

Worn Out *and* Invisible



Family Caregivers in Santa Barbara County

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Worn Out *and* Invisible: **Family Caregivers** in Santa Barbara County

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Generational demographics impact society in dramatic ways. While caregiving has always been critical for vulnerable populations, demand for care is projected to reach new heights in the years ahead as the number of older people increases. The Santa Barbara Foundation and the Area Agency on Aging believe this is a challenge we can embrace and solve. That's why we're bringing Santa Barbara County together to find ways to strengthen family caregivers and ensure that key community institutions support and recognize their important contributions.

Family caregivers are the mainstay of our nation's long-term care system. Yet, their contributions often go unrecognized by the larger society, and sometimes by the caregivers themselves. Day in and day out, they quietly perform simple and complex tasks that provide quality of life for friends and family members with physical and emotional challenges. That these activities go unacknowledged is not surprising. Caring is what we do as humans—it is part of our nature—and caring is usually about someone else. It is caring that drives us to take action and find solutions on behalf of those we care for. Because of this tendency to overlook the obvious, I often call family caregivers “the safety net hiding in plain sight.”

But caring exacts a toll on those who provide it. Alice is a poignant example of a Santa Barbara County woman who paid a high price for caregiving. Alice did not identify as a caregiver. As she put it “I’m just his wife of 55 years.” She was consumed by caring for her husband, a veteran suffering from PTSD, dementia and the effects of Agent Orange. When she first contacted the adult day care center in Lompoc, Alice hadn’t slept in many nights. Exhausted, she wasn’t getting the nutrition she needed. Both Alice and her husband began to get sleep and return to a more normal routine after he was enrolled in the day center. Unfortunately, when Howard’s condition worsened and he could no longer attend day care, Alice again had to become his full-time caregiver with no respite. She missed her medical appointments, fell ill with a bladder infection, and shortly after visiting the emergency room, passed away in her sleep.* This is a tragedy that doesn’t have to happen! And, it illustrates a stark reality. When society depends on family members to care, the needs of those providing such care must be seen and addressed.

Family Caregivers:
*the safety net
hiding in plain sight*

“Worn Out and Invisible” provides important demographic, health, and other information about family caregivers in Santa Barbara County. It also draws forth the voices of family caregivers living in the county, offering their own perspectives on the activities and impacts of caregiving. It provides community leaders, healthcare professionals, social service providers and other interested parties insight into the significant risks associated with caregiving as well as the burdens and rewards of being a family caregiver. My hope is that this profile will stimulate new efforts to address the needs of family caregivers and help us design the future of caring for adults in Santa Barbara County both now and in the years to come.



* Shared by Kathy Concepcion, Executive Director, Valley Haven Adult Day Center, Lompoc. Name of caregiver has been changed to protect her identity.

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Introduction and Purpose

We believe this profile to be the first countywide description of the demographic and health characteristics of adults (persons age 18 or older) in Santa Barbara County caring for family members or friends who have a long-term illness or disability.

Who are these unpaid caregivers?

They are our family members, our neighbors, friends, and work colleagues. The likelihood is that most of us will be a family caregiver at some time in our life. (The term family caregiver is typically used to include friends and neighbors as well as kin.)

These family caregivers provide the vast majority of long-term services and supports (LTSS), sometimes called long-term care, received in the U.S. About nine out of ten adults living in their communities who require help with chronic conditions rely on unpaid help as their primary source of assistance with everyday living.¹ Their unpaid labor has been estimated at \$57.7 billion in California, and at \$470 billion nationally in 2013, up from \$450 billion in 2009².

Unpaid family caregivers experience a wide variety of emotions while caring for friends or relatives, including many that are positive, such as being pleased they are able to help and finding unexpected joy in caregiving.³ At the same time, many caregivers also bear substantial costs, including emotional and physical stress, difficulties in balancing caring with work responsibilities, and direct out-of-pocket expenses. More than three out of four caregivers absorb out-of-pocket costs averaging nearly \$7,000 a year, according to a recent AARP report.⁴

The following pages will shine light on these caregivers in Santa Barbara County (SBC), including their gender, age, income status, ethnicity, and health status, as well as their individual perspectives on becoming a family caregiver. We hope that this doc-

ument will help our community and its health and social service providers better identify family caregivers and address their needs for services and supports.

What is Family Caregiving?

Family caregiving traditionally has been defined as providing assistance with the tasks of everyday living, such as bathing and dressing, shopping and cooking, transportation, and managing finances. Many caregivers also serve as their relative or friend's chief care coordinator and navigator through fragmented health and LTSS* systems.⁵ Moreover, recent research shows that caregivers are engaging in complex medical/nursing tasks, such as managing medications, giving injections, providing wound care, monitoring blood pressure or blood sugar, or operating in-home medical equipment.^{6,7} They often perform these activities out of necessity, with little or no training, after their relative or friend is discharged from a hospital or other institutional setting.



Definitions and Data Sources

In this report, caregivers were identified by the following question asked of adults 18 or older: *“During the past 12 months, have you provided care to a family member or friend who has a long-term illness or disability?”*

The data are from the UCLA School of Public Policy's California Health Interview Survey (CHIS), the largest state health survey in the nation. This survey is designed to be representative of the population at both state and county levels. More than 20,000 Californians of all ages, selected randomly, are interviewed every year. The latest year in which questions about family caregiving and long-term care were included was 2009.

* Long-term services and supports (LTSS), sometimes referred to as long-term care, include the array of paid and unpaid personal care, health and social services generally provided over a sustained period of time. Services can be provided in a variety of settings, such as nursing homes, residential care facilities, and individual homes.

