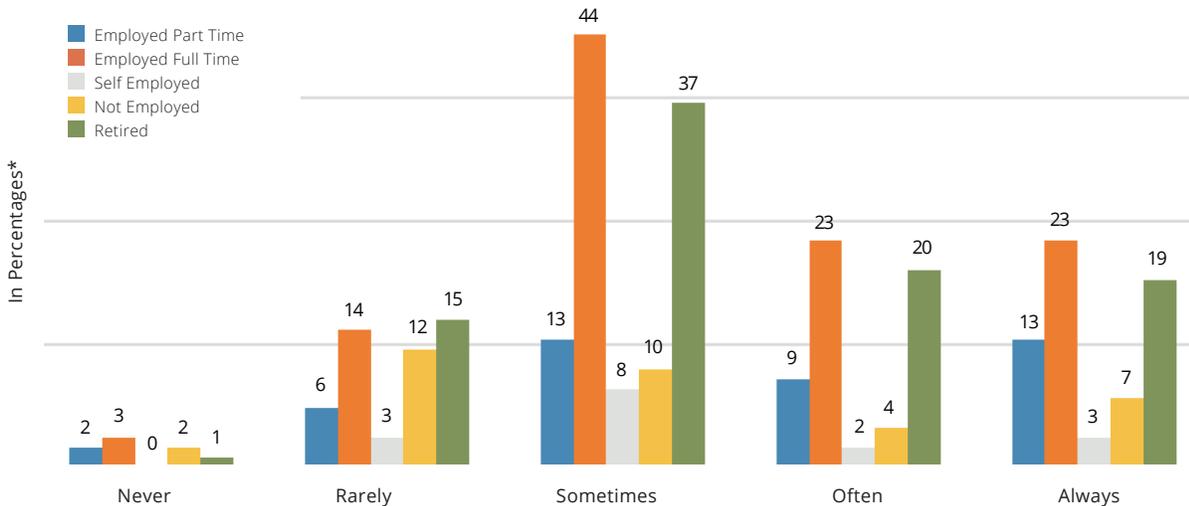


The pattern in the above chart shows that being a caregiver in general leaves less time for relaxing or having fun with friends and family, allowing the caregiver to enjoy oneself. However, it is clear that proportionally, there is much more pressure on those who work fulltime.

The line of investigating how being a caregiver and working at the same time was reviewed and a number of additional cross-tabulations and selected a number of additional information sources were run to report on this study.

FIGURE 98

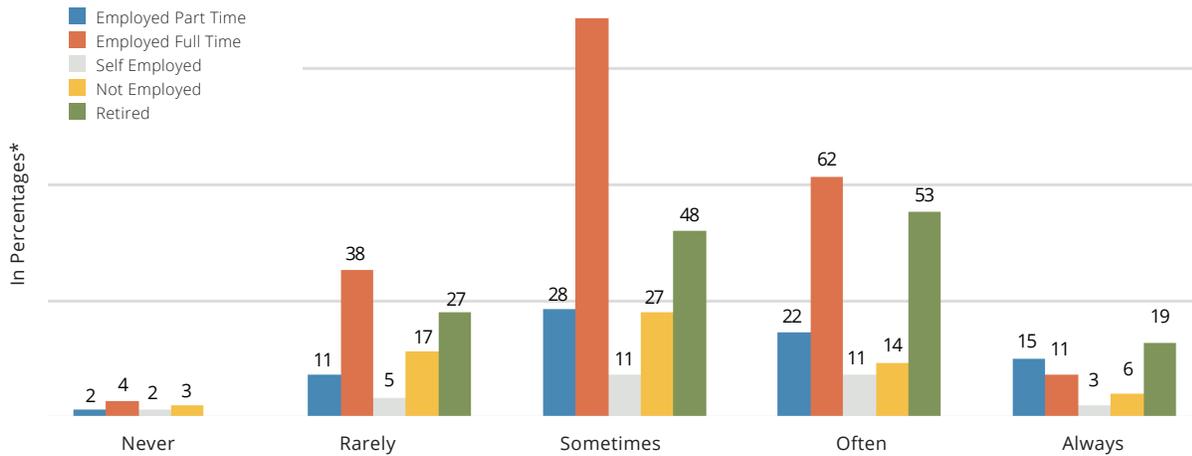
Employment Status and Eating a Well Balanced Diet, 2017-2018



*Values have been rounded to the nearest whole number.

FIGURE 99

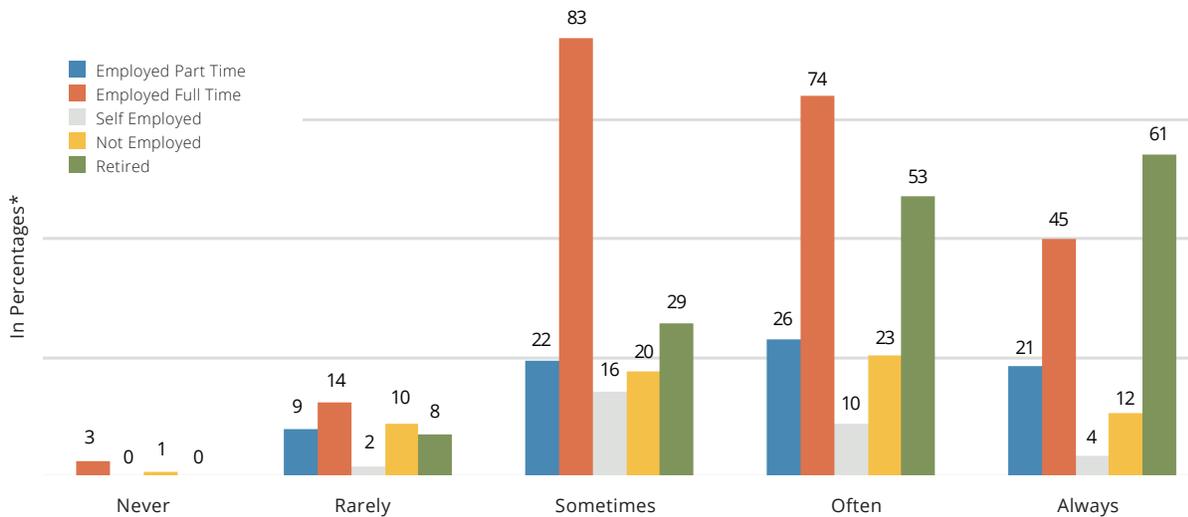
Employment Status and Getting Enough Sleep, 2017-2018



The last two charts present the same pattern, which have been emerging in a number of earlier charts. It appears that all categories of caregivers, based on their employment status, hardly ever get enough sleep. However, the plight of caregivers with fulltime employment is far more dire than other categories. Getting enough sleep is an observation. Getting enough sleep impacts one's overall health, reduces stress, and enables a person to be more focused and ultimately better able to help persons under their care.

FIGURE 100

Employment Status and Receiving Appropriate Health Care, 2017-2018

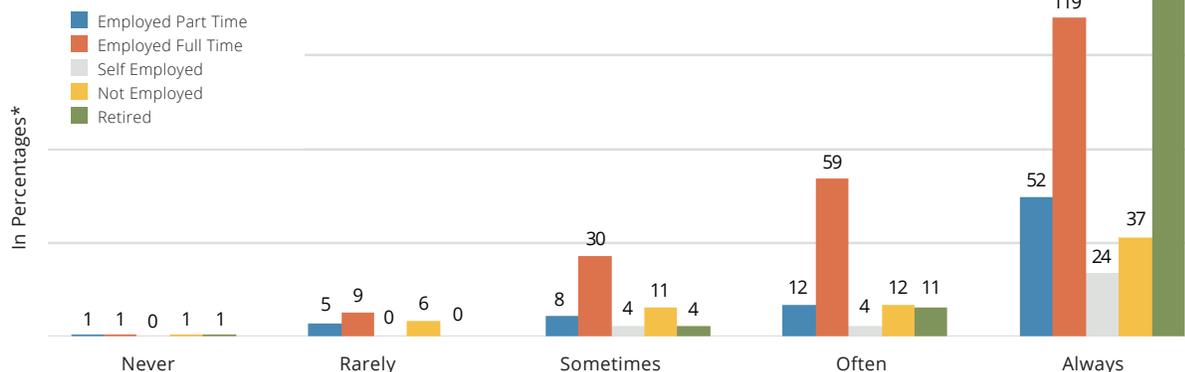


Caregivers who are retired seem to be enjoying a much better environment with regard to receiving appropriate health care for themselves. It could be said that **fulltime workers who are caregivers seem to be relatively more challenged with regard to receiving appropriate health care.**

*Values have been rounded to the nearest whole number.

FIGURE 101

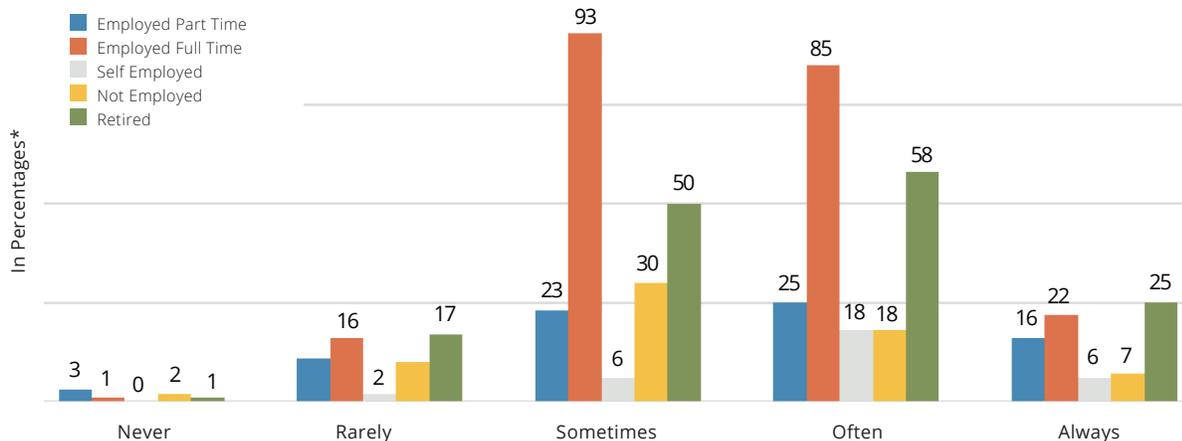
Employment Status and Having Adequate Shelter, 2017-2018



The above chart shows that almost all retired caregivers appear to have adequate shelters always or often. This is also true about most other categories, except fulltime workers and a limited number of those who are not employed. We should bear in mind that this survey is not based on a randomized selection of caregivers and therefore its findings cannot be used to make an inference applicable to the entire population. However, those who participated in the survey are groups selected based on their involvement as caregivers which represent a variety of conditions and life circumstances and, therefore, are very valid for appropriate policy decisions and social and community interventions.

