

Evercare® Study of
**Hispanic Family Caregiving
in the U.S.**



Findings From a National Study
November 2008

Evercare
and
National Alliance for Caregiving



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Study Publishers

Evercare

Evercare is one of the nation's largest health care coordination programs for people who have long-term or advanced illness, are older or have disabilities. Founded in 1987, Evercare today serves more than 350,000 people nationwide through Medicare, Medicaid and private-pay health plans, programs and services — from health plans for people in community and skilled nursing settings, to caregiver support and hospice care. Evercare offerings are designed to enhance health and independence, and in the complex world of health care, making getting care easier.

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National Alliance for Caregiving

Established in 1996, the National Alliance for Caregiving is a non-profit coalition of more than 40 national organizations that focus on issues of family caregiving across the life span. The Alliance was created to conduct research, do policy analysis, develop national programs and increase public awareness of family caregiving issues. It also works to strengthen state and local caregiving coalitions and work on international caregiving alliances. Recognizing that family caregivers make important societal and financial contributions toward maintaining the well-being of those for whom they care, the Alliance's mission is to be the objective national resource on family caregiving, with the goal of improving the quality of life for families and care recipients.

National Alliance for Caregiving
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www.caregiving.org

Evercare and the National Alliance for Caregiving (NAC) have collaborated on three national caregiving studies which put into sharper focus one of our society's most undervalued groups: family caregivers.

***Evercare Study of Caregivers in Decline* (2006) about the health risks caregivers face**

***Evercare Study of Family Caregivers: What They Spend, What They Sacrifice* (2007) highlighting the out-of-pocket costs of caring for an older loved one**

***Evercare Study of Hispanic Family Caregiving in the U.S.* (2008) the first-ever in-depth look at Hispanic caregivers**

Acknowledgments

The National Alliance for Caregiving and Evercare by UnitedHealthcare are proud to present this first nationwide comprehensive study of Hispanic family caregivers in the U.S.

Gail Gibson Hunt of the National Alliance for Caregiving and Sherri Snelling of Evercare set the direction for this study. In addition, they wish to acknowledge two experts who provided input to the questionnaire and its translation:

Maria Aranda, Ph.D. and LCSW, University of Southern California
Martha Pelaez, International Consultant on Aging and Health

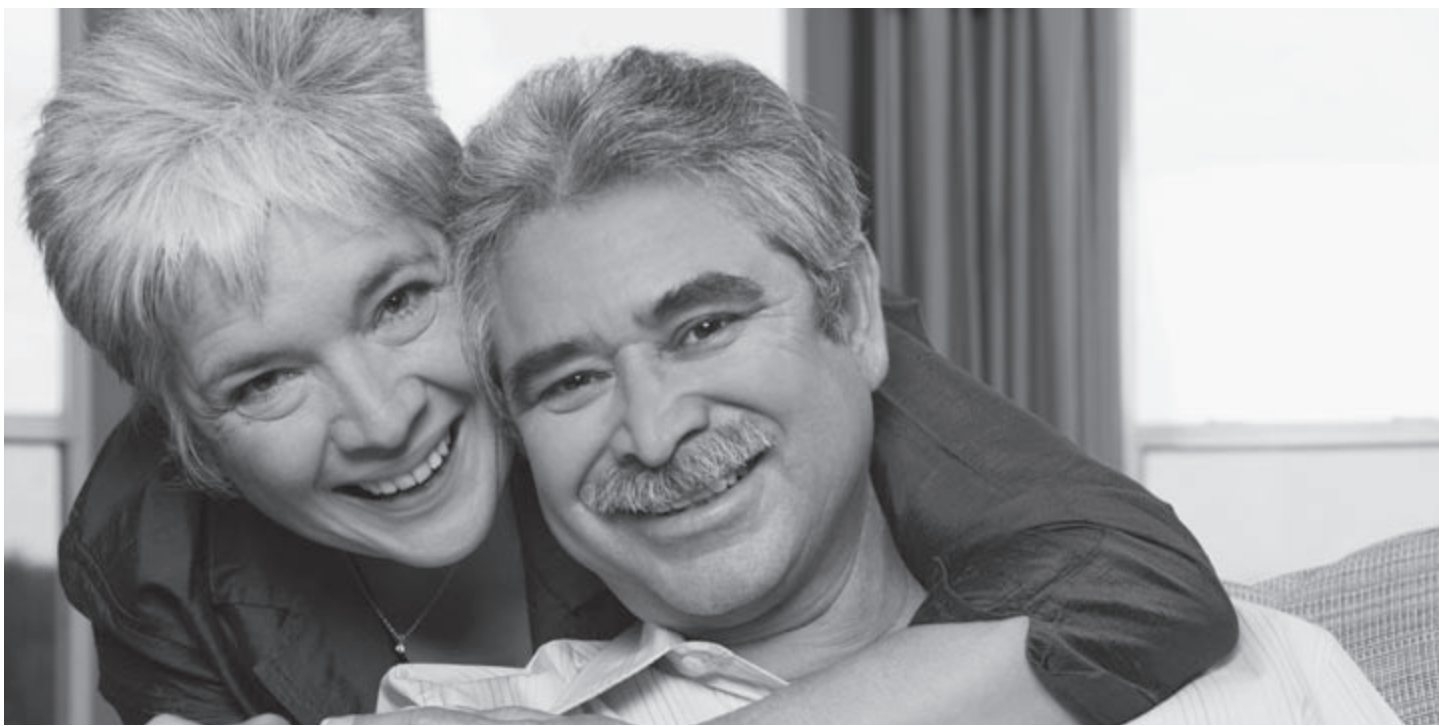
The research was conducted by Mathew Greenwald & Associates, with Linda Naiditch managing the study.

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Foreword



The family has always been at the heart of the Hispanic community. Caring for our elders is considered an honor and a role we perform willingly. Over the last three decades as life expectancies have grown, some say we are at the forefront of a “longevity revolution.” Living longer is a gift but with it comes concerns not just about health, such as chronic illnesses like diabetes and heart disease, but also about rising health care costs. Many of these issues have Hispanic families turning to each other even more for physical, emotional and financial support.

This study conducted by the National Alliance for Caregiving (NAC) and Evercare by UnitedHealthcare is significant in that it is the first-ever in-depth look at the Hispanic community and its family caregivers. Understanding the special situations, the language and cultural needs, and the programs and solutions available to Hispanic families is important as we all face this longevity revolution together.

For over 25 years, the National Hispanic Council on Aging (NHCOA) has recognized that the health and well-being of our padres y abuelitos is directly related to the care and nurturing from their families and communities. Our goal is to share the best of us so that our elders can enjoy their golden years in health and security surrounded by family and friends.

Since we know diabetes continues to be one of the most serious health care burdens impacting Hispanics — afflicting twice as many Hispanics as non-Hispanics in the U.S., especially Hispanic older adults, this study by NAC and Evercare now uncovers that Hispanic family caregivers — on a ratio of two to one — are saying they are providing more care for their elder due to diabetes. That is why NHCOA implements the *Salud Bienstar Program*. This program is designed to improve diabetes prevention and control among Hispanic older adults and their families through the development of culturally and linguistically appropriate and age-sensitive educational interventions. Working on a local level with the support of community-based organizations who are members of NHCOA, the program addresses the cultural barriers between health care providers and users to reduce the diabetes health disparities between Hispanics and non-Hispanic adults.

I am very proud to lead an organization which supports the growing number of aging Hispanic adults and their families through the building of support networks, advocacy, research and funding for community-based efforts. Through our support, families benefit from health programs, employment opportunities, advocacy, and research.

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



Introduction



As we celebrate National Family Caregiver Month this November, I wish to salute our “first responders” in long-term care — America’s family caregivers. I also want to commend the National Alliance for Caregiving and Evercare by UnitedHealthcare for conducting this study of Hispanic Caregivers in the U.S. which helps us in understanding the unique needs of family caregivers and how those needs vary across different segments of our society.

Family members are the primary providers of long-term care for older people in America. Today, 44 million Americans are providing care for an older loved one. Over the next 20 years as our baby boom population ages and, in effect, doubles the number of our nation’s seniors — the ranks of our country’s family caregivers will grow as well. Caregiving may be one of the most important roles someone will undertake in their lifetime, and it is typically not an easy role or one in which any of us come prepared. It often comes with significant financial, physical and emotional burdens.

All of us at the Administration on Aging are proud of the many programs we administer, in collaboration with our state, local and community partners, that serve over 10 million seniors and over 1.2 million family caregivers each year. Our National Family Caregiver Support Program provides a wide range of services and supports for America’s family caregivers who are struggling to keep their loved ones at home and in the community. Other major initiatives that AoA has launched to help both seniors and their caregivers include the Aging and Disability “one stop shop” Resource Center Program which makes it easier for individuals to learn about and access the services that are available in their communities; our Nursing Home Diversion Programs that helps seniors at high risk of nursing home placement to remain at home; and our Evidence-Based Prevention Program which is helping families who are caring for loved ones with Alzheimer’s disease and related disorders.

Not all caregivers face the same issues or have the same needs. In March 2008, the U.S. Department of Health and Human Services Agency for Healthcare Research and Quality (AHRQ) and The Advertising Council launched a Spanish-language national public service campaign designed to encourage Hispanics to become more involved in their health care. While studies have found that the majority of family caregivers often neglect their own health care needs, recent AHRQ data showed that Hispanics are 38 percent less likely than non-Hispanics to have visited the doctor within the past year and more than half of Hispanics have not taken other preventative health care measures, such as cholesterol, colonoscopy or mammogram screenings.

It is these valued family caregivers who truly exemplify compassion in action.

Josefina G. Carbonell
Assistant Secretary for Aging
U.S. Administration on Aging

*For more information on AoA programs that support both seniors and their family caregivers, please visit:
www.aoa.gov*



Background

Purpose of Study

Two national family caregiver surveys have been published by the National Alliance for Caregiving — one in 1997 and another in 2004. While both of these studies included over-sampling of Hispanic family caregivers, as well as African American and Asian American caregivers, neither study explored in-depth how Hispanic caregivers are unique or what their special needs might be. This study's objective was to develop a detailed profile of Hispanic family caregivers, to determine how they differ from non-Hispanic caregivers, and to explore their information and service needs.

The 2004 National Alliance for Caregiving study “Caregiving in the U.S.” found that 44 million Americans over the age of 18 were providing care for someone over the age of 18. This study will be the first comprehensive, nationwide look at the Hispanic caregiver, the fastest growing ethnic group in our society.

Summary of Methodology

The report is based primarily on 20+ minute telephone interviews with 1,007 Hispanic family caregivers and 209 non-Hispanic caregivers, conducted in August and September 2008. Respondents were given the option of conducting the interview in Spanish or English, and the majority chose Spanish.

In addition, five focus groups were conducted with Hispanic caregivers in advance of the survey in Miami, Houston and Los Angeles.

For detailed methodology information for this study, see separate section, pages 15-18.

Summary of Key Findings

Here is a snapshot of some of the most important key findings of this study:

- One-third of Hispanic households report having at least one family caregiver (36%). With an average of 1.83 caregivers per household, there are an estimated 8,147,000 Hispanic caregivers in the U.S.
- Just under three-quarters (74%) of Hispanic caregivers are female, with an average age of 43, caring for a loved one whose average age is 62. Most of the care recipients are female.
- Hispanic family caregivers tend to be in more intensive caregiving situations with 63% in high burden situations compared to 51% of non-Hispanic caregivers. And Hispanic caregivers spend more hours per week giving care (on average 37 hours vs. 31 hours) and provide a greater number of Activities of Daily Living, known as personal care (2.6 vs. 1.9). A high percentage of Hispanic caregivers live with their loved one (43%) — this is versus 32% of non-Hispanic caregivers.
- Yet despite these factors, Hispanic caregivers are more likely to rate their caregiving situation as *not at all stressful* (34% vs. 22%). In fact, 50% said they had little or no stress. They are more likely than non-Hispanic caregivers to feel fulfilled in their caregiving role (88% vs. 76%) and more likely to say that they are very satisfied with their social life outside of caregiving, including getting together with friends and going out (49% vs. 37%).
- Eighty-four percent of Hispanic caregivers believe that their role is an expectation within their upbringing. Seventy percent think that it would bring shame on their family not to accept their caregiving role versus 60% of non-Hispanics.
- And caregiving is a shared responsibility: 82% say that they get some help from a relative or friend.
- Four in ten working Hispanic caregivers report making a major workforce change, such as taking a leave of absence, changing jobs, cutting back hours or stopping work entirely.

- Diabetes emerges as the number one reason why caregivers' loved ones need care. Nearly one in four Hispanic caregivers also mentions that his/her loved one suffers from Alzheimer's or other dementia.
- When they seek information and services to help with caregiving, more Hispanic caregivers turn to health care professionals — such as doctors, nurses, social workers, pharmacists — than any other source (81%), followed by family and friends (66%), and then government agencies (49%). Three in ten have searched for information online. Roughly three-quarters feel that information and materials in Spanish are important (73%) and that services delivered in Spanish are important (78%). Eighty percent feel that a training class on caregiving duties would be helpful.

Policy Implications

While it is clear that Hispanic caregivers view caregiving as an important and natural role within the family, it would be a mistake to assume that they do not need support in this role. Like all caregivers, Hispanic caregivers would benefit from:

- Respite care
- Assessment of their needs as well as the care recipient's needs
- Training in caregiving activities, especially personal care and health-related tasks such as operating feeding tubes or respirators
- Financial support so that they do not go bankrupt as a result of health care and related costs
- Information about services for caregivers and care recipients
- Care coordination and assistance with navigating the long-term care system
- Support at the workplace so that they do not have to leave the workforce needlessly.

Of course, as the survey points out, Hispanic caregivers want and need culturally sensitive materials that are in Spanish.



Methodology

Quantitative Telephone Interview Study

The “definition” of family caregiver is someone age 18+ who has provided unpaid care to a relative or friend age 18+ in the last 12 months.

In the quantitative study, the Hispanic caregivers were reached through a nationwide sample targeting Hispanic surnames as well as random samples within specific geographic locations with high concentrations of Hispanics. Non-Hispanic caregivers were reached through a nationwide random sample.

The questionnaire was designed to replicate some of the questions posed in prior national studies as well as to explore new areas. It was designed by a team from the National Alliance for Caregiving, Evercare, and Mathew Greenwald & Associates, and was also shaped by input from several advisors.

The survey was conducted between August 7 and September 2, 2008. Respondents were given the option of conducting the interview in Spanish or English, and the majority of Hispanic respondents chose to be interviewed in Spanish. The average length of the interview was 18 minutes for non-Hispanics and 24 minutes for Hispanics.

Caregivers were defined by the following question:

In the last 12 months, have you provided unpaid care to a relative or friend 18 years or older to help them take care of themselves? Unpaid care may include help with personal needs or household chores. It might be managing a person's finances, arranging for outside services, taking them to appointments, or visiting regularly to see how they are doing. This person need not live with you.

In addition, the caregiver had to be at least 18 years of age and report helping the care recipient with at least one Activity of Daily Living or personal care task, known as ADLs (such as getting in and out of beds and chairs, getting dressed, getting to or from the toilet, or dealing with incontinence, bathing, or feeding), or Instrumental Activity of Daily Living, known as IADLs (such as giving medications, managing finances, grocery shopping, doing housework, and so on). To be counted, the caregiver had to verify by self-report that she/he provides care. No restrictions were placed on the amount, frequency, or duration of care provided.

All of the data gathered while screening potential respondents for caregivers were saved in order to estimate the proportion of Hispanic households that include one or more caregivers. The screening data and survey results are weighted by household, based on the household type and the age of the head of the household obtained from the initial respondent in each household. Results for Hispanics and non-Hispanics are weighted separately, each group to its own population targets as found in the 2006 Current Population Survey conducted by the U.S. Census Bureau. For statistical purposes, the base number of respondents shown in each table or graphic is unweighted.

The margin of error for the Hispanic caregivers is plus or minus approximately three percentage points at the 95% confidence level. This means that 95 times out of 100, a difference of greater than three percentage points would not have occurred by chance. For non-Hispanic caregivers, the margin of error is plus or minus seven percentage points at the 95% confidence level.

Focus Groups

Five focus groups were conducted March 11 to 13, 2008 — two in Miami, one in Houston, and two in Los Angeles. Respondents were all Hispanic family caregivers who spent at least four hours per week giving care, although most spent at least 15 hours per week. They were recruited to represent a mix of ages and income levels, as well as to have a mix of relationships with their care recipient.

All respondents were fluent in Spanish, and many could also speak English well. All but one of the groups was held in Spanish. The discussions focused mainly on assessing the needs of Hispanic caregivers, determining how they typically get information, and learning how best to reach them with information about caregiving. Questions explored their caregiving situation, their normal social and information networks, the sources of information they trust for health and caregiving, and service needs. The discussion guide is included on the Web site, www.caregiving.org.

Reading This Report

This report focuses on the profile of Hispanic caregivers. For each survey question, the comparative quantitative results for non-Hispanics are typically presented in a brief table or a graphical representation. To signal *key* differences between Hispanics and non-Hispanics, the report uses boldface to highlight any percentage that is significantly higher than the comparison figure.

In addition to comparing Hispanics to non-Hispanics, analyses examined differences between subgroups of Hispanics (e.g., male vs. female caregivers, those who live with their recipient vs. those who do not, etc.). All gray-shaded subgroup differences pertain only to Hispanic caregivers.