While we would prefer to have more current data, using 2009 data is not a big problem because family caregiving patterns have changed slowly over time.^{8,9} In addition, the 2009 CHIS is the only source of representative county-level caregiving data available in California or at the national level. Most of the data in this profile come from AskCHIS, a free user-friendly health database from UCLA.

This report also includes information gathered through in-depth interviews conducted in August and September 2017 with five individuals who care for a friend or family member in Santa Barbara County. These individuals were selected in order to shed light on the experiences of caregivers who differ by age, gender, and ethnicity, and who live in the North and South County. This qualitative data adds a human voice to the statistics and gives a broader picture of family caregiving. Excerpts from these interviews, with the names of respondents changed, are highlighted throughout this report.

Number of Family Caregivers in SBC

Over 50,000 individuals, representing about 17 percent of the adult population in SBC, were family caregivers in 2009.

It is likely that the proportion of family caregivers has grown since 2009 both because of the growth in the number of people age 65 or older and in the share of adults with a disability:

- The share of people age 65 or older in Santa Barbara grew more rapidly from 2009 to 2015 than any other age group, i.e., from 12.6% in 2009 to 15.7 % in 2015.

- In addition, the proportion of adults with a disability (due to a mental, physical, or emotional condition) grew from 22.5% in 2009 to 32.0% in 2015.

Relationships between Family Caregivers and Care Recipients¹⁰

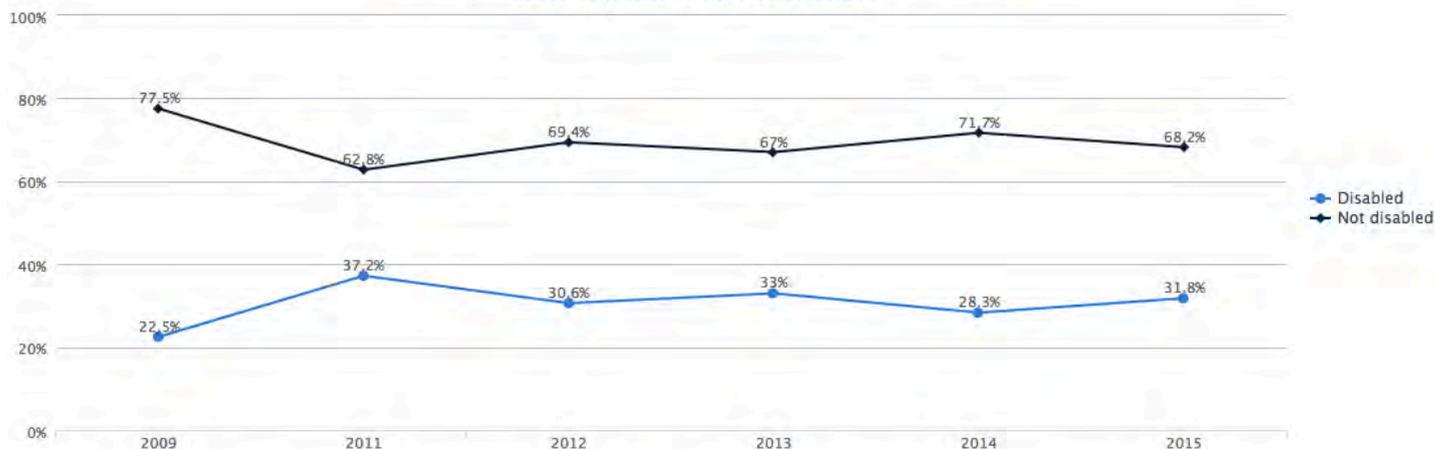
Who are the persons receiving the most help from caregivers? They are predominantly the caregiver’s mother or mother-in-law (39.6%) or other relative (29.3%), such as a spouse. However, almost one-third (31%) provide care for a friend, neighbor, or other non-relative, compared with 19.5% in the state as a whole.¹¹



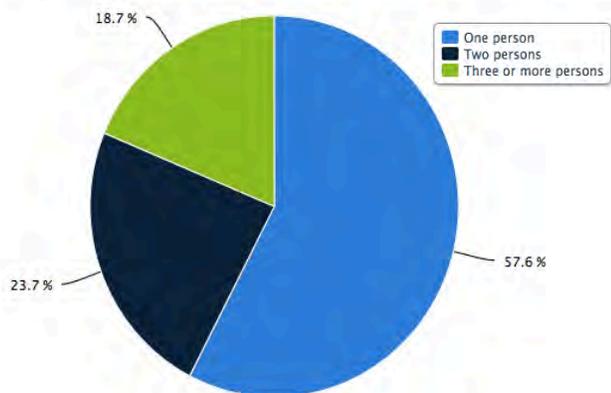
Roger and Jane are an example of caregivers for a friend to whom they have been providing care for five years. Their friend is an elderly woman with declining cognition, hearing and vision. Although they live apart from their friend, they still provide daily care. On a weekly and daily basis, they help her go through her mail, shop, take her to doctor’s appointments, and help clean her apartment. They also advocate for her medical and financial needs.

Additional data suggest that Santa Barbara County residents are doing their part to help fill unmet needs for LTSS in the community. More than four out of ten caregivers (42.4%) indicated they were providing long-term care for two or more persons, compared with 35.4% of caregivers in the state as a whole.

Disability status due to physical, mental or emotional condition
Source: UCLA Center for Health Policy Research



Number of people respondent has provided long-term care in past year
Source: UCLA Center for Health Policy Research



At the national level, about 18% were doing so, according to a 2015 survey.¹²

While the great majority of caregivers in Santa Barbara have been providing care for five years or less (75.5%), roughly 25 percent have been providing help for six or more years. More than one out of ten (12.8%) have been providing care for over ten years.

