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Latino Caregiver Needs Assessment: Report to SBSS and AARP – 2017

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SBSS-AARP Latino Caregiver Needs Assessment

Executive Summary

In early 2017, St. Barnabas Senior Services (SBSS) commissioned a needs assessment of Latino family caregivers who provide care to an adult family member 50 year of age or older. The needs assessment is part of a larger caregiving initiative titled *"Los Angeles Latino Caregiver Project."* Launched in 2016 by AARP California, in partnership with St. Barnabas Senior Services (SBSS) and AARP National Caregiving Unit, the initiative will explore a range of support services addressing the unique needs of Latino caregivers residing in Los Angeles County, California.

Fifty adult caregivers from select zip codes in Supervisorial District 1, Los Angeles County, were queried about the types of assistance they provide their family member, their psychological and emotional responses to the caregiving situation, and their use of caregiver support services and programs. In this report we summarize the needs assessment findings and offer recommendations to enhance caregiver services and the well-being of Latino family caregivers.

This report focuses on responses from 50 caregivers age 30 to 64 years of age providing care to an adult 50 years of age or older in select areas of Los Angeles County, Supervisorial District 1. Based on a convenience sample of 40 female and 10 male caregivers, we highlight key findings below.

KEY FINDINGS

- **CAREGIVER SOCIODEMOGRAPHIC CHARACTERISTICS**
  - Caregivers are more likely adult children in their mid-fifties caring for an elderly parent with multiple care needs. Although most adult children were females, 20% of the sample consisted of males.
  - Most caregivers were English-speakers born in the United States. One-half of non-US-born caregivers preferred to speak English perhaps indicating emigration to the US at an early age.
  - Socioeconomic indicators such as education and income indicate a more educated group, employed, with higher incomes; yet another group appears to emerge which is less educated and has less household income.
  - Only 8% were not covered by health insurance.

❖ CARE RECIPIENT SOCIODEMOGRAPHIC CHARACTERISTICS

- Care recipients are more likely females in their early 80s, Spanish-speaking, and born outside of the United States.
- Similar to their caregivers, they were more likely to be born in Mexico if non-US-born.
- Another similarity to their caregivers, is the high rate of health insurance coverage: 100% were covered by health insurance.

❖ CONTEXT OF CAREGIVING

- The majority of caregivers and care recipients co-resided in the same household.
- There was a wide range of years of caregiving from 1 to 41 years. The average number of years since the onset of caregiving was 8 years. Thus, on average, caregivers began caregiving in their mid-40s to older family members in their mid-70s.
- Caregiving hours per week ranged from 4 to 168 hours. A group of caregivers provided round-the-clock caregiving with minimal time off. For those who did not provide round-the-clock caregiving, the average hours per week was high: 68 caregiving hours per week.
- 18% received pay for the assistance they provided. One-third received help from another person, and 10% paid out of pocket for the help.
- Although most did not report significant financial strain, 1 out of 3 reported somewhat or very much financial strain as a result of caregiving.
- 28% cared for another adult, and 20% cared for children indicating that upwards more than one-half were caregivers to more than one family member.
- More than one-half cared for a family member with memory loss such as Alzheimer’s disease, or other dementia diagnosis. Most caregivers did not report the exact name for the dementia diagnosis but noted the term “dementia” as the type of memory disorder or problem.
- Of the array of 21 caregiving tasks, 6 were most likely endorsed (82 to 92%): paying attention to the psychological and emotional state of the care recipient, shopping, transportation, care coordination, household chores, and medication management.

  - A subgroup of caregivers provided more complex type tasks such as wound care, monitoring medical equipment, and preparing special meals/diets.

- **CAREGIVER STRENGTHS**
  - Caregivers reported relatively high levels of managing the meaning or appraisals of the caregiving situation—an indicator of caregiver strength in the face of high demands or stress. They indicated accepting the care recipient as she/he is, praying for strength, keeping a sense of humor, and looking for what was admired in the loved one.
  - Notwithstanding, these types of appraisals or reframing of the caregiving situation were never endorsed by a subgroup of respondents, or endorsed only once in a while.

- **CAREGIVER WELL-BEING**
  - About 3 out of 4 caregivers considered their health good, very good, or excellent. And, although 64% reported that their health was the same or better as one year ago, a subgroup of caregivers (1 out of 3) believed their health was worse than one year ago. One in 4 stated they experience physical strain.
  - Although the survey is not considered a clinical assessment, 22% scored at the conventional cut-off score of 3 indicating need for further depression screening.
  - Likewise, using a conventional cut-off score of 10 or more symptoms, 24% scored either at the moderate anxiety, or severe anxiety levels indicating need for further evaluation.
  - Almost 6 out of 10 respondents reported some problems with falling asleep, staying asleep, or sleeping too much.

- **CAREGIVER SUPPORT SERVICES**
  - Of all caregiver support services identified in the survey, educational materials and workshops were more likely used by the respondents followed by caregiver class series.
  - Educational materials were obtained from diverse sources with the health care provider or team being the most likely source of these materials. Other frequently noted sources of educational materials were local community-based organizations, or university-affiliated programs.

- Educational workshops were more likely sponsored by community-based organizations, and employer-required classes for paid health care workers.
- Class series were identified either as caregiver-specific (e.g., Powerful Tools, Stress Busters), or illness- specific (diabetes, dialysis), and provided by community-based or university-affiliated programs
- The least likely utilized services were support groups (8, 16%) and reminder texts/calls/E-mail messages (7, 14%).
- Church-affiliated sources of help, or personal cellphone applications were noted each by only one person.
- Although most caregivers who sought or received services noted they were satisfied with the services, level of satisfaction varied across the 5 services or programs listed. Educational materials and workshops were the most satisfying while class series was the least satisfying.
- The top three reasons caregivers did not seek or participate in services were not having time, not knowing a service existed, or thinking that help was not needed.

RECOMMENDATIONS

This sample of 50 female and male caregivers provides assistance which on average is the equivalent of about 1.5 full-time employment hours per week. Some provide mentally complex, physically tiring, and emotionally demanding care that has taken a toll. Although Latino families do their share of caregiving with a strong sense of meaning and purpose, they face high physical, emotional, social, and financial strain.

Recommendation 1: Countywide System of Care (SOC)

Caregiving, by its very nature, assumes a dyadic relationship, and in this case with an adult care recipient who also has a voice, beliefs, preferences, strengths, and needs. Some are providing care not for only one person, but multiple individuals including children. Use of caregiver services, although increasing, is still not on par with the demands of caregiving in Latino families. And, although socioeconomic indicators such as education and income indicate a more English-speaking, educated group with higher incomes, it appears that access to services remains limited. This was the case even with high health insurance coverage for both caregivers and care recipients.

Thus, not one service or program is considered sufficient over time when dealing with a complex issue such as family caregiving; nor can we expect that the needs of caregivers remain static over their trajectories of care—which may be upwards of one to four decades as we found in our sample.

We recommend a system of person- and family-centered care to provide services tailored to the needs of Latino caregivers in Los Angeles County. Systems of care (SOC), although not a new concept in other fields, comprises formal and informal family supports and services, and the navigation processes that links these with families. Combining the expertise of community-based organizations and health care providers, services can include assessment, information and referral, health services, adult respite care, education and skill-building, psychological counseling, and care coordination, to name a few. Enhanced services can include information and/or direct services such as: child/minor-specific services; language interpretation and translation; case and community advocacy; immigration consultation; transportation services; medical equipment; reduced costs for out-of-pocket medical and long term care expenses; employment opportunities; home modification services; etc.

In Los Angeles County, less than a handful of caregiving-affiliated organizations already exist that include many of the services listed above in their organizational mission. In fact, some of these organizations provided referrals to the caregiver survey, and were mentioned as sources of services by the survey respondents. Yet, these organizations did not provide direct health care services for caregivers or care recipients. The health care provider (physicians, allied health providers, health insurance plans) were mentioned as key sources of services and programs, yet according to the caregivers, it did not appear that the provider and provider organizations had expert knowledge in caregiving issues aside perhaps from offering information on illnesses or diseases affecting the care recipient. Thus, combining the expertise of community-based organizations and health care providers in a system of care is warranted.

Recommendation 2: Sources of Strength Campaign (SOS)

Caregivers reported relatively high levels of managing the meaning or appraisals of the caregiving situation. Others reported they were in good physical and psychological health, while many reported no financial strain. These results are indicators that something is going right among Latino caregivers, and that not all Latino caregivers are overwhelmed by their caregiving challenges. Articulating these strengths and examining why they exist is not just an academic exercise but meaningful ways to foment caregiver outreach and information diffusion campaigns.

We recommend caregiving outreach and information diffusion campaigns that integrate Latino caregiving realities and resilience. Accepting a loved one for who she/he is, praying for strength, keeping a sense of humor, looking for what was admired in her/him, are all indicators of resiliency, and rooted in culturally-embedded coping strategies. Individual and community engagement strategies that uphold narratives of caregiver and family resiliency should be used to diffuse information on Latino caregiving and available services and programs through multi-language, multi-media formats (radio, TV, public service announcements, social media, educational materials, workforce training modules, etc.). These strategies will need to be tailored to caregivers at different ages and generations with specific messages that address their common as well as unique needs and preferences.

Several examples of culturally- and linguistically-attuned outreach strategies exist but most are executed on an individual basis with time-limited attempts at reaching the Latino community--partly due to changing income revenue streams, workforce development and attrition, and redirection of organizational objectives.

Recommendation 3: Survey of Latino Caregivers (SOL-C)

Although our analysis did not explore results by subgroups or categories, studying larger samples of Latino caregivers is crucial in order to account for in-group differences that can inform service and product development.

We recommend implementation of a large-scale, prospective county-wide survey of Latino caregivers and care recipients across the lifespan. We need current estimates of the rates of caregiving, who is caring for whom and for what conditions, how caregiving is perceived and managed across subgroups of Latinos caregivers: gender self-identified groups; high vs. low income; Spanish-speaking vs. English-speakers; employed vs. not employed; etc. By including respondents from a wider range of incomes, education, caregiving contexts, etc., we are more likely to include responses from different types of caregivers at different points in their caregiving trajectory. Furthermore, examining their care trajectories over time is a valuable source of information to ascertain the dynamics process and “career” of caregiving and changing caregiving needs across generations.

SBSS-AARP Latino Caregiver Needs Assessment

Introduction

Providing care to family members with a medical condition or disability is an almost universal phase of the family life cycle. Families are diverse with regards to the types of caregiving they provide given the context of the unique challenges they face. Sometimes families care for toddlers with developmental disorders such as autism while other families navigate addictions among adolescents. Other families struggle with the burdens of caregiving for older members with memory loss due to Alzheimer's disease.

In each case, families meet caregiving challenges that are common across conditions (navigating roles and expectations, getting a diagnosis, reaching out for help), and challenges which may be unique to the specific caregiving context (finding early childhood education programs, engaging in substance use recovery services, providing end-of-life care). For the purposes of this report, *caregiver* is defined as a family member who provides help or assistance to a relative 50 years of age or older with personal care needs due to limitations in physical, mental, or cognitive functioning. *Caregiving* refers to the myriad of tasks, activities, and functions that the caregiver performs on behalf of the family member—whether the person is fully aware that she/he is a "caregiver," or not.

Family caregivers are the backbone of the health and long-term services and supports system in the United States. According to an AARP 2015 report, 43.5 million adults in the United States provided unpaid care to an adult or a child in the previous 12 months. About 79%, or 34.2 million of these caregivers, provide unpaid care to an *adult age 50 or older* (NAC and AARP Public Policy Institute, 2015). The 50+ population is expected to witness significant population growth from 101,849,000 in 2012 to over 118,000,000 in 2020 (US Census Bureau, 2012). Although medical, technical, and individual lifestyle advances have decreased the prevalence of chronic medical conditions in the United States, adults living with functional limitations and disabilities will require assistance from family members, intimate partners, friends, neighbors, and co-workers.

The economic value of family caregiving is estimated at $470 billion which is more than total Medicaid spending in 2013 for both health care and long-term care services and supports combined (Reinhard, Feinberg, Choula, & Houser, 2015). Why is this so? Caregivers perform an array of activities and tasks that often go unnoticed or unappreciated. These activities encompass assistance with bathing, preparing meals, providing transportation to medical appointments, shopping, and giving emotional support. Yet, family caregivers today go over and beyond assisting with activities of daily living by performing medical and nursing tasks such as managing complex medication regimens, handling medical equipment and assistive devices, preparing special diets or meals, and handling complex eligibility forms and legal documents in an often siloed and fragmented system of care (Reinhard, Levine, & Samis, 2012; Schulz, Eden, & Committee on Family Caregiving for Older Adults, 2016).

Caring for middle-aged and older adults can be a rewarding experience as family members fulfill personal, family and societal expectations, and do "what's right" for their loved ones. On the other hand, caregiving can exact a toll on a family caregiver's physical, psychological, emotional, and financial resources--which if persistent over time--can cause problems as the demands of caregiving outstrip the resources available to the caregiver and care recipient. Striking a healthy balance between caring for oneself and caring for a family member is the goal, yet a goal that sometimes eludes family members overwhelmed by the demands and stress of caregiving.

In the last four decades, family members, service providers, policymakers, educators, and researchers, have highlighted that caregiving is a public health issue given the personal, family, and societal costs of caregiving. In the seminal report titled, *Families Caregiving for an Aging America* (Schulz et al., 2016), considerable attention was given to the extant scientific evidence that family caregivers of older adults are at risk--compared to non-caregivers—of higher rates of depressive symptoms, anxiety, stress, and emotional difficulties. Although this report examines recipients of care ("care recipients") at age 50 or older, the key findings and recommendations are likely to apply to this group of caregivers to middle-aged persons with medical and functional conditions such as early-onset Alzheimer's disease and associated dementias, stroke, cancer, Parkinson's disease, physical frailty, and the like.