All figures have been weighted and rounded. In addition, “don’t know” or “refused” responses are not always presented. For these reasons, some charts and tables will not add to 100%. The results for multiple response questions may also add to greater than 100%.

Limitations

Because Hispanic caregivers were located using targeted geographic and surname samples, Hispanics whose names are not identifiably Hispanic and those who live in areas where the density of Hispanics is not particularly high are under-represented in the survey results. In addition, both Hispanic and non-Hispanic households without land-line telephones are also under-represented. Because the data were gathered through telephone interviews, any underlying respondent motivation to portray himself or herself positively could influence some responses.



Key Findings

Prevalence of Caregiving Among Hispanic Households

One-third of Hispanic households report having at least one caregiver (36%). With an average of 1.83 caregivers per household, there are an estimated 8,147,000 Hispanic caregivers in the U.S. The figure compares to the 2004 national caregiver survey figure for caregivers in the U.S. population of 44.4 million family caregivers.

Basics of the Caregiving Situation

Hispanic caregivers are predominantly female (74%). They are 43 years of age, on average, and younger than non-Hispanic caregivers (49 years old).

The majority of Hispanic caregivers' care recipients are female (57%), with an average age of 62 years, also younger than the average age of non-Hispanic caregivers' recipients (68 years old).

Eight in ten Hispanic caregivers take care of a relative (84%), including 23% who take care of their mother and 13% who care for their father.

Caregiving Activities and Burden of Care

Hispanic caregivers tend to be in more intensive caregiving situations than non-Hispanic caregivers. Six in ten Hispanic caregivers are in high burden situations (63%), compared to 51% of non-Hispanic caregivers. Underlying the burden classification:

- Hispanic caregivers spend more hours per week giving care than non-Hispanic caregivers do (37 hours vs. 31 hours, on average).
- They provide help with a greater number of Activities of Daily Living (ADLs) (2.6 vs. 1.9).

Nevertheless, Hispanic caregivers are more likely than non-Hispanic caregivers to rate their caregiving situation as *not at all* stressful (34% vs. 22%). In fact, 50% said they have little or no stress. Still, 28% indicate that caring for their loved one is highly stressful, giving a rating of 4 or 5 on a 5-point scale.

Over half of Hispanic caregivers help their care recipient with getting in and out of beds and chairs (58%) or feeding (53%), and almost as many help their loved one get dressed (47%). Four in ten help with getting to and from the toilet (43%) or bathing/showering (40%). One in four deals with incontinence or diapers (24%).

Eight in ten Hispanic caregivers report helping with housework (84%), transportation (84%), grocery shopping (84%) or preparing meals (82%). Almost all keep their loved one company or provide emotional support (96%).

Presence of Other Caregivers

Two-thirds of Hispanic caregivers say they are the primary caregivers (65%), including 9% who share the caregiving equally with someone else.

A large majority (82%) say that at least one other unpaid relative or friend helps their care recipient. On average, Hispanic caregivers report 2.4 other unpaid caregivers. Among those who have one or more others helping, seven in ten feel the other family members are doing at least their fair share (73%), while 24% feel they are not.

In spite of the fact that other unpaid caregivers are generally involved, one in four Hispanic caregivers reports it would be *very* difficult to find someone to take on his/her responsibilities if he/she needed a break (24%), a considerably larger proportion than the 13% of non-Hispanic caregivers who believe it would be as difficult.

One-quarter of Hispanic caregivers report that paid nurses, home health aides, or health workers provide care to their loved one (24%), and slightly fewer say that paid housekeepers (17%) or other paid services (16%) are used.

Care Recipient Living Situation

It is more common for the care recipients of Hispanic caregivers than those of non-Hispanic caregivers to be sharing the caregiver's home (43% vs. 32%) or someone else's (13% vs. 8%). By contrast, a larger share of non-Hispanic caregivers say their loved one lives in his or her own home (51% vs. 39%).

Three-quarters of Hispanic caregivers live either with their care recipient or within twenty minutes of their care recipient's residence (77%).

Care Recipient's Condition

Diabetes is the top reason why Hispanic caregivers say their recipients need care, and it is almost twice as prevalent a reason for them as it is for non-Hispanics (15% vs. 8%). Cancer, old age, and arthritis are next most common (7% each). Although Alzheimer's or mental confusion is cited by only 6% of Hispanic caregivers as the primary reason why their care recipient needs care, a total of 23% say their loved one does suffer from this condition.

Employment and Balance in Caregiver's Life

Roughly half of Hispanic and non-Hispanic caregivers are employed (52% and 57%, respectively), but a smaller share of Hispanic caregivers are employed full time (31% vs. 47%). Further, a smaller proportion report being retired (7% vs. 17%). On the other hand, Hispanic caregivers are more likely to report working part time (20% vs. 10%) or being homemakers (25% vs. 11%).

Four in ten Hispanic caregivers (41%) say, as a result of caregiving, they made a major change to their work situation, such as cutting back on their working hours, changing jobs, stopping work entirely, or taking a leave of absence. A smaller share of non-Hispanic caregivers report having made such changes to their work situation (29%).

Two-thirds of Hispanic caregivers report they were employed at some point while they were caregiving (66%), though only 52% are currently working or were in their last two months of caregiving — a decline of 14 percentage points. Non-Hispanic caregivers show a similar decline. These figures may support caregivers' assertions of the impact caregiving has had on their employment.

Although the notable proportion of Hispanic caregivers who made major employment-related changes while caregiving might lead one to believe that they would be less satisfied with the balance between caregiving and work, they are actually more highly satisfied than non-Hispanic caregivers are. Nearly half of Hispanic caregivers report being *very* satisfied with this balance (47%), compared to 36% of non-Hispanic caregivers.

Hispanic caregivers also show greater satisfaction with the social side of their life, including visiting with friends and going out — eight in ten are satisfied, with 49% *very* satisfied. Among non-Hispanic caregivers, 37% are *very* satisfied. This is the case in spite of the finding that Hispanic caregivers spend more hours caregiving and are less likely to say that their social activities occur during their caregiving hours. Specifically, half (51%) report that their social activities or visits with other people *rarely* or *never* occur during their caregiving time, compared to 39% of non-Hispanic caregivers who report this is the case.

Attitudes About Nursing Care and Health Workers

Among the Hispanic caregivers who make decisions for their loved one, three-quarters would consider placing their loved one in a nursing home or assisted living facility (77%), about equal to the proportion of non-Hispanic caregivers who would (83%). However, Hispanic caregivers are less likely than non-Hispanic caregivers to consider placing their loved one in a residential facility in these specific situations:

- If their loved one needed more skilled care than they could provide (64% Hispanic caregivers vs. 76% of non-Hispanic caregivers would consider nursing care or assisted living)
- If their care recipient began to struggle or hit them (42% vs. 53%)
- If they began dangerous behavior like leaving the stove on or the water running (37% vs. 50%)
- If they began wandering away from home (33% vs. 53%)

Hispanic caregivers' greater reticence to use nursing homes or assisted living may be related to their more prevalent belief that it is common for home health workers or nursing home staff to mistreat their patients (40% vs. 30%).

Beliefs and Feelings About Caregiving

Strong expectations that they will care for sick or elderly relatives are highly prevalent among Hispanic caregivers — 84% say their upbringing conveys such an expectation, and 70% feel it would bring shame on a family if no family members were willing to care for a relative who needed it. A smaller share of non-Hispanic caregivers agree a family would be shamed in that situation (60%).

Caregiving brings a sense of fulfillment to nearly nine in ten Hispanic caregivers (88%), even though half acknowledge they would be happy if some other family member or friend took over most of their caregiving duties (54%). Non-Hispanic caregivers are less likely to report being fulfilled by caregiving (76%), but also less apt to agree that they would be happy to turn over their caregiving role to someone else (31%).

Religious faith gives strength to 93% of Hispanic caregivers, as well as to a smaller but still notable proportion of non-Hispanic caregivers (83%).

Most Hispanic caregivers feel they have enough time for themselves (72%), but one in five feels isolated (20%).

Caregiving Challenges and Sources of Information and Services

Lack of time is the caregiving challenge cited most commonly by Hispanic caregivers (25%). In addition, 12% name medical care for their loved one as their top challenge, and 9% cite lifting or getting their loved one in and out of beds/chairs. Their challenges range widely, from dealing with personal care, to feeling sympathy for their loved one's condition, to feeling impatient over their loved one's behavior, to worrying or experiencing stress.

Only one in three Hispanic caregivers has sought information or services to help address his/her challenge (35%). Of those who have not, one-third say the situation was not bad enough to warrant it (33%) and 19% never thought to look for help.

Among the Hispanic caregivers who did seek information or services to help them with their caregiving challenge, eight in ten turned to a health professional such as a doctor, nurse, health worker, pharmacist, etc. (81%). Two-thirds turned to family or friends (66%). Half of Hispanic caregivers have turned to government programs or agencies (49%), whereas only 31% of non-Hispanic caregivers have. More than one-third of Hispanic caregivers consulted disease-specific organizations (37%), and three in ten looked for information on the internet (29%). Six in ten of those who looked for information or services report having found *moderate* or a *great deal* of success (63%).

Of note, Hispanic caregivers are only half as likely as non-Hispanic caregivers to have ever used the internet to search for information on any subject (43% vs. 81%).

Spanish Language Caregiving Information and Services

Roughly three-quarters of Hispanic caregivers feel it is *very* or *somewhat* important for any caregiving materials they use to be in Spanish (73%) and for caregiving services for their loved one to be delivered in Spanish (78%). Among those who say it is important for information to be in Spanish, most are satisfied with the availability of such information (85%), while 12% are *not* satisfied.

Helpful Training and Services

Hispanic caregivers are very receptive to the idea of both training and services. Eight in ten would find training on caregiving skills to be helpful (80%) and the idea of online caregiver skills training is also well received (73%). Two-thirds would find a paid service that relieved them once a week to be helpful (67%), and half rate an adult day care service as helpful (54%). Hispanic caregivers are more likely than non-Hispanic caregivers to consider each of these services as helpful.

Caregiver Demographics

Two-thirds of Hispanic caregivers are married (66%), but they also are more likely than non-Hispanic caregivers to be single, never married (18% vs. 13%).

Half have children under the age of 18 in the household (53%) compared to only 34% of non-Hispanic caregivers.

On average, Hispanic caregivers have a much lower educational level than non-Hispanic caregivers. Three in ten have not completed high school (29%) whereas only 3% of non-Hispanic caregivers have not. On the other end of the educational spectrum, 15% have graduated from college, compared to 44% of non-Hispanic caregivers who have.

The Hispanic caregivers also are in lower income households relative to non-Hispanic caregivers. In particular, half are in households with less than \$30,000 in income (52%), compared to 19% of non-Hispanic caregivers.

The racial composition of the Hispanic caregivers is not clear, since when asked their race, a large proportion of them respond with their Latino/Hispanic ethnicity. The non-Hispanic caregivers are predominantly white (86%), with 7% black.

Most of the Hispanic caregivers say their family or ancestors originated in Mexico (75%). Others come from Central America (5%), Spain (4%), South America (3%), Puerto Rico (2%), Cuba (2%), or the Dominican Republic (2%).

While one in three of the Hispanic caregivers has lived his/her entire life in the U.S. (36%), four in ten have lived less than half of their life in the U.S. (39%).

Given the choice of completing their interview in Spanish or English, six in ten Hispanic caregivers chose to complete it in Spanish (63%).



Detailed Findings

Prevalence of Caregiving in Hispanic Households

Of the more than 2,800 Hispanic households that were screened for this survey, 35.6% reported at least one caregiver in the household. Given a 2006 estimate from the Current Population Survey of 12,519,000 Hispanic households in the U.S., the study leads to an estimate of 4,452,000 Hispanic households with one or more caregivers in them.

On average, the Hispanic households that had caregivers in them reported an average of 1.83 caregivers per household. This leads to an estimate of 8,147,000 Hispanic caregivers in the U.S. In the 2004 national caregiver survey there were an estimated 44.4 million U.S. family caregivers.

Among non-Hispanics, the incidence of caregiving in households was found to be 25.2%, slightly higher than the 21% found among a representative sample (including all ethnic groups) in the last national caregiver survey. Taking into account the considerably smaller sample of these non-Hispanics (837 were screened) and the margin of error of three percentage points, the estimates are relatively close to one another.

On average, the non-Hispanic households had 1.51 caregivers per household.

I feel happy because I am helping my aunt, and I don't know if someday I will need help. I feel happy when I see her and she's not alone and I can help her.

Basics of the Caregiving Situation

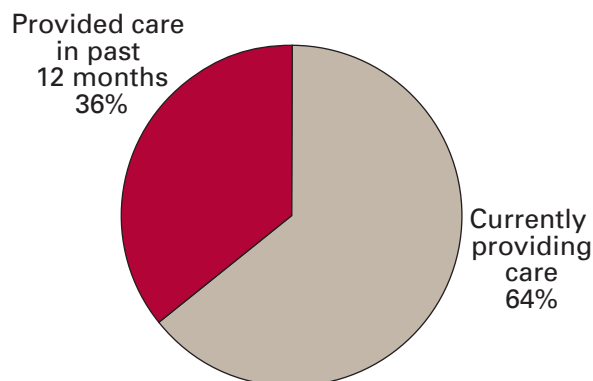
Current vs. Past Care

About two-thirds of Hispanic caregivers (64%) are currently caring for a loved one, while one-third (36%) provided care in the last 12 months but are no longer doing so.

Figure 1

Q1. Are you currently providing unpaid help to a relative or friend, or was this something you did in the past 12 months but are no longer doing?

Base: Hispanic caregivers
(n=1,007)



Non-Hispanic caregivers
(n=209)

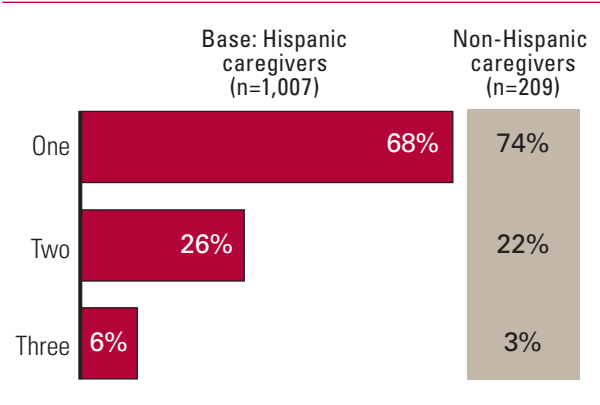
Currently 68%

Number of Care Recipients

Two-thirds of Hispanic caregivers (68%) take care of one care recipient, but 26% take care of two people, and 6% take care of three.

Figure 2

Q2. How many people age 18 or older do/did you provide this care for [in the past 12 months]?



Hispanic Caregiver Subgroups

Hispanic caregivers who live with their care recipient and also give at least 21 hours of care per week are more likely than all others to say they take care of just one person (78% vs. 64%).

Gender of Caregiver and Care Recipient

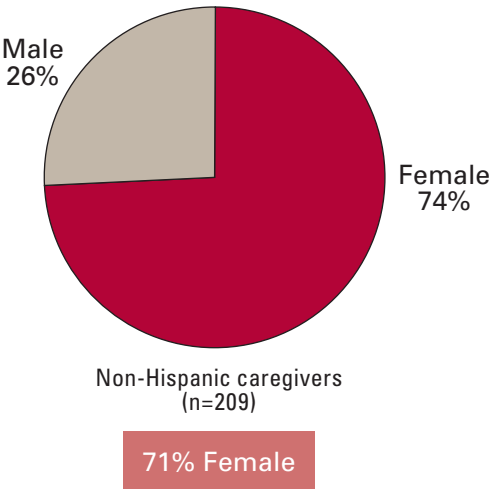
Three-quarters of Hispanic caregivers are female (74%), and one in four is male (26%). A majority of Hispanic caregivers' recipients are female (57%). Non-Hispanics are similar on both counts.

Figure 3

Q4. [IF NEEDED] Would you mind telling me if that person is male or female?
Caregiver gender recorded by interviewer

Base: Hispanic caregivers (n=1,007)

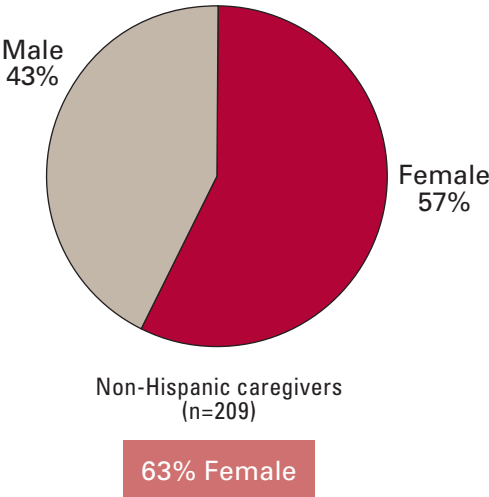
Caregiver Gender



Non-Hispanic caregivers (n=209)

71% Female

Care Recipient Gender



Non-Hispanic caregivers (n=209)

63% Female

Hispanic Caregiver Subgroups

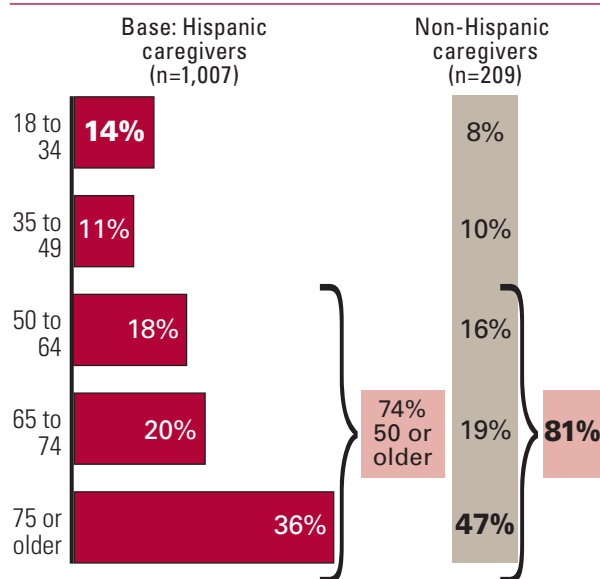
Co-resident caregivers are more likely than those who live apart from their care recipient to take care of someone who is male (51% vs. 37%).