Eight out of ten caregivers (81.1%) spend 20 hours per week or less helping the care recipient. The remainder (almost 20 percent) spend 20 or more hours: The equivalent of a part-time job. About ten percent of the latter group provide care for 40 hours or more per week, equal to a full-time job (with upward of five percent doing so for a remarkable 80 hours). These numbers underscore the intense levels of care needed by some recipients, who likely have multiple chronic conditions, high levels of disability,

and cognitive impairment. The labor of these unpaid caregivers exemplifies what the authors of the legendary book on caring for people with Alzheimer’s disease and related dementias termed *“The 36 Hour Day.”*¹³

The interviews performed with family and friend caregivers exemplify the many types of work and intense amount of time that is put into helping a friend or family



member who needs care. For example, Mary performs the work of coordinating between her siblings and her mother’s caretakers. Her mother has Alzheimer’s and receives care from her 10 children and three paid caregivers. In terms of the difficulty of coordinating everything and everyone caring for her mother, Mary says, *“With what’s required of taking care of my mom at this day and age, there is something for everyone to do. From preparing meals, shopping for groceries, taking her to doctor’s appointments, reviewing paperwork – because there is an incredible amount of paperwork and coordination that needs to happen – keeping up with her medications, keeping up with the care providers, coordinating with the family to make sure everyone is on the same page.”*

Bernadette provides 24/7 care for her husband with Alzheimer’s, including feeding him and dressing him: *“I do meals. I now have to be very careful because food tends to overwhelm him. I have to not only prepare it, but if it’s something like a piece of meat, I have to cut it up into small bite size pieces. I have to help him get dressed. I have to help him with bathing... I manage his medication because he can’t do that. Right now, he’s taken to tearing the skin off his hand. So, I wrap and bandage and clean and all that kind of stuff.”*

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Diana is an example of a full-time caregiver for her husband who performs complex nursing tasks as well as constant daily care. Because of his Parkinson’s, *“He’s always at risk of falling. The care I provide for him primarily is the activities of daily living. He bathes himself, though I monitor him. He dresses himself. He can feed himself. He can go to the bathroom himself. I have to put a nighttime expo [type of catheter] catheter on and take care of all that paraphernalia.”*

Roughly one-fifth (20.8%) of caregivers in SBC live

with the care recipient. While we do not have data for Santa Barbara on whom these caregivers are, they may be predominantly older spouses, partners, or other family members. Data for California as a whole from the 2009 CHIS survey indicate that persons age 65 or older are more likely to be: (1) Caring for a spouse or partner, (2) living in the same residence, and (3) providing more intense levels of care than their younger caregiving counterparts.¹⁴ Other data on the living arrangements of persons 65 or older in SBC show that 64% of persons age 65 or older live with a spouse or other relative.¹⁵

Both Diana and Bernadette are women above the age of 65 who care for their husbands. As an elderly person herself, Bernadette often struggles with taking care of her husband, saying: *“Mostly it’s not a terrible physical strain, although there are times when it can be. Like right now because I have a bad knee and I’m trying to help him get dressed, get his meds, fix his meals and I can barely walk.”* Age is a significant factor not only for the person receiving care but for those providing care. The caregiver also experiences physical changes through aging that affect their ability to care for their loved one.

Demographic Characteristics of Family Caregivers in Santa Barbara County

(Table 1 in Appendix)

Compared to non-caregivers, higher percentages of caregivers are:

- Age 65 and older
- Female
- Widowed, separated, or divorced
- Non-Latino*

Caregivers and non-caregivers are roughly similar in terms of their employment status. Over half (52%) of



caregivers are working full-time, compared with 49 percent of non-caregivers.

Higher shares of caregivers also are more likely to have annual incomes at or above 300

percent or of the Federal Poverty Level (\$32,490 for a one-person family in 2009†), as well as higher educational levels than non-caregivers.

Some of the interview respondents did not find caregiving to be a current financial burden, but were concerned about future financial costs. These individuals were middle and upper middle-class families. As Diana points out, her husband does not need outside hired care at this point, *“Jacob doesn’t need any professional help in terms of bathing and all that, but if he did, he’s too big for me to bathe him. It’s expensive, hiring people and Medicare has a very limited ability in what they do and things could get worse in terms of the cutbacks that might happen.”*

Bernadette expresses similar sentiment when asked if caretaking is a financial strain, *“I think it’s going to be. I don’t think we’re quite there yet, but we’re approaching that time where I’m going to need more help in caring for him and it’s probably going to be paid help.”* Although Diana and Bernadette do not say caretaking is a financial burden now, they are both aware of the potential for the need to pay formal caregivers in the future.

Physical and Emotional Health of Family Caregivers in Santa Barbara County

(Table 2 in Appendix)

a. Health Status and Health Care Access Among Family Caregivers

Compared to non-caregivers, more caregivers:

- Are in fair or poor health
- Have delayed or not gotten medical care they needed in the last year
- Have delayed or not gotten prescription medicine in the last year
- Have visited the ER within the last year
- Have been diagnosed with high blood pressure, and
- Have been diagnosed with asthma

* Quite possibly because more Whites are age 65 or older in SBC

† <https://aspe.hhs.gov/2009-hhs-poverty-guidelines>

b. Emotional and Mental Health

More than twice as many caregivers as non-caregivers have:

- Seen a provider for mental health or substance abuse issues in the past year,
- Had serious psychological stress in the last year, and
- Ever seriously thought about committing suicide in the past year.

c. Disability due to a Physical, Mental or Emotional Disorder

More caregivers than non-caregivers:

- Have a disability (due to a physical, mental, or emotional disorder),
- Experience moderate to severe impairment in their social life, and
- Experience moderate to severe impairment in their ability to do household chores.