Frequently cited caregiving stressors, regardless of the medical condition or functional challenge, include such issues as not knowing where to go for help, not having time for oneself or taking a break from caregiving, problems managing difficult relationships (including the relationship with the care recipient and/or with other family members), not having enough financial resources, or feeling overwhelmed by the tasks and expectations of the caregiving role (Schulz, Eden, & Committee on Family Caregiving for Older Adults, 2016).

For racial and ethnic minorities, limited English-speakers, and families from low socioeconomic backgrounds, the situation can be especially challenging. Additional challenges include low access to quality health and long term services and supports, exposure to discriminatory and non-inclusive practices, paucity of bilingual/bicultural providers, complicated eligibility and service delivery procedures, and increased risk of persistent disabling illnesses and injuries. Even with these increased challenges, families continue to provide the lion's share of unpaid caregiving services to their loved ones even at great sacrifice to their own physical and economic health. The paucity of information on Latino families is staggering given that older US Latinos over the age of 65 will grow upwards of 21 million by 2060 (22% of the US older adult population) comprising the largest minority group of adults over 65 year of age (Administration on Aging, 2015).

Purpose of the Latino Caregiver Needs Assessment

In 2017, St. Barnabas Senior Services (SBSS) commissioned a needs assessment of Latino family caregivers who provide care to an adult family member 50 year of age or older. The needs assessment is part of a larger caregiving initiative titled *"Los Angeles Latino Caregiver Project."* Launched in 2016 by AARP California, in partnership with St. Barnabas Senior Services (SBSS) and AARP National Caregiving Unit, the initiative will explore a range of support services addressing the unique needs of Latino caregivers residing in Los Angeles County, California.

This report focuses on responses from 50 caregivers age 30 to 64 years of age providing care to an adult 50 years of age or older in select areas of Supervisorial District 1, Los Angeles County. Caregivers were queried about the types of assistance they provide their family member, their psychological and emotional strengths and responses to the caregiving situation, and their use of caregiver services. In this report we summarize the needs assessment findings and offer recommendations to enhance caregiver services and the well-being of Latino family caregivers.

According to a Los Angeles County Department of Public Health report, 1 million adults 50 years of age or older needed assistance (LA County Department of Public Health, 2010). If we apply the percent of Latinos caregiving in Los Angeles County, or 14.7, we estimate that there are about 147,000 Latino caregivers who are currently providing care to a family, friend, or neighbor 50 years of age or older. *If we count caregivers only between the ages of 30 and 64*, the estimate would decrease to 71.4% of all caregivers: thus, there are approximately 105,000 Latino caregivers 30-64 years of age currently providing care to persons 50 years of age or older. This report addresses this group of caregivers.

Overall Approach and Methods

We conducted a needs assessment survey (herein "survey") based on 50 English- or Spanish-speaking Latino respondents between March and May 2017.

Respondent Eligibility Criteria

AARP California selected the zip codes and age ranges for both caregivers (50-64) and care recipients (50 or older). We targeted 22 zip codes in Los Angeles County, CA in Supervisorial District 1 (see table below) that are comprised of significant proportions of Latino residents.

The respondent[1] eligibility criteria included the following:

1. The caregiver self-identifies with being Latino, Hispanic, or American of Latino or Hispanic descent.
2. The caregiver or care recipient lives in one of the targeted zip codes.
3. The caregiver is between 30 to 64 years of age.
4. The caregiver provided care or assistance to a relative, friend, or neighbor 50 years of age or older in the last 12 months, whether paid or unpaid.
5. The caregiver is willing to participate voluntarily in a survey on family caregiving.

Targeted Zip Codes	Local Areas in Supervisorial District 1 Los Angeles County
90022	Los Angeles – East Los Angeles
90023	Los Angeles – Boyle Heights
90031	Los Angeles – Lincoln Heights
90032	Los Angeles – El Sereno
90033	Los Angeles – El Sereno
90040	City of Commerce
90063	Los Angeles – City Terrace
90201	Bell Gardens, Bell, Cudahy
90255	Huntington Park
90270	Maywood
90280	South Gate
90640	Montebello
90660	Pico Rivera
91706	Baldwin Park
91731	El Monte
91732	El Monte
91733	South El Monte
91744	La Puente
91746	La Puente
91747	La Puente
91749	La Puente
91770	Rosemead

Sampling and Recruitment

We relied on non-probability sampling, namely convenience sampling methods, whereby respondent referrals were received from community-based agencies known by the study collaborators. A total of 72 caregiver referrals were provided to the consultant team from diverse sources which yielded a total sample of 50 completed surveys, or a 69.4% referral-to-survey completion rate. Reasons for non-participation were the following in order of frequency: no answer or phone number not working; too busy to participate. We contacted each referral up to a total of 8 times before listing the referral as no longer a viable referral.

Respondent Referral Source	Number of Referrals Provided (#69)	Number of Completed Surveys (#50)
Community-based services serving caregivers	9	8
Health-care talent agency employing family caregivers	10	5
AARP respondents from prior caregiver survey	32	16
Project Consultant Team	21	21
Total	**72**	**50**

The Needs Assessment Survey

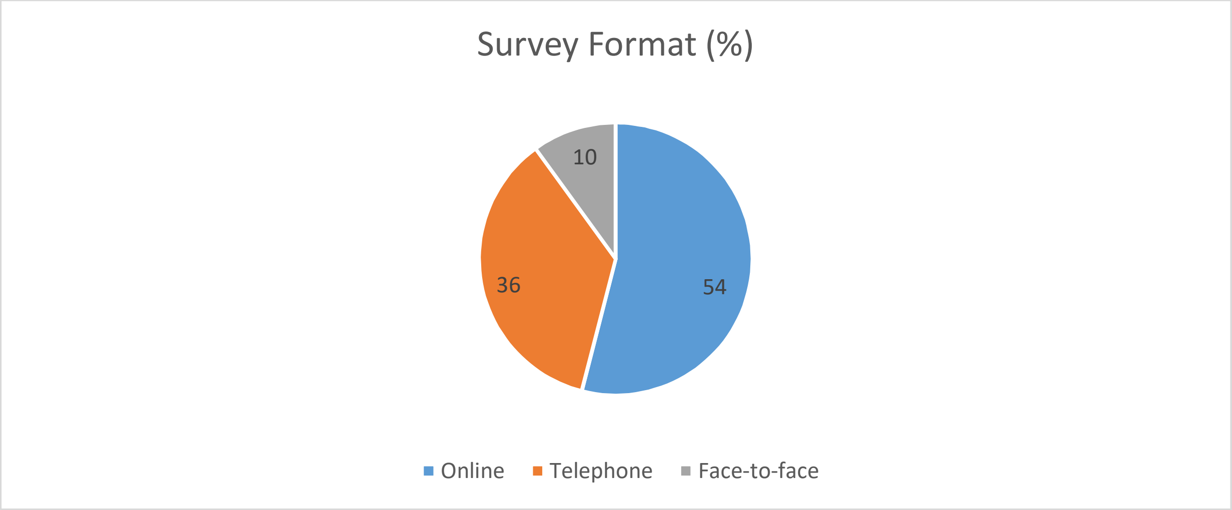
Survey items were developed with input from the project consultant team, SBSS executive leadership, AARP California state directors, AARP National Caregiving Unit directors and research staff.

We queried respondents about their sociodemographic characteristics (theirs and their family member), the caregiving context, types of assistance they provide their family member, their psychological and emotional responses to the caregiving situation, and their use of caregiver support services and programs. Survey items were obtained from extant caregiving studies in the scientific, community-based services, and clinical practice literature.

Respondents could elect to take the survey in multiple ways: English or Spanish; in-person, via telephone, or self-administered online.

All item responses were based on respondents' self-report. Most preferred to take the survey online (27, 54%). For those who preferred to take the survey with a trained bilingual/bicultural interviewer, 36% (18) took the survey by telephone; or face-to-face (5, 10%).

Out of the 50 completed surveys, 41 (82%) took the survey in English and the remainder in Spanish.



The average time for survey completion was approximately 30 minutes. Respondents received a $20.00 gift card for the completed survey.

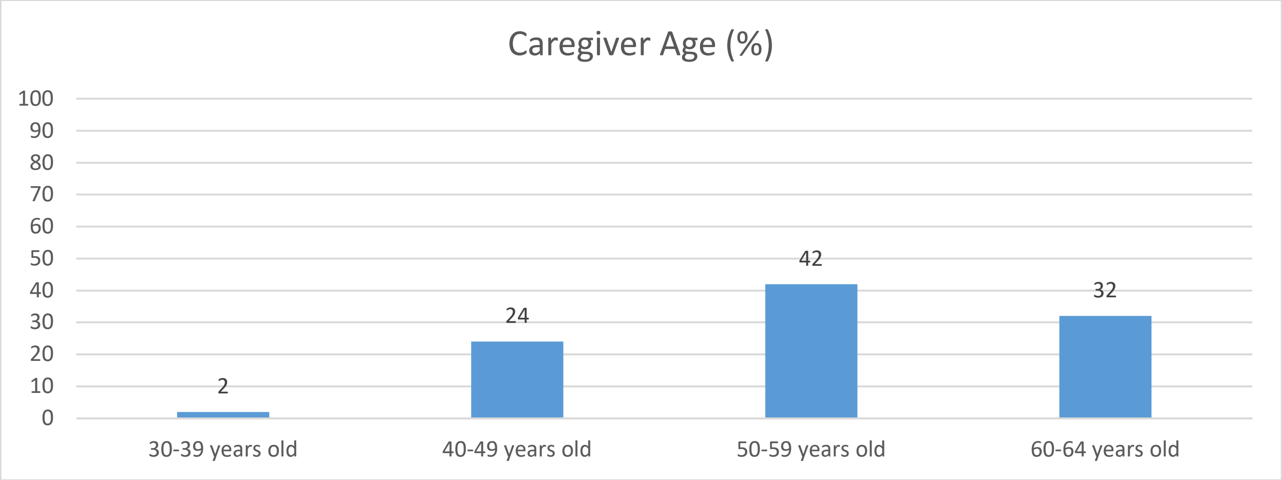
Results

This section presents results on caregiver and care recipient sociodemographic characteristics, the caregiving context, caregiver strengths and overall well-being, and use of caregiver support services.

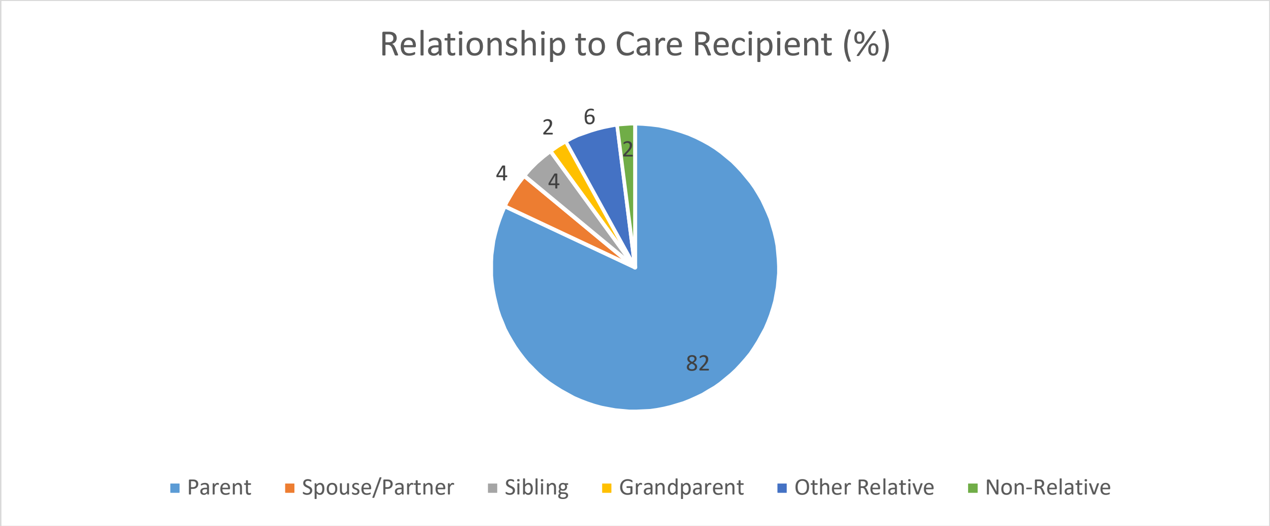
Caregiver Sociodemographic Characteristics

Caregiver sociodemographic characteristics include preferred language, gender, relationship to the care recipient, marital status, education, employment, income, health insurance, birthplace, and language.

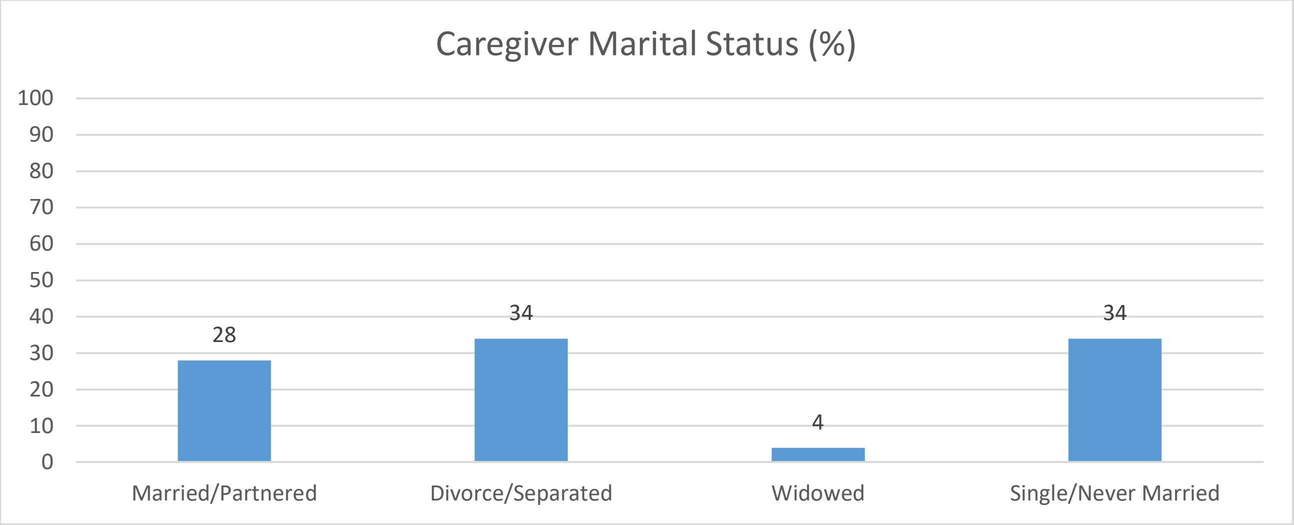
The caregiver sample is comprised of 70% female (35)[2], or male (15, 30%). No other gender was reported. Respondents ranged from 36 to 64 years with an average age of 54 years (SD. 7.4)[3].