FIGURE 102

Employment Status and Feeling Good about Yourself, 2017-2018

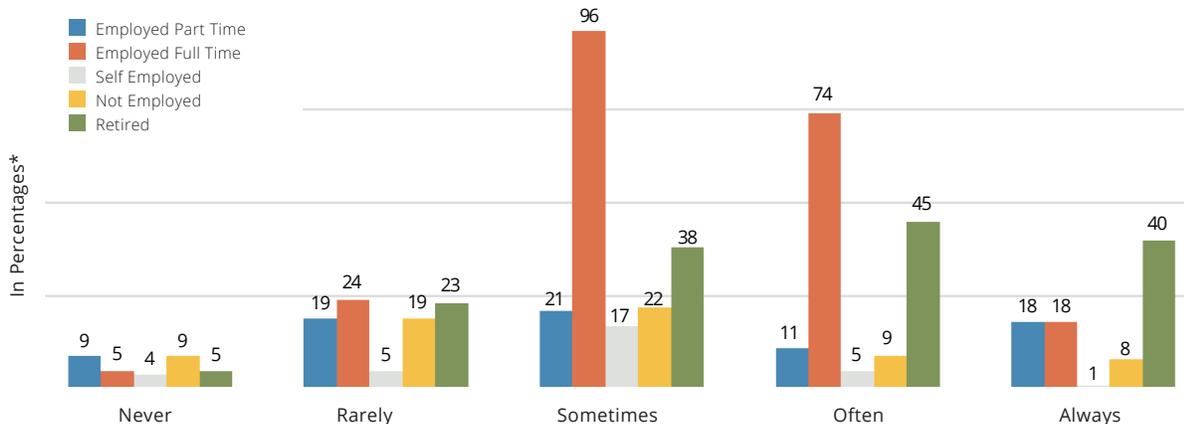


The findings expressed in the above chart are to some extent rather alarming and are a cause for concern. In general, the findings show that a large number of caregivers feel good about themselves only sometimes. A noticeable number, which includes both those employed in part-time work and caregivers who are retired, feel rarely good about themselves. The cause of such feelings should be further studied and looked into for appropriate solutions.

*Values have been rounded to the nearest whole number.

FIGURE 103

Employment Status and Feeling Secure about Your Financial Future, 2017-2018



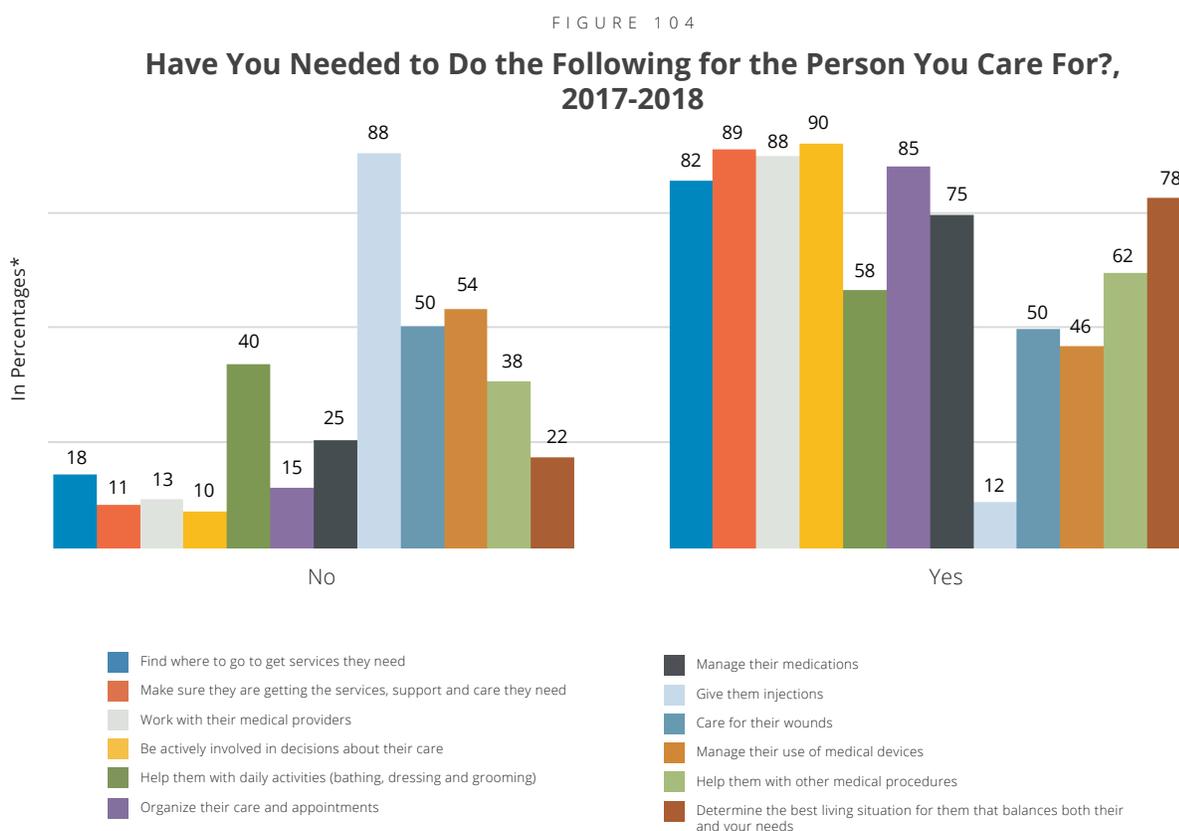
One's financial future is an important concern for millions of American families and unfortunately, economic uncertainty for many lower and middle income families have made it even more troubling. This question may bring greater concern among those who are caregivers. The above chart confirms such uncertainty among all categories of respondents.



*Values have been rounded to the nearest whole number.

What Can Be Done To Help Caregivers to Meet the Needs of Their Care Recipients

In this section, we brought attention to what the combined surveys find with regard to the needs of care recipients as they pertain to measures and actions taken by their caregivers.



The above chart presents a number of actions that caregivers take in helping people under their care. They cover a range of services that may be needed or not based on the extent of their care recipients' needs. Not doing a particular service is not necessarily a function of a lack of service when needed. For example, dressing and caring for wounds may not be required for all or even a major proportion of care recipients. This list may bring attention to another important point, that being the ability of caregivers to provide a particular service. The latter is a function of being prepared and having the opportunity to be trained for such services.

Based on the findings, only 11.8% of caregivers give injections. 45.9% of caregivers help their care recipients with managing the use of medical services. Slightly less than 50% care for their wounds.

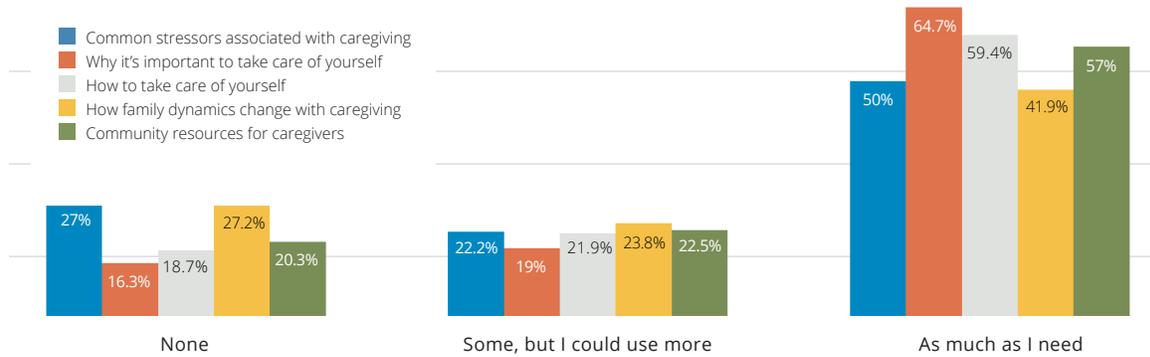
*Values have been rounded to the nearest whole number.

“

Information about “how family dynamics can change with caregiving” and “community resources for caregiving” can be considerably strengthened.

FIGURE 105

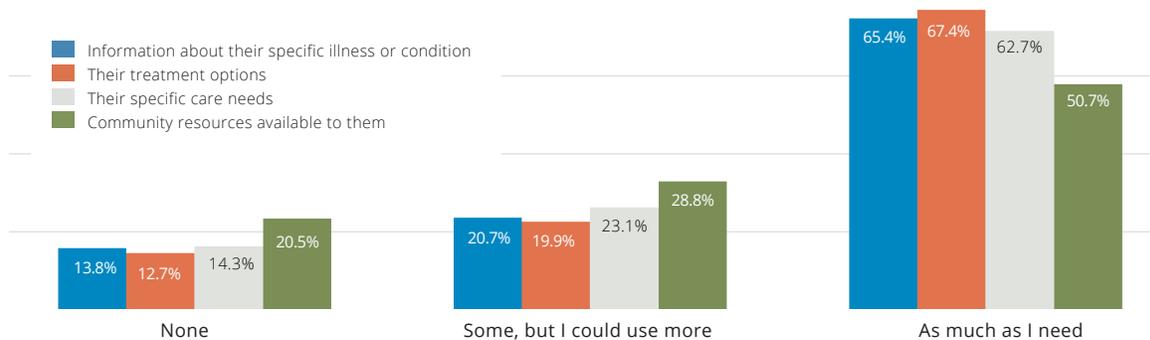
How Much Information for Caregivers Have you Received on the Following Topics?, 2017-2018



In general, caregivers have received a fair amount of information in a number of important areas, which can impact their wellbeing in a significant way. At the same time, the areas which show “none” or “some but I could use more” together indicates in what areas more or much more can be done. In general, we can say that more information in all five areas of attention is needed. However, areas indicating **information about “how family dynamics can change with caregiving” and “community resources for caregiving” can be considerably strengthened.**

FIGURE 106

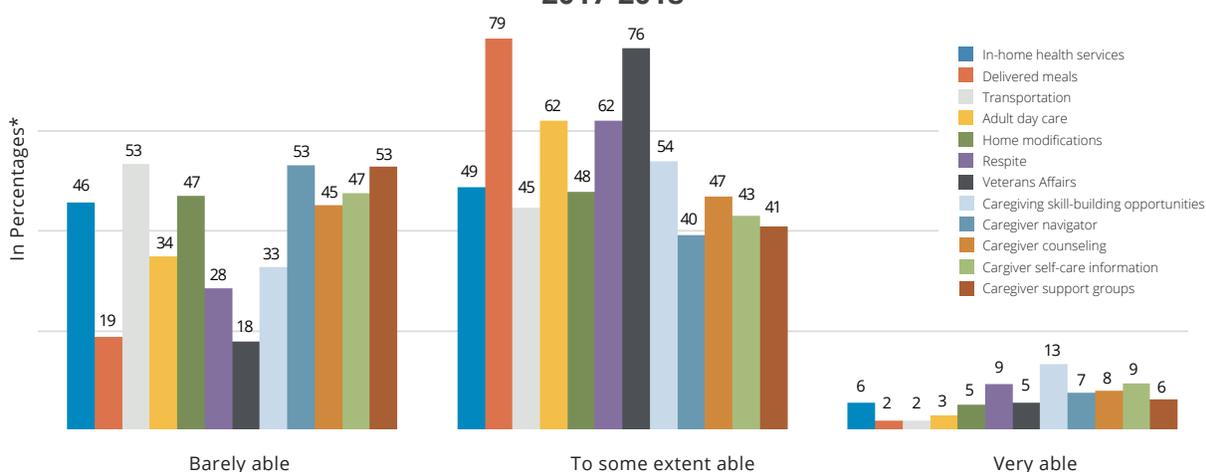
How Much Information Have You Received about the Person You Care for on the Following Topics?, 2017-2018



In general, caregivers have been receiving a fair amount of information about the person they care for. However, much more can be done in order to provide them with more information that they need. Once again, information about “community resources available to them” has a much greater capacity for improvement.