The interview respondents were asked to rate their physical and mental health. Mary, around age 40, responded that on a scale from excellent, good, fair, and poor, her mental health was fair. She said, *“I think it’s the mental aspect that kind of drains me a little bit more in trying to figure out how am I going to do this. Knowing that some days are going to be long days. How do I keep up with everything that needs to be done?”*

“There’s so much sadness. One day my son asked me if I was mad and I said no. And I realized the next day, as I was driving down the street crying, that I wasn’t mad I was just sad. It’s very depressing, the whole thing. You don’t even have something to look forward to. There is no way out.”

About her mental health, Bernadette replied, *“There’s so much sadness. One day my son asked me if I was mad and I said no. And I realized the next day, as I was driving down the street crying, that I wasn’t mad I was just sad. It’s very depressing, the whole thing. You don’t even have something to look forward to. There is no way out.”*

The respondents demonstrate the mental and emotional strain that comes with caring for a loved one. And as Bernadette pointed out earlier, caregiving can also be a physical strain for the caregiver. Because she is responsible for everything, including grocery shopping and driving, she is physically active most of the day. Her injured knee prevents her from fully performing her daily duties. Care-taking takes a toll on both the physical and mental health of the caregivers.



Characteristics of Family Caregivers in Santa Barbara County by Age Groups

(Table 3 in Appendix)

- Among all caregivers ages 18 to 64, almost two-thirds are women, compared with about 82 percent of caregivers age 65 or older.
- Well over half (57%) of older caregivers are widowed, separated or divorced, compared with 15 percent of their younger counterparts.
- Over 70% of younger caregivers have higher income, (i.e., at or higher than 300% of the Federal Poverty Line) and are working outside of the home.
- About one in five of the older caregivers are of Latino origin.
- A higher percentage of the older age group (57%) is in fair or poor health, while two-thirds have a disability.

Roger was the only male caregiver (also above the age of 65) interviewed for this project. He and his wife care for a long time female friend. Roger discussed the challenges of caring for their friend, *“It gets more challenging for us, you have to admit. We’re both basically professionals. We’ve been working with people who have dementia and issues that go with that. She gets very angry about things. We keep trying to turn it positive. Some days we don’t have the patience to do that.”*

Characteristics of Family Caregivers in Santa Barbara County by Gender

(Table 4 in Appendix)

Almost two-thirds of Santa Barbara’s caregivers are women. Compared with men caregivers, a higher percentage of women caregivers:

- Are older, and fewer are married or living with a partner,
- Have lower income, with fewer employed full-time,
- Are in fair or poor health.
- Are of Latino or Hispanic origin.



“I see myself as a wife who has no choice.

It’s part of the contract.”

As statistics demonstrate, the majority of caregivers are women. Based on traditional gender roles in the United States, women have been expected to care for their families and their homes. It is possible that many women see it as an extension of their roles as wives and daughters to care for their husbands and other family members in older age. Diana discusses this when asked if she sees herself as a caregiver: *“I see myself as a wife who has no choice. It’s part of the contract. I’m also a nurse, so I know how to do some things. It’s not anything hard to learn. I think a wife who’s not a nurse can learn to do the same stuff I do.”* A potential barrier to identifying as a caregiver is historically entrenched gender roles that normalize the intense labor women provide for their husbands or partners as they age.

Characteristics of Family Caregivers in Santa Barbara County by Race/Ethnicity*

(Table 5 in Appendix)

Compared to White (non-Latino) caregivers, a higher percentage of Latino caregivers:

- Are age 65 or older, female, and widowed, separated, or divorced,
- Have incomes below 299% of the Federal Poverty Level, are not working outside of the home, and
- Are in fair or poor health.
- The percent of Latino caregivers who said they were in excellent or very good health was under one percent, compared with 68 percent of white non-Latinos, a huge difference.

The percent of Latino caregivers who said they were in excellent or very good health was under one percent, compared with 68 percent of White non-Latinos, a huge difference.

As part of a large Latino family, Mary and her nine siblings take care of their mother. They all split shifts and duties, *“My brother deals with the bills, I deal with the paperwork with the doctors and support services she receives, another sister helps with collecting the contributions from the family because we all share some of the cost.”*

Due to language barriers, segregated communities, and other factors, there may be less outreach to and information provided to the Latino community about Alzheimer’s, and a host of other medical and mental conditions, making it difficult for Latino families to access valuable resources.

“We didn’t even really know what Alzheimer’s was for several years...”

Mary discusses how she and her family could have used more help in learning about Alzheimer’s, highlighting the need for more public awareness, *“We didn’t even really know what Alzheimer’s was for several years so I wish we would have known more of what to expect.”*

Rewards of Caregiving

No doubt caregiving is a tough job. However, respondents discuss the rewards for caring for someone you love. When asked about the rewards of caretaking, Bernadette responded, *“Well, there is the reward of knowing you’re helping someone you love. That’s certainly a reward.”*

Similarly, Roger said, *“It really is giving back. I know it sounds trite. For 25 years of my professional career*

“...there is the reward of knowing you’re helping someone you love. That’s certainly a reward.”

I was doing business – contracts, business deals etc. When the company closed I was fortunate enough to start working in long-term care. I went into nursing homes and facilities and the passion hit with that. I saw such unmet needs.”