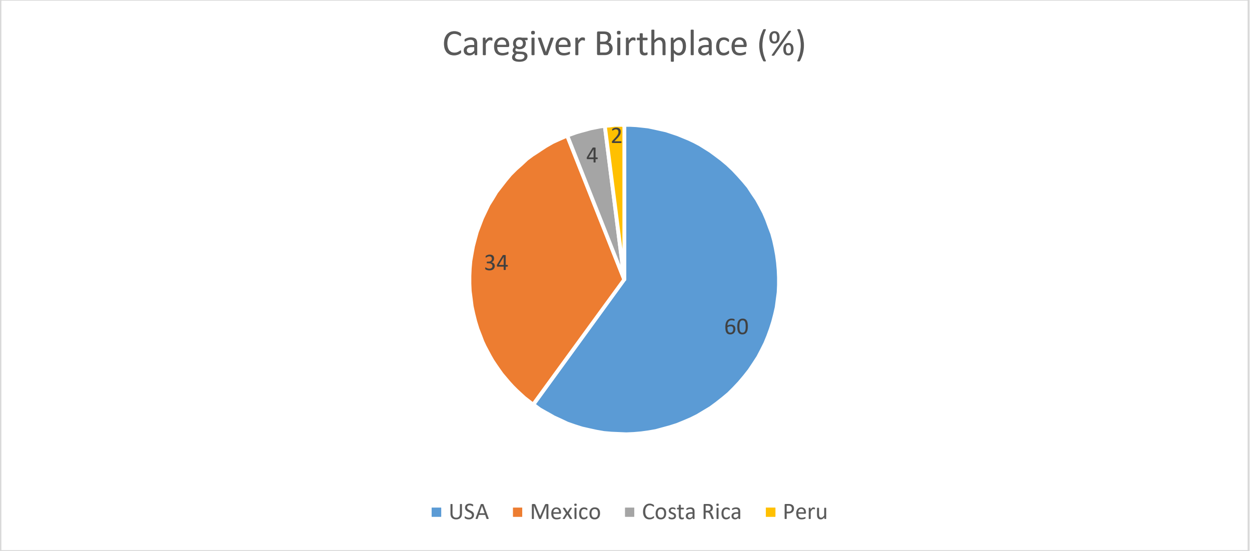
Eight out of 10 respondents are adult children (41, 82%) caring for their elderly parents.



About 1 out of 3 reported being single/never married or partnered (17, 34%), followed by divorced or separated (17, 34%), married/living with partner (14, 28%), and widowed (2, 4%).

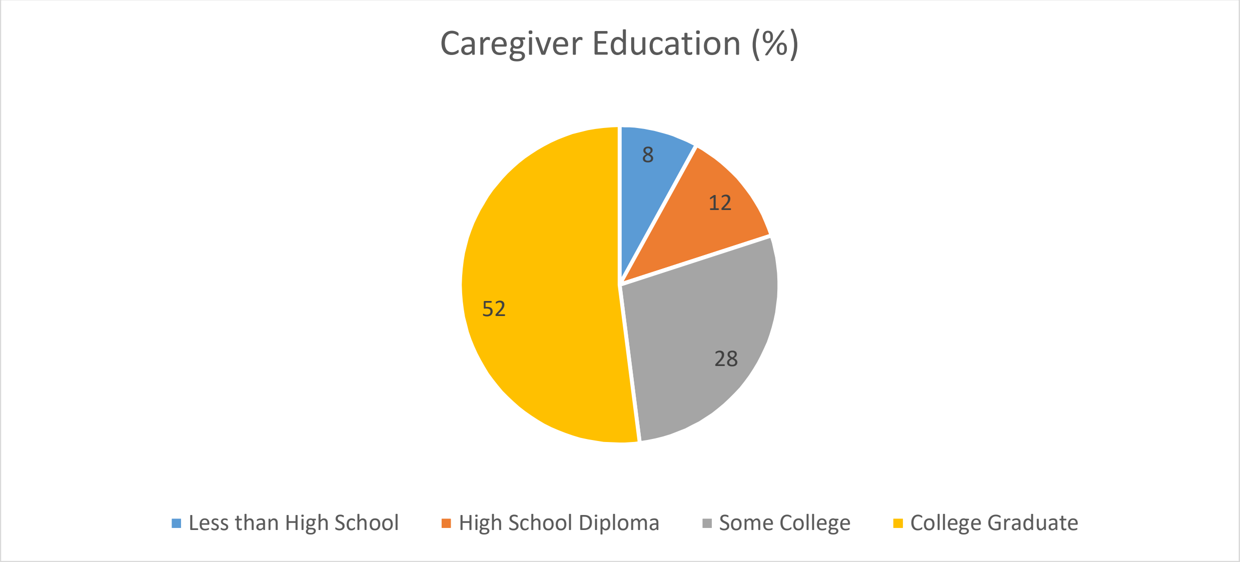


Six out of 10 were born in the United States (30, 60%). About one-third were born in Mexico (17, 34%), 6% (3) were born in other Latin American countries (Costa Rica, Peru).

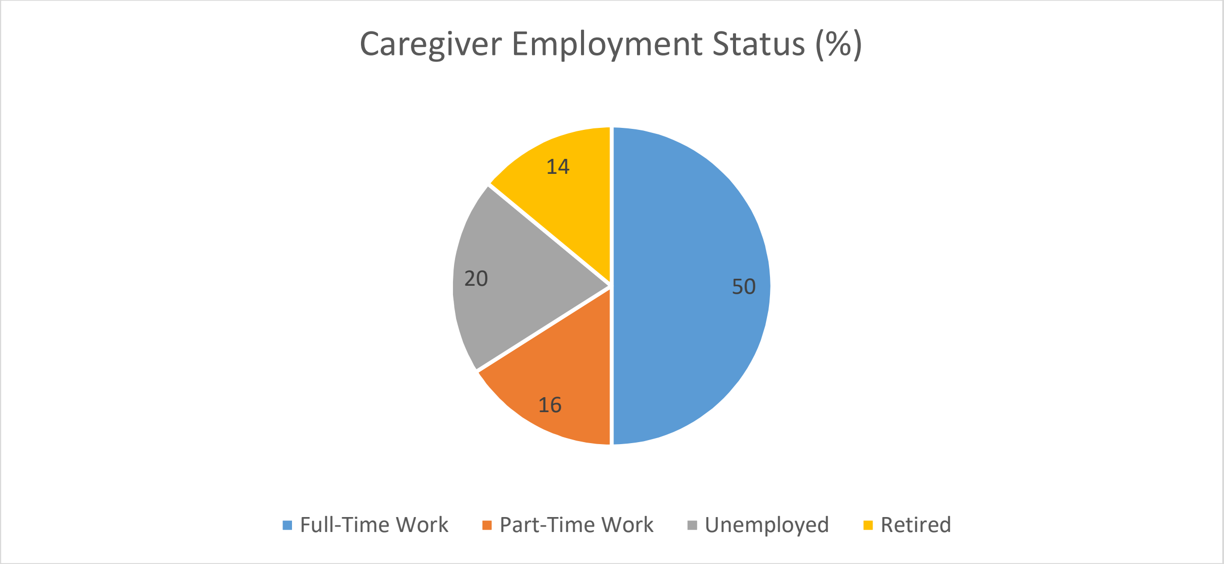


Over 8 out of 10 preferred to speak English (41, 82%).

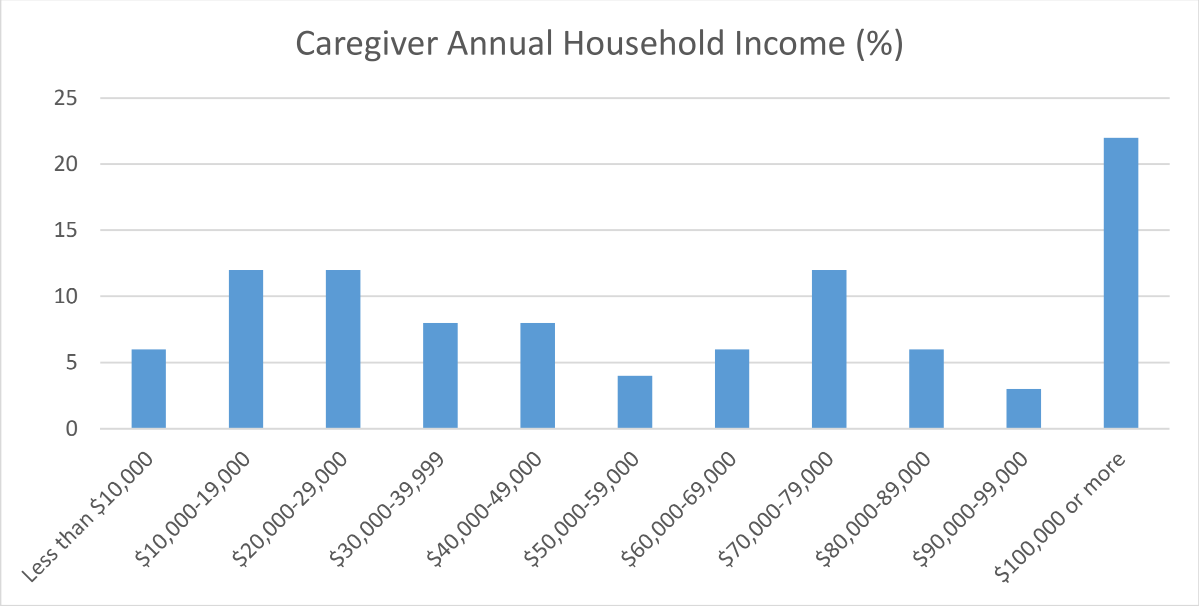
In terms of educational attainment, 14 (28%) reported taking some college courses and 26 (52%) received a college degree (Associates of Arts degree or higher). Six (12%) reached high school graduation and only 4 (8%) had less than a high school diploma.



One-half of the sample reported working full-time (25, 50%), and another 8 (16%) worked part-time. The remaining sample was unemployed (10, 20%), or retired (7, 14%).



Household income ranged from less than $10,000 to more than $150,000 per year. The median household income category was $50,000-59,000 per year.

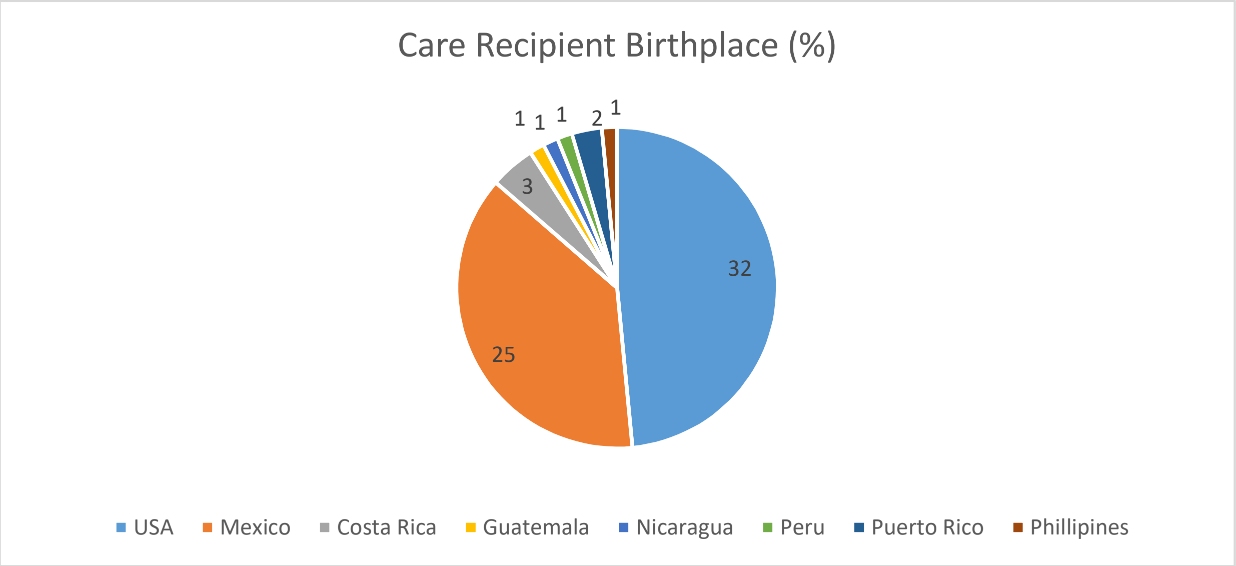


Ninety-two percent (46) of the respondents had health insurance.

Care Recipient Sociodemographic Characteristics

Care recipient demographic characteristics include age, gender, health insurance, birthplace, and language. Care recipients were more likely female (34, 68%). They ranged from 50 to 93 years of age with an average age of 81 years (SD. 10.11). All care recipients had health insurance.