Age of Care Recipient

Hispanic caregivers take care of younger individuals than non-Hispanics do, on average (62.4 vs. 67.8 years of age). One in four Hispanic caregivers (26%) provides care to someone 18 to 49 years of age, compared to 18% of non-Hispanics who do. Further, only 36% of Hispanics care for a care recipient aged 75 or older, compared to nearly half of non-Hispanic caregivers who do (47%).

Figure 4

Q10. How old is/was your [relation]?



Note: Bold figures are significantly higher than their comparison figure.

Hispanic Caregiver Subgroups

Male Hispanic caregivers take care of younger individuals than females do, on average (58.2 vs. 63.9 years of age).

The caregivers who are themselves age 50 or older are much more likely than 18- to 49-year-olds to state that their loved one is age 75 or older (53% vs. 29%). On the other hand, the 18- to 49-year-old caregivers are more likely than 50+ year-old caregivers to take care of recipients in the younger age groups.

Hispanic caregivers who have spent much of their lives outside of the U.S. are more likely than others to take care of someone under the age of 50 (35% vs. 23%).

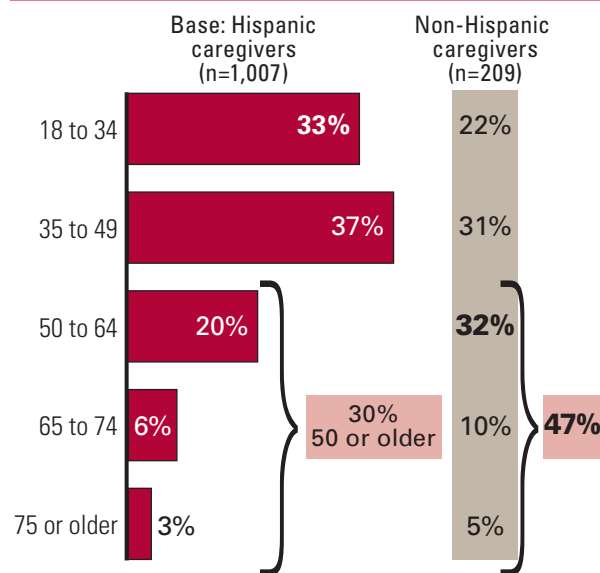
Hispanic caregivers who live with their care recipient but give 20 hours or fewer of care per week are twice as likely as all others to care for a younger care recipient, age 18 to 34 (28% vs. 13%).

Age of Caregiver

The average age of Hispanic caregivers is 42.6, younger than the 48.9 year average for non-Hispanics. A larger proportion of the Hispanic caregivers is 18 to 34 (33% vs. 22% of non-Hispanics).

Figure 5

S11. How old were you on your last birthday?



Note: Bold figures are significantly higher than their comparison figure.

Hispanic Caregiver Subgroups

Caregivers who live with their care recipient tend to be older on average (45.8 vs. 40.3 years of age).

Others who tend to be older include those with a high level of care¹ (44.1 years of age vs. 39.2 for those with a low burden) and primary caregivers (45.0 vs. 38.3 non-primary).

¹ See the definition of care burden levels in Appendix A.

Care Recipient Relation to Caregiver

The large majority of Hispanic caregivers take care of a relative (84%), and 15% care for a friend, neighbor, or other non-relative. More care for a parent than any other relation (35%). Specifically, 23% of Hispanic caregivers care for their mother and 12% care for their father. Almost one in ten gives care to a grandparent (9%) or a spouse (8%).

Figure 6

Q3. What is/was his or her relation to you?

	Hispanic caregivers (n=1,007)	Non-Hispanic caregivers (n=209)
Relative	84%	87%
Parent	35	37
Grandparent or great-grandparent (incl. in-law)	9	9
Sibling	9	4
Spouse or partner	8	11
Parent-in-law	7	9
Child	5	7
Uncle, aunt, great-uncle, or great-aunt	5	5
Sibling-in-law	3	1
Other relatives	7	5
Non-relative	15%	13%
Friend/neighbor	15	13

Note: Bold figures are significantly higher than their comparison figure.

Hispanic Caregiver Subgroups

The care recipient’s relationship varies greatly depending on the caregiver’s age. For example, caregivers who are 50 or older are more likely than younger caregivers to care for a spouse (18% vs. 3%) or a child (11% vs. 2%). By contrast, the 18- to 49-year-old caregivers show a greater likelihood of caring for relatives of an older generation, such as their father (13% vs. 8%) or a grandparent (12% vs. 1%). Of note, caregivers younger than 50 are equally likely as those 50 or older to be caring for their mother (23% each).

Those who live apart from their care recipient are much more likely than co-resident caregivers to be caring for a non-relative (21% vs. 8%).

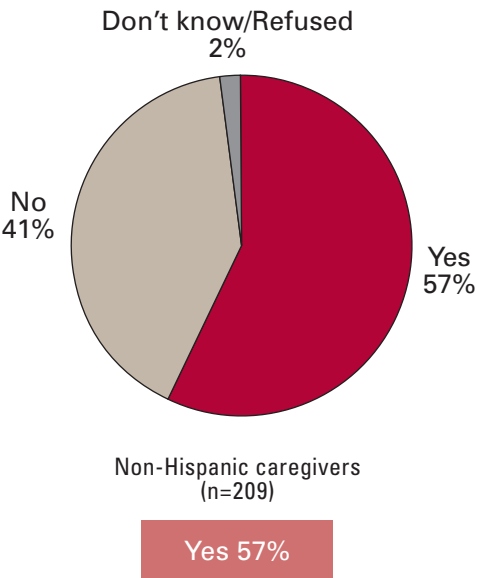
Choice in Taking on Caregiver Role

Four in ten Hispanic caregivers do not feel they had a choice in whether or not they wished to take on their caregiving responsibility (41%).

Figure 7

Q26. We have been talking about the help you provide/provided for your [relation]. Do you feel you had a choice in taking on this responsibility for caring for him/her?

Base: Hispanic caregivers (n=1,007)



The lines between “choice” and “obligation” may blur for Hispanic caregivers. Focus group respondents commonly refer to caregiving as a “family obligation,” even though they emphasize that they act as caregivers out of love.

Taking care of them is like giving back our love. They were the first to give us love and attention, so we have a moral obligation to respond. So it's a way to give back that love that was given to us.

Hispanic Caregiver Subgroups

Primary caregivers are more likely than others to feel they did not have a choice (44% vs. 35%).

A larger proportion of female caregivers than males also feel this way (43% vs. 35%).

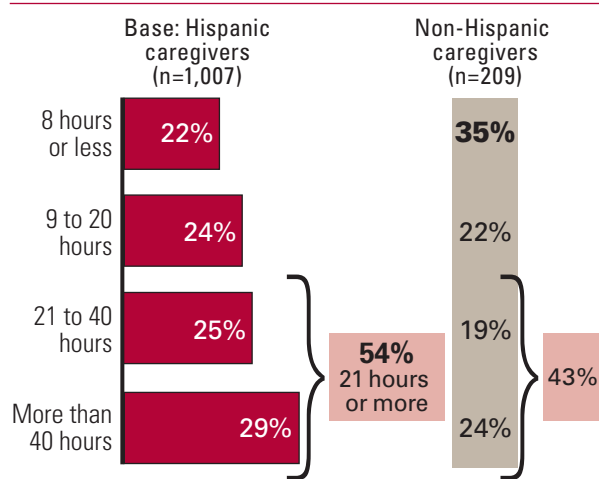
Caregiving Activities and Burden of Care

Hours of Care Provided

On average, Hispanic caregivers spend 36.7 hours per week giving care, compared to 30.6 hours for non-Hispanic caregivers.² One in five Hispanic caregivers is in a situation where his/her time commitment is modest, no more than eight hours each week (22%), while 35% of non-Hispanic caregivers are.

Figure 8

Q8. Thinking now of all the kinds of help you provide/provided for your [relation], about how many hours do/did you spend in an average week doing these things?



Note: Bold figures are significantly higher than their comparison figure.

Hispanic Caregiver Subgroups

As one might expect, Hispanic caregivers who live with their care recipient provide care for a greater number of hours on average (50.6 vs. 25.8 hours).

Primary caregivers spend considerably more hours giving care (41.3 per week, on average) than non-primary caregivers (28.9 hours).

Caregivers ages 18 to 49 provide care for notably fewer hours per week than do older caregivers (32.2 vs. 47.5 hours).

Hispanic caregivers who are not employed tend to spend more time as caregivers (40.4 vs. 33.3 hours per week).

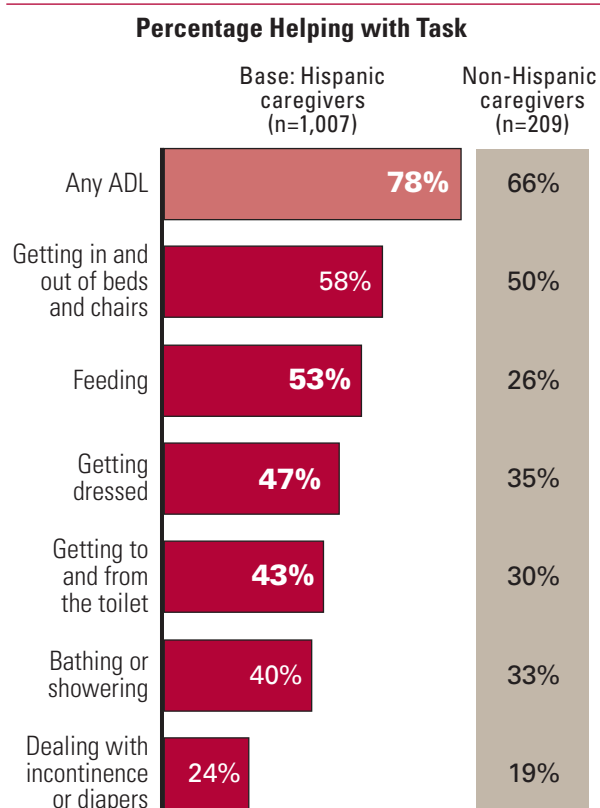
Caregivers in lower income households provide more hours of care (39.3 vs. 33.6 hours for those in households with \$30,000 or more in income).

Help With Activities of Daily Living (ADLs)

A large majority of Hispanic caregivers help their loved one with at least one Activity of Daily Living (78%), while fewer non-Hispanics do (66%). In particular, the Hispanics are twice as likely to help feed their loved one (53% vs. 26%), and are also more apt to help him or her get dressed (47% vs. 35%) or get to and from the toilet (43% vs. 30%). On average, Hispanic caregivers provide help with 2.6 ADLs while non-Hispanic caregivers help with 1.9.

Figure 9

Q5. I'm going to read a list of kinds of help which might be provided to a person if the person cannot do this by him or herself. For each, just tell me if you provide/provided this kind of help. Do/did you help your [relation] with...?



Note: Bold figures are significantly higher than their comparison figure.

² Any reports of constant care or caregiving in excess of 98 hours per week are capped at this level.

Hispanic Caregiver Subgroups

Hispanic caregivers who spend more than 20 hours per week giving care average 3.2 ADLs, compared to 2.0 for those who spend fewer hours giving care. They are also more likely to help with each of the ADLs.

A larger share of those who live with their care recipient say they help with bathing (47% vs. 34% of those who are not co-resident).

Female caregivers report helping their loved one with specific tasks more commonly than male caregivers: getting dressed (51% vs. 35%), bathing (44% vs. 27%), and dealing with incontinence (26% vs. 19%).

Lower income Hispanic caregivers — those with less than \$30,000 in household income — are more apt to say they help bathe or shower their care recipient (43% vs. 36% of those in higher income households).

Caregivers age 50 or older are more likely than younger caregivers to report helping with dressing (52% vs. 45% of younger caregivers), bathing (46% vs. 37%), and dealing with incontinence (32% vs. 21%).

Hispanic caregivers who have lived at least two-thirds of their life outside of the U.S. are more likely than those born in the U.S. to report helping with ADLs, specifically helping with getting in and out of chairs, feeding, and toileting. They average 2.8 ADLs, compared to 2.4 for those who have lived only in the U.S.

This disease has just deteriorated her bit by bit so that she is almost in a vegetable state and she does not receive any help or a nurse to come to the house. I cook for her, I clean for her, I bathe her. I use the lift to switch her from bed to wheelchair. I change her diapers. I have to do everything for her.

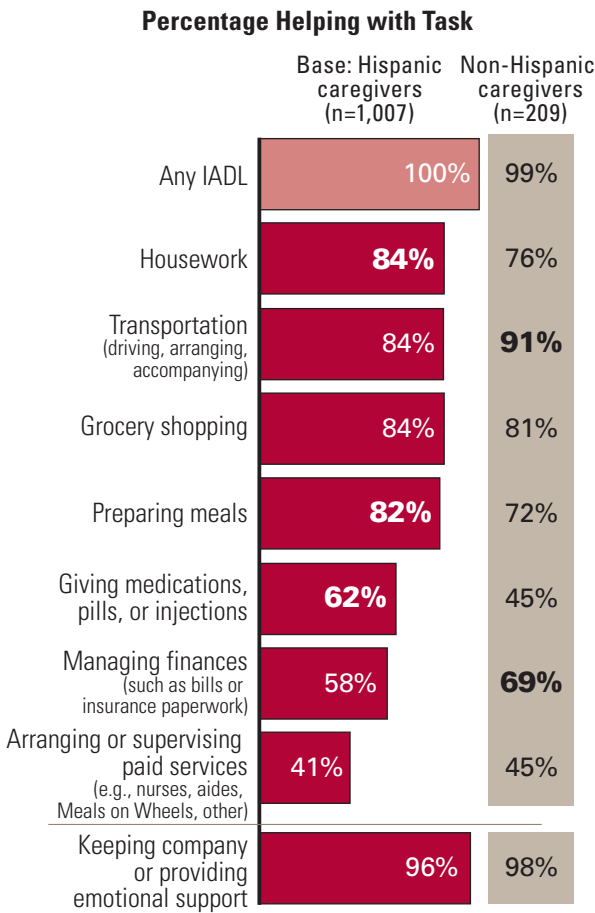
Help With Instrumental Activities of Daily Living (IADLs)

On average, both Hispanic and non-Hispanic caregivers help their loved one with five Instrumental Activities of Daily Living (IADLs). The IADLs that Hispanic caregivers help with most commonly are housework (84%), transportation (84%), grocery shopping (84%), and meal preparation (82%).

Larger proportions of Hispanic caregivers than non-Hispanic caregivers help their care recipients with housework (84% vs. 76%), meal preparation (82% vs. 72%), and medication or injections (62% vs. 45%). However, Hispanic caregivers are *less likely* to help with transportation (84% vs. 91%) and managing finances (58% vs. 69%).

Figure 10

Q6, 7. I'm going to read a list of kinds of help which might be provided to a person if the person cannot do this by him or herself. For each, just tell me if you provide/provided this kind of help. Do/did you help your [relation] with...?



Note: Bold figures are significantly higher than their comparison figure.

Nearly all Hispanic and non-Hispanic caregivers say they spend time keeping their loved one company or providing emotional support (96% vs. 98%). Some focus group caregivers say that keeping their loved one company and lifting his or her spirits is one of their key roles.

I help warm up the food. He had a stroke and he walks with difficulty. I write out the checks. I go to the bank, reconcile the bank statements. I do some accounting and we also watch TV; he likes to watch soccer and we watch a lot of South American channels, a lot of soccer. It is like a light companionship.

I prepare the breakfast. I try to baby him. My dad had a stroke, so basically half of his body is paralyzed. I sit him on the wheelchair to take him to the bathroom. I let him take his time and he calls me when he's done to take him back to bed. I take him to the kitchen so he can eat...Today I had to bathe him... I take him out in the wheelchair so his hair dries and then bring him back in.

Hispanic Caregiver Subgroups

Among Hispanic caregivers, the average number of IADLs rises in relation to burden of care, with low burden Level 1-2 caregivers helping on average with 3.7 IADLs and Level 4-5 caregivers performing 5.4 IADLs.

Not surprisingly, co-resident caregivers also help with more IADLs, on average (5.4 vs. 4.6 for who live separately), and primary caregivers do also (5.2 vs. 4.6).

With regard to specific IADLs, those who were born in the U.S. are more likely to help their loved one with managing finances (63% vs. 49% of those who have spent at least two-thirds of their life outside the U.S.) and transportation (88% vs. 80%). By contrast, Hispanic caregivers who spent at least two-thirds of their lives outside of the U.S. are more inclined to help with meal preparation (89% vs. 78%).