FIGURE 107

Did you or the Person You Care for Need any of the Following Services?, 2017-2018

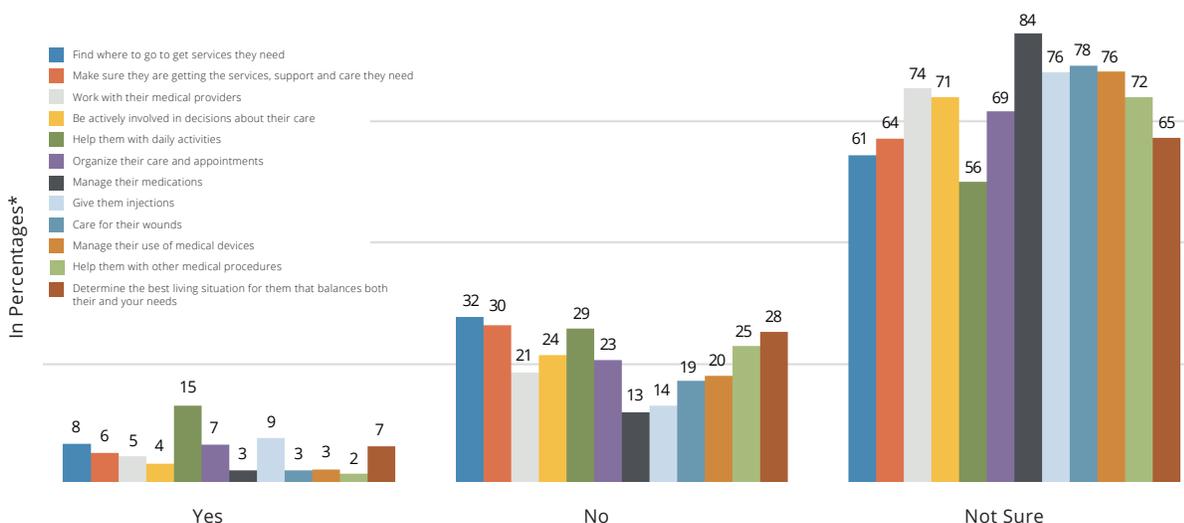


The relevance of the above chart is to find out the level of assistance that caregivers have been receiving. A quick comparison between the percentages of “yes” and “no” can tell us what has been achieved as well as the potential for improvement. The areas in need of much more attention include:

- Deliverable meals
- Adult day care
- Respite (e.g. short-term care for your loved one)
- Veteran affairs
- Caregiving skill-building opportunities

FIGURE 108

How Able Were You to do the Following for the Person You Care For?, 2017-2018

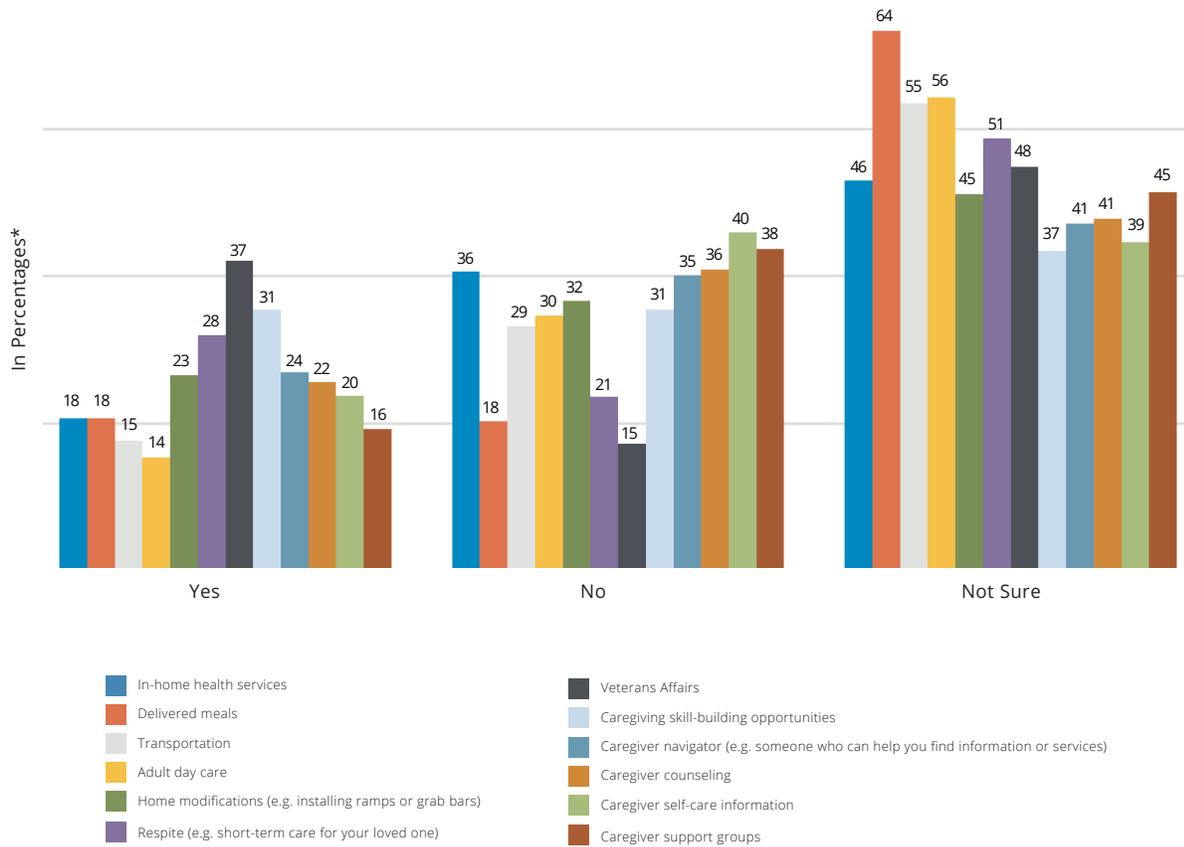


The above chart provides an extensive list of services that one can provide for the person or people under their care. In general, caregivers were unsure if they were able to provide the care needed for their care recipients.

*Values have been rounded to the nearest whole number.

FIGURE 109

Were the Following Services Available, and Did You or the Person You Care for Use Them?, 2017-2018



This chart reflects that large percentages of caregivers were unsure if they would use the various social services available in the community. This may suggest that in this area (e.g. the availability of available services that the caregiver or the person under care can use) has not been communicated very well. There is, however, a very small proportion of people using these services to some extent. In both cases, there appears to be a need for better communication and finding ways to make these services functional and effective in the lives of caregivers and care recipients.

“

There appears to be a need for better communication and finding ways to make these services functional and effective in the lives of caregivers and care recipients.

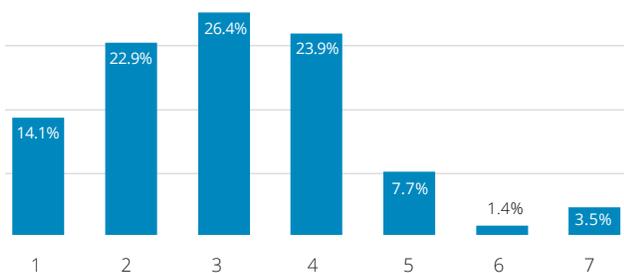
*Values have been rounded to the nearest whole number.

Evaluating the Effectiveness of the Help and Services Received

In this segment of the study, we looked into the information that can shed light on the effectiveness of the measures taken and services available.

FIGURE 111

How Many Organizations Did You and the Person You Care for Receive These Services or Support to Caregivers?, 2017-2018

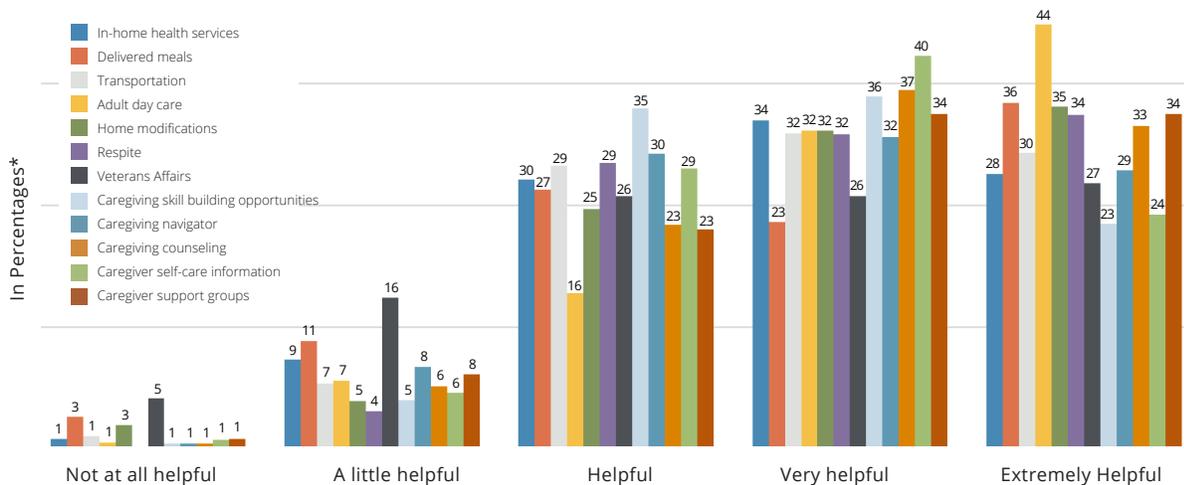


The above chart provides more information on the availability of services through existing institutions. It is hard to associate the higher number of institutions offering services as a clear indication of a higher level of services offered. Nonetheless, the functioning of any infrastructure to some extent depends on the existence of choice in the offerings of institutions, which in turn depends on a higher number of institutions which offer such services. Fewer institutions offering services could also mean improvements may occur within a narrow perspective and offering services may become somewhat easier.

Based on the information presented in the chart, some 14.1% of caregivers did not receive any services from any organizations. About half of the respondents (49.3%) received services from one or two organizations. About 5% receive services from five or more organizations.