For Diana, *“it gives you a purpose. I was more aware of that when it all first started. You don’t ever expect that this is how your life is going to end up, but yeah it gives you a purpose. It’s good to know that he’s remained healthy.”*

Mary reflected on caring for her mother who raised 10 children, *“I guess that’s the least we can do when our parents gave so much of themselves to us and I can’t even imagine caring for each and every one of us, I think that’s the gratifying part and I think the reward is as a child, your parents provide that safety component and I guess for me what brings me comfort is knowing that I can provide my mom with a sense of security and safeness and I know that when we are there she feels cared for and loved. I feel it and I know she feels it.”*

Many of the interviewees discussed humor as an important part of coping with the difficult situation. Mary talked about her mother’s sense of humor as she aged, *“Another reward is that growing up because we were the youngest, our parents were kind of like our grandparents because they were so much older. The gift of being able to see a very different side of my mom. She was very reserved, hard worker, giving of herself, and I never saw her sense of humor and now what is so funny is that her personality has changed so much and*

she’s super silly about little things and she sings now and she jokes around and I find that so ... it’s a treat. With her Alzheimer’s that has come out and I think taking those moments to see that light side, that silly side of her.”

Help for Caregivers

When family caregivers were asked what they could use more help with, many of them responded with wishing they had more time and more help.

Diana wishes her family would help out a bit more, *“Well, my daughter could give me a little more help with driving, but she has a life.”* Roger says he wishes he had more, *“Time. I’ve spent a lot of time with Jennifer the last couple weeks and it’s been intense. And, again, we have other commitments. We have a lot of things going on. Sometimes I think it’s just too much. It’s not as overwhelming as some of the caregivers I work with who work 24/7.”*

Interview respondents demonstrate a need for more mental and emotional support. Bernadette received some information about support groups, *“I just got some information on a couple of support groups and I’m going to see if I can connect with them. I did go to one of the classes at the local hospital that was very good. It wasn’t that they told me something I didn’t already*

know, but they reinforced it. I am going to try, but the problem is that when I go to these things I have to leave my husband

“...she’s super silly about little things and she sings now and she jokes around and I find that so ... it’s a treat.”



alone. He can be alone for a while as long as he doesn’t get into his head that he’s going to chop down the tree or try and take the car. He can’t drive anymore.”

Although Bernadette desires to go to support groups and classes that would benefit her mental health, a barrier stands in her way. She has no one to take care of her husband while she goes to the support groups. Not only is there a need for more services providing

mental health support but there is a need for providing respite for the caregiver so they can accomplish tasks as simple as grocery shopping.

Caregivers also need resources. They need access to information about caregiving and the illnesses of their family members. They also need mental health support groups. Another huge need is respite care. Bernadette wishes she was able to attend more support groups but finds it difficult because she has no one to watch her husband while she's gone. She says, *"There's a center here. One of these days I am going to tackle the job of getting through the paperwork to try and get my husband enrolled in that at least one day a week. I don't think I can afford any more than that. That would be something that would allow me to do shopping. Right now, if I need to go to a store. He wants to sit in the car. So, I let him sit in the car and I hide the keys. I shop as quickly as I can. I really just run in and grab something and get out. So, that support would help."*



Mary wishes her large family knew more about Alzheimer's before her mother was diagnosed, *"How do you work together in a large family with a large network to care for someone having the right tools or the right resources? Where do you start? Navigating this has been challenging because this is new to us. More guidance. What to expect, what tools may be helpful. How do you find good care providers? It's really really hard."*

This quote from Mary brings up many of the issues that arise from the beginning of providing care for a family member or friend. Certain illnesses like Alzheimer's and Parkinson's

require specific types of care for which families need to be educated and trained.

Data Highlights

The data presented in this profile begin to paint a portrait of Santa Barbara County's diverse family caregivers. Far more caregivers than non-caregivers report having a disability themselves and delaying or not getting needed medical care or prescription

medicine, all while caring for relatives or friends with a long-term illness disability. Almost one-quarter have provided care for six or more years.

The data also suggest that those who seem most vulnerable are older women, often Latino, frequently with low income, and often in only fair or poor health. The in-depth interviews indicate that

"Right now, if I need to go to a store, he wants to sit in the car. So, I let him sit in the car and I hide the keys. I shop as quickly as I can. I really just run in and grab something and get out."



these caregivers need better access to information and resources.

The findings on mental health bear special mention. These data suggest a pressing need to identify family caregivers at risk of serious depression or other mental health disorders and make appropriate services available to them.

Compared to the state as a whole, Santa Barbara County stands out as a community where a higher share of caregivers are providing help to friends, neighbors, and other non-relatives. In addition, higher percentages of caregivers are providing long-term care to two or more persons. While we do not have data to explain these findings, it is possible that more families are not able to find nearby jobs or afford housing or the other costs of living in SBC when their relatives need care. Hence friends and neighbors often step in to assume some caregiving roles for persons with long-term illnesses or disabilities.



Conclusions

National demographic trends show that the pressures on family caregivers may reach a crisis level as the number of potential caregivers declines, a trend that began in 2010 and will accelerate sharply by 2030.¹⁶ Steps need to be taken now to help family caregivers carry the responsibility of caring for relatives and friends.

Family caregivers need “more recognition, information, and support to fulfill their responsibilities and maintain their own health, financial security, and well-being,” states a recent report from the National Academies of Science.¹⁷ In addition, the report underscores that **“The emphasis on person-centered care needs to evolve into a focus on both person- and family-centered care.”**

It is unlikely that many family caregivers view themselves as being caregivers. Built into their roles as husbands, wives, children, and friends are the obligations to care for their loved ones. Diana points out that she never felt like she had a choice in being a caregiver for her husband, *“It’s not particularly anything I want to do, but I don’t have any choice.”*

Mary became a caregiver at a young age (late 20s, early 30s), *“As our parents grew older the older kids got married established their families. The younger half*

of the kids we started being care providers earlier than we even thought and I think it’s because we were the last ones in the house.” As one of the younger siblings, by default she helped care for her aging parents.