The fact that female caregivers more commonly report that they help with meal preparation (85% vs. 76% of male caregivers) hints at traditional gender roles, as does the higher rate of male than female caregivers helping with transportation (91% vs. 82%).

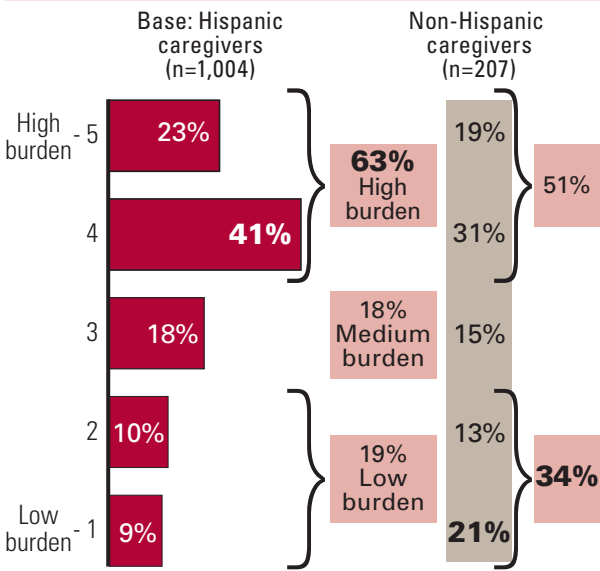
Caregivers who are at least 50 years of age show a greater tendency to help with medications (69% vs. 59% of younger caregivers) as well as arranging or supervising outside services (47% vs. 39%).

Burden of Care

A level of care index was developed in the 1997 study *Family Caregiving in the U.S.*, and is replicated here, to convey in a simple measure the level of “burden” experienced by the caregiver. The index is based on the number of hours of care given and the types of care provided. (See Appendix A for details.)

Six in ten Hispanic caregivers are in high burden situations (63%), 18% have a medium burden, and 19% have a low burden. Non-Hispanic caregivers are less likely to have a high burden of care (51%).

Figure 11
Level of Burden Index



Note: Bold figures are significantly higher than their comparison figure.

For each level of care, the average number of hours of care given, ADLs performed, and IADLs performed are as follows:

Level of Care	Hours of Care per Week	Number of ADLs	Number of IADLs
Low burden	7.8	0.2	3.7
Medium burden	13.4	2.1	4.6
High burden	51.7	3.5	5.4

Hispanic Caregiver Subgroups

High burden (Levels 4-5) situations are more prevalent among caregivers who live with their care recipient than they are among those who live separately (74% vs. 55%).

They are also more common among the following subgroups of Hispanic caregivers:

- Women (66% vs. 57% of male caregivers)
- Primary caregivers (67% vs. 59% of non-primary caregivers)
- Those with less than \$30,000 in household income (68% vs. 59% of higher income caregivers)

As the age of the caregiver rises, so does the likelihood of the caregiver being in a high burden situation, as shown in the following table:

	Caregivers Ages 18 to 34 (n=228)	Caregivers Ages 35 to 49 (n=332)	Caregivers Ages 50 or older (n=444)
Low burden	24%	19%	13%
Medium burden	19%	18%	17%
High burden	57%	63%	71%

Note: Bold figures are significantly higher than their comparison figure.

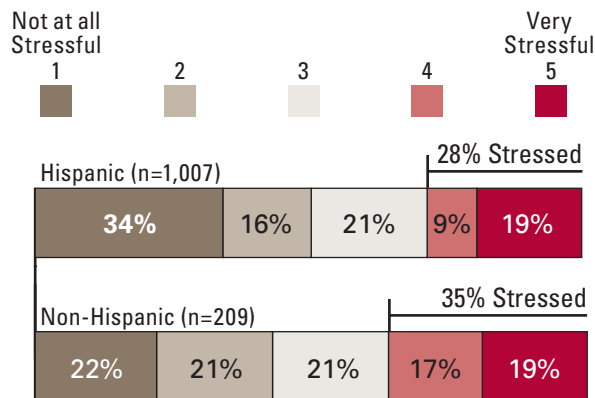
Stress of Caregiving

Although more than one in four Hispanic caregivers consider their caregiving situation to be stressful (28% rating stress 4 to 5 on a 5-point scale), half indicate little to no stress (50%). Hispanic caregivers are more likely than non-Hispanics to report that their situation is *not at all* stressful (34% vs. 22%).

Figure 12

Q25. Please think of a scale from 1 to 5, where 1 is not at all stressful and 5 is very stressful. How stressful would you say that caring for your [relation] is/was for you?

Base: All caregivers



Note: Bold figures are significantly higher than their comparison figure.

Hispanic Caregiver Subgroups

Reported stress levels among Hispanic caregivers rise in relation to:

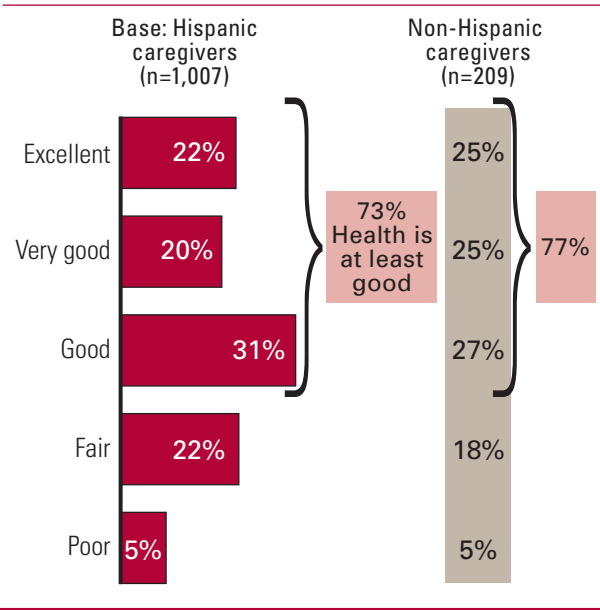
- Caregiving burden (20% with a low burden of care rate stress highly (4-5), compared to 31% of high burden caregivers who do)
- Caregiving hours (24% of those giving up to 20 hours of care rate their stress as high compared to 32% of those who give care for 21+ hours)
- Caregiver age (26% of caregivers ages 18 to 49 report high stress compared to 34% of older caregivers)
- Perceived lack of choice in taking on their caregiving role (25% of those who feel they had a choice report high stress compared to 32% of those who feel they did not have a choice)

Caregiver Health

Seven in ten Hispanic caregivers consider their health to be at least *good* (73%). A similar proportion of non-Hispanic caregivers do as well (77%). A national survey of U.S. population health by the CDC has only 9% reporting their health as fair or poor, in contrast to 27% of the Hispanic caregivers and 23% of non-Hispanic caregivers.

Figure 13

Q42. How would you describe your own health (when you were caregiving)?



Hispanic Caregiver Subgroups

Co-residing caregivers are more likely than those who live apart from their loved one to describe their health as *fair* or *poor* (32% vs. 23%).

Primary caregivers are also more likely to say their health is *fair* or *poor* (31% vs. 18% of non-primary caregivers).

Other groups who are more apt to say their health is *fair* or *poor* include:

- Caregivers who are not employed (30% vs. 24% of employed caregivers)
- Those who feel they did not have a choice in taking on their role (31% vs. 23% of those who feel they did have a choice)
- Caregivers over the age of 50 (38% vs. 22% of younger caregivers)

Presence of Other Caregivers

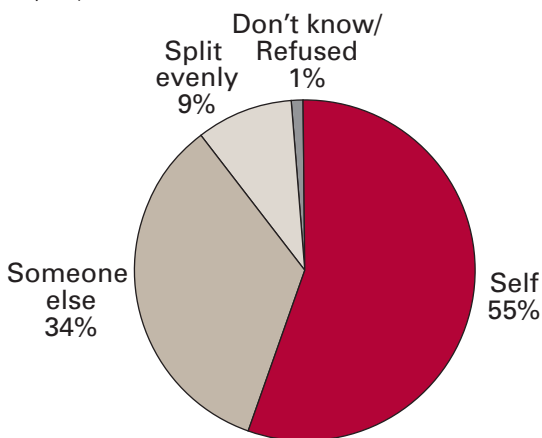
Primary Caregiver Status

Two-thirds of Hispanic caregivers perceive themselves as a primary caregiver (65%), including 55% who provide most of the unpaid care themselves and 9% who split caregiving equally with others.³ Only one in three indicates that someone else is the primary caregiver. Hispanic and non-Hispanic caregivers have nearly identical distributions across these primary/non-primary caregiver categories.

Figure 14

Q16. Who would you consider to be the person who provides/provided most of the unpaid care for your [relation] — you yourself, or someone else?

Base: Hispanic caregivers
(n=1,007)



Non-Hispanic caregivers
(n=209)

Self 60%

Hispanic Caregiver Subgroups

The Hispanic caregivers who are more likely to say they themselves provide most of the unpaid care include:

- Those who live with their care recipient (72% provide most of the unpaid care vs. 43% of those who live separately)
- Caregivers age 50 or older (68% vs. 50% of 18- to 49-year-old caregivers)
- Women (58% vs. 47% of men)
- Those who are not employed (61% vs. 50% of employed caregivers)
- Caregivers who feel they did not have a choice in becoming a caregiver (61% vs. 51% of those who feel they had a choice)

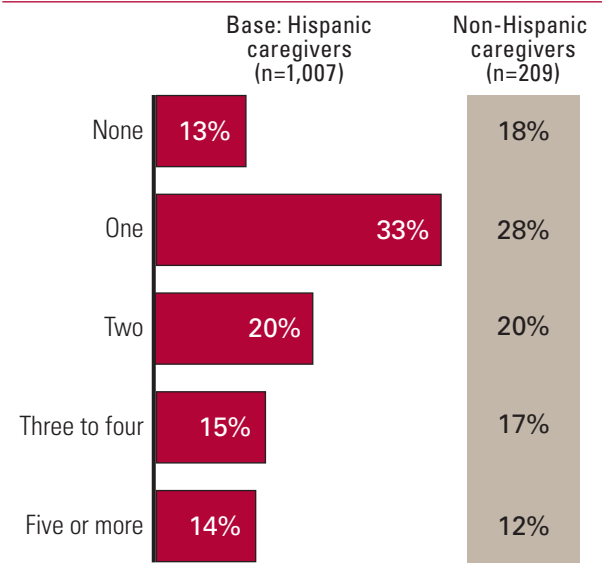
³ In subgroup analyses, anyone who indicates they provide most of the care or they share care equally with someone else is considered to be a “primary” caregiver. Only those who say someone else gives most of the care are considered “non-primary” caregivers.

Presence of Other Unpaid Caregivers

A large majority of Hispanic caregivers say at least one other unpaid relative or friend helps their care recipient (82%), with 53% saying one or two others help out and 28% saying three or more do. On average, Hispanic caregivers report there are 2.4 other caregivers, and non-Hispanic caregivers report a similar number (2.2).

Figure 15

Q15. How many other unpaid relatives or friends of your [relation], if any, provided care to him/her at least occasionally during the last 12 months [that you cared for him/her]?



The focus groups indicate that family support is on a structured schedule in some cases, where different family members take specific days of the week or times of the day, depending on their schedules for work or school. In other cases, family support is more fluid or informal.

I take care of my dad for 21 hours over three days of the week. It all depends on my schedule with the housekeeping and my sister and brother. We try to organize each other.

Hispanic Caregiver Subgroups

On average, primary caregivers report fewer other unpaid caregivers (1.9) than do non-primary caregivers (3.3). Of course sole caregivers are by definition “primary,” but even primary caregivers who are not the sole caregiver report fewer other unpaid caregivers helping their care recipient.

Other groups who report a lower number of other unpaid caregivers, on average, include:

- Hispanic caregivers who live with their recipient (1.9 vs. 2.7 for those who live separately)
- Older caregivers, those age 50+ (2.0 vs. 2.5 for those ages 18 to 49)
- Hispanic caregivers who have a household income of less than \$30,000 (2.1 vs. 2.6 for higher income caregivers)
- Those who are not employed (2.1 vs. 2.6 for employed caregivers)
- Caregivers of origin from countries other than Mexico (2.0 vs. 2.5 of those with Mexican origin)
- Those who were born in the U.S. (2.2 vs. 2.7 for those spending at least two-thirds of their life outside the U.S.)

The number of other unpaid caregivers helping each Hispanic caregiver raises questions about the percentage of caregivers who claim to provide most of the care, shown in Figure 14. Logically, if each Hispanic caregiver’s recipient has an average of 3.4 unpaid caregivers — including the respondent and 2.4 others — in a random sample of caregivers one would expect less than one-third to report that they are the ones who provide most of the unpaid care. However, in this sample, more than half of Hispanic caregivers actually do (and non-Hispanic caregivers respond similarly). Thus, it appears that these results are skewed somewhat in the direction of primary caregivers.

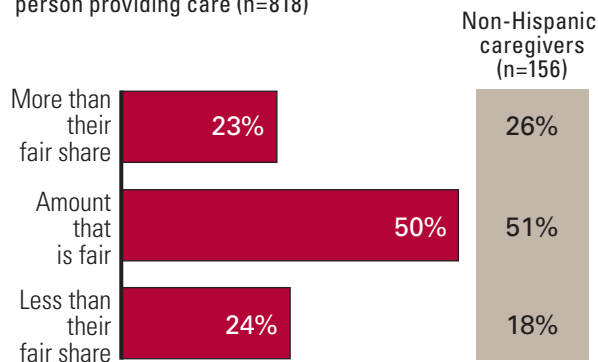
Whether Other Unpaid Caregivers Do Their Fair Share

Of those Hispanic caregivers who say one or more other friends or relatives are helping provide care, most feel other family members are doing at least their fair share (73%). One in four feels the others are doing less than they should to be fair (24%). Non-Hispanic caregivers report similar opinions.

Figure 16

Q17. Thinking about the amount of caregiving help that all family members provide/provided, would you say they do/did more than their fair share, the amount they do/did is fair, or they do/did less than their fair share?

Base: Hispanic caregivers with at least one other unpaid person providing care (n=818)



Hispanic Caregiver Subgroups

Primary caregivers are twice as likely as non-primary caregivers to feel the division of labor is not fair (30% vs. 15%).

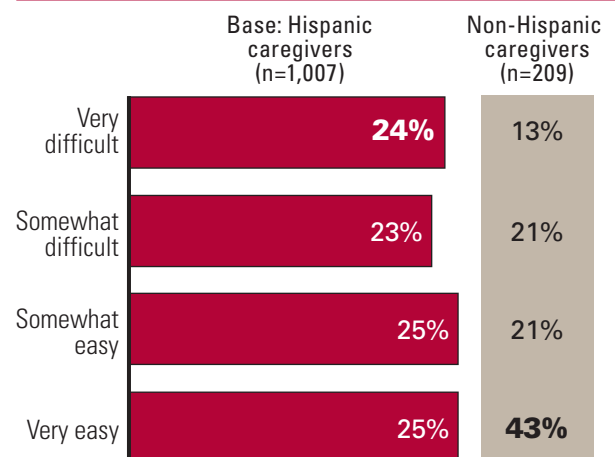
Ease of Finding a Back-up Caregiver

Hispanic caregivers say they find it harder than non-Hispanics do to find back-up help if they need a break from caregiving. In particular, one-quarter of Hispanic caregivers believe it would be *very difficult* to find someone to take on their responsibilities if they needed a break (24%), while roughly half as many non-Hispanics do (13%).

My children help me too. I have a 17-year-old son and a 15-year-old daughter, and I have an aunt who lives with me, so sometimes they help me.

Figure 17

Q18. If you ever needed to take a break from caregiving one of the days when you were expected to be/have been providing care — let's say it was because you yourself had a bad case of the flu — how easy or difficult would it be/have been for you to get someone else to take on your caregiving responsibilities?



Note: Bold figures are significantly higher than their comparison figure.

Hispanic Caregiver Subgroups

Those who have lived some part of their lives outside of the U.S. report more difficulty finding someone to give them a break from caregiving than do those who were born in the U.S. (51% vs. 40% *very* or *somewhat* difficult).

Caregivers in more intensive caregiving situations — primary caregivers, caregivers with a high level of burden (Levels 4-5), those who provide care for 21 or more hours per week, and those who live with their care recipient — tend to find it more difficult to find someone to give them relief.

Caregivers who are 50 years of age or older indicate greater difficulty finding someone to take on their responsibilities than younger caregivers do (31% vs. 21% *very* difficult), perhaps because they report fewer other caregivers and are more often primary caregivers.

Male caregivers are more likely than female caregivers to feel it is *very* easy to find back-up help (32% vs. 22%).

I make their appointments, run their errands for them. They don't speak English so I have to translate when I go to the doctors, and when dad had the surgery. I was responsible for everything in the hospital. They did not know what the doctors were talking about.

Use of Paid Services

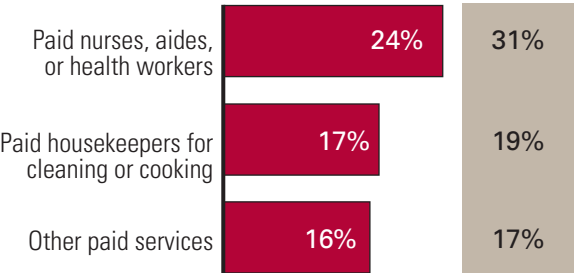
Most Hispanic caregivers say no paid nurses or health workers provided care for their loved one in the last 12 months, although one in four say they had this type of paid care (24%). Fewer than one in five Hispanic caregivers reports that his/her loved one had paid housekeeping help (17%) or any other paid services (16%). Non-Hispanic caregivers report similar levels of all three types of paid help.