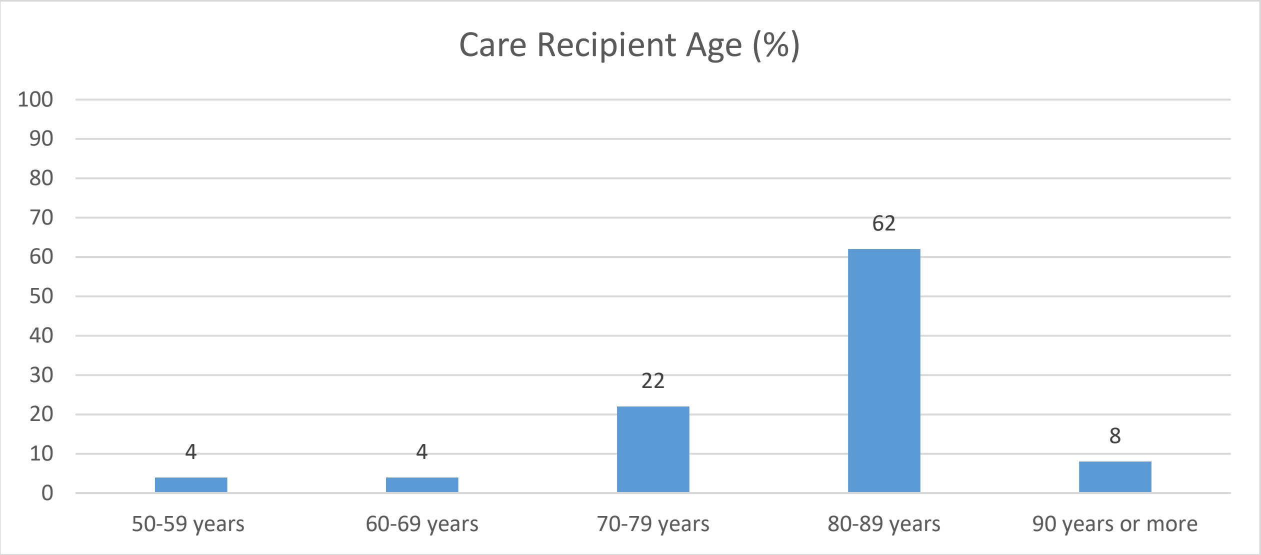
One-half of the care recipients were born in Mexico (25, 50%) while 32% (16) were born in the mainland United States. The remaining respondents were born in 6 Latin American countries or US territories (Costa Rica, Guatemala, Nicaragua, Peru, Puerto Rico), and one was born in the Philippines.



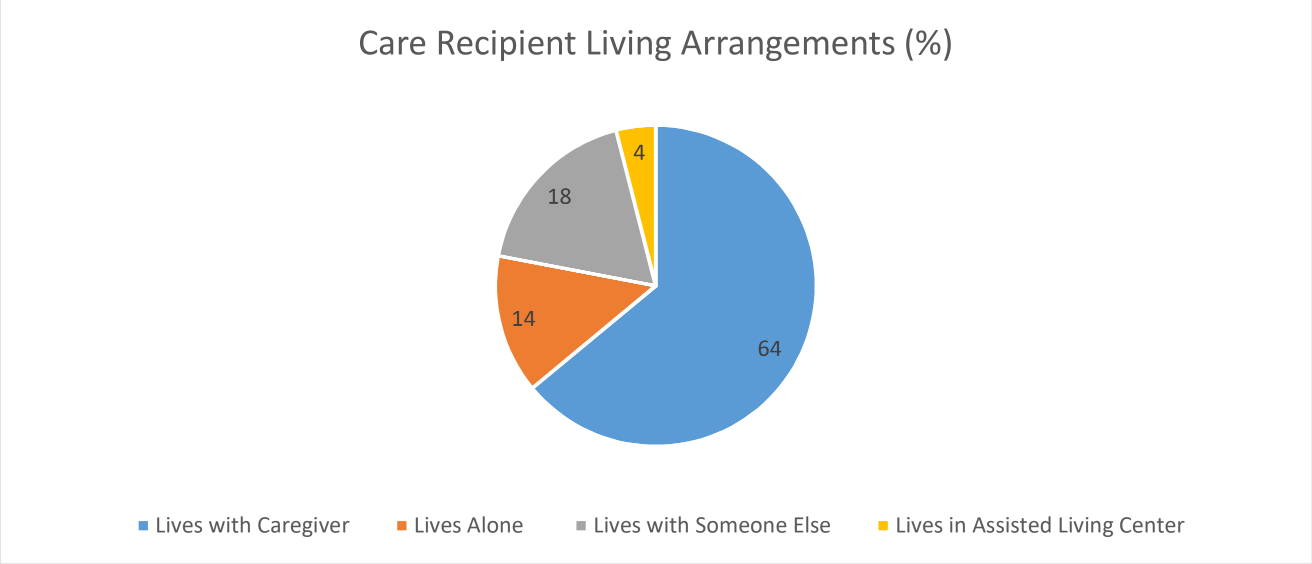
Caregiving Context

Caregiving context includes care recipient age, co-residence with care recipient, number of years providing care, number of caregiving hours per week, receipt of help from others, financial strain of caregiving, other caregiving responsibilities, caring for someone with dementia, and caregiving tasks.

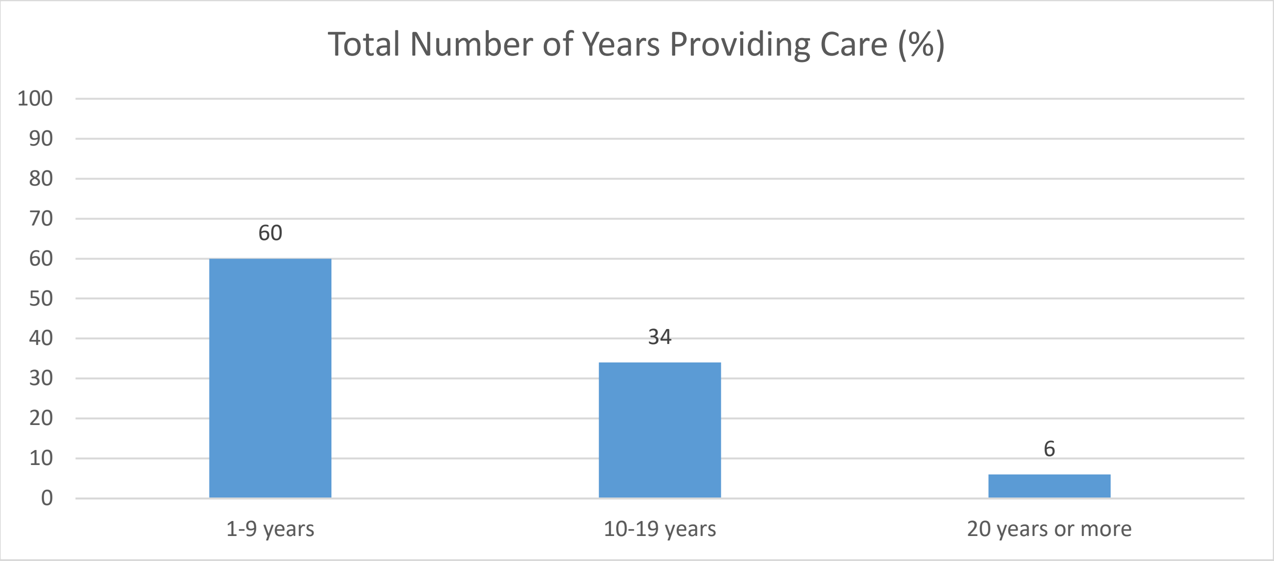
Care recipients were in their early eighties (81.16 years; SD=8.89) ranging from 50 to 92 years.



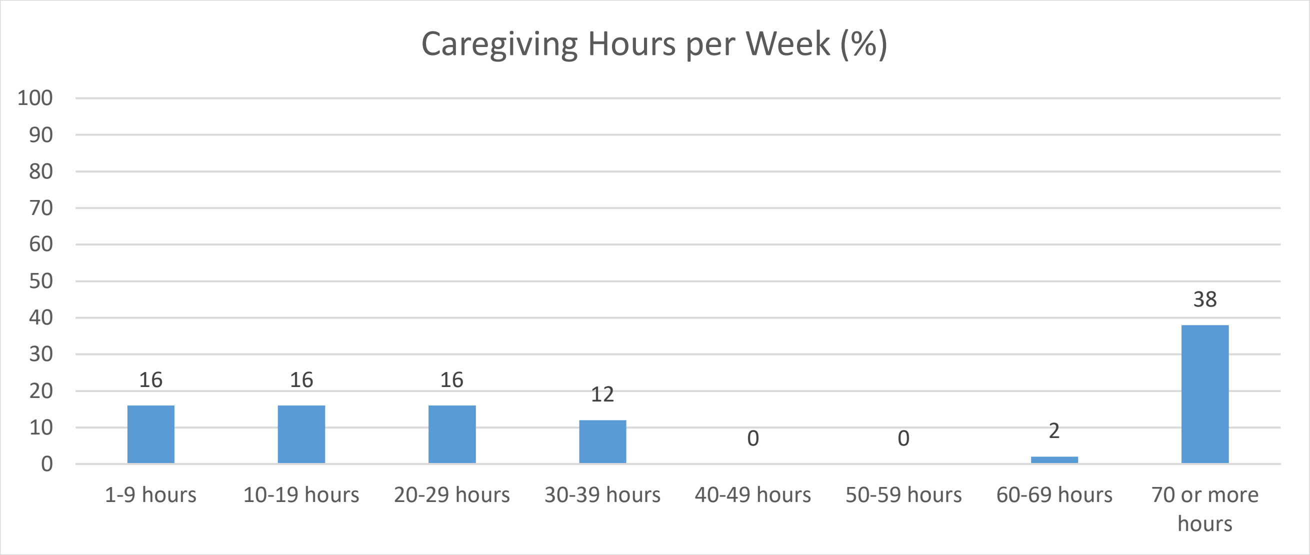
Almost 2 out of 3 respondents reported currently living in the same household as the care recipient (64, 32%). The remaining care recipients were living with someone else (9, 18%), living alone in own residence (7, 14%), or living in an assisted living center (2, 4%).



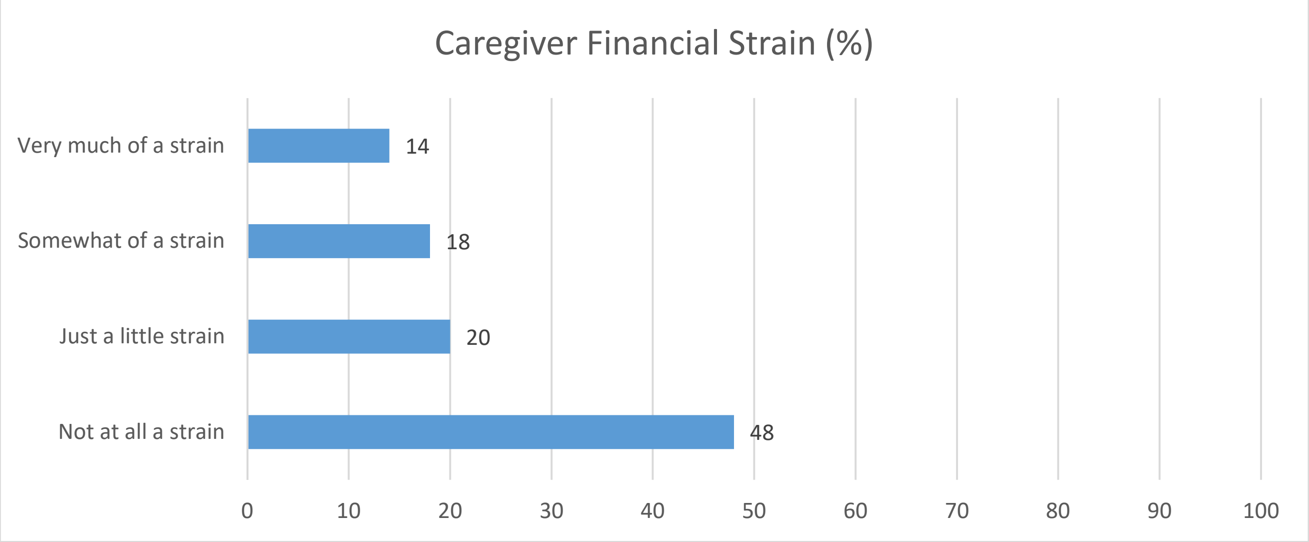
When asked about the total number of years providing care to the family member, caregivers reported on average 8.0 years (SD. 6.8) with a range of 1 to 41 years.



The average number of caregiving hours provided ranged from 4 to 168 hours per week. Twelve caregivers or 24% stated they provided care at or almost "24/7" meaning around the clock. *For the remaining 38 respondents who did not report 24/7 care,* the total number of hours ranged from 4 to 148 hours per week with an average of 68 hours (SD. 66.3) of caregiving reported per week.