FIGURE 112

How Helpful Were Each of These Services Received?, 2017-2018

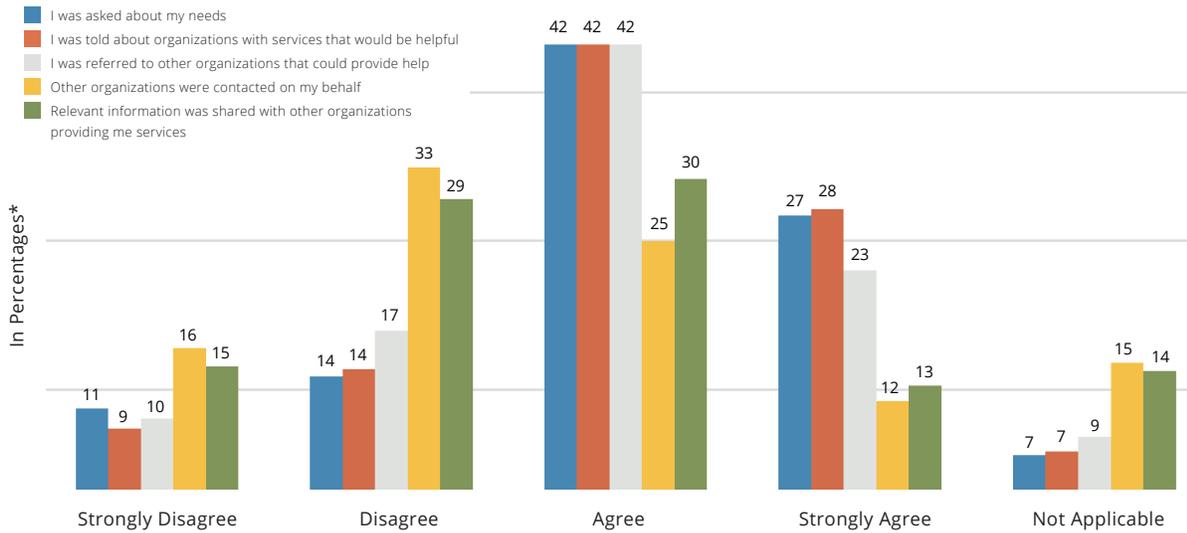


With some differences, the level of satisfaction regarding services received has been positive. By comparison, the level of satisfaction from veteran affairs has been less, though nonetheless, still quite satisfactory.

*Values have been rounded to the nearest whole number.

FIGURE 113

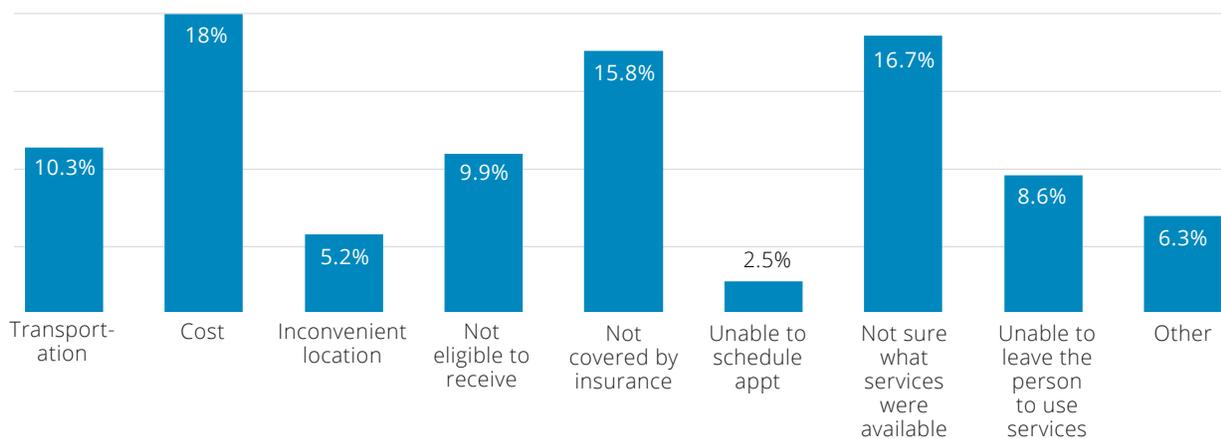
Thinking About the Services Received, How Much do You Agree with the Following Statements?, 2017-2018



Adding the levels of “strongly agree” with “agree” together and allowing for “not applicable” to be used, we discovered that there is a significant level of agreement for most of the statements. However, one can see some level of reservation about the statements concerning “I was asked about my needs” and “I was told about organizations with services that would be helpful.”

FIGURE 114

What Challenges, if any, Did You or the Person You Care for Have Using These Services?, 2017-2018

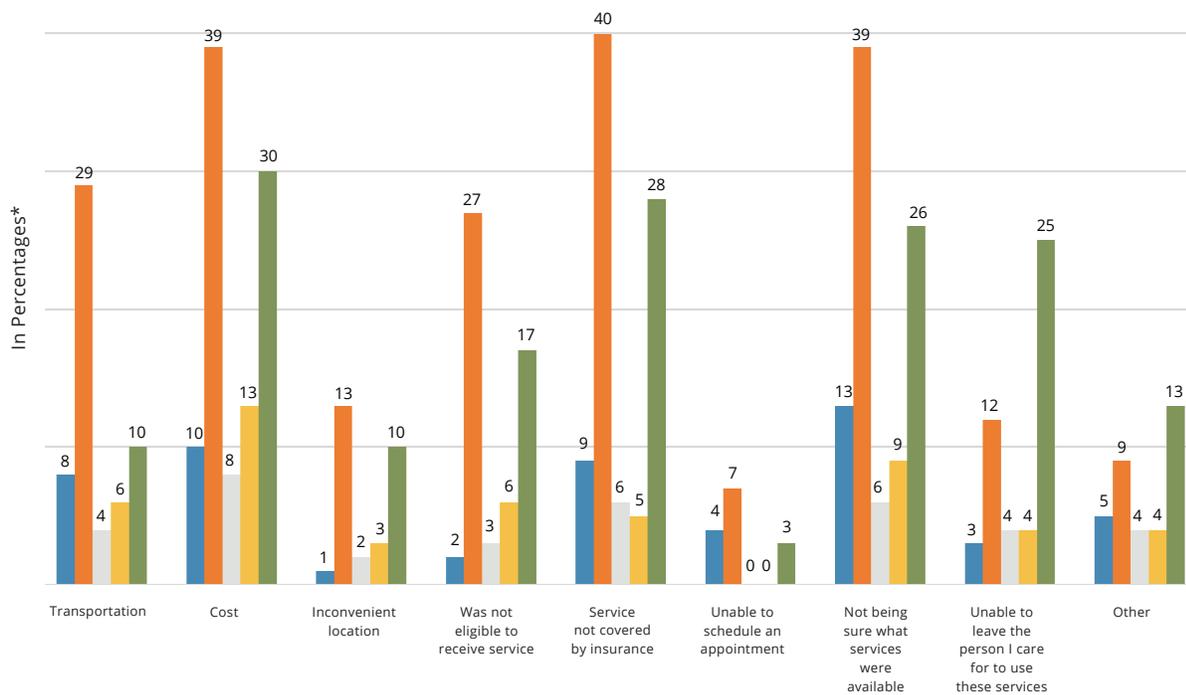


The information presented in the above chart is very informative. Overall, the percentages of responses to various questions are relatively low, and this is very encouraging. However, cost appears to be the most recognized challenge. Services not being covered by patients’ insurance is also noteworthy, which unfortunately appears to be emerging in many areas of healthcare during the last few years. Not knowing or being sure what services were available is a challenge for a considerable proportion of caregivers.

*Values have been rounded to the nearest whole number.

FIGURE 115

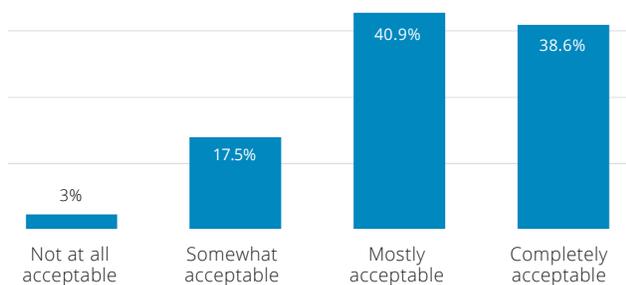
Employment Status and Challenges to Use Caregiving Services, 2017-2018



Adjusting the number of responses to the size of the respondent group will bring us to the conclusion that cost is a common concern for all involved. However, cost is more of a concern for the group who are retired or are not employed.

FIGURE 116

How Acceptable Were Services Received (Thinking About Your Language, Cultural Background, Religion, Sexual Orientation, and Age)?, 2017-2018



Findings show a relatively positive result. The level of acceptance was about 80%, which is positive. There was, however, a considerable area for improvement. In order to know how to move forward and bring improvement about, it may be helpful to itemize the areas of inquiry. These areas are all important and the sources of said challenges may range from the attitudes of people offering services, to institutional policies which prevail over care, and finally the level of preparedness within service provider organizations.

*Values have been rounded to the nearest whole number.

FIGURE 117

How Much Do You Agree with the Following Thinking About These Services?, 2017-2018

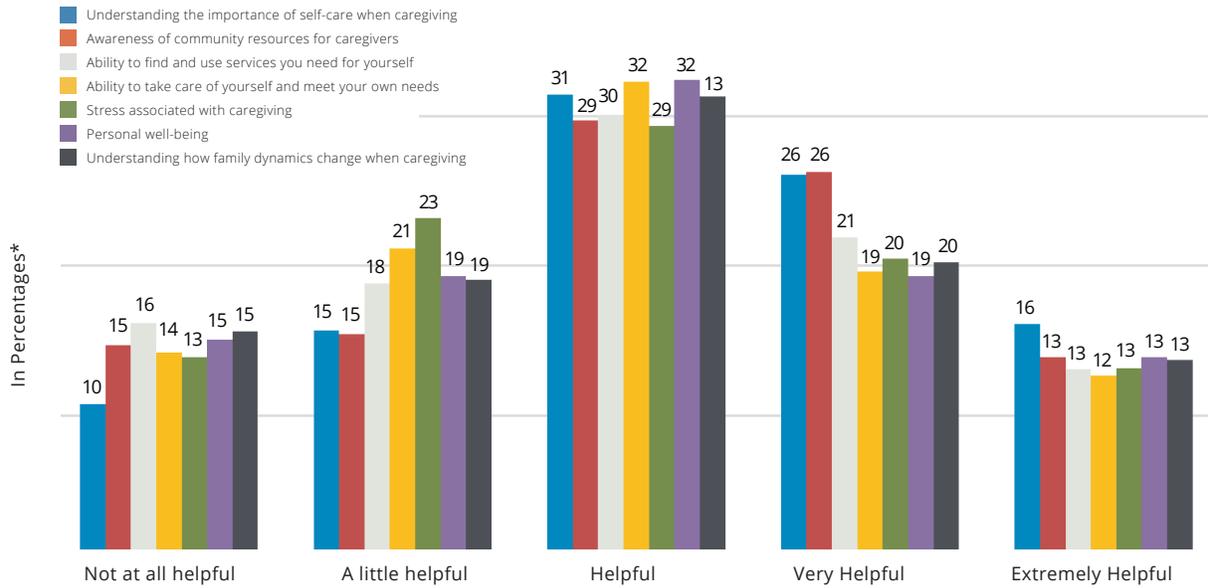
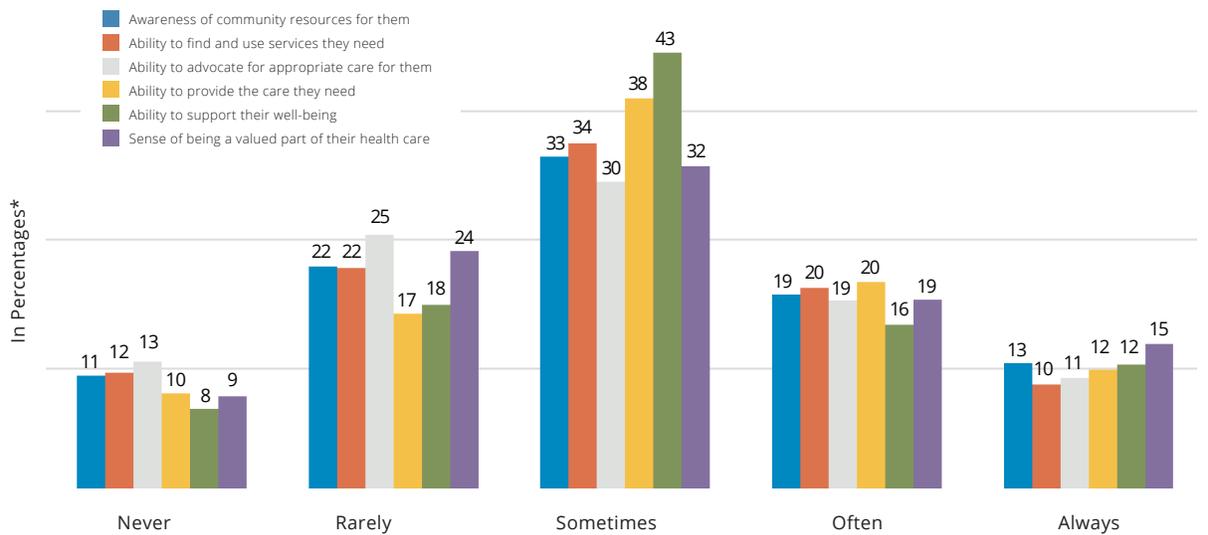