Figure 18

Q19. Did any of the following provide help to your [relation] at home during the last 12 months [that you cared for him/her]?

Base: Hispanic caregivers whose recipient is not in a nursing home or assisted living (n=991)

	Percentage Yes	Non-Hispanic caregivers (n=189)
Paid nurses, aides, or health workers	24%	31%
Paid housekeepers for cleaning or cooking	17%	19%
Other paid services	16%	17%



Hispanic Caregiver Subgroups

Caregivers with a high burden of care (Levels 4-5) are more likely than those with low to medium care burdens to report paid help from nurses or health workers (28% vs. 17%).

Likelihood of using paid nurses or health workers declines among Hispanic caregivers who have spent a greater proportion of their life outside the U.S. Specifically, 30% of those who were born in the U.S. report this type of paid help, but only 17% of those who have spent at least two-thirds of their lives outside of the U.S. do. Paid housekeeping help is also less common among caregivers who spent at least two-thirds of their lives outside the U.S. (11% vs. 19% of others).

Other subgroups who are more likely to report paid health workers and paid housekeeping help are:

- Caregivers age 50 or older (health workers: 30% vs. 22% of younger caregivers; housekeeping help: 21% vs. 15%)
- Caregivers who live apart from the recipient (health workers: 28% vs. 21% of those who live with their recipient; housekeeping help: 19% vs. 14%)

Care Recipient Living Situation

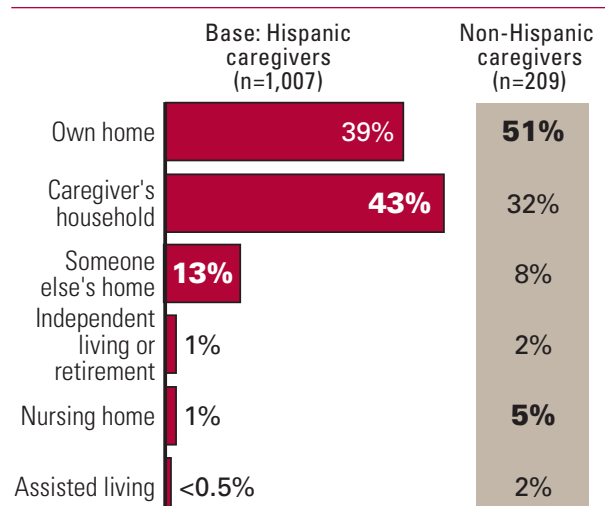
Where Care Recipient Lives

Four in ten Hispanic caregivers say their loved one lives in their household (43%), and about as many indicate the care recipient lives in his or her own home (39%). Co-residency is more common among Hispanic caregivers than non-Hispanics (43% vs. 32%), as are situations in which the care recipient lives in someone else's home (13% vs. 8%). By contrast, non-Hispanic caregivers are more likely to indicate their loved one lives in his or her own home (51% vs. 39%).

The difference between Hispanic and non-Hispanic caregivers in the proportion of care recipients who live with their caregiver disappears when looking solely at caregivers who live in households with less than \$30,000 in income — 45% of the low income caregivers in each ethnic group live with their care recipient. It is among households with \$30,000 or more in income where the difference emerges (39% of Hispanic caregivers live with their care recipient while 28% of non-Hispanic caregivers do). This difference is apparent both for caregivers in households with \$30,000 to \$49,000 in income and among those with income of \$50,000 or more.

Figure 19

Q12. [IF NOT IN CAREGIVER'S HOUSEHOLD]
Does/did s/he live in his or her own home, someone else's home, an independent living or retirement community, an assisted living facility where some care may be provided, a nursing home, or somewhere else?
(Analyzed with Q11: Does/did your [relation] live in your household, less than twenty minutes from your home, etc.?)



Note: Bold figures are significantly higher than their comparison figure.

Hispanic Caregiver Subgroups

Caregivers who are 50 or older are more likely than younger caregivers to share their home with their care recipient (57% vs. 37%), probably in part because they more commonly care for their spouse or child.

Co-residency is twice as common among primary caregivers as non-primary caregivers (54% vs. 24%). By contrast, non-primary caregivers are more likely to report that their care recipient lives in his or her own home (46% vs. 35% for primary caregivers) or in someone else's home (24% vs. 7%).

Co-residency is also seen more frequently among Hispanic caregivers who give more than 20 hours of care per week (57% vs. 27% of those giving fewer hours of care). Those who provide 20 or fewer hours of care per week are more apt to have a care recipient who lives in his or her own home (52% vs. 28%).

The likelihood of the care recipient living in the caregiver's home rises in relation to the burden of care, with 26% of Level 1-2 caregivers saying their recipient lives in their home compared to 50% of Level 4-5 caregivers reporting co-residency. By contrast, the likelihood of the recipient living in his or her own home is more common in situations of lower burden, with 59% of Level 1-2 caregivers reporting this is the case compared to 34% of Level 4-5 caregivers.

Half of Hispanic caregivers who are not employed live with their care recipient (48%), compared to 38% of employed caregivers.

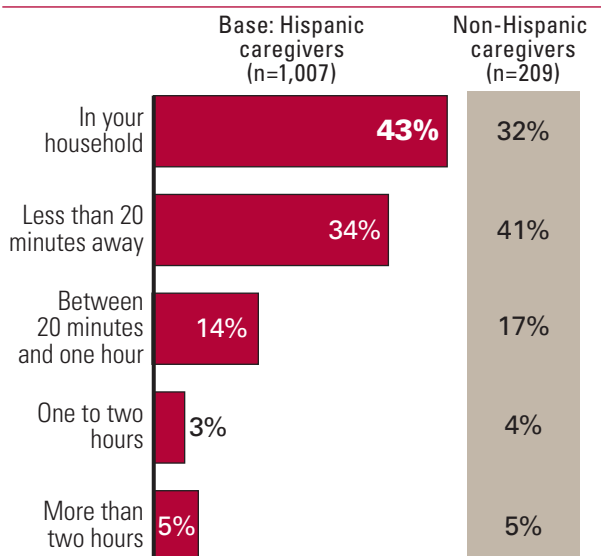
Hispanic caregivers who were born in the U.S. are more likely than those who have lived outside of the U.S. to have care recipients who live in their own home (47% vs. 35%).

Caregiver Distance From Care Recipient

Three-quarters of Hispanic caregivers live within twenty minutes of their care recipient (77%). Only 8% of Hispanic and 9% of non-Hispanic caregivers are long-distance caregivers, living more than one hour away from their care recipient.

Figure 20

Q11. Does/did your [relation] live in your household, less than twenty minutes from your home, between twenty minutes and an hour from your home, a one to two hour drive from your home, or more than two hours away?



Note: Bold figures are significantly higher than their comparison figure.

Hispanic Caregiver Subgroups

Hispanic caregivers who have lived outside of the U.S. are more apt than those who were born in the U.S. to be long-distance caregivers (7% vs. 2%).

Those of Mexican origin are twice as likely as those of other Hispanic origins to be long-distance caregivers (6% vs. 3%).

In contrast to the finding above that high burden Level 4-5 caregivers are more likely than low burden caregivers to live with their care recipient, the likelihood of living close to one's care recipient but not in the same household is greater among low burden Level 1-2 caregivers. Specifically, 49% of low burden caregivers live less than 20 minutes from their loved one but do not share a home with them, whereas 29% of high burden Level 4-5 caregivers report this type of situation.

Care Recipient's Condition

Care Recipient's Main Problem or Illness

Diabetes emerges as the top illness for which Hispanic caregivers' recipients need care. Fifteen percent of Hispanic caregivers cite this illness as the reason for care, compared to 8% of non-Hispanic caregivers who do. Other top illness or conditions for which the Hispanic caregivers' loved ones need help include cancer, old age, and arthritis (7% each) as well as Alzheimer's disease or other mental confusion, heart disease, and mental/emotional illnesses (6% each).

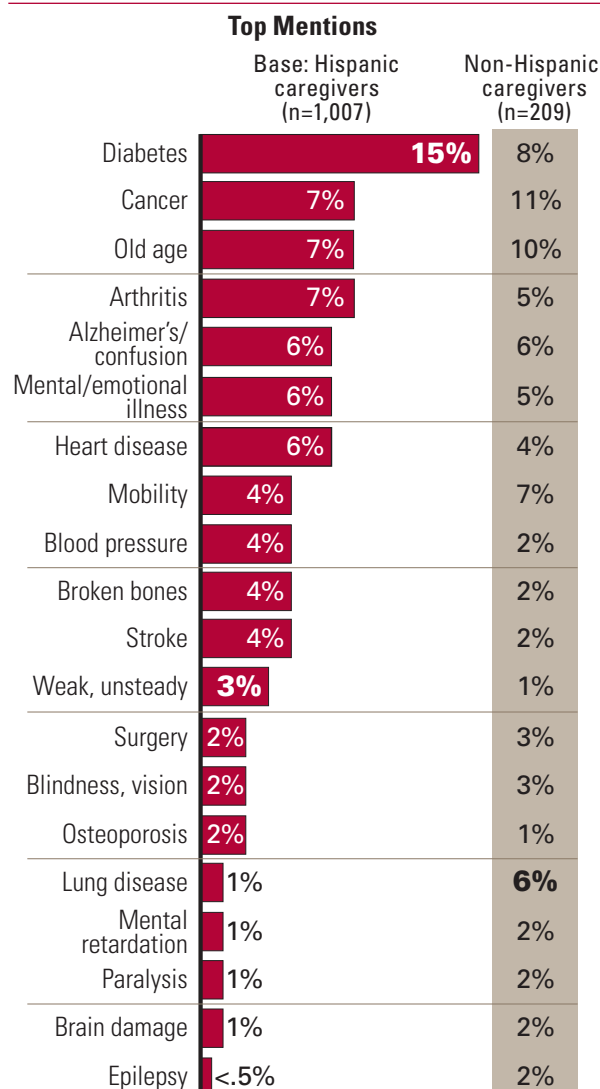
Hispanic Caregiver Subgroups

Situations in which the care recipient has had broken bones or a stroke appear more likely to result in heavy burden to the caregiver. Specifically, high burden Level 4-5 caregivers are more likely to report these conditions than are caregivers with a Level 1-2 burden (broken bones: 6% vs. <0.5%; stroke: 4% vs. 1%).

She's diabetic. Since I took a course on diabetes, I try to prepare meals that help her so her condition doesn't worsen.

Figure 21

Q13. What would you say is/was the main problem or illness your [relation] has/had?



Note: Any condition mentioned by 2% or more of either Hispanic or non-Hispanic respondents is shown.

Note: Bold figures are significantly higher than their comparison figure.

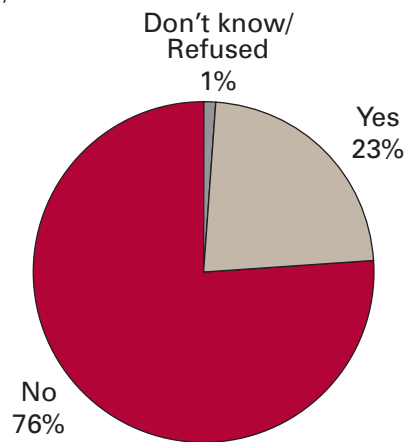
Presence of Alzheimer’s or Mental Confusion

Although Alzheimer’s or mental confusion is cited by only 6% of Hispanic caregivers as the primary reason why the care recipient needs help, an additional 17% of respondents also cited Alzheimer’s or mental confusion as a condition of their care recipient, for a total of 23% of all Hispanic caregivers.

Figure 22

Q14. Does/did your [relation] suffer from Alzheimer’s or mental confusion?

Base: Hispanic caregivers (n=1,007)



Non-Hispanic caregivers (n=209)

Yes 26%

Hispanic Caregiver Subgroups

Mental confusion among care recipients is more commonly reported by Hispanic caregivers who provide more than 20 hours of care (27% vs. 20% of those providing fewer hours).

This condition is also associated with a higher burden of care. Twice as many medium to high burden caregivers as low burden caregivers say their recipient has Alzheimer’s or mental confusion (26% vs. 13%).

Older caregivers tend to report their recipient having Alzheimer’s or mental confusion more than younger ones (30% of 50+ caregivers vs. 21% of younger ones).

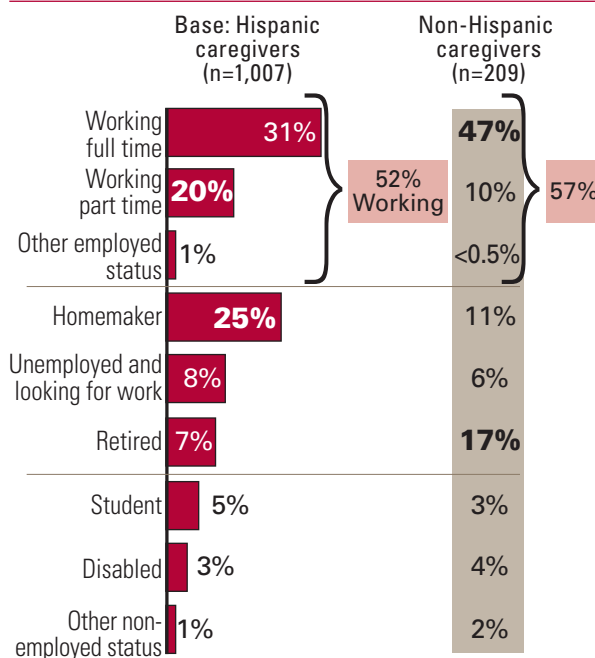
Employment and Balance in Caregiver's Life

Caregiver Employment Status

Although Hispanic caregivers and non-Hispanic caregivers are equally likely to be employed, Hispanic caregivers are less likely to be employed full time (31% vs. 47%) and more apt to be part-timers (20% vs. 10%). There are two other key differences in the employment status of these two ethnic groups. First, fully one-quarter of Hispanic caregivers say they are homemakers (25%), whereas only 11% of non-Hispanic caregivers do. Secondly, Hispanic caregivers are far less likely to say they are retired (7% vs. 17%).

Figure 23

Q20. Are you currently/During your last two months as a caregiver, were you working full time, working part time, a student, disabled, retired, a homemaker, unemployed and looking for work, or something else? [Multiple responses allowed]



Note: Bold figures are significantly higher than their comparison figure.

Even when controlling for age, some of these sharp contrasts in employment status are still apparent. However, much of the contrast may be due to the different usage or applicability of the terms “retired” and “homemaker” between the two ethnic groups, because when the retirement and homemaker employment categories are combined, the Hispanics and non-Hispanics look much more similar.

Looking just among those who are 65 or older, one finds 49% of Hispanic caregivers reporting they are retired and 24% who say they are homemakers, whereas among non-Hispanics, 65% consider themselves retired and only 2% report being homemakers. Similar shares of the Hispanic and non-Hispanic groups report having worked while they were caregivers, so the difference in the percentage retired is not explained by different rates of prior employment. It may be that the Hispanic caregivers, with their more common part-time status, are less likely to have held the sort of job from which they would “retire” as opposed to “stop working.” Alternatively, they may simply be more likely to use the term “homemaker” or “amo de casa” to classify a stay-at-home work status.

Hispanic Caregiver Subgroups

Employment is more prevalent among the following subgroups of Hispanic caregivers:

- Non-primary caregivers (60% employed vs. 48% of primary caregivers). On the other hand, the non-primary caregivers are *less* likely to be homemakers (20% vs. 27%) or retirees (3% vs. 9%).
- Those who live apart from their care recipient (56% employed vs. 46% of those who live with their loved one).
- Males (70% employed vs. 46% for female caregivers). Counterbalancing this is the fact that 33% of the female caregivers consider themselves homemakers, compared to only 1% of males.
- Those with household incomes of \$30,000 or more (63% employed vs. 47% of lower income caregivers). Caregivers in the lower income households are disproportionately homemakers (29% vs. 17%).
- Caregivers under the age of 50 (56% employed vs. 42% of older caregivers). A related finding — 22% of the older caregivers say they are retired, compared to only 1% of the younger caregivers).

Work Accommodations Due to Caregiving

When it becomes difficult to balance caregiving with work, or if the demands of work come into conflict with one's caregiving responsibilities, sometimes caregivers choose to make changes to their work situation. Four in ten Hispanic caregivers report making changes such as cutting back on their working hours, changing jobs, stopping work entirely, taking a leave of absence, or other such changes as a result of their caregiving role (41%). A smaller proportion of non-Hispanic caregivers say they have made such changes (29%).

In fact, two-thirds of Hispanics were employed at some point while they were caregiving (66%), whereas only 52% are currently⁴ working, a decline of 14 percentage points. Non-Hispanic caregivers show a decline of the same magnitude.

Hispanic Caregiver Subgroups

Caregivers in the more intensive care situations — those who provide 21+ hours of care each week, have a high burden of care (Levels 4-5), are the primary caregiver, or share a household with their care recipient — tend to report these work accommodations more frequently than their counterparts. For example, those with a high burden of care (Levels 4-5), are twice as likely as those in low burden situations to have made these changes (49% vs. 24%).