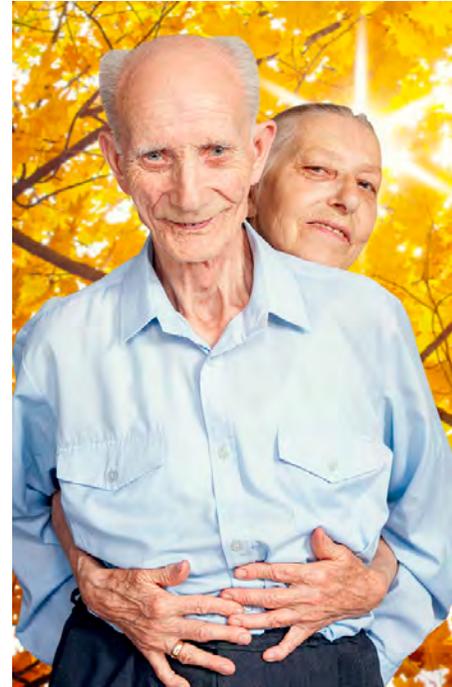
Such examples illustrate how caregiving is an important public health issue. Many caregivers do not identify themselves as caregivers and do not seek assistance. This isolation worsens the toll on their mental and physical health, even as they face rising

costs for LTSS. As observed in LA County’s report on the implications of caregiving as a public health issue,

communities, health professionals and local agencies can take steps to raise public and professional awareness about the health and financial consequence of being a caregiver.¹⁸

Recommendations for Public Agencies and Private Organizations in SBC

- Help the general public learn more about the facts of family caregiving in SBC, such as its frequency, what it entails, and who is doing it. Educate the public about the contributions of family caregivers, as well as the financial and health challenges they often face to both their mental and physical health.
- Make LTSS more available, accessible, and culturally and linguistically acceptable to persons with long-term illnesses or disabilities and their caregivers—in their homes, in residential care settings, and in nursing homes.
- Educate health and social service professionals so that they can identify family caregivers and help connect them to appropriate LTSS and services.
- Educate health care providers (including mental health providers) about health risks associated with caregiving and offer alternative forms of care interventions for family caregivers, such as in-home visits and telehealth options.
- Expand health care workforce training in SBC to include the knowledge and skills needed by health and LTSS providers to work with the growing population of family caregivers with high needs.
- Educate employers about family caregiving and its impact on employees. Encourage policies, such as flexible working hours and paid time off, to allow employees to access health care for themselves and care for their family members.



- Develop new forms of affordable housing that provide options for family members to live closer to their aging relatives in SBC, including accessible dwelling units, sometimes called “granny flats.”
- Make more information about family caregiving and community LTSS resources available in health care settings, such as physician offices, clinics and hospitals. Develop models to make these settings “caregiver friendly” in cost-effective ways.
- Design and disseminate culturally and linguistically appropriate educational materials and deliver health and social services with culturally competent staff.
- Collect data on the diverse contributions and needs of family caregivers in SBC.

Support Local, State, and Federal Legislation that Helps Family Caregivers

- **Support the 2017 federal Credit for Caring Act**, which was developed to help address the financial challenges of family caregiving and to help family caregivers stay in the workforce and be more financially secure. (The legislation would give

eligible family caregivers the opportunity to receive a tax credit for 30 percent of the qualified expenses above \$2,000 paid to help a loved one, up to a maximum credit amount of \$3,000).

- **Support the 2017 federal Family and Medical Insurance Leave Act (FAMILY Act)** which establishes the Office of Paid Family and Medical Leave within the Social Security Administration (SSA) and offers every qualifying caregiver a family and medical leave insurance (FMLI) benefit payment.
- **Implement the California State CARE (Caregiver Advise, Record, and Enable) Act** in local hospitals and other institutions. Its key provisions (1) require hospitals to ask patients to identify a family member (if they wish), (2) record the name of the caregivers in the medical records, and (3) inform the caregiver of the discharge plans. When a patient is discharged, hospitals are required to tell caregivers what continuing care a patient needs, including counseling about medications. When appropriate, they also must show caregivers how to perform such tasks as cleaning wounds and moving persons with disabilities from a wheelchair to commode or bed. When longer-term care is required, hospitals must provide information on community resources that can help with referrals.

- **Support the reauthorization of the federal Older Americans Act** which will be considered by Congress in late 2019. The Act supports a range of home and community-based services for older adults and family caregivers. The Act provides financial support to the Area Agencies on Aging to assist in developing local services. Specifically, the National Family Caregiver Support Program (Title III of the Act) provides support for information about and assistance to access available local services, as well as caregiver counseling and support groups, training related to caregiving, respite care, and other supplemental services.





Caregiver Story of Alice*

I received a call from a very tired, emotionally drained caregiver. She was looking for any kind of help for her husband. She was his primary caregiver; their two children lived out of town and really did not provide any support for her. The VA considered her husband, Howard, 100% disabled, as he suffered with the effects of PTSD and Agent Orange. She did not self-identify as a caregiver. As she put it, "I'm just his wife of 55 years." After Alice and I spoke for a while, I told her that I was able to help her get the rest she needed, and that the VA would possibly pay the cost of day program. She cried with joy, saying that out of all the calls she had made, everyone else said that they could not help her. Howard became our first veteran enrolled at Valley Haven. She paid out of pocket for the day program until the VA paperwork was authorized. He was approved for three days a week.

The first day I met with Alice she was so tired. She hadn't slept in many nights, wasn't eating right and wasn't taking care of herself. Howard was soon doing great in program. We also noticed a big change in Alice. She'd drop him off in the morning and she looked amazing. She was dressed up, had makeup on and her hair was styled. She was sleeping because he was sleeping after being so tired from being busy in the day program. He was getting back into a routine of doing things that gave him meaning and purpose and was in the company of other seniors. Alice went to the beauty shop, out to lunch with friends, and to her favorite place, the casino. She seemed to be full of joy again, and took part in our support group.

