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COLLEGE OF ARTS AND SCIENCES
Center for Community Capital

The True Costs of Home Care:

The Impact on Working
Latino Caregivers



UnidosUS, previously known as NCLR (National Council of La Raza), is the nation's largest Hispanic civil rights and advocacy organization. Through its unique combination of expert research, advocacy, programs, and an [Affiliate Network](#) of nearly 300 community-based organizations across the United States and Puerto Rico, UnidosUS simultaneously challenges the social, economic, and political barriers that affect Latinos at the national and local levels.

For more than 50 years, UnidosUS has united communities and different groups seeking common ground through collaboration, and that share a desire to make our country stronger.

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EXECUTIVE SUMMARY

Overview

UnidosUS partnered with the UNC Center for Community Capital to conduct interviews with working Latino caregivers in order to understand the true costs of providing care to elderly and young dependent loved ones. Interviewers asked in-depth questions on a variety of issues relevant to the lives of working caregivers, including the financial, social, emotional, health, and career costs of caregiving; the availability and cost of nonfamilial care; the intersection of caregiving and employment before COVID-19; and the effect of the pandemic on caregiving and employment. Interviews were conducted between July and October 2020 in three locations: New York, NY; Los Angeles, CA; and Raleigh, NC. In total, 14 working caregivers were interviewed.

Key Findings

From the interviews with Latino caregivers in our study, we learned that:

- In the day-to-day of caregiving, the more people one is caring for, the greater their individual needs, and the more diverse the needs across that group of people, the more complicated caregiving is.
- The stress and actual work of caregiving are reduced when one has a solid support network. It is especially helpful if members of that support network live in the home.
- Paid and unpaid care arrangements are adaptive and change over time based on loved ones' needs, life circumstances, caregivers' capacities, and external care options.
- Reliable, quality child care is particularly hard to find in rural areas, and no matter where one lives—in a rural or urban area—trust is a key component in the search for nonfamilial care providers.
- The need to provide care for loved ones inevitably crosses into the workday, and a workplace that allows time off for caregiving makes a big difference.
- With few exceptions, the caregivers we spoke with are not given paid time off for care activities. When it comes to time off if they themselves are sick, paid sick leave is also a rarity.
- Caregiving obligations impact job choices, which in turn can affect income.
- The financial costs of care vary widely and are experienced differently across households, depending on the predictability and amount of household income.
- The most prevalent nonfinancial cost of caregiving is stress.

INTRODUCTION

Background

Family caregivers in the United States provide the vast majority of care for elderly loved ones.¹ Current estimates are that nearly one in five Americans acts as an unpaid caregiver to an adult family member or friend, with 24% of these individuals caring for two or more recipients.² Caregiving is focused not only on the elderly, of course: 41% of U.S. family households³ have at least one child under the age of 18 living in the home, and in 43% of these households one or more of the children being cared for is younger than six,⁴ not yet in grade school. For the 20% of American caregivers who are part of the “sandwich generation,”* caregiving is complicated by tending to the needs of children and elders at the same time.⁵

Caring for elders or children is even more complicated for those who work outside the home, which is true for the majority of family caregivers. In the United States, 91% of families with children have at least one working parent; among married-couple families with children, nearly all (98%) have at least one employed parent and almost two-thirds (64%) have two employed parents.⁶ Among unpaid elder caregivers, 63% work outside the home, with 76% of these individuals employed full time.⁷ Balancing the needs of dependent loved ones with the need to earn a living is difficult, and caregiving can affect employment decisions. In one study, 41% of working elder caregivers reported having made “a major workforce change, such as taking a leave of absence, changing jobs, cutting back hours, or stopping work entirely” as a result of their caregiving.⁸ In fact, family caregiving can be akin to having a full-time job with caregivers reporting, on average, that they provide 37 hours of care per week.⁹