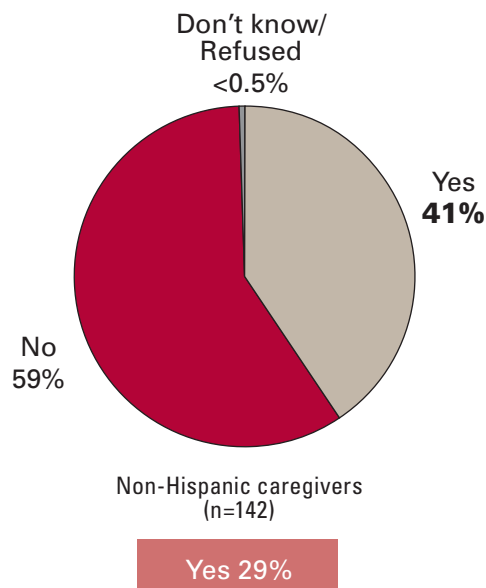
Caregivers who felt they did not have a choice in taking on their role are more apt to have made major changes in their work situation as a result of caregiving than are those who felt they had a choice (47% vs. 38%).

Female caregivers are more likely than males to have done so (45% vs. 34%).

Figure 24

Q21a. As a result of caregiving, did you cut back your hours, change jobs, stop working, take a leave of absence, or make any other major changes to your job situation?

Base: Hispanic caregivers who were employed while a caregiver (n=647)



Note: Bold figures are significantly higher than their comparison figure.

⁴ For caregivers who gave care in the past 12 months but are not current caregivers, the analysis looked at their working status during their last two months of caregiving instead of their current working status.

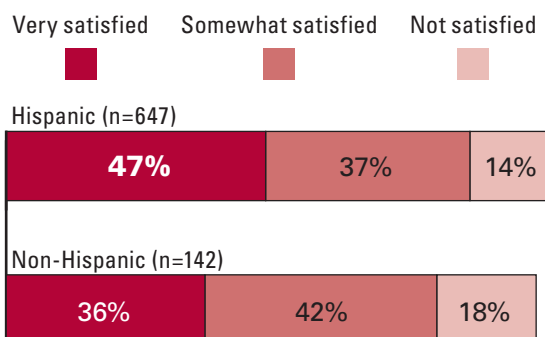
Satisfaction With Balance Between Work and Caregiving

About eight in ten working caregivers are satisfied with the balance they have between work and caregiving. Hispanics are more likely than non-Hispanics to maintain that they are *very* satisfied (47% vs. 36%). This difference is not due to the larger share of part-timers among Hispanics, because the contrast between the two ethnic groups is significant among both full-timers and part-timers.

Figure 25

Q23c. How satisfied are you/When you were a caregiver, how satisfied were you with your balance between caregiving and work?

Base: Caregivers who were employed at any time while a caregiver



Note: Bold figures are significantly higher than their comparison figure.

Hispanic Caregiver Subgroups

Caregivers with a lower burden of care (Levels 1-2) show a greater tendency to be satisfied with the work/caregiving balance (91% satisfied among those with low to medium burden vs. 81% of Level 4-5 caregivers). Predictably, since hours of caregiving help define the burden of care, those who spend fewer hours caregiving are more apt to report satisfaction with their work/caregiving balance.

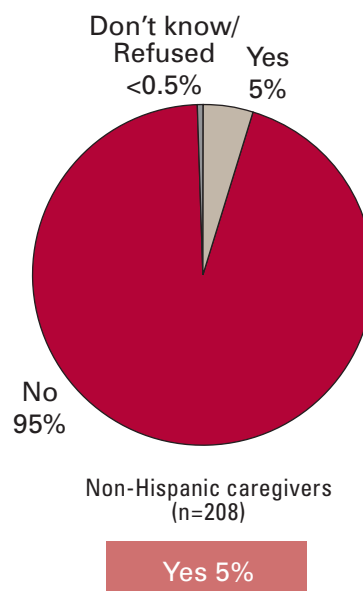
Paid Caregiver Status

One in twenty Hispanic caregivers and an equal proportion of non-Hispanic caregivers claim to be *paid* caregivers for someone else (5% each).

Figure 26

Q22. Are you/When you were a caregiver were you also a PAID caregiver for someone outside of your family?

Base: Hispanic caregivers employed full or part time (or for past caregivers, they were in the last two months of caregiving) (n=994)

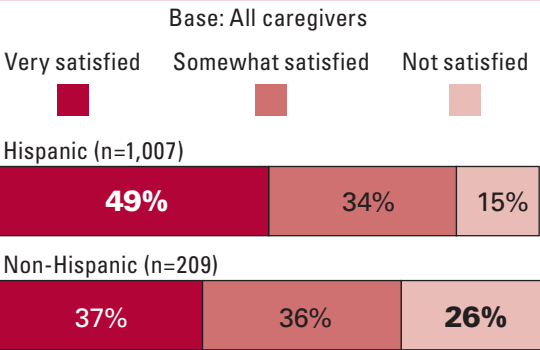


Satisfaction With Social Life

Most caregivers are at least somewhat satisfied with their social life, including getting together with friends or going out. Hispanic caregivers show a higher level of satisfaction than non-Hispanics, with 49% versus 37% *very* satisfied. One in four non-Hispanics does not feel satisfied.

Figure 27

Q23a. How satisfied are you/When you were a caregiver, how satisfied were you with your social life, including getting together with friends or going out?



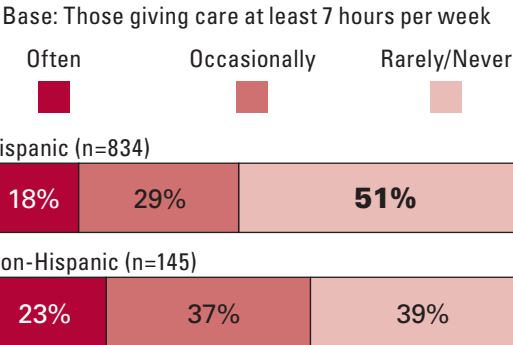
Note: Bold figures are significantly higher than their comparison figure.

One hypothesis for this difference between the two groups that was explored through the survey is that the social lives of Hispanic caregivers may intermingle more frequently with their caregiving, perhaps with family visits taking place during caregiving hours or caregivers bringing their care recipients on social outings. The survey findings do not support this hypothesis, since non-Hispanics are the more likely group to report that their social activities *often* or *occasionally* coincide with their caregiving hours (60% vs. 47% for Hispanics).

In my family's case, we visit two or three times a week with friends from church. And on Sunday, we go in the morning to church, then sometimes friends invite us to a birthday party. We go as well for a little while and have fun.

Figure 28

Q24. How often do/did your visits or social activities with other people occur during the same hours that you are/were caregiving?



Note: Bold figures are significantly higher than their comparison figure.

However, this difference between the Hispanic and non-Hispanic groups is apparent only in situations where the caregiver lives with the care recipient (41% of Hispanic caregivers *often* or *occasionally* have social activities during caregiving hours vs. 66% of non-Hispanics who do). When the care recipient lives elsewhere, both groups are equally likely to mingle their social and caregiving hours (52% vs. 56%).

Hispanic Caregiver Subgroups

As burden of care rises, satisfaction falls. In particular, 62% of those with a low burden of care (Levels 1-2) rate themselves *very* satisfied, while 45% of those with a high burden do. Hours spent caregiving, a component of the burden measure, follow the same pattern.

Other Hispanic caregiver subgroups among whom we find greater satisfaction include:

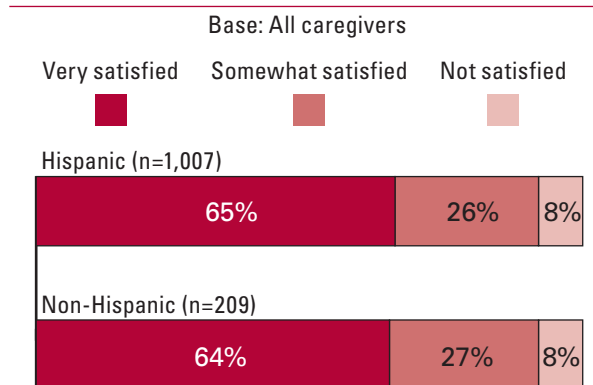
- Caregivers who feel they had a choice in their role (88% satisfied vs. 78% of those who feel they did not have a choice)
- Those in households with less than \$30,000 in income (86% vs. 80% in higher income households)
- Caregivers of Mexican origin (86% vs. 76% of those with another Hispanic origin)
- Younger caregivers, those 18 to 49 years of age (86% vs. 78% for older caregivers)

Satisfaction With Family Relationships

The vast majority of Hispanic and non-Hispanic caregivers are satisfied with their family relationships (91% each). Nearly two-thirds of each group consider themselves *very* satisfied.

Figure 29

Q23b. How satisfied are you/When you were a caregiver, how satisfied were you with your family relationships?



Hispanic Caregiver Subgroups

There is a greater tendency for caregivers who live separately from their loved one to be satisfied, relative to those who co-reside (94% vs. 88% satisfied).

Non-primary caregivers are also more apt than primary caregivers to be satisfied with their family relationships (95% vs. 90%).

A larger share of caregivers who had choice in taking on their responsibility describe themselves as *very* satisfied (68% vs. 61%).

Caregivers in households with at least \$30,000 in income also show greater satisfaction with their family relationships than do those in lower income households (69% vs. 62% *very* satisfied).

Attitudes and Beliefs
About Nursing Care and
Health Workers

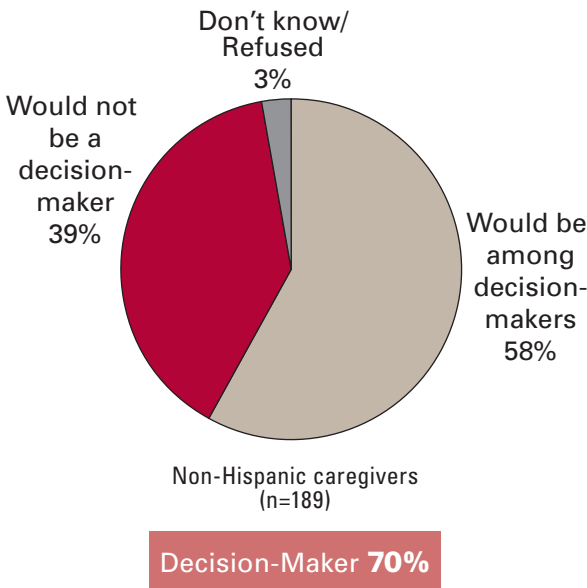
Decision-Maker Status for Decisions About
Nursing Home or Assisted Living Care

More than half of Hispanic caregivers whose loved one is not already living in a nursing home or assisted living facility would be among those who would help decide if their care recipient needed to be placed in some sort of care facility (58%), but seven in ten non-Hispanics say they would (70%).

Figure 30

Q27. If it looked like your [relation] might need to be placed in a nursing home or other residence that offers care, what family members or friends would help decide? Would you be one of the people who helped decide whether or not to do that?

Base: Hispanic caregivers whose recipient is not in a nursing home or assisted living
Split sample (n=574)



Note: Bold figures are significantly higher than their comparison figure.

Hispanic Caregiver Subgroups

Among Hispanics, a larger proportion of primary caregivers than non-primary caregivers indicate they would be among those who make this type of care decision (65% vs. 45%).

The caregivers who live with their loved one are much more likely than those who live apart to say they would help make a decision about nursing care or assisted living (70% vs. 49%).

Greater caregiving hours and a larger burden of care are also associated with a greater likelihood of taking part in this decision.

Caregivers age 50 or older are more likely than younger caregivers to be among the decision-makers for residential care (64% vs. 55%).

Six in ten of the Hispanic caregivers who were born in the U.S. say they would take part in this decision (64%), whereas only 48% of those who have lived most of their lives outside of the U.S. say they would.

Consideration of Nursing Home/Assisted Living Placement

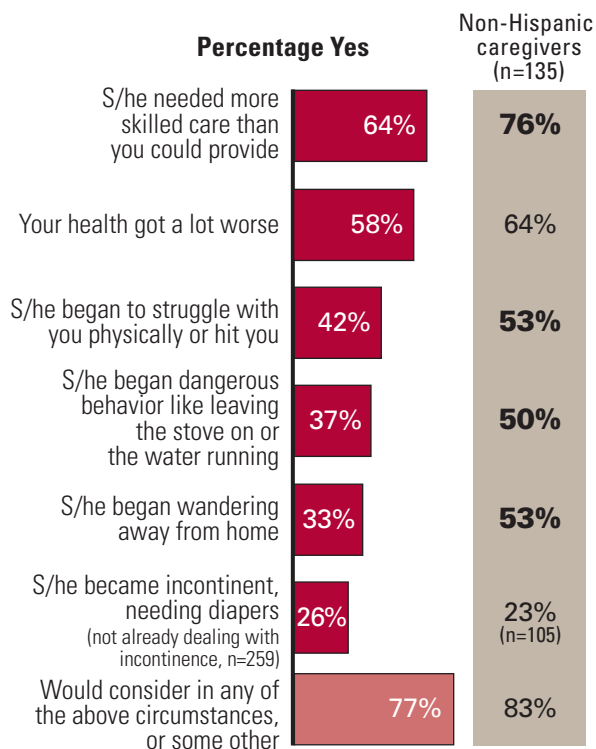
Among the caregivers who would have decision-making status, roughly equal proportions of Hispanic and non-Hispanic caregivers indicate they would consider placing their loved one in a nursing home or assisted living facility in some conceivable situation. However, in several specific circumstances, Hispanics are less likely than non-Hispanics to consider such a placement. Specifically, they would be less apt to consider a nursing home or assisted living facility if their loved one needed more skilled care than the caregiver could provide (64% vs. 76%), struggled or hit them (42% vs. 53%), began exhibiting dangerous behavior like leaving the stove on or water running (37% vs. 50%), or began wandering from home (33% vs. 53%).

Figure 31

Q28. If the following occurred, would you consider/have you considered placing your [relation] in a nursing home or some other residence that offers care?

Q29. [IF NO TO ALL] Would you ever consider/have you ever considered placing your [relation] in a nursing home or some other residence that offers care?

Base: Care recipient does not live in a nursing home and caregiver would decide on care placement (n=338)



Note: Bold figures are significantly higher than their comparison figure.

Many focus group respondents are hesitant to consider a nursing home because they believe the care recipient is better off with family, may die sooner away from family, and could be vulnerable to mistreatment in a nursing home.

She has told me, "Never take me to one of those places, because your mom was in one of those places and they never treated her right."

Still, they acknowledge that they have other family responsibilities besides caregiving, and they express willingness to make a difficult decision if circumstances demand it.

Hispanic Caregiver Subgroups

Male Hispanic caregivers are almost twice as likely as females to report that incontinence would prompt them to consider a nursing or assisted living facility (39% vs. 21%).

Hispanic caregivers who are in low burden situations are more likely than those in high burden situations to consider a specialized care facility in cases of dangerous behavior (52% vs. 33%) or physical struggling or hitting (55% vs. 38%).

Caregivers whose household income is at least \$30,000 are more apt to consider nursing care if their own health were to greatly worsen (66% vs. 52% for those in lower income households).

Hitting or physical struggling prompts a greater share of caregivers who were born in the U.S. to consider residential care (51%) compared to those who have lived some part of their life outside the U.S. (36%).

Beliefs About Health Workers

Based on area focus group input, the survey included a series of agree/disagree statements about health workers that might reflect the respondents’ views. Six in ten Hispanic caregivers believe that someone who is placed in a nursing home will experience declining health (63% agree). More than four in ten think home health workers are more competent to take care of their loved one than they are (45%). Non-Hispanics hold similar beliefs on both counts. However, Hispanics are more likely to believe that it is common for home health workers or nursing home staff to mistreat patients (40% vs. 30%).

Figure 32

Q30. I’m going to read you some statements.
For each one, tell me whether you agree or disagree.

Percentage Agree

	Base: Hispanic caregivers (n=1,007)	Non-Hispanic caregivers (n=209)
If someone is placed in a nursing home, their health will go downhill from being there	63%	58%
Home health workers are more competent than you are/were to take care of your [relation]	45%	40%
It is common for home health workers or nursing home staff to mistreat their patients	40%	30%

Note: Bold figures are significantly higher than their comparison figure.

Hispanic Caregiver Subgroups

Beliefs in greater competence of home health workers rise in relation to the proportion of one’s life spent outside the U.S., from 33% of Hispanics who have lived their entire lives in the U.S. to 56% of those who have lived at least two-thirds of their life in some other country.

Those who have lived their entire lives in the U.S. are more skeptical of nursing homes than those who have lived at least two-thirds of their lives outside the U.S. In particular, the former are more likely to agree that health workers or nursing home staff mistreat their patients (50% vs. 28%), and they are more apt to believe the health of someone who is placed in a nursing home will go down from being there (67% vs. 58%).

Beliefs that a patient’s health will decline as a result of a nursing home placement rise as the burden of care rises from 55% of those in low burden situations to 65% of those in high burden situations.

56

“If one of my kids get sick and something happens and I have to be taking care of my kids, you have to make choices.”