After about a year, Howard took a few falls and his PTSD became worse. He was combative, and didn't know who Alice was. He called her "that lady." He had to leave the day program for a while until his meds were corrected by the VA doctor. During that time (six months maybe), Alice also took a turn for the worse as she was not taking her own health-care needs into consideration. She was having trouble with agency caregivers not showing up on time or not showing up at all. She became sick with a bladder infection. I told her to please take care of herself but she was all about taking care of her husband. She missed a few medical appointments for herself.

I spoke with Alice on the Monday evening Howard was cleared to return to the program. She was excited. She told me she had spent six hours in the ER on Sunday for her infection. Alice passed away in her sleep Monday night.

Kathy Concepcion

Executive Director
Valley Haven

*names have been changed

Worn Out *and* Invisible: **Family Caregivers** in Santa Barbara County

About the Area Agency on Aging



The Central Coast Commission for Senior Citizens, Area Agency on Aging (AAA), is one of the state-designated agencies, and has served as the designated AAA for San Luis Obispo and Santa Barbara Counties since 1975. The AAA is responsible for planning, coordinating and implementing programs that promote the health, dignity, and well being of older adults.

This project furthers our goal of identifying the needs and services that benefit older adults. As we continue our work to coordinate, monitor and evaluate existing programs, services, and funding sources, we also explore and plan new resources and funds to meet and expand services for the senior population.

About the Authors

Phylene Wiggins – Phylene Wiggins is the Vice President for Programs and Grants at the Ventura County Community Foundation. Previously, she developed and directed the Community Caregiving Initiative (CCI) at the Santa Barbara Foundation. The CCI is a community wide effort to strengthen long-term care by focusing on individual caregivers, health and social systems, research, and policy. Using the multiple lenses of health, human services and workforce development, Phylene has developed innovative programs and projects addressing the needs of vulnerable populations for over 30 years.

Mary Jo Gibson – Mary Jo Gibson's career spans thirty years of work on family caregiving, health care, and long-term services and supports (LTSS) policy. She began her career in aging policy with the International Federation on Aging, served as AARP's first long-term care policy analyst, and continued her work with AARP's Public Policy Institute as director of its health policy team and as a strategic policy adviser with its LTSS team. She is now retired and resides in Santa Barbara, California.

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About the Santa Barbara Foundation

The mission of the Santa Barbara Foundation is to facilitate the building of philanthropy, strengthen the nonprofit sector, and identify and strategically address important community opportunities and needs. Founded in 1928, the Santa Barbara Foundation has been at the center of civic activity, a vibrant expression of its engaged citizenry, a solver of problems, a partner in philanthropy, and a critical supporter of community organizations and efforts serving the residents of Santa Barbara County, California.



*Worn Out and Invisible is a joint project of the
Area Agency on Aging and the
Santa Barbara Foundation*

APPENDIX

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

Table 1
Demographic Characteristics
of Family Caregivers

*Age 18 and Older in Santa Barbara County,
by Caregiver Status*

Santa Barbara County Age 18 and Older	Caregivers	Non-Caregivers
Estimated population	53,000	253,000
	Percent	Percent
Age		
18-64	75.5	85.0
65+	24.5	15.0
Gender		
Female	69.0	46.8
Male	31.0	53.2
Marital Status		
Married/Living with Partner	64.1	67.2
Widowed, Separated or Divorced	25.2	10.2
Never Married	10.7	22.6
Rural/Urban		
Urban	88.9	91.8
Rural	11.1	12.2
Poverty Level		
0-99 FPL	14.4	17.8
100-199 FPL	14	17.8
200-299 FPL	8.1	
300 FPL or Higher	63.5	48.0
Employment Status		
Full-Time	52.1	49.0
Part-Time	9.5	14.5
Not Working	38.3	36.4
Race/Ethnicity		
Latino	23.2	32.3
White (non-Latino)	68.4	58.5
Others (non-Latino)	8.4	9.3
Language Spoken at Home		
English	71.7	63.9
Spanish, English and Spanish	22.3	24.2
Chinese, Vietnamese, other language	6.0*	11.9
Education Level		
Less than High School	12.7*	15.9
Finished High School	12.9*	28.3
Some college	12.8	11.1
Vocational School, AA, AS degree	20.4	8.3
MA/MS degree, PhD or equivalent	20.7	13.4

* Estimate should be interpreted with caution because it is either unstable (coefficient of variation $\geq 40\%$) or it has a wide confidence interval ($> 20\%$).

APPENDIX

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

Table 2
Health-Related Characteristics and Health Care Access
Among Family Caregivers Ages 18 and Older in Santa Barbara County

Santa Barbara County Age 18 and Older	Caregivers	Non-Caregivers
	Percent	Percent
Health Status		
Excellent	17.9	25.6
Very Good	30.2	33.7
Good	24.0	26.3
Fair/Poor	27.9	14.5
Delayed or Didn't Get Medical Care		
Yes	26.4	10.5
No	86.9	95.1
Delayed or Didn't Get Rx Medicine		
Yes	17.5	4.9
No	82.5	95.1
Visited ER		
Yes	18.9	12.8
No	81.1	87.2
Ever Diagnosed with High Blood Pressure		
Yes	29.9	24.3
No	70.1	75.7
Ever Diagnosed with Asthma		
Yes	15.0	10.0
No	85.0	90.0
Saw Provider for Mental Health/Substance Abuse Issue		
Yes	16.1	8.0
No	83.9	90.2

Table 2 continues

* Estimate should be interpreted with caution because it is either unstable (coefficient of variation $\geq 40\%$) or it has a wide confidence interval ($> 20\%$).