FIGURE 118

How Helpful Were The Following in Improving Your Caregiving?, 2017-2018

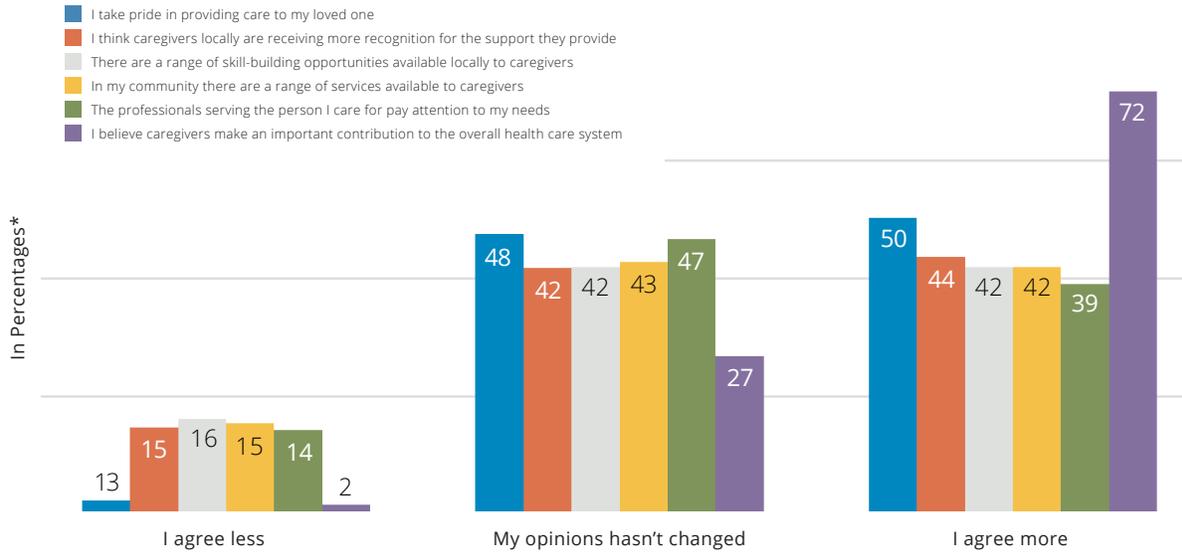


We have good reason to work on all areas of inquiry based on the pattern that has emerged and has been presented in the above charts. The objective was to ensure that services were at least helpful. The pattern of responses stated as “a little helpful” and “not at all helpful” indicate where the focus should be. Based on such criteria, we need to bring about improvement in all areas.

*Values have been rounded to the nearest whole number.

FIGURE 119

How Much Have These Service Experiences Changed Your Opinions about the Following?, 2017-2018



The pattern presented in the above chart shows how much the experience of receiving such services has changed the perception and the opinions of the caregivers. In most areas, the experience has changed minds of caregivers. The most significant change occurred in believing caregivers make an important contribution to the overall healthcare system. There is, however, an important observation that one has to make with the conclusion that can be drawn from those who have said “my opinion hasn’t changed.” The idea of not having an opinion changed can mean that they already believed in the importance of these statements and felt that nothing has changed, or they have not been convinced that these areas are important. In retrospect, not having a clear direction in the point of this question makes the interpretation of the findings difficult.

However, the respondents that indicated they agree less should be interpreted as a negative development. As such, we need to look deeper at four areas where respondents indicated that response after experiencing the services they received.

“

The experience of receiving supportive services has changed the perception and the opinions of the caregivers in believing they that make an important contribution to the overall healthcare system.

*Values have been rounded to the nearest whole number.



5

Summary Conclusion,
Takeaways and Ideas for
Further Consideration

This study takes a broad range of economic and social issues that are likely to impact the lives of millions of Americans as caregivers and recipients of long-term care. They include issues that impact everyone within the nation and issues that are focused on Ventura County and its neighboring community, Santa Barbara County.

In order to conclude this discussion, we placed our findings, takeaways, and ideas for further consideration into a table, where each segments are itemized in a clear fashion. We then went further and proposed what the next steps can be.



Summary of Findings and Takeaways

Overall Information About Challenges to Caregivers and Care Recipients

SOURCE OF CHALLENGES



National Trends:

- The share of Millennials and Gen-Xers together is larger than Baby Boomers and the mature generations. They provide 56% of the care needed at the present time.
- AARP's report, *Caregiving in the U.S.* (2015) states that some 43.5 million adults in the U.S. (about 18.2% of Americans over the age of 18) reported that they have provided unpaid care in the previous 12 months.
- It is expected that the ranks of family caregivers will grow due to the population aging, increasing longevity, and the growing number of individuals with chronic conditions associated with an aging population such as Alzheimer's disease and related dementias (ADRDs), and the increasing cost of LTSS.
- A higher proportion of both caregivers and care recipients are women. A high proportion of care recipients are 75 years old or older. This segment of the population is expected to experience a much higher rate of growth than the younger group of population.
- According to the 2015 AARP survey, the highest proportion of caregivers are between the ages of 50 to 64 years (34%). There are, however, a high proportion of caregivers who are between 18 to 34 years of age (24%) and an equally high proportion who are between 35 to 49 years of age (23%). Some 19% of caregivers are 65 years of age or older (7% older than 75 years of age).



“

The ranks of family caregivers will grow due to the population aging, increasing longevity, and the growing number of individuals with chronic conditions



Local & Regional Trends:

- In Ventura County, the population of that is 85 years of age and older will increase by 294.2% by 2060.
- The population that is 65 years of age and older will increase by 85.3% by 2060. • The proportion of people with disabilities will increase from 13% in 2017 to 31% by 2060.
- A significant number of people with disabilities participate in the labor market and work.
- Being disabled often does not correlate to an inability to work. However, the work place must be a suitable environment and, to the extent possible, suitable for the needs of people with such disabilities.
- In 2017, some 23,756 people, or 2.8% of the Ventura county's population, were disabled and living below 200% of the federal poverty level. A significant proportion of these people were between the ages of 18 and older.
- The overwhelming majority of the older population in Ventura County is white. There are, however, sizable populations of older Hispanics and Asians.
- The older population in Ventura County is well-educated. There are, however, a considerable number of the older population whose educational attainment is below a high school diploma or GED.
- In 2017, there were over 50,000 of the older population (60 years of age and older) who had one or more disabilities in Ventura County.
- Some 31% of people aged 60 years and over are employed. There are more than 2,500 people 60 years old and above who were looking for a job and could not find one in 2017.

POSSIBLE CONSEQUENCES & WAYS TO REMEDY THE CHALLENGES



Steps to Bring Remedy:

- Informing the public about the upcoming waves of changes that will impact their lives fundamentally over the next few decades.
- Providing long-term care needs to be compatible with taking care of children.



- The essence of change is becoming a caring community with a vision, ideas, and convictions for bringing about the change needed.
- Put efforts to change policies in at all levels and start with local policies.
- Bring the business sector into the list of advocates for change and count on helping them to understand the benefits of it for their own success.
- The obvious consequence is a decisive shift of the burden of economic support from a larger segment of the population to a relatively smaller proportion of population.
- As populations age and grow more slowly, the GDP and national income growth will most certainly slow down, but the effect on individuals—as measured by per capita income and consumption—may be quite different. A graying population will mean more old-age dependency, to the extent that these people cannot support themselves by relying on their assets or their own labor. Nevertheless, it may also bring more capital per worker and rising productivity and wages, particularly if government debt does not crowd out investment in capital (Lee 2016).
- The important issue is that a nation, like a family, should think about what is likely to occur in the years to come and put in place a macroeconomic framework that is capable of meeting its needs. That requires change in our federal government policies.

Areas of Needs & Challenges

SOURCE OF CHALLENGES

- A national survey found that for 49% of people who were in the role of a caregiver did not have an option to become one.
- According to the CDC, the population who needed personal care fluctuated from 1997 to 2017 within a relatively narrow range of six to seven percent.
- According to the CDC, during the same period of time (1997 to 2017), the rate of hospitalization fell. The decline may be due to better care and the ability to reduce the needs for hospitalization.
- According to national surveys, there is a high rate of inaccurate estimations of the need for some form of ongoing living assistance in our lifetimes. The large rate of underestimation applies to all age categories of respondents, and in particular, the younger group of respondents.
- The rate of homecare workers per 1,000 adults aged 75 and older is increasing continually. Bearing in mind that the number of the older population aged 75 and older will increase rapidly in the decades ahead, we can conclude that as it stands, there seems to be an emerging reduction in the proportion of caretakers per group of older adults in need.
- There will be a relatively sharp rise in the number of people with Alzheimer's over the next three decades. This projection is primarily based on demographic changes and the rise in the number of older Americans.
- There is a wide variety of medical and other types of assistance that caregivers need to provide.
- Transportation and other duties to keep a house running are among the most likely needs for the overwhelming majority of care recipients.
- Some 57% of respondents to national surveys have stated that they need help with medical or nursing tasks.
- According to a national survey (AARP), some 55% of respondents need to perform some medical or nursing tasks.
- Some 42% of respondents are not trained for such tasks. If we apply this proportion as given by those who need to perform such task, we get 55% who need to perform said tasks but lack training.
- The proportion of those who perform the task but are not trained will reach 76%.
- In other words, 76% of those who perform medical or nursing tasks are not trained for such tasks. Overall, only 14% of respondents said that they take on such tasks and have been trained for it.