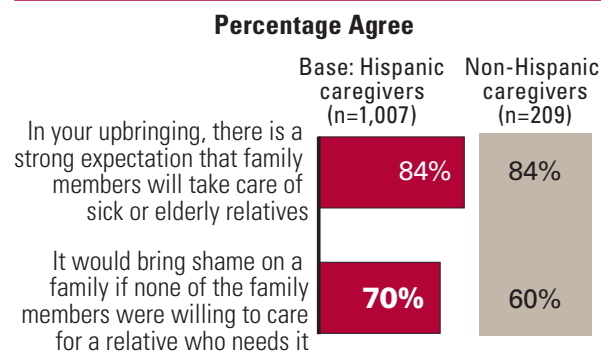
Beliefs and Feelings About Caregiving

Cultural Perspectives on Caregiving

Feelings of shame if no family members are willing to care for a relative in need are more prevalent among Hispanic caregivers than non-Hispanics (70% vs. 60%). Both groups are equally likely to report that there is a strong expectation in their upbringing that family members will take care of sick or elderly relatives (84% each).

Figure 33

Q30/31. Please tell me whether you agree or disagree with each statement.



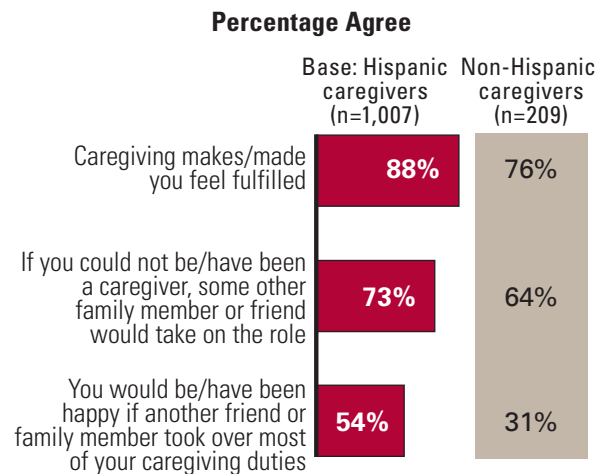
Note: Bold figures are significantly higher than their comparison figure.

Caregivers' Personal Perspective on Caregiving

Nearly nine in ten Hispanic caregivers say caregiving makes them feel fulfilled (88%), compared to three-quarters of non-Hispanic caregivers who feel this way (76%). At the same time, Hispanic caregivers are also more likely to say they would be happy if some other person took over their caregiving responsibilities (54% vs. 31%). Seven in ten Hispanic caregivers believe some other family member or friend would serve as caregiver if they were not able to (73%), more than the 64% of non-Hispanic caregivers who believe someone else would step in.

Figure 34

Q31. Please tell me whether you agree or disagree with each statement.



Note: Bold figures are significantly higher than their comparison figure.

Hispanic Caregiver Subgroups

The Hispanic caregivers who spent at least two-thirds of their lives outside of the U.S. are most likely to feel fulfilled by caregiving (93% vs. 84% of those who were born in the U.S.).

In spite of this fulfillment, they are also more likely than those who have lived only in the U.S. to acknowledge they would be happy if someone would take over their caregiving duties (61% vs. 39%). Caregivers with less than \$30,000 in household income are also more likely to feel this way (60% vs. 50% of higher income caregivers).

The subgroups of Hispanic caregivers who are more inclined to think that another family member or friend would take on their role if they could not do it include:

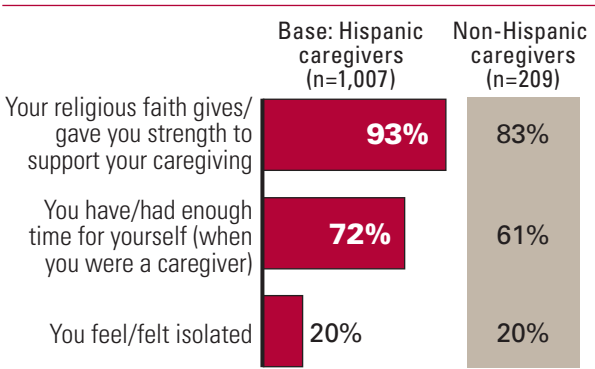
- Hispanic caregivers who feel they had a choice in taking on their responsibility (78% vs. 67% of those who had no choice)
- Non-primary caregivers (84% vs. 68% of primary caregivers)
- Those who live separately from their care recipient (77% vs. 68% of those co-residing)
- Those who have lived at least two-thirds of their life outside the U.S. (81% vs. 71% of those spending no part or a smaller part of their lives outside the U.S.)
- Those of Mexican origin (75% vs. 67% of Hispanics of different origin)

Caregiving Impacts and Religious Support

Religious faith gives nine in ten Hispanic caregivers strength to support their caregiving (93%), according to their self-report. A smaller proportion of non-Hispanic caregivers agree (83%). Hispanic caregivers are also more likely to feel they have enough time for themselves (72% vs. 61%). Only one in five of both ethnic groups reports feeling isolated (20% each).

Figure 35

Q31. Please tell me whether you agree or disagree with each statement.



Note: Bold figures are significantly higher than their comparison figure.

Hispanic Caregiver Subgroups

Caregiver perceptions that their faith supports them are more common among women than men (94% vs. 88%), those not employed (95% vs. 91% employed), and those spending most of their lives outside of the U.S. (96% vs. 91% of those who were born in the U.S.).

As one might expect, non-primary caregivers are more apt to feel they have enough time for themselves (81% vs. 68% of primary caregivers), and low to medium burdens of care (Levels 1-3) are also more likely to coincide with this perception (79%) than are high burdens (Levels 4-5) (69%).

Caregivers who are not employed report adequate time for themselves more than do employed caregivers (76% vs. 69%).

Choice in taking on the caregiving role is also associated with a perception of more adequate time for oneself (80% vs. 62% of those who feel they had no choice).

The Hispanic caregivers who are more apt to feel isolated are:

- Those who live in the same household as their care recipient (26% vs. 15% of those who live separately)
- Primary caregivers (22% vs. 15%)
- Those who lacked choice in becoming a caregiver (23% vs. 18%)
- Those with a high burden of care (Levels 4-5) (23% vs. 15% of those with a low to medium burden) and those who provide care for 21+ hours per week (24% vs. 16% of those spending less time caregiving)
- Those aged 50 or older (25% vs. 18% of younger caregivers)

Caregiving Challenges and Sources of Information and Services

Caregiving Challenges and Difficulties

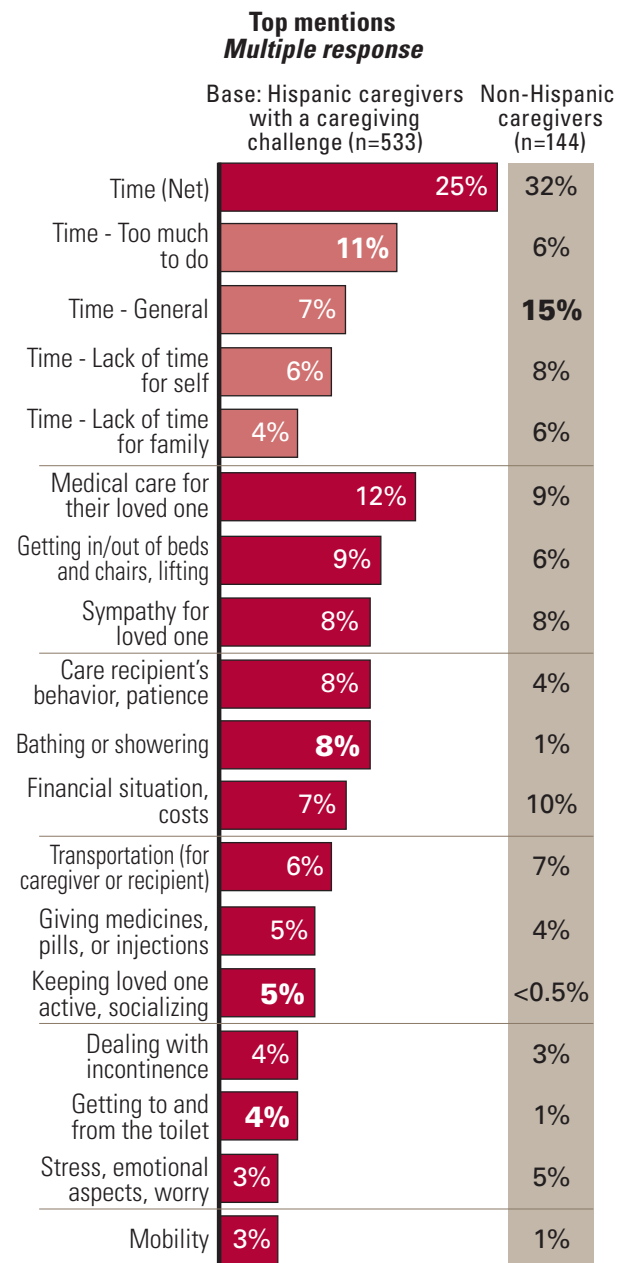
In response to an open-ended question about aspects of caregiving that are challenging or difficult for them, half of Hispanic caregivers are able to name a challenge (54%), while 70% of non-Hispanic caregivers are. Among the Hispanic caregivers who name a caregiving challenge, by far the most common challenge is lack of time (25%). Some specifically identify the difficulty as lacking time for themselves (6%) or their family (4%). The next most common challenges are medical care for their loved one's condition (12%) and transferring/lifting their loved one, often in and out of chairs and beds (9%). The range of challenges they name is quite broad.

In general, the pattern of challenges mentioned by non-Hispanics is similar to that of Hispanics. However, bathing or showering is mentioned as a challenge more frequently by Hispanics than non-Hispanics (8% vs. 1%), as are keeping their loved one active (5% vs. <0.5%) and getting to and from the toilet (4% vs. 1%).

For me the most difficult thing is the supervision, having to supervise 24 hours a day.

Figure 36

Q32. What two aspects of caregiving are/were the most difficult or challenging for you?



Note: Bold figures are significantly higher than their comparison figure.

Hispanic Caregiver Subgroups

Time is mentioned as a challenge more frequently by caregivers with at least \$30,000 in income (32%) than by lower income caregivers (22%).

Transportation is a more prevalent concern among non-primary caregivers than among primary caregivers (10% vs. 3%).

High burden caregivers (Levels 4-5) are more likely than those with a lower burden to name specific ADLs as the most challenging aspect of caregiving, including getting in and out of beds and chairs, bathing, and dealing with incontinence.

Those who live apart from their care recipient are more likely than co-resident caregivers to cite sympathy over their loved one’s condition as the most difficult aspect of caregiving (11% vs. 5%).

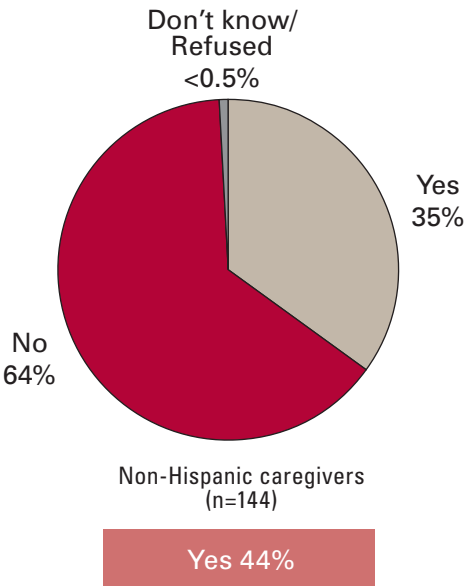
Search for Information/Services To Help With Caregiving Challenges

Of the Hispanic caregivers who mentioned a caregiving challenge, only one-third report having sought out information or services to help them deal with their challenge (35%).

Figure 37

Q33. Did you ever seek out information or services to help you with your caregiving challenge/difficulty?

Base: Hispanic caregivers with a caregiving challenge (n=533)



60

When someone else that has a car takes him, it’s not a problem. But when I have to go with him on the bus, there are limited seats for wheelchairs.

Hispanic Caregiver Subgroups

Caregivers in high burden situations (Levels 4-5) are more likely than those in low to medium burden situations to have looked for information or services (41% vs. 25%), perhaps because greater need motivates them to look for a solution.

Hispanic caregivers who have at least \$30,000 in household income are more apt to have sought help for their challenge (41% vs. 31% of lower income caregivers), perhaps because they would not be as concerned about potential fees for services.

Caregivers over the age of 50 also more commonly sought information or services (42% vs. 33% of younger caregivers).

Sources of Information/Services Used To Help With Caregiving Challenges

Most of the Hispanic caregivers who sought information for a caregiving challenge report turning to doctors, nurses, health workers, pharmacists, or other health professionals (81%). Two-thirds cite family or friends (66%), and half contacted government programs or agencies (49%). More than one-third turned to a disease-specific organization (37%) or their church (35%). Three in ten used the internet to seek information (29%). Non-Hispanic caregivers show a similar usage of information and service providers, except that they are less likely to say they turned to a government program or agency (31%).

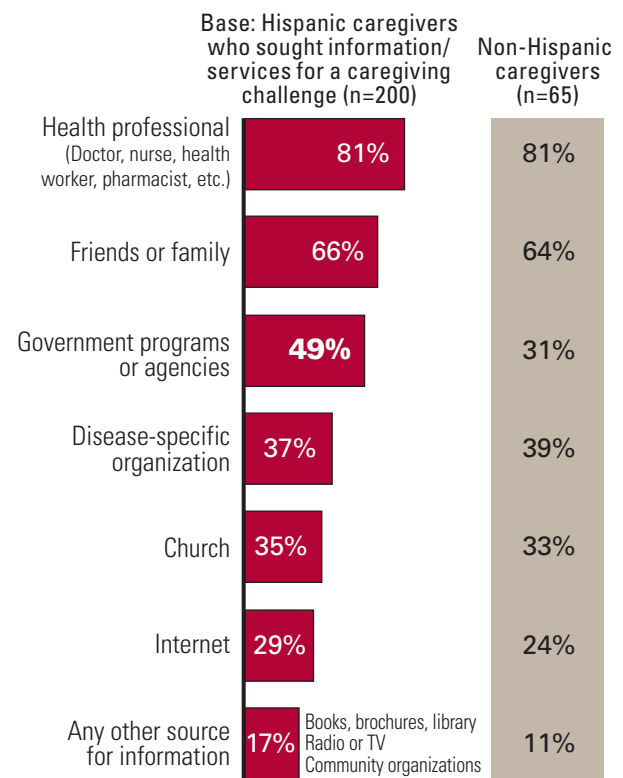
The physician is a good and very fundamental source of information. When my mother was sick, the doctor would make his recommendations or he would call the social worker or call this place or the other or look for this.

Friends who have gone through the same thing will give you a referral. They tell me where I can go and what doctors are the least expensive, and they give me tips on where and how to apply for medications.

Figure 38

Q34. In looking for information or services to help you with your caregiving challenge or difficulty, which of the following sources did you turn to?

Percentage Turning to Each Source



Note: Bold figures are significantly higher than their comparison figure.

I would like a TV show [with caregiving information]. I would like a channel that would provide this information.

Hispanic Caregiver Subgroups

Hispanic caregivers who have spent most of their lives outside the U.S. are far less likely to turn to government agencies or programs for information (29%) than those who were born in the U.S. (61%). This difference may reflect beliefs — expressed by focus group participants who were less acculturated — that government programs would not provide services to a care recipient who was not a citizen, or that program staff would raise the issue of citizenship status that they would prefer to avoid.

Employed caregivers are far more likely to mention turning to the internet (41% vs. 14% of non-employed caregivers).

Caregivers in the focus groups say they learn about activities, products, and services from the television, and they consider it a credible source. It is not uncommon for these caregivers to call a phone number or visit a Web site that was publicized on a television commercial or public service announcement.

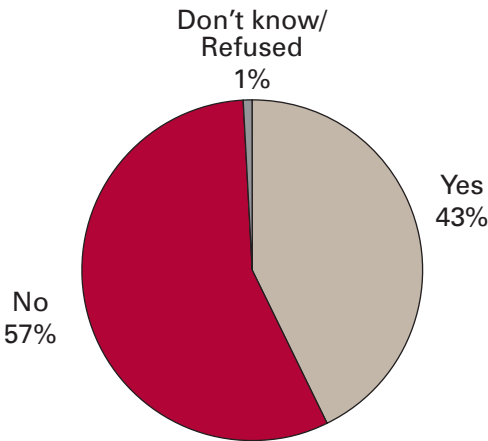
Internet Usage

When asked if they have ever conducted an internet search for information on any subject, four in ten Hispanic caregivers report they have (43%), while twice as many of non-Hispanic caregivers report having done so (81%).

Figure 39

Q43. Have you ever used the internet to search for information of any kind on any subject?

Base: Hispanic caregivers (n=1,005)



Non-Hispanic caregivers (n=208)

Yes **81%**

Note: Bold figures are significantly higher than their comparison figure.

I go to the internet for everything. If you search [under] "Alzheimer's," it gives you information regarding the GPS system [chip] that [the person with Alzheimer's] can be [wearing] so you can track this person via satellite. There are all types of information, including information on medication. Everything is on there.

Hispanic Caregiver Subgroups

Once again, Hispanic caregivers who are employed are more likely than non-employed caregivers to report having used the internet for any information search (50% vs. 35%). They may have conducted these searches for their job, or workplace computers may simply increase their access to the internet.

Those who were born in the U.S. are more apt than those who have lived outside the U.S. to have done an internet search (54% vs. 36%). Those of non-Mexican origin are also more likely than Mexicans (54% vs. 39%).

A larger share of young caregivers than older ones have searched on the internet (47% of 18- to 49-year-old caregivers have vs. 33% of older caregivers).