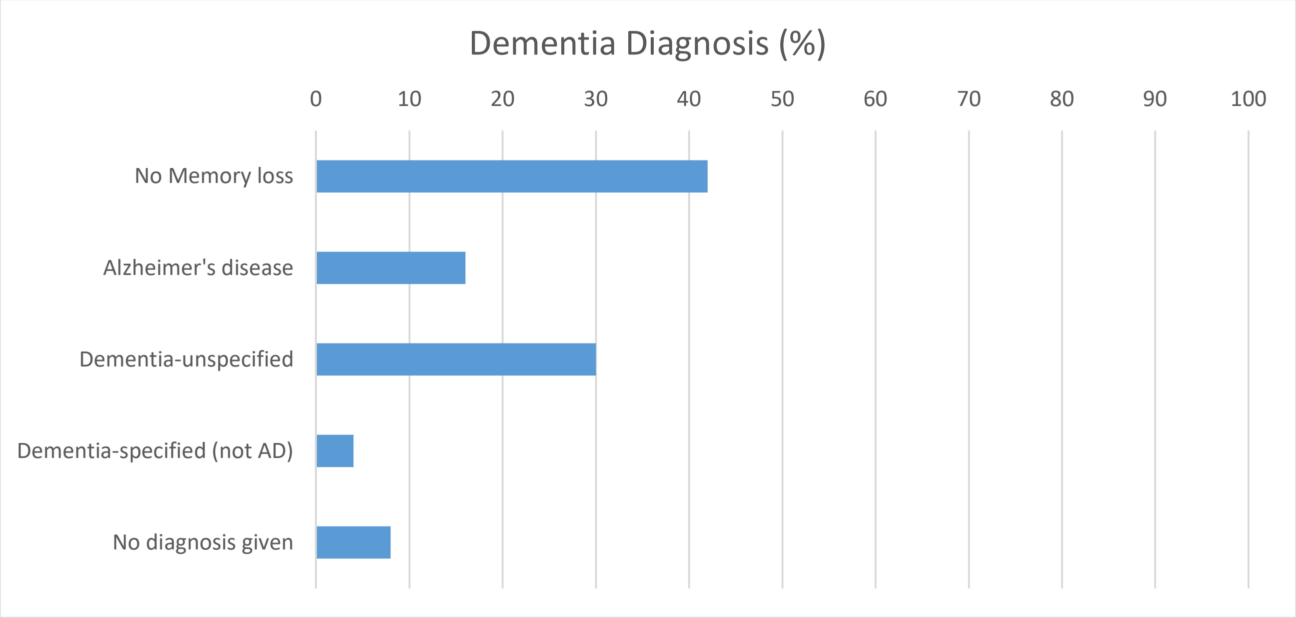


Nine (18%) stated they received payment for providing care. One-third of the respondents reported that they received help from another person, *and of those that received help*, 20% (10) paid out of pocket for this assistance. Over two-thirds reported that they felt no financial strain (24, 48%), or "just a little" strain (10, 20%) compared to about one-third who experienced either "somewhat" (9, 18%), or "very much" financial strain (7, 14%) as a result of providing care.



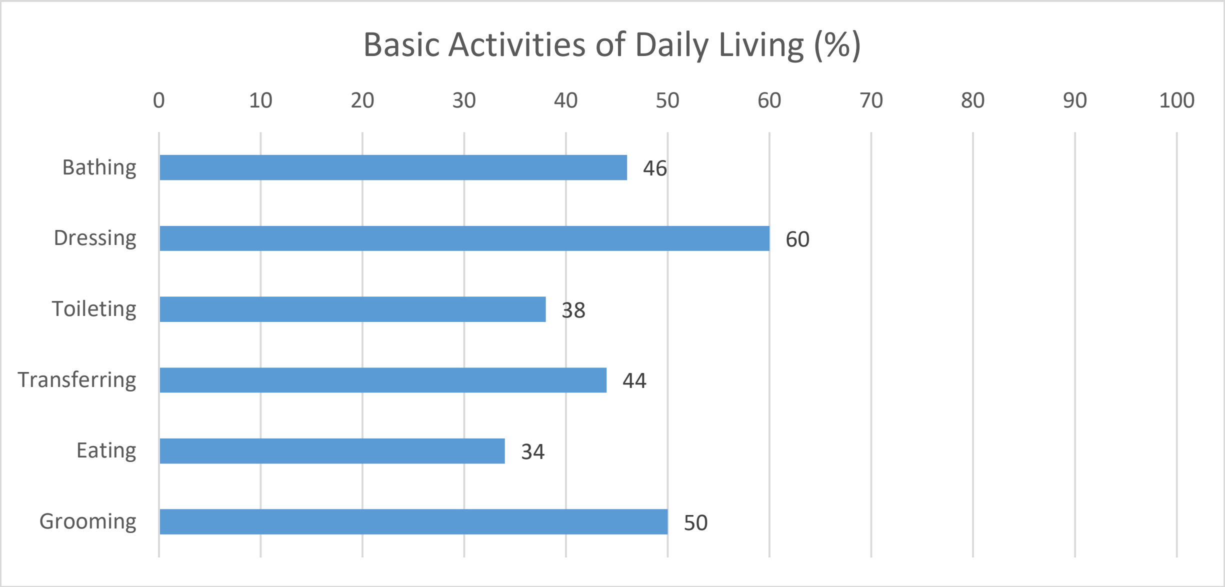
When asked if they were taking care of others beyond the help they provide to the care recipient, respondents reported caring for another adult (14, 28%). Twenty percent stated they cared for children or minors (10, 20%).

Four out of 10 caregivers reported that the care recipient did not have memory loss. The remaining care recipients exhibited memory loss with close to one-third diagnosed with "dementia" but unspecified (15, 30%; specific diagnosis unknown). The remaining care recipients had an Alzheimer's disease diagnosis (8, 16%), or other dementia-type illness (no Alzheimer's disease), or memory loss with no diagnosis given.

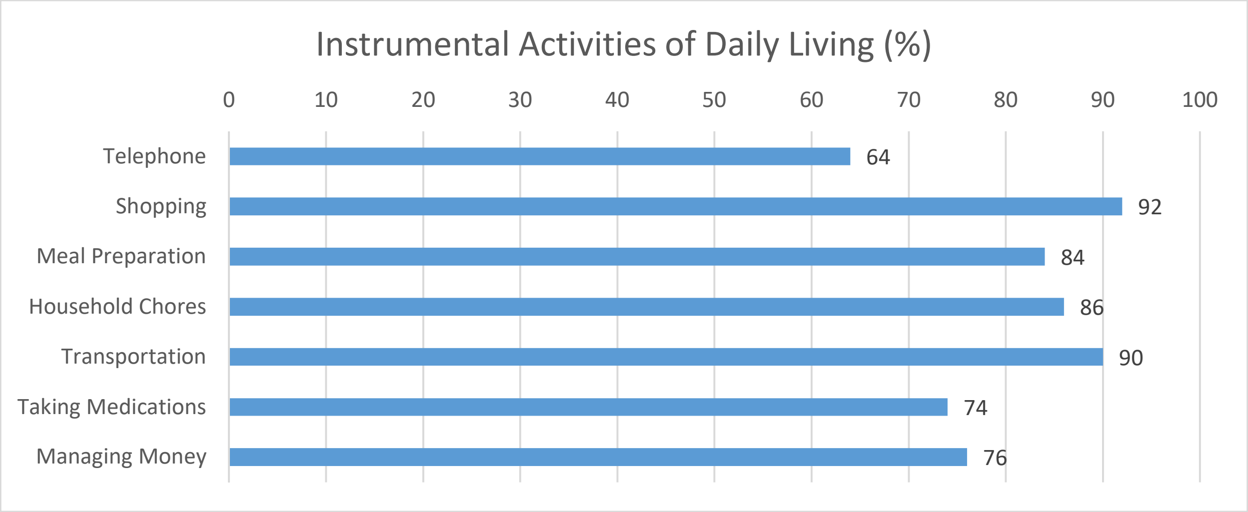


In order to ascertain the extent to which caregivers were providing care to their family member, they were asked if they provided specific caregiving tasks. These tasks cover a wide array of activities that caregivers typically provide to adults with functional limitations and disabilities. The following graphs indicate the percent of respondents that report performing the specific caregiving tasks.

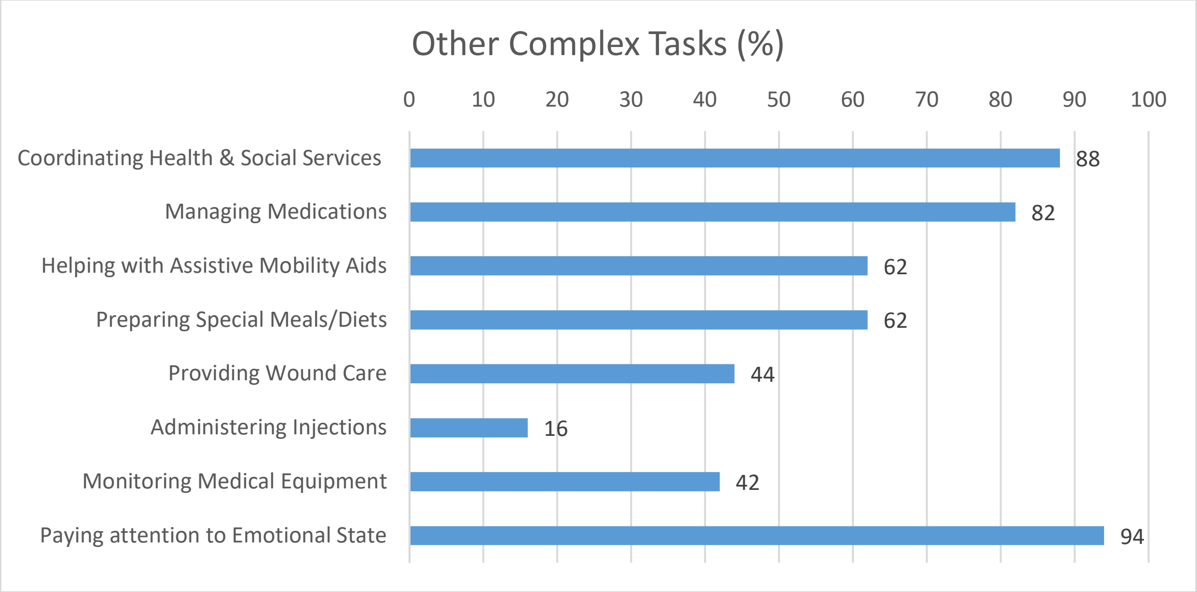
Basic activities of daily living such as bathing, dressing, toileting, etc., are usually provided to care recipients with higher medical or personal care needs. These activities were taken from the original ADL scale developed by Katz and associates (Katz, Down, Cash, & Grotz, 1970). Assisting with hygiene and personal care activities such as bathing (23, 46%), grooming (25, 50%), and dressing (30, 50%) were the top three most endorsed items.



Instrumental activities of daily living typically address those functions that enhance an individual's ability to live independently. The items were based on a modified scale of the original Lawton IADL scale (Lawton & Brody, 1969). The caregiving tasks most likely endorsed by the respondents in this area were shopping (46, 92%), and transportation (45, 90%), household chores (43, 86%), and meal preparation (42, 84%).



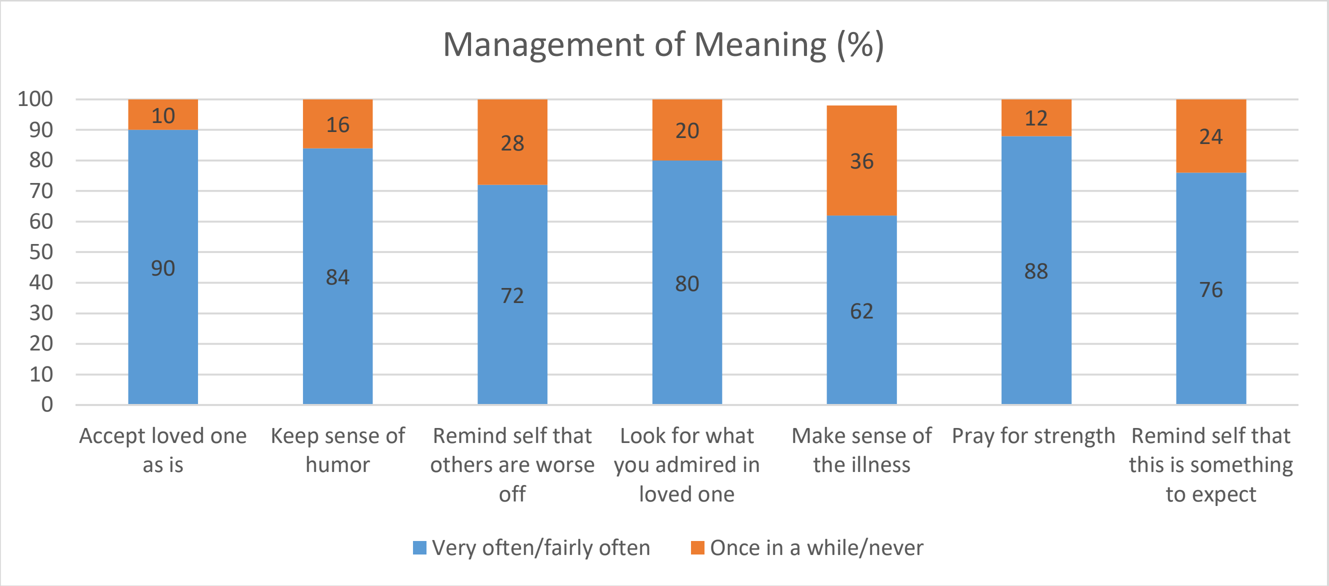
Other complex caregiving tasks include knowledge and skills about medical or nursing aspects of the family member's medical condition(s) or disability. The complex tasks most likely endorsed include paying attention to the care recipient's mental or emotional state (47, 94%), coordinating care (44, 88%), and managing medications (41, 82%).



Caregiving Strengths

Caregivers were queried about their own personal strengths such as the extent to which they manage the meaning of caregiving in their lives. The seven caregiver meaning questions are cited in the literature as important strengths in the management of appraisals or perceptions of the caregiving situation. We included a modified version of the Management of Meaning scale (Pearlin, Mullan, Semple, & Skaff, 1990), and the results are described below.

Overall, the respondents endorsed that they "very often" or "fairly often" managed the meaning of the caregiving situation by such behaviors as accepting the care recipient as she/he is, keeping a sense of humor, and reminding oneself that there are others worse off. The most positively endorsed items ("very" or "fairly often") were acceptance of the care recipient (90%), praying for strength (83%), keeping a sense of humor (84%), and looking for what was admired in one's loved one (80%). Nevertheless, a subgroup of respondents responded that they only "once in a while" or "never" (10 to 36%) had these perceptions or behaviors about their caregiving situation, most notably, making sense of the illness (36%), reminding oneself that others are worse (28%), and reminding oneself that this is something to expect.