- Again, taking the ratio of 55% as those who have to perform medical or nursing tasks, the percentage of those who perform the tasks and are trained for them reaches 25%.
- Finally, from the same survey, we learned that some 60% of respondents would like to have a qualified person to show them how the work is done. In response to a similar question, some 53% said that they would like this training be hands-on. There are other options that were chosen by other caregivers. In looking at the pattern of responses, some expressed interest in having such training in multiple ways.

“

Caregivers would like to have a qualified person to show them how medical and nursing tasks are done, preferably hands-on.

POSSIBLE CONSEQUENCES & WAYS TO REMEDY THE CHALLENGES

- Putting the burden of care on a younger generation should be coupled with helping the younger generation to take care of their needs.
- Looking into long-term care must be seen in an interrelated matter to other social and economic needs of families.
- On state and federal levels, we should revise our existing policies in the following areas:
 - Employment rules and regulations in the direction of giving long-term caregivers the same advantages as childcare or other dependents.
 - Medical benefits with a focus on long-term care.
 - Research and development funds related to long-term and eldercare needs.
 - Increase in higher education opportunities related to long-term care and eldercare.
- Putting greater emphasis on assisting entrepreneurship and development of new and innovative ideas and technologies that can help the older segments of the population.
- Providing greater opportunities for caregiver training and enhancing their ability to assist their care recipients with less time and expenses.
- Increasing local and regional capacities for sharing resources that can help everyone in the following areas:
 - Transportation.
 - Developing provisions that can help caregivers periodically when they need it and there is no other way to receive it.
 - Increase in activism that can help long-term care giving.

Economic and Social Costs of Caregiving

SOURCE OF CHALLENGES

- Caregivers spend a sizeable proportion of their income in providing care in an explicit manner. However, a relatively higher cost they bear comes through non-direct payment by their caregiving's impact on their lives, work, health, and their ability to maintain a balance between their lives, work and caregiving tasks.
- According to national surveys, one third of caregivers spent between one to 20% of their monthly budget on providing care for the people they look after. Some 40% spent between 20 to 60 percent of their monthly budget. Some 24% could not provide any estimate for how much they spend on people under their care.
- In surveying caregivers within the broadest age category of 18 years of age and older, only 15% said that their lifestyle was not impacted by caregiving. Some 38% stated that their lifestyle was greatly impacted by caregiving. Almost 47% said that their life was moderately impacted by becoming a caregiver.
- A significant proportion of employers are not supportive of their employees who are caregivers. According to national surveys, only 41% of employers were very supportive of caregivers as their employees.
- According to an AARP survey, 60% of caregivers are employed. Out of those who work, 72% work more than 30 hours per week and 56% work 40 hours per week or longer. Some 79% work for others, which usually implies stricter working conditions and the necessity of showing up for work under pre-determined and often less flexible conditions.
- In 2017, nearly 18.4 billion hours have been dedicated to unpaid caregiving. Putting a modest value on each hour of such allocation of time brought the value of unpaid care to a total of \$232.2 billion.
- One of the most important responses from the AARP national survey is that some 67% said that they have faced discrimination in their work place because of being caregivers.
- In total, 52% enjoy paid sick days and only 32% have paid family leave. Only 23% have programs to help caregivers with information and referrals, or have an EAP (Employment Assistance Program). Only 22% of workers can benefit from telecommuting.
- Some 30% have programs that allow caregivers to be paid for some hours of care. Only 30% have income tax credits and no more than 11% have partially paid leave. The other important finding is that a large proportion of respondents, some 29%, do not know what kind of support programs their working institutions have for caregivers, which shows an information vacuum in many of our workplaces when it comes to the prevailing working conditions of caregivers.

- The same survey indicates that some 61% of respondents said that one or more of the listed developments have impacted them. Almost half of the respondents (49%) said that they have had to leave early, go in late, or take leave at times in order to keep up their duties as caregivers. Some 14% had to reduce work or take less demanding jobs because of being a caregiver. Some 15% had to take a leave of absence. Some 7% received warnings for the impact on their job performance and 6% gave up working altogether.
- Some 41% of caregivers are faced with very high or somewhat high levels of a burden of care on a day-to-day basis. Some 38% face severe or somewhat severe levels of emotional stress. Some 25% have very high or somewhat high levels of problems with affordable assistance in the areas of care recipients. Some 19% have high or somewhat high levels of difficulties with daily living activities. Some 18% feel a very high or high level of physical strain in providing care as a caregiver.
- In other national surveys of caregivers ages 18 and over, some 54% of respondents have stated that being a caretaker affected their job or career. Some 21% had to reduce their working hours, while 20% had to change their work schedule. Another 18% had to increase their working hours. Some 13% had to resign from their work and 9% of respondents had to change jobs or their entire career.
- The overwhelming majority of respondents to the AARP survey, some 77%, do not believe that being a caregiver influenced their health. However, a considerable proportion, some 22%, believe that being a caregiver made their health worse. On the other hand, a smaller proportion of 6% believe that being a caregiver affected their health positively.
- In 2017, nearly 18.4 billion hours have been dedicated to unpaid caregiving. Putting a modest value on each hour of such allocation of time brought the value of unpaid care to a total of \$232.2 billion.

POSSIBLE CONSEQUENCES & WAYS TO REMEDY THE CHALLENGES

- Recognizing the direct and indirect cost of long-term care that caregivers need to accept and having specific policies that address such costs and that try to reduce it.
- Providing direct support that assists caregivers with their emotional and personal challenges.
- Bringing local and regional employers together and assisting them in allowing a greater areas of benefits that can help caregivers such as flexible work hours, telecommunication, paid leave, financial assistance at times of financial crisis and heightened needs, sick day pay, etc.
- Mobilizing nonprofits to look into areas of needs of caregivers as a priority area.

Findings From UCLA Center for Health Policy Research on Caregiving in Ventura County

SOURCE OF CHALLENGES

- Changes in demography have important consequences on the emerging wellbeing of any community. One of such issue, which is a direct derivative of demographic change, is the change in the caregiving support ratio.
- This ratio is calculated by dividing the number of the population between the ages of 45 to 64 over the total population of 80 years of age and older.
- We have used the existing information and calculated this ratio for six decades starting from 2010 and going to 2060.
- The results show that by 2020, the ratio of support will be 6.5 people in the first age category for every one person in the second. The ratio will decline to a 3.4 ratio by 2030. By 2040 and beyond, this ratio will go down to almost 2.
- More than 91% of caregivers in Ventura County are within the ages of 18 to 64.
- Some 59% of them are white and 33% are Latino. This is because the white ethnicity at this point of time represents the biggest share of older people. The proportion is likely to change with the passage of time, and the Latino ethnic group will increase their share of this number.
- Some 69% of caregivers work fulltime.
- Some 16% of caregivers are below 100% of the poverty line. 7% are between 100% to 199% of the poverty line, and 14% are between 200% and 299% of the FPL. This shows that a considerable proportion of caregivers are below the poverty line or designated low income.
- A UCLA study shows that caregivers in Ventura County suffer from a variety of stress-related complications. A quarter of caregivers have visited emergency rooms for their problems. The problem that stands out very clearly is the tendency of caregivers to delay or do not pay enough attention to their own physical or emotional needs.
- A large percentage of caregivers (almost 40%) have been binge drinkers in the past year, and more than 15% have seen mental care providers or had substance abuse issues. An alarming rate of 17.1% have thought about committing suicide.

“

The tendency of caregivers to delay or do not pay enough attention to their own physical or emotional needs.

- Out of the population (158,000) of caregivers in Ventura County, some 88,000 are women and the remaining 70,000 are men. This shows a ratio of 55.7% women compared with 44.7% men.
- The study shows women caregivers are far more likely to be in poverty (below 100% FPL) than men. Nearly 24% of women caregivers are in poverty compared with just over 7% among men who provide care.

POSSIBLE CONSEQUENCES & WAYS TO REMEDY THE CHALLENGES

- Communicate this information with all interested parties concerned within the county.
- Plan for providing institutional, financial, and other support for the emerging problems while we still have time.
- Look into local and regional methods of solving this problem by sharing our resources.
- Improving conditions of working caregivers can improve their living conditions, and in turn, help to provide better care for those who need long-term care in the county.



Santa Barbara Foundation Community Caregiving Initiative (CCI) Surveys

PARTICULARS OF SURVEYS:

- We combined three separate surveys with mostly the same questions from 2017 and 2018, cleaned the data, and reached a pool of over 550 respondents.
- Having a combined survey is important for our analyses since this will allowed us to run cross-tabulations of some of the responses across a variety of patterns of respondents which can be statistically significant.
- An overwhelming majority of caregivers and the people they care for live in Santa Barbara County.
- About one third of the respondents do not work and nearly three quarters of the caregivers are currently working.
- Only 2.2% of caregivers are younger than 30 years of age and 7.2% are 80 years old or older.
- About 75% of caregivers are women.
- More than half of caregivers (51.4%) are looking after their parents. Altogether, nearly 90% of care is given to family members.
- More than 80% of those who are care recipients are 70 years of age or older. Indeed, 57.4% of care recipients are 80 years of age or older.
- Almost nine out of ten of them have been caregivers for longer than a year. Some six out of ten of them have been caregivers for more than three years. Some 28.7% of them (almost 1 out of 3) have been caregivers for five years or longer.
- Some 60% of the caregivers are currently working and 40% of the 60% or better say some 67% of those who work hold fulltime employment. Only 27.9% are retired. This is a very significant finding and very much along the same findings from the national survey reported on earlier in this study.
- The largest group of caregivers who are working fulltime or part-time are in the ages of 30 to 59 years of age. The number of working caregivers who are also in the labor market and work are in the age range of 60 to 69 are noteworthy.
- A larger proportion of employers do not offer many caregivers supports, such as: flexible work hours, unpaid leave, telecommunications, etc.

- An overwhelming majority of workers would use the services listed, if the employers offered them. Among the popular options are: flexible work hours, paid sick days, paid family leave, and employee assistance programs, if they were offered. Over 70% stated that they would take unpaid leave, if the employers offered it.
- About 90% of caregivers have been under stress because of caregiving. Indeed, 50% of the respondents have always or often been under stress.
- Coping with emotional stress, feeling secure about one's own financial future, feeling good about oneself, getting enough sleep, and receiving appropriate healthcare appear to emerge as the areas in need of greater attention.
- Fulltime employment is more likely to be missed out on when taking care of daily caregiving activities. Also, the risk of a lack of attention paid to one's own medical and financial needs are more likely to occur among caregivers with full-time employment.
- It appears that all categories of caregivers based on their employment status hardly or never get enough sleep. However, the plight of caregivers with fulltime employment is far dire than other categories. Getting enough sleep is important. Getting enough sleep impacts one's overall health, reduces stress, and enables a person to be more focused and ultimately better able to help persons under their care.
- In general, the findings show that caregivers in large numbers only feel good about themselves some of the time.
- A noticeable number, which includes both part-time workers and caregivers who are retired, rarely feel good about themselves. The cause of such feelings should be further studied, brought up and looked into for appropriate solutions.
- Insufficient insurance and not having coverage for medical needs appears to be a problem for a significant proportion of respondents.