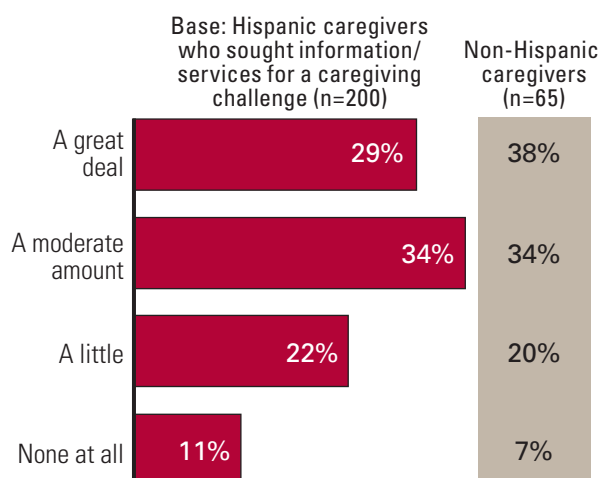
A larger proportion of low burden Level 1-2 caregivers have turned to the internet for information relative to high burden Level 4-5 caregivers (52% vs. 39%).

Success in Finding Information To Help With Caregiving Challenge

Regardless of the source turned to, more than six in ten Hispanic caregivers who sought information or services report having had a *moderate amount* or *great deal* of success (63%), and a similar share of non-Hispanics did as well (72%).

Figure 40

Q36. How much success did you have at finding something to help?



The fastest way to learn about programs that could help would be via the television.

Reasons for Not Looking for Information/Services Regarding Caregiving Challenge

Among the Hispanic caregivers who did not seek information or services to help them deal with their challenges or difficulties, lack of need was the top reason why (33%), followed by just not thinking about it (19%). One in twelve Hispanic caregivers admits not knowing where to look (8%), and an equal percentage do not believe they could find anything that would help them (8%).

Non-Hispanic caregivers are more apt to justify not seeking help by explaining that their situation is not severe enough to merit it (50% vs. 33%), results that coincide with the earlier finding that non-Hispanic caregivers are less likely to have a high burden of care. Hispanic caregivers are more likely than non-Hispanics to offer as a reason the fact that they did not know where to look (8% vs. 2%).

Figure 41

Q37. What are the main reasons why you did not look/have not looked for information or services regarding your caregiving challenge or difficulty?

Base: Did not seek information for caregiving challenge

Top mentions	Hispanic caregivers (n=330)	Non-Hispanic caregivers (n=79)
No need, situation is not bad enough	33%	50%
Never thought about it	19%	19%
Don't know where to look	8%	2%
Nothing would help	8%	7%
No time to look	6%	8%
Unsure about quality, trustworthiness of information	4%	2%
Care recipient would be resistant	4%	1%
Services would cost too much	3%	5%
Caregiver wants to do everything him/herself	2%	3%

Note: Bold figures are significantly higher than their comparison figure.

Illustrations of some of these reasons from focus group respondents are as follows:

Lack of need	<i>"For me, we do not need the service. With all of the family members, we can do all of it."</i>
	<i>"The obstacle for me is that I still think she does not need that type of service yet."</i>
Don't know where to look	<i>"I didn't know they had an association for strokes."</i>
Cost	<i>"Those services are expensive and I cannot pay for them. The transportation, for example...I went to find out and it was very expensive because he does not have Medicaid."</i>

Although few of the Hispanic caregivers interviewed say a reason they have not sought information is due to lack of citizenship (<0.5%), this was a prominent barrier to information seeking for focus group respondents — several recounted being turned away from services because of lack of citizenship.

Hispanic Caregiver Subgroups

Several subgroups of Hispanic caregivers are more likely than their counterparts to say they did not seek out information or services because they would not know where to look: caregivers who live with their recipient (13% vs. 6%), those who are not employed (12% vs. 5%), those who live in households with less than \$30,000 in income (11% vs. 4%), and those age 50 or older (15% vs. 6%).

Women are more likely than men to cite lack of time as a reason (8% vs. 2%).

About a year and a half ago they brought my grandmother to live here. She's got Alzheimer's. Since she didn't have any papers, we couldn't get anything for her, not even medicine.

Importance of Spanish Language Information and Services

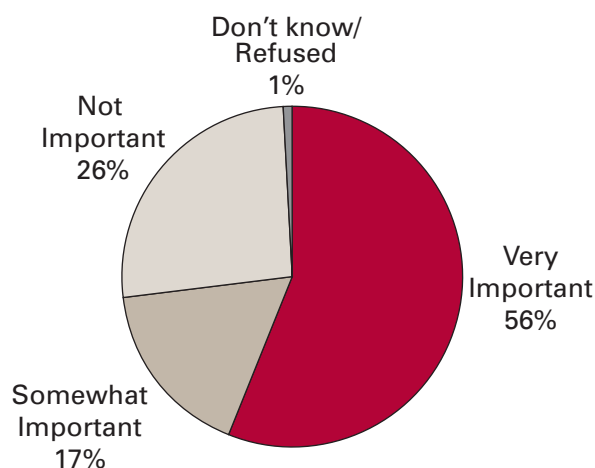
Importance of/Satisfaction With Spanish Language Caregiving Information

More than seven in ten Hispanic caregivers think it is *very* or *somewhat* important for them personally that any caregiving information be in Spanish (73%), including 56% who say it is *very* important. Of those who feel Spanish language materials are important, half are *very* satisfied with their availability (52%), and 33% are *somewhat* satisfied. One in eight (12%) are *not* satisfied.

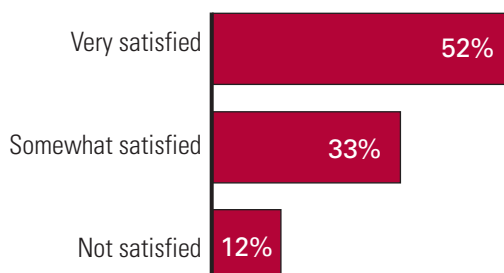
Figure 42

- Q38. For you personally, how important is it that any caregiving information you use be in Spanish?
Q39. How satisfied are you with the availability of Spanish language information about caregiving?

Base: Hispanic caregivers
Split sample (n=574)



Base: Hispanic caregivers who feel Spanish caregiving info is somewhat/very important (n=414)



Hispanic Caregiver Subgroups

Even among those who were born in the U.S., half feel Spanish language materials would be *very* or *somewhat* important (49%). As time living outside of the U.S. rises, so does the importance of these materials, to the point that 96% of those who have spent at least two-thirds of their life outside the U.S. note the importance of Spanish language materials. In fact, 83% rate them as *very* important.

Hispanics of Mexican origin are also more likely to note the importance of having caregiving information in Spanish (78% vs. 57% of other origins rating them at least *somewhat* important). However, this may be explained in part by the fact that the Mexican Hispanics have, on average, spent a larger proportion of their life outside of the U.S.

Non-employed caregivers are also more likely than employed caregivers to feel Spanish language materials are important (78% vs. 68%).

Of those who feel Spanish materials are important, employed caregivers are most likely to say they are *not* satisfied, (18% vs. 7% of those who are not employed).

Those who have spent most of their lives outside the U.S. tend to be more highly satisfied (62% *very* satisfied) than those who were born in the U.S. (39%).

Satisfaction is also more prevalent among caregivers with a high level of burden (Levels 4-5) (58% *very* satisfied vs. 33% of low burden caregivers).

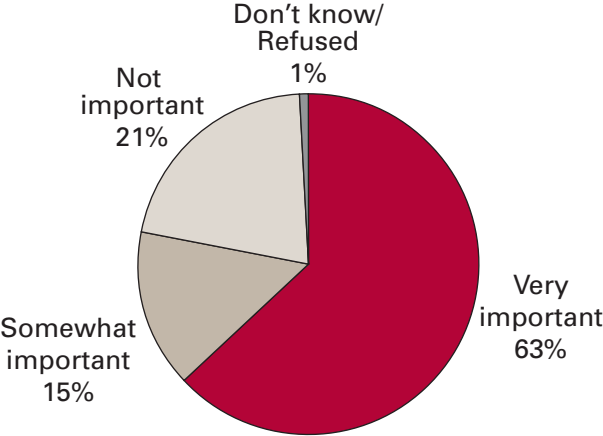
Importance of Delivering Caregiving Services in Spanish

Three-quarters of Hispanic caregivers believe it is important that caregiving services for their care recipient be delivered by Spanish speakers (78%), with 63% saying it is *very* important.

Figure 43

Q40. How important is it to you for any caregiving services that may be used for your [relation] to be delivered by Spanish speakers?

Base: Hispanic caregivers
Split sample (n=574)



Hispanic Caregiver Subgroups

Similar to patterns found with regard to Spanish language caregiving materials, the importance of Spanish language services is higher among those who have spent the greatest part of their life outside of the U.S. (96% *very/somewhat* important) than among those who were born in the U.S. (56%).

Lower income caregivers — those with less than \$30,000 in household income — are also more likely than higher income caregivers to value services delivered in Spanish (83% vs. 71%).

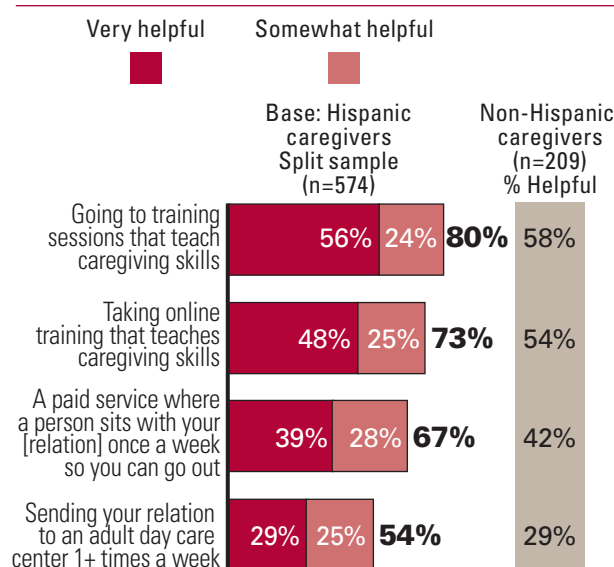
Helpful Training and Services

Helpfulness of Training and Services

Of four types of caregiver support services presented to Hispanic caregivers, training sessions that teach caregiving skills emerge as the one that the largest share would consider helpful (80%). Seven in ten would find online training in caregiving skills to be helpful (73%), followed by a once-per-week paid service that would allow the caregiver to go out (67%), and an adult day care center (54%). Hispanic caregivers are much more likely than non-Hispanic caregivers to rate each of these services as helpful.

Figure 44

Q41. In your situation, how helpful would the following be/have been?



Note: Bold figures are significantly higher than their comparison figure.

Hispanic Caregiver Subgroups

Caregivers who have spent a larger share of their lives outside of the U.S. are the most likely to rate each of these services as helpful.

The paid sitter service is most appealing to high burden caregivers; 71% rate it *very/somewhat* helpful, compared to 51% of low burden caregivers who do.

Younger caregivers, under the age of 50, are more likely than older caregivers to consider each of the services as helpful with the exception of the adult day care center. Older caregivers are more likely than younger ones to rate that service as *very* helpful.

Focus group caregivers explain that if they had services that allowed them a break from their caregiving, the main benefit would be that they would have additional energy to put into their caregiving.

I would rest a little from the tension of seeing her how she is. I would be more relaxed to continue helping her.

I would have more strength to continue with the responsibility. More energy.

Another medium for caregiver training suggested by focus group respondents is to have television shows focusing on how to handle the types of medical issues their loved ones face or on caregiving skills in general.

There are programs on how to garden and take care of your plants. Just like that, they should do a program on different illnesses so people can learn.



Respondent Profile

As mentioned earlier, Hispanic caregivers are predominantly female. They tend to be younger than non-Hispanic caregivers (42.6 years of age, on average, vs. 48.9).

Most Hispanic caregivers are married (66%). They are more likely than non-Hispanic caregivers to be single, never married (18% vs. 13%).

Half have children under the age of 18 in the household (53%) compared to only 34% of non-Hispanic caregivers who do.

	Hispanic caregivers (n=1,007)	Non-Hispanic caregivers (n=209)
Gender		
Male	26%	29%
Female	74	71
Age of Caregiver		
18 to 34	33%	22%
35 to 49	37	31
50 to 64	20	32
65 or older	9	15
Mean age	42.6	48.9
Marital Status		
Married or living with partner	66%	72%
Single, never married	18	13
Separated, divorced	11	8
Widowed	4	4
Don't know/Refused	1	3
Children Under Age 18 in Household		
Yes	53%	34%
No	47	64
Don't know/Refused	<0.5	2

Note: Bold figures are significantly higher than their comparison figure.

On average, Hispanic caregivers have a much lower educational level than non-Hispanic caregivers. Three in ten have not completed high school (29%) whereas only 3% of non-Hispanic caregivers have not. On the other end of the educational spectrum, 15% have graduated from college, compared to 44% of non-Hispanic caregivers who have.

The Hispanic caregivers are also in lower income households than non-Hispanic caregivers. In particular, half are in households with less than \$30,000 in income (52%), compared to 19% of non-Hispanic caregivers who are.

The education and income levels of Hispanic caregivers who were born in the U.S. are higher, on average, than those who have spent at least part of their life outside the U.S. In particular, far fewer of those who were born in the U.S. have less than a high school education (13% vs. 39%), and twice as many have graduated from college (22% vs. 11%). Likewise, they are more likely to have a household income of at least \$30,000 (47% vs. 34%).

	Hispanic caregivers (n=1,007)	Non-Hispanic caregivers (n=209)
Education		
Less than high school	29%	3%
High school graduate	36	22
Some college	14	25
Technical school	5	4
College graduate	11	30
Graduate school	3	14
Don't know/Refused	1	2
Household Income		
Less than \$15,000	21%	6%
\$15,000 to \$29,999	31	12
\$30,000 to \$49,999	20	14
\$50,000 to \$74,999	11	26
\$75,000 to \$99,999	4	14
\$100,000 or more	4	15
Don't know/Refused	10	12

Note: Bold figures are significantly higher than their comparison figure.

As mentioned earlier, Hispanic caregivers are less likely than their non-Hispanic counterparts to be working full time (31% vs. 47%) and more likely to be working part time (20% vs. 10%). A smaller share are retired (7% vs. 17%). More than twice as many Hispanic caregivers are homemakers (25% vs. 11%).

The racial composition of the Hispanic caregivers is not clear, since when asked their race, such a large proportion of them respond with their Latino/Hispanic ethnicity. The non-Hispanic caregivers are predominantly white (86%), and 7% are black.

	Hispanic caregivers (n=1,007)	Non-Hispanic caregivers (n=209)
Employment Status (multiple response)		
Working full time	31%	47%
Working part time	20%	10%
Other employed status	1%	<0.5%
Homemaker	25%	11%
Unemployed and looking for work	8%	6%
Retired	7%	17%
Student	5%	3%
Disabled	3%	4%
Other non-employed status	1%	2%
Other	<0.5%	0%
Don't know/Refused	<0.5%	0%
Race/Ethnicity (multiple response)		
White	40%	86%
Black	2%	7%
Asian	<0.5%	<0.5%
Other	1%	3%
Hispanic, Latino, Mestizo, or other non-racial category	47%	1%
Don't know/Refused	9%	4%

Note: Bold figures are significantly higher than their comparison figure.

While one in three Hispanic caregivers has lived his/her entire life in the U.S. (36%), four in ten have lived less than half of their life in the U.S. (39%).

Most of the Hispanic caregivers say their family or ancestors originated in Mexico (75%). Others come from Central America (5%), Spain (4%), South America (3%), Puerto Rico (2%), Cuba (2%), or the Dominican Republic (2%).

Given the choice of completing their interview in Spanish or English, six in ten Hispanic caregivers chose to complete it in Spanish (63%).

	Hispanic caregivers (n=1,007)	Non-Hispanic caregivers (n=209)
Percentage of Lifetime Spent Outside U.S.		
None – entire life has been in U.S.	36%	91%
1 to 49% of life	24	6
50% to 74% of life	26	2
75% or more of life	13	1
Country of Hispanic Origin (multiple response)		
Mexico	75%	NA
Central America	5%	NA
Spain	4%	NA
South America	3%	NA
Puerto Rico	2%	NA
Cuba	2%	NA
Dominican Republic	2%	NA
Other Hispanic country	<0.5%	NA
Other non-Hispanic country	5%	NA
Don't know/Refused	3%	NA
Language of Interview		
Entirely Spanish	63%	<0.5%
Mainly Spanish	1	0
Half and half	1	0
Mainly English	4	1
Entirely English	31	99

Note: Bold figures are significantly higher than their comparison figure.



Appendix A

Calculation of the Level of Burden Index

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

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

In addition, points are assigned for the number of ADLs and IADLs performed, as follows:

Types of Care Provided	
0 ADLs, 1 IADL	1 point
0 ADLs, 2+ IADLs	2 points
1 ADL, 0 to 7 IADLs	3 points
2+ ADLs, 0 to 7 IADLs	4 points

Then, the total number of points is consolidated into five levels. In this report, analysis often further collapses the levels into “high burden” (Levels 4 to 5), “medium burden” (Level 3), and “low burden” (Levels 1 to 2).

Consolidating Points Into Level of Burden Categories		
2 to 3 points	Level 1	Low burden
4 points	Level 2	
5 points	Level 3	Medium burden
6 to 7 points	Level 4	High burden
8 points	Level 5	



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