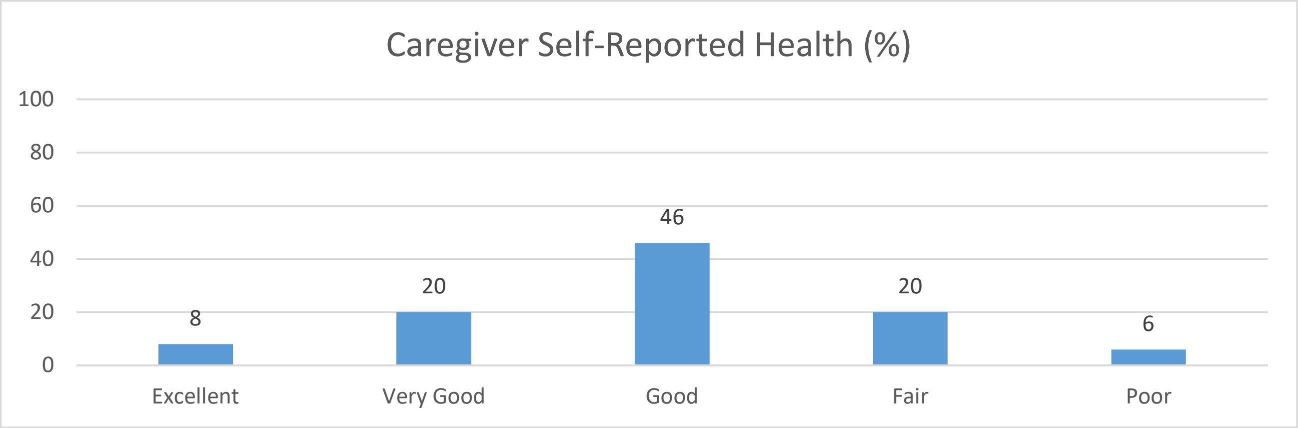


Caregiving Well-Being

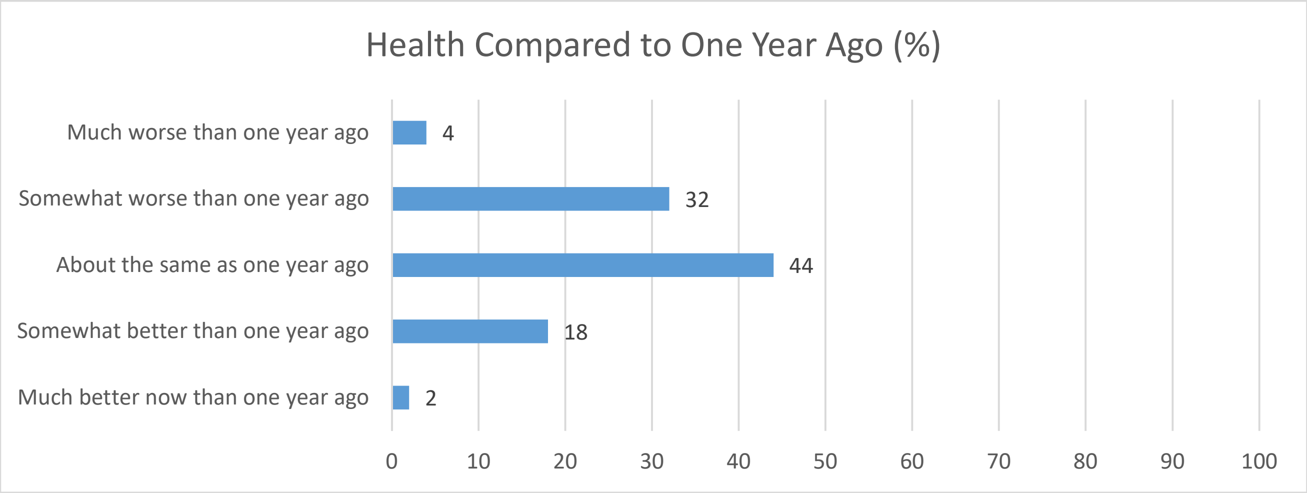
This section includes caregiver responses to items on health-related, psychological, emotional, and social well-being such as self-reported health, depressed mood, sleep problems, and anxiety.

Self-Reported Health

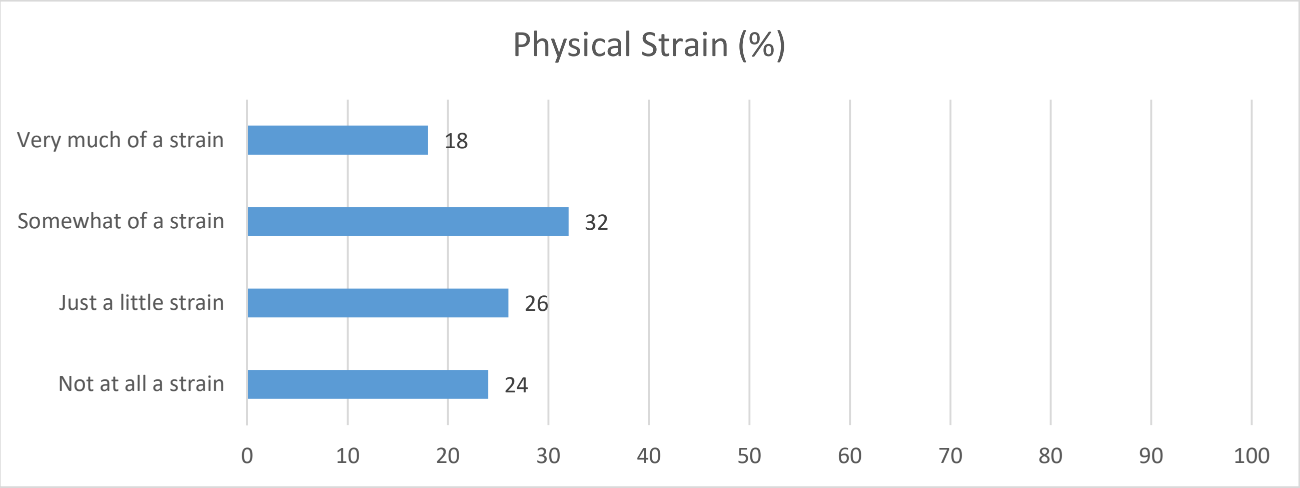
When asked about their health in general, about 3 out of 4 respondents stated their health was "good," "very good," or "excellent" (37, 74%).



Compared to one year before taking the survey, 44% (22) respondents indicated that their health was “about the same as the prior year,” or “somewhat” or “much better” (10, 20%). Still, more than 1 out of 3 reported “somewhat worse” or “much worse” health than one year ago (18, 36%).



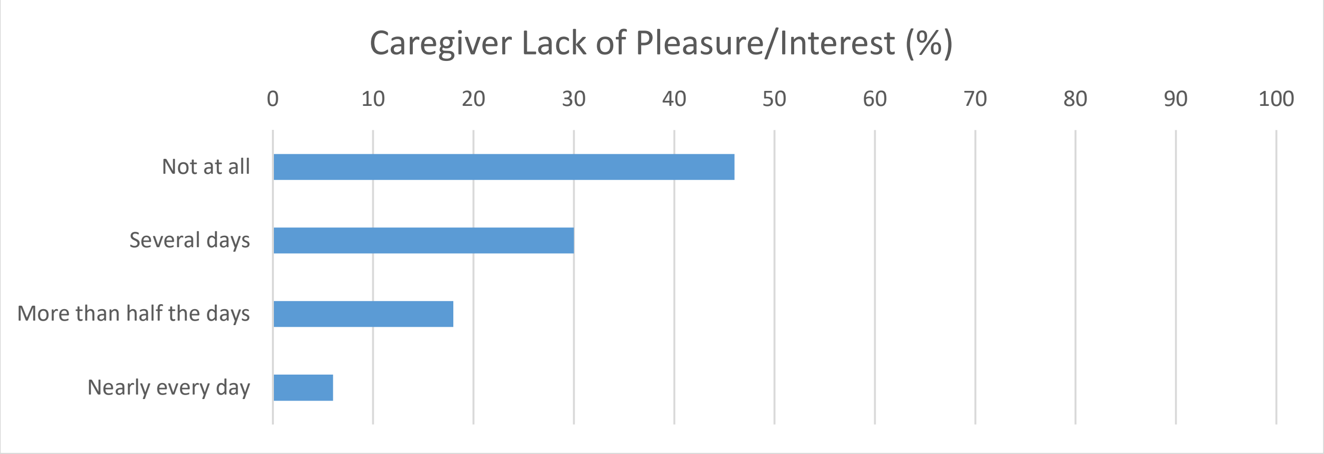
When asked if they experienced physical strain because of caring for their loved one, most replied that “just a little” (13, 36%) or “not at all a strain” (12, 24%). Still, about 1 in 4 stated that they experience physical strain “somewhat” (16, 18%), or “very much” (9, 6%) as a result of their caregiving activities.



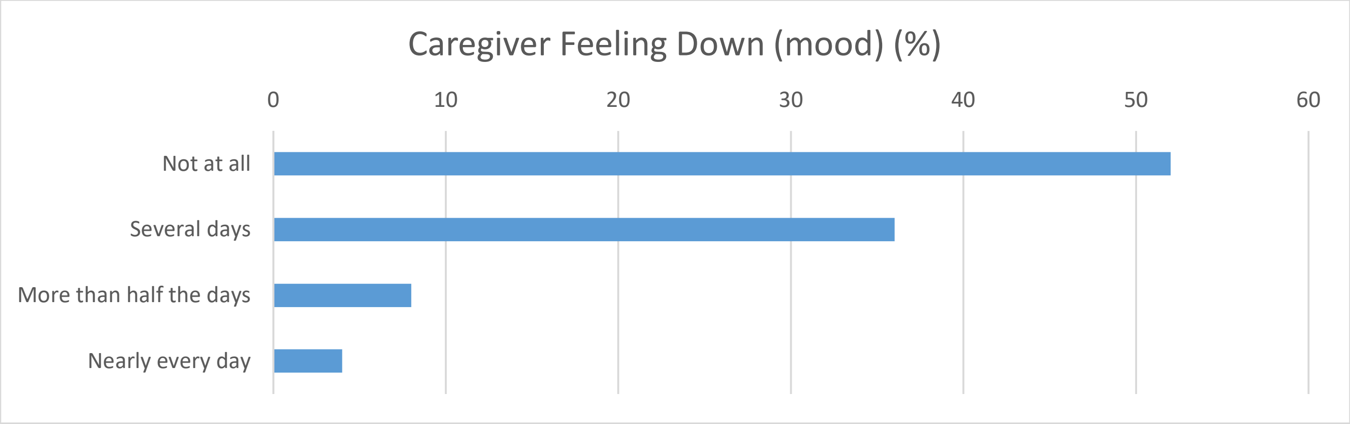
Depressed Mood

Two questions addressed how often the respondents were bothered in the last two weeks by “little interest or pleasure in doing things,” and “feeling down, depressed, or hopeless.” The questions comprise the 2-item Patient Health Questionnaire (PHQ-2) which asks about the frequency of lack of interest, and depressed or sad mood (Kroenke, Spitzer, & Williams, 2003).

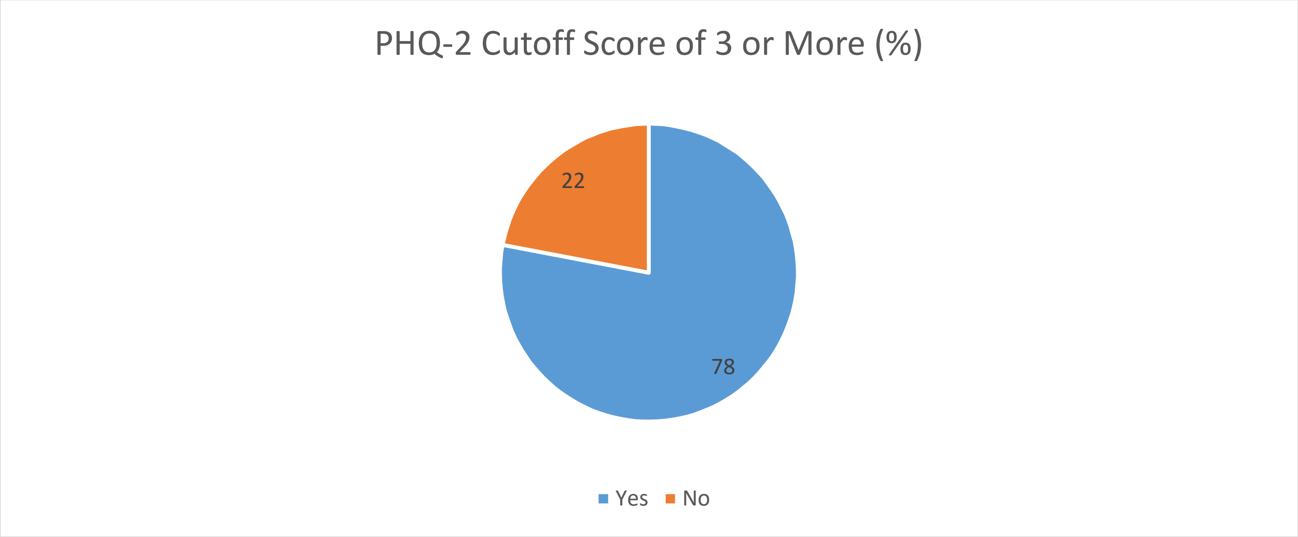
Over one-half of all caregivers reported lack of interest or pleasure in doing things (27, 54%) sometime during the prior two weeks before they took the survey: “several days” (15, 30%), “more than half the days (9, 18%),” or “nearly every day” (3, 6%).