LESSONS FOR HELPING CAREGIVERS:

- More can be done to provide caregivers with information that they need. Particularly information about community resources available to them.
- The areas in need of more attention include:
 - Deliverable meals
 - Adult day care
 - Respite (e.g. short-term care for your loved ones)
 - Veterans' affairs
 - Caregiving skill-building opportunities

“

About 90% of caregivers have been under stress because of caregiving

- Some 14.1% of caregivers did not receive any services from any organizations. About half of the respondents (49.3%) received services from one or two organizations. About 5% received services from five or more organizations. The task of improving communication and quality of services requires reaching out to those organizations and sharing the existing insights about their services and how they can be improved.
- The level of acceptance concerning diversity among caregivers was quite high. The acceptance rate was about 80%, which is positive. There was, however, a considerable area for improvement. In order to know how to move forward and bring improvement about, it may be helpful to itemize the areas of inquiry in terms of various diversity. These areas are all important and sources of challenges may range from attitude of people offering services to institutional policies which prevail, and finally, the level of preparedness within service provider organizations.
- The pattern of responses for the impact of the experience of receiving such a variety of services changing the mind of the caregivers was positive in terms of bringing about the change was positive. The most significant change occurred in believing caregivers make an important contribution to the overall healthcare system.
- There is, however, an important observation that one has to make with the conclusion that can be drawn from those who have said, "my opinion hasn't change." The idea of not having a change of mind can mean that they already believed in the importance of these statements and felt that nothing has changed.
- This could also be presented as these respondents have not been convinced that these areas are important.
- In retrospect, not having a clear direction in the results of this question makes the interpretation of the findings difficult.



Next Steps Forward

One of the principal aims of this study was to provide information, insight and analyses about the status of long-term care with a focus on eldercare with the idea of using the information for a county and region-wide conversation on how to move forward. The outline of such conversation and communication will come from the Ventura County Community Foundation in its good time.

Based on the content of this study, we propose the following areas of attention for pertinent roundtables for discussion:

- Working conditions and work-related issues and provisions for unpaid caregivers.
- Work issues and working conditions for paid caregivers.
- Health insurance with a focus on coverage as it relates to caregivers and care recipients.
- Community-based assistance with a focus on sharing resources and developing a greater capacity for offering services to caregivers and care recipients.
- Developing a community focus on underserved families and communities.
- Workforce development and its relationship with skill development and the expansion of knowledge and educational programs to enhance the existing and emerging capacity within the county and the region.
- Advancement of entrepreneurship and innovative thinking and related technology, which can directly impact long-term care with a focus on eldercare.
- Reaching, advancing, building, and strengthening international relations with countries and communities who are ahead of the curve in managing such services.



Bibliography

- AARP. (2017, August). *California* [PDF]. Retrieved from https://www.aarp.org/content/dam/aarp/research/surveys_statistics/econ/2017/Longevity%20Economy/California.doi.10.26419%252fres.00172.008.pdf
- AARP. (2015, June). *Caregiving in the U.S.* [PDF]. Retrieved from <https://www.aarp.org/content/dam/aarp/ppi/2015/caregiving-in-the-united-states-2015-report-revised.pdf>
- AARP. (n.d.). *Picking up the pace of change in California: A report from the California task force on family caregiving.* [PDF]. Retrieved from http://tffc.usc.edu/wp-content/uploads/2018/07/USC_CA_TFFC_Report_Digital-FINAL.pdf
- Adler, R., Avery, M. L., Hamamoto, B., & Maguire, R. (2016). *Caregiving 2031* [PDF]. Retrieved from http://www.iftf.org/fileadmin/user_upload/downloads/hh/IFTF_Caregiving2031_ScenarioToolkit_SR-1853a.pdf
- Arno, P. S., Levine, C., & Memmott, M. M. (1999). The economic value of informal caregiving. *Health Affairs (Project Hope)*, 18(2), 182–188.
- Association for Long Term Care Planning. (2018). Long term care. Retrieved from <http://www.altcp.org/long-term-care/>
- Association for Long Term Care Planning. (2018). Long term care facilities: Types & benefits. Retrieved from <http://www.altcp.org/long-term-care/long-term-care-facilities/>
- Beck, L. (2015, November). *California's in-home support program* (Rep.). Retrieved from <http://www.ppic.org/publication/californias-in-home-support-program/>
- Caffrey, C., & Sengupta, M. (2018). Variation in residential care community resident characteristics, by size of community: United States, 2016. *NCHS Data Brief*, (299), 1–8. Retrieved from <https://www.cdc.gov/nchs/data/databriefs/db299.pdf>
- California Employment Development Department. (n.d.) Occupational Detail Guides, San Bernardino County. <https://www.labormarketinfo.edd.ca.gov/OccGuides>
- California Department of Health Care Services. (n.d.). Home and Community-Based Services (HCBS) waivers. Retrieved from <https://www.dhcs.ca.gov/services/Pages/HCBSWaiver.aspx>
- California Department of Social Services. (n.d.) Local Assistance Estimates, Governor's Budgets 2012-13 through 2018-19. Retrieved from <https://www.cdss.ca.gov/inforesources/Fiscal-Financial/Local-Assistance-Estimates>
- California Department of Social Services, Public Records Request by SEIU Local 2015, Request ID: 2015-096PRA: SEIU 2015-933 Adult IHSS 12-14-15. Retrieved 12/23/2015.
- Caregiving in the U.S. 2015. (n.d.). Retrieved from <https://www.caregiving.org/caregiving2015/>
- Center for Partnership Studies. (2014, November). *Social wealth economic indicators* [PDF]. Retrieved from <http://caringeconomy.org/wp-content/uploads/2015/03/Social-Wealth-Economic-Indicators-Full-Report-20152.pdf>

- Department of Finance. (2018, May 1). *New demographic report shows California population nearing 40 million mark with growth of 309,000 in 2017* [Press release]. Retrieved from http://www.dof.ca.gov/Forecasting/Demographics/Estimates/e-1/documents/E-1_2018PressRelease.pdf
- Evaluation Specialists Santa Barbara Foundation Community Caregiving Initiative (CCI). (2017). *Interim Report Summary Fall 2017* [PDF]. Retrieved from <https://www.sbfoundation.org/wp-content/uploads/2018/04/CCI-Interim-Report-Detailed-Findings-Fall-2017.pdf>
- Evaluation Specialists Santa Barbara Foundation Community Caregiving Initiative (CCI). (2017, August). *Training on understanding and using CCI survey data* [PDF].
- Genworth. (2017). Cost of care survey 2017 [PDF]. Retrieved from https://www.genworth.com/dam/Americas/US/PDFs/Consumer/corporate/cost-of-care/131168_081417.pdf
- Gervès, C., Bellanger, M. M., & Ankri, J. (2013). *Economic analysis of the intangible impacts of informal care for people with Alzheimer's disease and other mental disorders*. *Value In Health: The Journal Of The International Society For Pharmacoeconomics And Outcomes Research*, 16(5), 745–754.
- Gibson, M. J. (2003). *Beyond 50.2003: A report to the nation on independent living and disability* [PDF]. Retrieved from https://assets.aarp.org/rgcenter/il/beyond_50_il_1.pdf
- Gibson, M. J., & Houser, A. (2007). *Valuing the invaluable: a new look at the economic value of family caregiving*. *Issue Brief (Public Policy Institute (American Association of Retired Persons))*, (IB82), 1–12. Retrieved from https://assets.aarp.org/rgcenter/il/ib82_caregiving.pdf
- Grabowski, D. C. (2006). *The cost-effectiveness of non-institutional long-term care services: review and synthesis of the most recent evidence*. *Medical Care Research And Review: MCRR*, 63(1), 3–28.
- Harris-Kojetin, L. (2017). National Study of Long-Term Care Providers (NSLTCP): Updates & what's new [PowerPoint presentation]. Retrieved from <https://www.nadsa.org/wp-content/uploads/2011/08/NADSA-Annual-2017-Conf-handouts.pdf>
- Harris-Kojetin, L., Sengupta, M., Park-Lee, E., & Valverde, R. (2013). *Long-Term Care Services in the United States: 2013 Overview*. *Vital & Health Statistics. Series 3, Analytical And Epidemiological Studies*, (37), 1–107. Retrieved from https://www.cdc.gov/nchs/data/series/sr_03/sr03_038.pdf
- Heimlich, R. (2014, February 07). *Baby boomers retire*. Retrieved from <http://www.pewresearch.org/fact-tank/2010/12/29/baby-boomers-retire/>
- Institute for the Future. (2016). *Caregiving 2031* [PDF]. Retrieved from http://www.iftf.org/fileadmin/user_upload/downloads/hh/IFTF_Caregiving2031_ScenarioAppendixI_SR-1853.pdf
- Kane, R. L., & Kane, R. A. (2001). *What older people want from long-term care, and how they can get it*. *Health Affairs (Project Hope)*, 20(6), 114–127.
- Laporte, J. (n.d.). *Alzheimer's disease and other dementias* [PDF]. Retrieved from <https://www.statista.com/topics/3722/alzheimer-s-disease-and-other-dementias/>
- Laporte, J. (n.d.). *Caregivers in the U.S.* [PDF]. Retrieved from <https://www.statista.com/topics/4113/caregivers-in-the-us/>