APPENDIX

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

Table 2 (continued)

Health-Related Characteristics and Health Care Access

Among Family Caregivers Ages 18 and Older in Santa Barbara County

Santa Barbara County Age 18 and Older	Caregivers	Non-Caregivers
	Percent	Percent
Likely had Serious Psychological Stress in Last Year		
Yes	10.7	2.0*
No	89.3	98.0
Ever Seriously Thought About Committing Suicide in Past Year		
Yes	9.2	4.5
No	90.8	95.5
Binge Drinking in Past Year		
Yes	26.4	38.2
No	73.6	61.8
Disability due to Physical, Mental, or Emotional Disorder		
Yes	35.0	19.6
No	65.0	24.3
Impairment in Social Life		
None	81.6	89.6
Moderate to Severe	18.4	10.5
Impairment in Household Chores		
None	82.8	89.1
Moderate to Severe	17.2	10.9

* Estimate should be interpreted with caution because it is either unstable (coefficient of variation $\geq 40\%$) or it has a wide confidence interval ($> 20\%$).

APPENDIX

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

Table 3

Caregivers by Age Groups

Characteristics of Santa Barbara County Caregivers Ages 18 and Older, by Age Groups

Santa Barbara County Caregivers by AGE	18-64	65 and Older
Estimated caregiver population	40,000	13,000
	Percent	Percent
Gender		
Female	64.6	82.5*
Male	35.4	17.5*
Marital Status		
Married/Living with Partner	71.2	42.3
Widowed, Separated or Divorced	14.9	57.1
Single, Never Married	13.9	N/A
Poverty Level		
0-299 % FPL	27.4	64.4
300 % FPL or Higher	72.6	35.6
Employment Status		
Full-Time or Part-Time	73.4	25.6*
Not Working	26.6	74.4*
Ethnicity		
Latino/Hispanic Origin	20.5	31.8*
Not of Latino/Hispanic Origin	79.5	68.2*
Language Spoken at Home		
English	74.1	64.2*
Spanish, English and Spanish	19.8	35.8*
		All Other Languages
Chinese, Vietnamese, Other Language	6.1*	
Health Status		
Excellent, Very Good	53.8	30.3
Good	27.6	12.8*
Fair, Poor	18.6	56.8
Disability		
Yes	24.6	66.8
No	75.4	33.2

* Estimate should be interpreted with caution because it is either unstable (coefficient of variation $\geq 40\%$) or it has a wide confidence interval ($> 20\%$).

APPENDIX

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

Table 4

Caregivers by Gender

Characteristics of Santa Barbara County Caregivers Ages 18 and Older, by Gender

Santa Barbara County Caregivers by GENDER	Men	Women
Estimated caregiver population	16,000	36,000
	Percent	Percent
Age		
18-64	86.1*	70.7
65+	13.9*	29.3
Marital Status		
Married/Living with Partner	70.5*	61.3
Other Marital Status (Widowed, Separated or Divorced, Single or Never Married)	29.5*	38.7
Poverty Level		
0-299% FPL	14.3*	46.5
300 FPL% or Higher	87.5*	53.5
Employment Status		
Full-Time (21 or more hours per week)	69.6	44.2
Part-Time	3.3*	12.3
Not Working	26.8	43.5
Race/Ethnicity		
Latino/Hispanic origin	8.7*	29.8
Not of Latino/Hispanic origin	91.3*	70.2
Health Status		
Excellent, Very Good	53.2	45.8
Good	31.9*	20.4
Fair, Poor	14.8*	33.8
Language Spoken at Home		
English	71.7	63.9
Spanish, English and Spanish	22.3	24.2
Chinese, Vietnamese, other language	6.0*	11.9

Because the sample of family caregivers age 65 or older is relatively small (13,000) compared with those ages 18-64 (40,000), many of the results for persons 65 and older are statistically unstable, as noted in the table. With this caution in mind, we chose to display these results so that potentially important differences by age are not ignored.

Similarly, the samples of male caregivers and Latinos are relatively small (12,000). With this caution in mind, we chose to display these results so that potentially important differences by gender and race/ethnicity are not ignored.

* Estimate should be interpreted with caution because it is either unstable (coefficient of variation $\geq 40\%$) or it has a wide confidence interval ($> 20\%$).

APPENDIX

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

Table 5
Caregivers by Race/Ethnicity

Characteristics of Santa Barbara County Caregivers Ages 18 and Older, by Race and Ethnicity

Santa Barbara County Caregivers by RACE and ETHNICITY	Latino	**White (non-Latino)
Estimated caregiver population	12,000	36,000
	Percent	Percent
Age		
18-64	66.5	84.8
65 or older	33.5	15.2
Gender		
Female	88.4*	60.3
Male	11.6*	39.7
Marital Status		
Married/Living with Partner	64.4*	67.2
Widowed, Separated or Divorced	29.8*	19.5
Single, Never Married	-----	13.2*
Poverty Level		
0-299 % FPL	69.0*	19.6
300 % FPL or Higher	31.0*	80.4
Employment Status		
Full-Time or Part-Time	53.0	63.1
Not Working	46.1	36.9
Health Status		
Excellent, Very Good	-----	68.0
Good	44.9	17.0
Fair, Poor	54.7	15.0

Because the sample of Latinos is relatively small (12,000), many of the results for this group statistically unstable, as noted in the table. With this caution in mind, we chose to display these results so that potentially important differences by race/ethnicity are not ignored.

* Estimate should be interpreted with caution because it is either unstable (coefficient of variation $\geq 40\%$) or it has a wide confidence interval ($> 20\%$).

** A small share of caregivers are classified as "Others (non-Latino)." They include Asians, African Americans, American Indians/Alaska Natives, and others.

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