With regards to feeling down, depressed, or hopeless, over one-half stated this did not describe them at all (26, 52%). Yet, 48% (24) endorsed this question: “several days” (18, 36%), “more than half the days (4, 8%), or “nearly every day” (2, 4%).

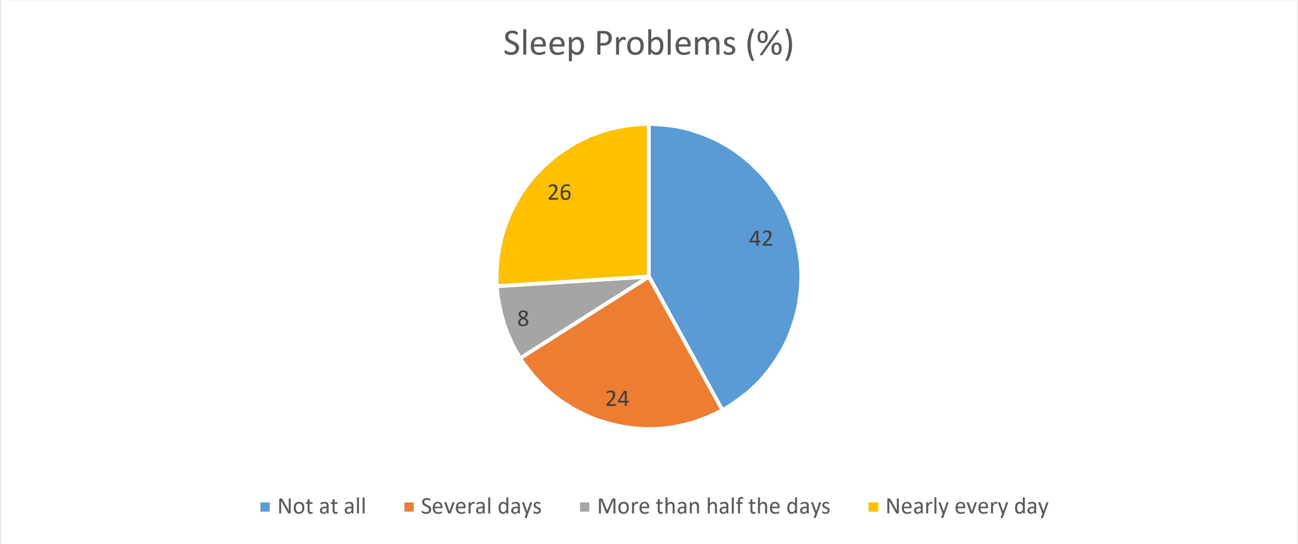


Using the conventional cut-off score of 3 as the cut point for further depression screening, 22% (11) scored in this category.



Sleep Problems

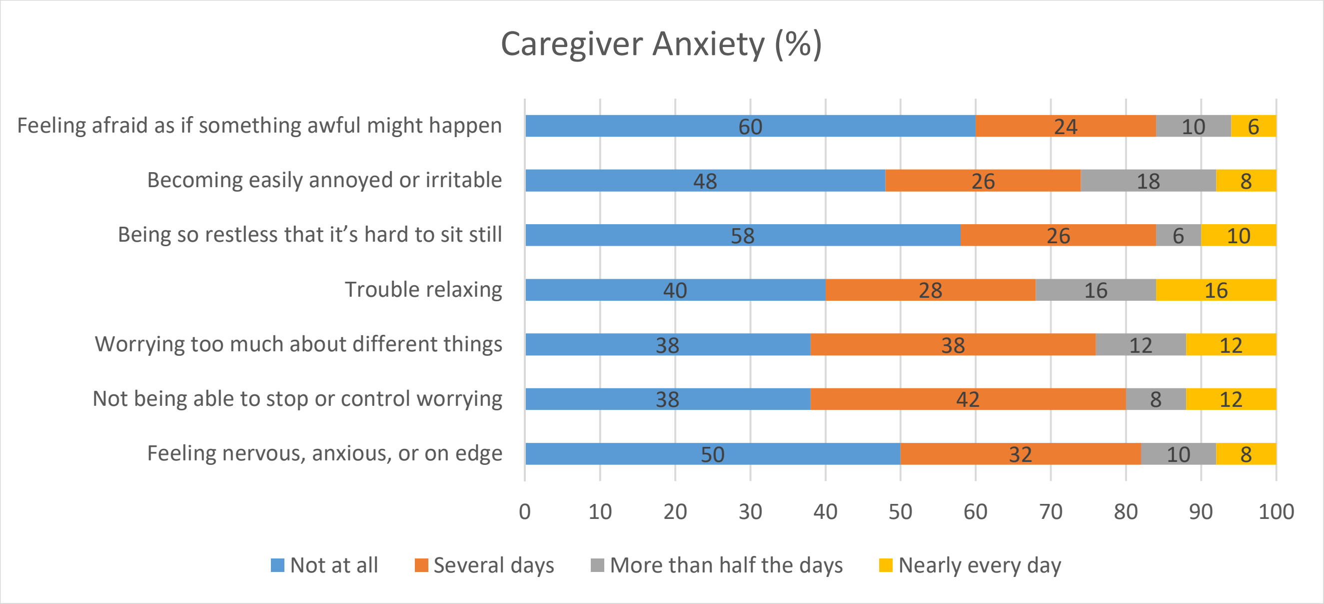
Almost 6 out of 10 respondents (29, 58%) reported they experienced problems with sleeping either "several days" (12, 24%), "more than half the days" (4, 8%), or "nearly every day" (13, 4%).



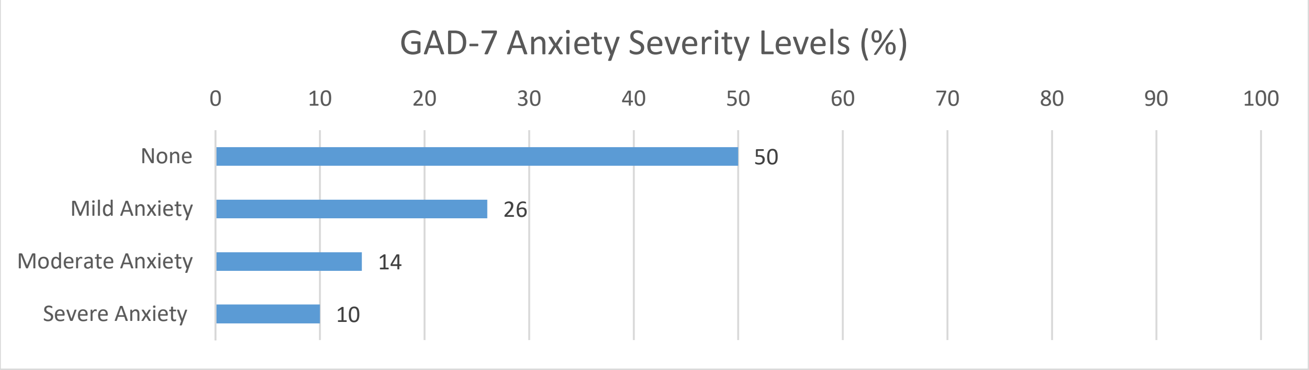
Anxiety

Respondents were asked seven questions regarding anxiety symptoms during the last two weeks. The items comprise a scale to measure anxiety (GAD-7; Spitzer, Kroenke, Williams, & Lowe, 2006).

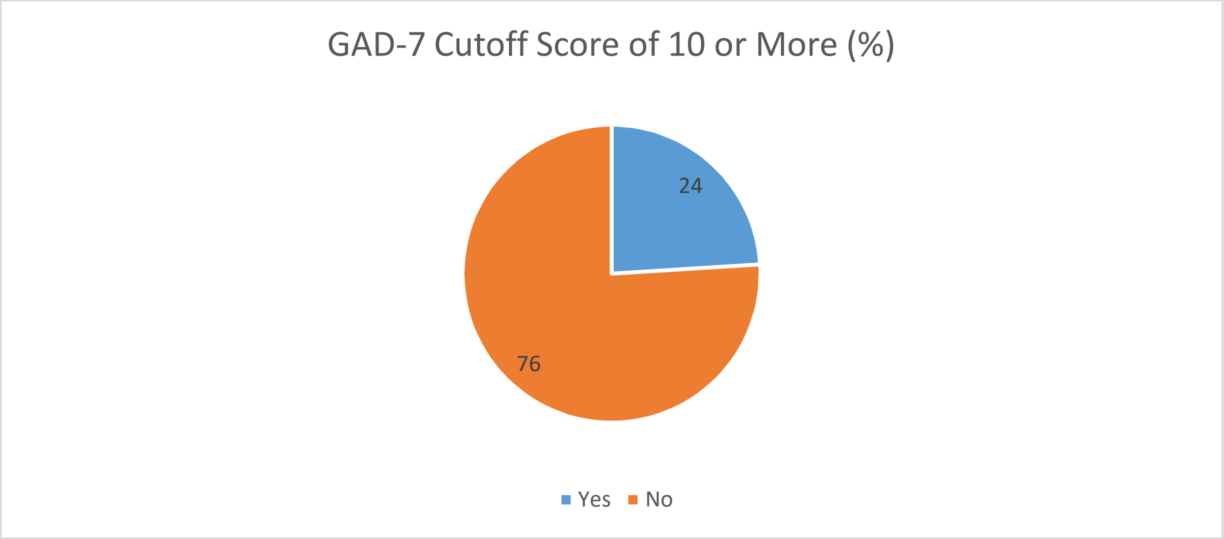
Taking in all seven items, respondents tended to endorse that they worried too much (31, 62%), or could not stop or control worrying (31, 62%). They were less likely to report that they were afraid that something awful would happen, that they were so restless they could not sit still, or to say that they felt nervous or anxious, or annoyed/irritable. Yet, a subgroup of respondents reported anxiety symptoms "more than half the days" or "nearly every day" ranging from 6 to 18% depending on the question posed.



Using conventional cut-off scores for the anxiety scale, 24% (31) scored either at the moderate anxiety (7, 14%), or severe anxiety levels (5, 10%), indicating need for further evaluation.



A score of 10 is the conventional cut-off score for further anxiety screening: 24% (12) fell into this category.



Caregiving Support Services

Caregivers were queried regarding their use of community-based caregiver support services or programs. These items were defined as educational or informational materials, one-time workshops or lectures, support groups, class series, and reminder texts, phone calls, or texts. They also provided information on their consideration of nursing home placement for the care recipient.

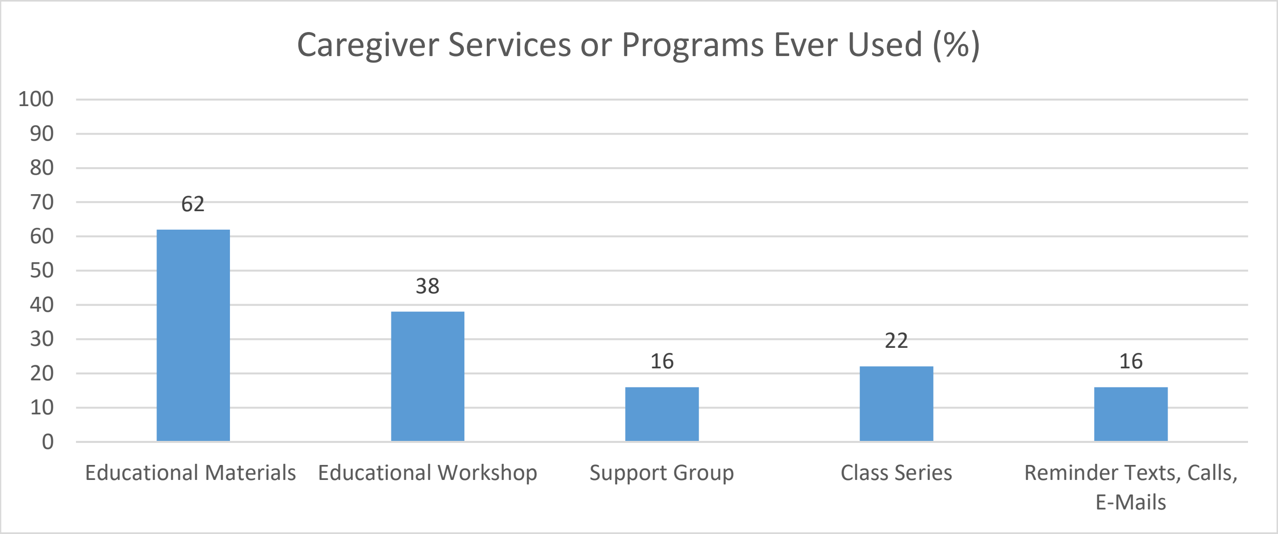
Nursing Home Consideration

None of the respondents stated she/he had considered nursing home placement in the last six months.

Community-Based Caregiver Support Services or Programs

Below are the results regarding the percent of respondents who ever used five different types of caregiver services or programs, and their feedback on their level of satisfaction if they used or received the service or program.

Educational materials (31, 62%), and workshops (19, 38%) were more likely used by the respondents followed by caregiver class series (11, 22%). The least likely utilized services were support groups (8, 16%) and reminder texts/calls/E-mail messages (7, 14%). Class series were identified either as caregiver-specific (e.g., Powerful Tools, Stress Busters), or illness- specific (diabetes, dialysis).