- Laporte, J. (n.d.). *Home care in the U.S.* [PDF]. Retrieved from <https://www.statista.com/topics/4049/home-care-in-the-us/>
- Laporte, J. (n.d.). *Long-term care* [PDF]. Retrieved from <https://www.statista.com/topics/2925/long-term-care/>
- Laporte, J. (n.d.). *Nursing homes in the U.S.* [PDF]. Retrieved from <https://www.statista.com/topics/3982/nursing-homes-in-the-us/>
- Lubitz, J., Cai, L., Kramarow, E., & Lentzner, H. (2003). *Health, life expectancy, and health care spending among the elderly. The New England Journal of Medicine*, 349(11), 1048–1055.
- Masters, T., & Vanslyke, J. (2018, May). *Caregiver experiences seeking and receiving services* [PDF].
- Northwestern Long Term Care Insurance Company. (n.d.). *Important information about long term care* [PDF]. Retrieved from http://media.nmfn.com/contentassets/images/FR/weinstock_doc01.pdf
- O'Shaughnessy, C. V., MA. (2014, March 27). *National spending for long-term services and supports (LTSS), 2012*[PDF]. Retrieved from http://www.nhpf.org/library/the-basics/Basics_LTSS_03-27-14.pdf
- Paraprofessional Healthcare Institute. (2010, December). *California's direct-care workforce* [PDF]. Retrieved from <https://phinational.org/wp-content/uploads/legacy/clearinghouse/CA%20Fact%20Sheet-%2011-04-10.pdf>
- Paraprofessional Healthcare Institute. (2013). *Minimum wage and overtime for home care aides. Value the Care!*, 7. Retrieved November, 2013, from <https://phinational.org/wp-content/uploads/legacy/phi-value-the-care-08.pdf>.
- Public Policy Institute of California (PPIC). *"Anticipating Changes in Regional Demand for Nursing Homes."* November 2016. <https://www.ppic.org/publication/anticipating-changes-in-regional-demand-for-nursing-homes/>
- Reaves, E. L., & Musumeic, M. (2015). *Medicaid and long-term services and supports: A primer* [PDF]. Retrieved from <http://files.kff.org/attachment/report-medicare-and-long-term-services-and-supports-a-primer>
- Reinhard, S. C., Feinberg, L. F., Choula, R., & Houser, A. (2015, July). *Valuing the invaluable: 2015 update. AARP Public Policy Institute*. (104). Retrieved from <https://www.aarp.org/content/dam/aarp/ppi/2015/valuing-the-invaluable-2015-update-new.pdf>
- Santa Barbara Foundation Community Caregiving Initiative. (2017, October 31). *Summary of findings from in-depth interviews with CCI stakeholders* [PDF].
- Schulz, R., & Eden, J. (2016). *Families caring for an aging America*. Washington, DC: The National Academies Press.
- Senate Select Committee. (2014, December). *A shattered system: Reforming long-term care in California*. [PDF]. Retrieved from http://www.cicaihss.org/sites/default/files/aginglong_termcarereport.pdf
- Sengupta M, Rome, V, Harris-Kojetin L, Caffrey, C. (2016). *Long-term care providers and services users in the United States—Residential care component: National study of long-term care providers, 2015–2016: Weighted national estimates and standard errors*. National Center for Health Statistics. Retrieved from https://www.cdc.gov/nchs/data/nsltcp/2016_NSLTCP_RCC_Weighted_Estimates.pdf
- Shaulova, E., & Biagi, L. (n.d.). *Geriatric health in the U.S.*[PDF]. Retrieved from <https://www.statista.com/study/46537/geriatric-health-in-the-us/>

- Shaulova, E., & Biagi, L. (n.d.). *Housing for seniors in the United States* [PDF]. Retrieved from <https://www.statista.com/study/56730/seniors-housing-in-the-united-states/>
- Social Security Administration. (2017, September). SSI Recipients by State and County, 2016. Retrieved from https://www.ssa.gov/policy/docs/statcomps/ssi_sc/2016/index.html
- Soumerai, S. B., Pierre-Jacques, M., Zhang, F., Ross-Degnan, D., Adams, A. S., Gurwitz, J., ... Safran, D. G. (2006). *Cost-related medication non-adherence among elderly and disabled medicare beneficiaries: a national survey 1 year before the Medicare drug benefit*. *Archives of Internal Medicine*, 166(17), 1829–1835.
- The Scan Foundation. (2012, June). *Growing demand for long-term care in the U.S. (Updated)* [PDF]. Retrieved from https://www.thescanfoundation.org/sites/default/files/us_growing_demand_for_ltc_june_2012_fs.pdf
- UCLA Center for Health Policy Research (2009), AskCHIS
<http://ask.chis.ucla>
- United States Census Bureau. (2018). Table 2. *Projections of the population by selected age group and sex for the United States: 2010 to 2050* [Data File]. Retrieved from <https://www.census.gov/data/tables/2008/demo/popproj/2008-summary-tables.html>
- Van den Berg, B., Bleichrodt, H., & Eeckhoudt, L. (2005). *The economic value of informal care: a study of informal caregivers' and patients' willingness to pay and willingness to accept for informal care*. *Health Economics*, 14(4), 363–376.
- Wiggins, P., Gibson, M. J., & Gonzales, G. (2018). *Worn out and invisible* [PDF]. Retrieved from https://www.sbfoundation.org/wp-content/uploads/2018/10/Family-Caregivers-in-SB_online-FINAL-1.pdf
- Wittke, M., & Spangler, J. (2018, November). *Family caregivers need to be included in the national conversation on paid leave* [PDF]. Retrieved from https://www.caregiving.org/wp-content/uploads/2018/11/NAC_FactSheet1_FINAL_Electronic1.pdf



Appendix

Using Latent Class Analysis to Understand Differences Among Caregivers

The average number of services (like meal delivery or transportation) used by Santa Barbara County caregivers overall is 3.6. But within this overall picture, there are four groups of caregivers who use services very differently. Understanding the characteristics of these caregiver subgroups can give us insight into their particular service needs.

Latent Class Analysis (LCA) is a statistical technique that empirically identifies subgroups of individuals based on multiple factors simultaneously. Evaluation Specialists used LCA with data from caregivers surveyed in spring 2017 by the SBF's Community Caregiving Initiative partners.

We identified four caregiver groups and describe them here. Table 1 provides details on the identification of caregiver subgroups.

1.

Very Low Service Users were about one in four (23%) of participating caregivers. People in this group used less than one service on average. They were unlikely to use any services for caregivers themselves (such as self-care information). The service they were most likely to use was meal delivery.

2.

Moderate Service Users were about a third (32%) of participating caregivers. People in this group used three services on average, including some for caregivers themselves.

3.

Moderate/High Service Users were also about a third (32%) of participating caregivers. People in this group used five services on average. They used a lot of services for caregivers themselves, including things like skill-building and support groups.

4.

High Service Users were a little more than one in ten (13%) of participating caregivers. People in this group used 7.5 services on average. They made use of nearly all services offered, particularly respite care and in-home health care. This group also used a lot of services for caregivers themselves.

We also tested for differences among caregiver subgroups, which we summarize here. Tables 2, 3, and 4 provide details on these comparisons.

- Most people in all 4 groups are caring for parents. People in the High Service Use group are a little more likely to be caring for spouses.
- Caregiver self-care and wellbeing are similar across groups. People in every group report feeling caregiver stress about the same amount, between "sometimes" and "often."
- Service use groups are not different regarding how often they are able to
 - Help loved ones with daily activities,
 - Organize their care and appointments, or
 - Determine the living situation that balances their needs and yours.
- Caregivers in the High Service Use group reported providing better care in some areas. They were more often able to:
 - Figure out where to get services for their loved ones,
 - Make sure care recipients got the services they needed,
 - Work with medical providers, and
 - Be actively involved in care decisions.

Questions?

For more information, methods details, and complete LCA results, please contact Tatiana Masters, PhD, at tatiana@evaluationspecialists.com or (206) 380-5921

TABLE 1:

Subgroups of caregivers based on their service use over the past 6 months, empirically identified using Latent Class Analysis (LCA)

SERVICE USE INDICATOR VARIABLES	Service use subgroups				Full Sample (n=256)
	Very low (n = 58, 23%)	Low moderate (n = 83, 32%)	High moderate with self care (n = 83, 32%)	High with self care (n = 32, 13%)	
Number of services used (mean)	0.62	2.87	4.91	7.53	3.57
Likelihood used each service					
In-home health services	0.05	0.28	0.31	0.88	0.31
Delivered meals	0.12	0.26	0.23	0.19	0.21
Transportation	0.06	0.34	0.35	0.32	0.28
Adult day care	0.06	0.27	0.47	0.59	0.33
Home modifications	0.04	0.23	0.47	0.33	0.28
Respite care	0.07	0.13	0.26	0.65	0.22
Veterans Affairs services	0.06	0.11	0.23	0.19	0.15
Caregiving skill building	0.02	0.22	0.42	0.88	0.32
Navigator	0.03	0.12	0.50	0.80	0.31
Caregiver counseling	0.02	0.38	0.52	0.80	0.40
Caregiver self-care information	0.06	0.26	0.70	1.00	0.45
Caregiver support groups	0.08	0.30	0.50	0.93	0.39

TABLE 2:

Caregiver service use subgroups compared on how often (past 6 months) they were able to accomplish caregiving tasks

CAREGIVING TASKS	Chi-Square	Service use subgroups				Full Sample (n=256)
		Very low (n = 58, 23%)	Low moderate (n = 83, 32%)	High moderate with self care (n = 83, 32%)	High with self care (n = 32, 13%)	
Figure out where to get services they need	7.87*	3.41	3.74	3.66	3.98	3.67
Make sure they get services they need	10.93*	3.56	3.66	3.79	4.19	3.74
Work with their medical providers	8.05*	3.67	4.06	3.94	4.32	3.96
Be actively involved in decisions about their care	8.77*	3.81	3.96	3.93	4.39	3.94
Help them with daily activities	5.24	No significant mean differences between groups on these caregiving tasks indicators All means in 2.90 to 4.02 range (equivalent to "sometimes" (3) to "often" (4) on 1 to 5 scale)				3.41
Organize their care and appointments	4.25					3.78
Determine the living situation that balances their needs and yours	3.14					3.75

* $p < 0.05$, ** $p < 0.01$, *** $p > 0.001$

TABLE 3:

Caregiver service use subgroups compared on self-care and wellbeing over the past 6 months

CAREGIVER SELF-CARE & WELLBEING	Chi-Square	Service use subgroups				Full Sample (n=256)
		Very low (n = 58, 23%)	Low moderate (n = 83, 32%)	High moderate with self care (n = 83, 32%)	High with self care (n = 32, 13%)	
How often felt stressed caring for your loved one	4.29	No significant mean differences between groups on any caregiver self-care and wellbeing indicators All means in 3.2 to 3.7 range (equivalent to "sometimes" on 1 to 5 scale)				3.45
Practical self-care (e.g., daily activities, medical, financial)	2.40					3.51
Meeting physical needs (e.g., eating right, sleeping, shelter)	1.32					3.63
Meeting emotional needs (e.g., feeling good about yourself)	2.60					3.37

*p < 0.05, **p < 0.01, ***p > 0.001

TABLE 4:

Caregiver service use subgroups compared on characteristics of their caregiving experience

CHARACTERISTICS OF CAREGIVING EXPERIENCE	Chi-Square	Service use subgroups				Full Sample (n=256)
		Very low (n = 58, 23%)	Low moderate (n = 83, 32%)	High moderate with self care (n = 83, 32%)	High with self care (n = 32, 13%)	
Time spent caregiving:	11.71 (12)					
Less than 1 year		0.05	0.10	0.16	0.04	0.10
1-2 years		0.32	0.38	0.34	0.34	0.35
3-5 years		0.39	0.36	0.27	0.41	0.34
5-10 years		0.12	0.10	0.17	0.18	0.14
10 or more years		0.13	0.06	0.07	0.03	0.07
Care recipient:	25.55 (9)**					
Spouse		0.29	0.33	0.25	0.40	0.30
Parent		0.59	0.54	0.54	0.57	0.56
Family member		0.07	0.08	0.13	0	0.09
Other person		0.05	0.05	0.07	0.03	0.05

*p < 0.05, **p < 0.01, ***p > 0.001