Level of Satisfaction

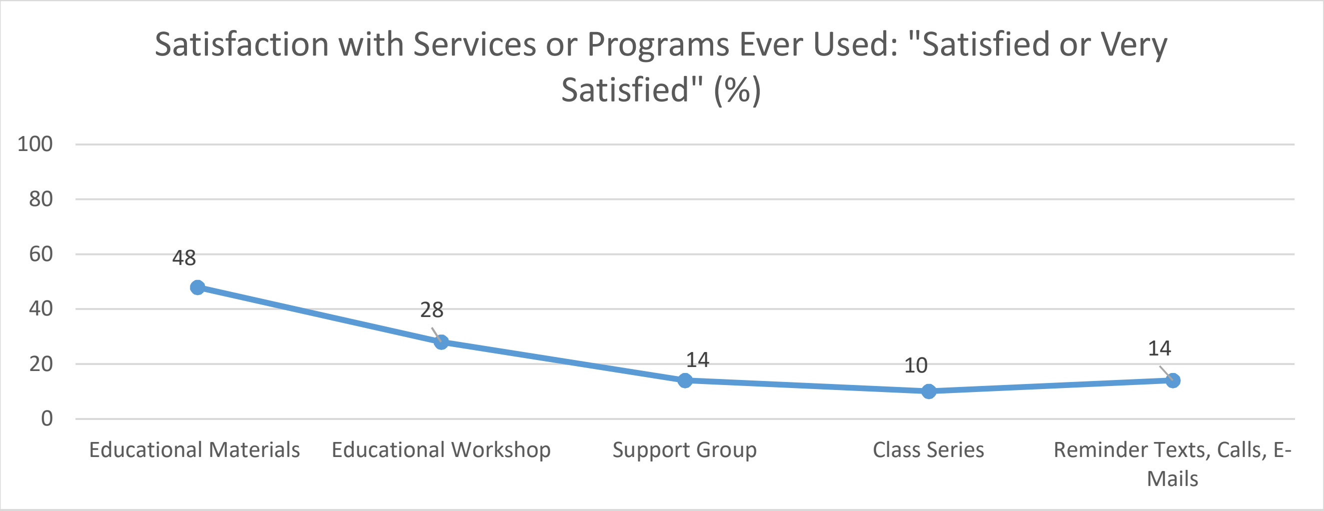
Level of satisfaction was ascertained for *the subgroup of caregivers who responded that they used a service or program*. Level of satisfaction with all services was relatively good with most caregivers responding that they were satisfied or very satisfied with the services received.

Notwithstanding, some services were more satisfying to the caregivers. Level of satisfaction was higher for educational materials as 48% (24) of caregivers replied that they were "satisfied" or "very satisfied" with the materials.

The satisfaction level for educational workshops followed as the second most satisfying service or program such that 28% (14) reported they were "satisfied" or "very satisfied" with the workshops.

The third most satisfying service was tied between support group and reminder texts/calls/E-mails: 18% (9) reported they were "satisfied" or "very satisfied" with these two types of services.

Lastly, class series had the lowest satisfaction levels with 10 % (5) responding "satisfied" or "very satisfied."



Sources of Caregiver Services

Caregivers who used services or programs were asked where they obtained these services, or who sponsored them. The majority of services were obtained from the following sources: health care providers (medical offices, health care teams, health insurance plans such as Kaiser Permanente); or community-based agencies such as the East Los Angeles office of the Alzheimer's of Greater Los Angeles (AlzGLA); local programs sponsored by municipal governments (cities of Bell Gardens, Cudahy); university-sponsored affiliated organizations (Los Angeles Caregiver Resource Center at the University of Southern California); employer-required classes for paid health care workers (Health Talent). Support groups were co-sponsored by AlzGLA and community organizations such as local hospitals (Beverly Hospital, Huntington Hospital).

Caregivers relied on diverse sources of educational materials *over and beyond the sources mentioned above:* They relied as well on the internet, books, magazines, and newspapers to obtain specific information.

Educational workshops were more likely sponsored by community-based organizations, and employer-required classes for paid health care workers.

Church-sponsored services were mentioned for education workshops, support groups, but only by one person. Although the least endorsed, reminder texts/calls/E-mails came primarily from health care providers. Only one person noted the use of a personal cellphone application.

Reasons for Not Seeking Services

If caregivers *did not* seek or receive services, they were queried as to the reasons why. Ten reasons were provided as possible selections. The three top reasons caregivers offered as reasons why services were not sought were 1) Not having the time to look for or participate in the service or program; 2) Not knowing that the service or program even existed, so did not seek it; and 3) Thinking that help was not needed.

Key Findings

This report focuses on responses from 50 caregivers age 30 to 64 years of age providing care to an adult 50 years of age or older in select areas of Los Angeles County, Supervisorial District 1. Caregivers were queried about the types of assistance they provide their family member, their psychological and emotional responses to the caregiving situation, and their use of caregiver support services and programs.

Based on a convenience sample of 40 female and 10 male caregivers, we highlight key findings below.

- **CAREGIVER SOCIODEMOGRAPHIC CHARACTERISTICS**
  - Caregivers were more likely adult children in their mid-fifties caring for an elderly parent with multiple care needs. Although most adult children were females, 20% of the sample consisted of males.
  - Most caregivers were English-speakers born in the United States. One-half of non-US-born caregivers preferred to speak English perhaps indicating emigration to the US at an early age.
  - Socioeconomic indicators such as education and income indicate a more educated group, employed, with higher incomes; yet another group appears to emerge which is less educated and has less household income.
  - Only 8% were not covered by health insurance.

- **CARE RECIPIENT SOCIODEMOGRAPHIC CHARACTERISTICS**
  - Care recipients are more likely females in their early 80s, Spanish-speaking, and born outside of the United States.

- Similar to their caregivers, they were more likely to be born in Mexico if non-US-born.
- Another similarity to their caregivers, is the high rate of health insurance coverage: 100% were covered by health insurance.

❖ CONTEXT OF CAREGIVING

- Care recipients were in their early eighties ranging from 50 to 92 years of age.
- The majority of caregivers and care recipients co-resided in the same household.
- There was a wide range of years of caregiving from 1 to 41 years. The average number of years since the onset of caregiving was 8 years. Thus, on average, caregivers began caregiving in their mid-40s to older family members in their mid-70s.
- Caregiving hours per week ranged from 4 to 168 hours. A group of caregivers provided round-the-clock caregiving with minimal time off. For those who did not provide round-the-clock caregiving, the average hours per week was high: 68 caregiving hours per week.
- 18% received pay for the assistance they provided. One-third received help from another person, and 10% paid out of pocket for the help.
- Although most did not report significant financial strain, 1 out of 3 reported somewhat or very much financial strain as a result of caregiving.
- 28% cared for another adult, and 20% cared for children indicating that upwards more than one-half were caregivers to more than one family member.
- More than one-half cared for a family member with memory loss such as Alzheimer’s disease, or other dementia diagnosis. Most caregivers did not report the exact name for the dementia diagnosis but noted the term “dementia” as the type of memory disorder or problem.
- Of the array of 21 caregiving tasks, 6 were most likely endorsed (82 to 92%): paying attention to the psychological and emotional state of the care recipient, shopping, transportation, care coordination, household chores, and medication management.
- A subgroup of caregivers provided more complex type tasks such as wound care, monitoring medical equipment, and preparing special meals/diets.

CAREGIVER STRENGTHS

- Caregivers reported relatively high levels of managing the meaning or appraisals of the caregiving situation—an indicator of caregiver strength in the face of high demands or stress. They indicated accepting the care recipient as she/he is, praying for strength, keeping a sense of humor, and looking for what was admired in the loved one.
- Notwithstanding, these types of appraisals or reframing of the caregiving situation were never endorsed by a subgroup of respondents, or endorsed only once in a while.

CAREGIVER WELL-BEING

- About 3 out of 4 caregivers considered their health good, very good, or excellent. And, although 64% reported that their health was the same or better as one year ago, a subgroup of caregivers (1 out of 3) believed their health was worse than one year ago. One in 4 stated they experience physical strain.
- Although the survey is not considered a clinical assessment, 22% scored at the conventional cut-off score of 3 indicating need for further depression screening.
- Likewise, using a conventional cut-off score of 10 or more symptoms, 24% scored either at the moderate anxiety, or severe anxiety levels indicating need for further evaluation.
- Almost 6 out of 10 respondents reported some problems with falling asleep, staying asleep, or sleeping too much.

CAREGIVER SUPPORT SERVICES

- Of all caregiver support services identified in the survey, educational materials and workshops were more likely used by the respondents followed by caregiver class series.
- Educational materials were obtained from diverse sources with the health care provider or team being the most likely source of these materials. Other frequently noted sources of educational materials were local community-based organizations, or university-affiliated programs.
- Educational workshops were more likely sponsored by community-based organizations, and employer-required classes for paid health care workers.

- Class series were identified either as caregiver-specific (e.g., Powerful Tools, Stress Busters), or illness- specific (diabetes, dialysis), and provided by community-based or university-affiliated programs
- The least likely utilized services were support groups (8, 16%) and reminder texts/calls/E-mail messages (7, 14%).
- Church-affiliated sources of help, or personal cellphone applications were noted each by only one person.
- Although most caregivers who sought or received services noted they were satisfied with the services, level of satisfaction varied across the 5 services or programs listed. Educational materials and workshops were the most satisfying while class series was the least satisfying.
- The top three reasons caregivers did not seek or participate services were not having time, not knowing a service existed, or thinking that help was not needed.

Recommendations

This sample of 50 female and male caregivers provides assistance which on average is the equivalent of about 1.5 full-time employment hours per week. Some provide mentally complex, physically tiring, and emotionally demanding care that has taken a toll. Although Latino families do their share with a strong sense of meaning and purpose, they face high physical, emotional, social, and financial strain.

Recommendation 1: Countywide System of Care (SOC)

Caregiving, by its very nature, assumes a dyadic relationship, and in this case with an adult care recipient who also has a voice, beliefs, preferences, strengths, and needs. Some are providing care not for only one person, but multiple individuals including children. Use of caregiver services, although increasing, is still not on par with the demands of caregiving in Latino families. And, although socioeconomic indicators such as education and income indicate a more English-speaking, educated group with higher incomes, it appears that access to services remains limited. This was the case even with high health insurance coverage for both caregivers and care recipients.

Thus, not one service or program is considered sufficient over time when dealing with a complex issue such as family caregiving; nor can we expect that the needs of caregivers remain static over their trajectories of care—which may be upwards of one to four decades as we found in our sample.

<u>We recommend a system of person- and family-centered care to provide services tailored to the needs of Latino caregivers in Los Angeles County</u>. Systems of care (SOC), although not a new concept in other fields, comprises formal and informal family supports and services, and the navigation processes that links these with families. Combining the expertise of community-based organizations and health care providers, services can include assessment, information and referral, health services, adult respite care, education and skill-building, psychological counseling, and care coordination, to name a few. Enhanced services can include information and/or direct services such as: child/minor-specific services; language interpretation and translation; case and community advocacy; immigration consultation; transportation services; medical equipment; reduced costs for out-of-pocket medical and long term care expenses; employment opportunities; home modification services; etc.

In Los Angeles County, less than a handful of caregiving-affiliated organizations already exist that include many of the services listed above in their organizational mission. In fact, some of these organizations provided referrals to the caregiver survey, and were mentioned as sources of services by the survey respondents. Yet, these organizations did not provide direct health care services for caregivers or care recipients. The health care provider (physicians, allied health providers, health insurance plans) were mentioned as key sources of services and programs, yet according to the caregivers, it did not appear that the provider and provider organizations had expert knowledge in caregiving issues aside perhaps from offering information on illnesses or diseases affecting the care recipient. Thus, combining the expertise of community-based organizations and health care providers in a system of care is warranted.

Recommendation 2: Sources of Strength Campaign (SOS)

Caregivers reported relatively high levels of managing the meaning or appraisals of the caregiving situation. Others reported they were in good physical and psychological health, while many reported no financial strain. These results are indicators that something is going right among Latino caregivers, and that not all Latino caregivers are overwhelmed by their caregiving challenges. Articulating these strengths and examining why they exist is not just an academic exercise but meaningful ways to foment caregiver outreach and information diffusion campaigns.

<u>We recommend caregiving outreach and information diffusion campaigns that integrate Latino caregiving realities and resilience.</u> Accepting a loved one for who she/he is, praying for strength, keeping a sense of humor, looking for what was admired in her/him, are all indicators of resiliency, and rooted in culturally-embedded coping strategies. Individual and community engagement

strategies that uphold narratives of caregiver and family resiliency should be used to diffuse information on Latino caregiving and available services and programs through multi-language, multi-media formats (radio, TV, public service announcements, social media, educational materials, workforce training modules, etc.). These strategies will need to be tailored to caregivers at different ages and generations with specific messages that address their common as well as unique needs and preferences.

Several examples of culturally- and linguistically-attuned outreach strategies exist but most are executed on an individual basis with time-limited attempts at reaching the Latino community--partly due to changing income revenue streams, workforce development and attrition, and redirection of organizational objectives.

Recommendation 3: Survey of Latino Caregivers (SOL-C)

Although our analysis did not explore results by subgroups or categories, studying larger samples of Latino caregivers is crucial in order to account for in-group differences that can inform service and product development.

We recommend implementation of a large-scale, prospective county-wide survey of Latino caregivers and care recipients across the lifespan. We need current estimates of the rates of caregiving, who is caring for whom and for what conditions, how caregiving is perceived and managed across subgroups of Latinos caregivers: gender self-identified groups; high vs. low income; Spanish-speaking vs. English-speakers; employed vs. not employed; etc. By including respondents from a wider range of incomes, education, caregiving contexts, etc., we are more likely to include responses from different types of caregivers at different points in their caregiving trajectory. Furthermore, examining their care trajectories over time is a valuable source of information to ascertain the dynamics process and “career” of caregiving and changing caregiving needs across generations.

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Acknowledgements

We would like to thank all of the 50 caregivers who participated in the survey. Their insights will contribute to enhancing caregiver services and programs for Latinos.

Footnotes

1. The words respondent and caregiver are used interchangeably in the report.
2. Results are reported in frequencies, and percentages.
3. SD = standard deviation

Recommended Citation

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For more information on the *"Los Angeles Latino Caregiver Project"* visit http://www.sbssla.org/latino-caregiver-project/