Research reveals some interesting findings about Latino[†] elder caregivers. More than one-third (36%) of Latino households report having someone at home caring for an adult relative or friend, compared with 25% of non-Latino households. The majority of Latino caregivers (54%) provide more than 20 hours of unpaid care each week.¹⁰ Evercare and the National Alliance for Caregiving found that 36% of Hispanic households have one caregiver in the home, and that 52% of Hispanic caregivers are employed, with 31% employed full time.¹¹ Research into the typical caregiver profile¹² found that, on average, Hispanic caregivers provide a higher level of support for everyday tasks (e.g., housework, managing money, medication management) than they do for personal tasks (e.g., bathing, assistance with in-house mobility), though they

* The sandwich generation is commonly used by the Bureau of Labor Statistics to describe **a generation of people who are caring for their aging parents while supporting their own children.**

† The terms “Hispanic” and “Latino” are used interchangeably by the U.S. Census Bureau and throughout this document to refer to persons of Mexican, Puerto Rican, Cuban, Central and South American, Dominican, Spanish, and other Hispanic descent; they may be of any race. This document may also refer to this population as “Latinx” to represent the diversity of gender identities and expressions that are present in the community.



provide both types of support. Hispanic caregivers typically provide support on their own, acting as “the primary, unpaid care provider for [their] loved one and provide[ing] care without the assistance of paid help.”¹³

When it comes to caring for children, Latina mothers (62%) are less likely than White mothers (74%) to work outside the home. Yet, working Latina mothers are more likely than White mothers to be the primary earners in their households (41% and 25%, respectively).¹⁴ Mothers who work outside the home have two types of child care available to them: home-based care, which is provided by family, friends, or acquaintances in the child’s home or in another residence, and center-based care, which is provided by licensed professionals in a nonresidential setting. Research has found that the children of parents born outside of the United States are less likely than their peers to be enrolled in center-based care and that Latino families (regardless of immigration status) are less likely than White or Black families to use center-based care.¹⁵ Several factors contribute to Latina immigrant mothers’ choice in care for their children, including a lack of information about the American child care system (including information about subsidy eligibility), the proximity and flexibility of available care, and cost and affordability.¹⁶

Of course, the financial and logistical complications of providing home care are exacerbated for Latinos in the sandwich generation. Research has shown that 31% of Latino adults have a parent age 65 or older *and* a dependent child; this compares with 24% of Whites and 21% of Blacks.¹⁷ Another study found that 53% of Hispanic elder caregivers have children under the age of 18 in the household.¹⁸ Latinos are



also disproportionately feeling the financial pinch of multigenerational care: among Latinos, 21% report they provided financial assistance to an aging parent in the past year and that they are either raising a young child or supporting a grown child. This compares with 8% of **Blacks** and 5% of **Whites**.¹⁹

When one thinks of the “costs of care,” financial costs are the first to come to mind. The financial costs of adult caregiving include both the out-of-pocket expenses associated with providing care at home and/or the costs of paying someone else to provide care. One study found that 78% of those providing adult care incur out-of-pocket expenses associated with that care, and that these caregivers spend an average of \$6,954 per year.²⁰ The majority of adult care spending (41%) goes toward household expenses (rent/mortgage or home modifications, for example) with medical expenses coming second (25% of spending).²¹ In terms of the share of income spent on adult caregiving, Latino caregivers are the most cost-burdened. On average, Latinos spend 44% of their income on care expenses, while Black caregivers spent 34% on average, and White caregivers, just 14%.²²

The costs of child care in the United States are notoriously high, with one study finding that “in many states, the cost of a year’s tuition and fees at a four-year public college is comparable to the average cost of child care.”²³ The average monthly cost of center-based child care in the United States has been estimated at \$1,230 for an infant, \$910 for a toddler, and \$760 for a preschooler.²⁴ Family-based (e.g., private, home-based) child care is only marginally less expensive, averaging \$800 per month per child.²⁵ While the U.S. Department of Health and Human Services considers child care affordable when it does not exceed 7% of family income, one study concluded that, “In no state does the cost of center-based infant or toddler child care meet the federal definition of affordable.... In 12 states, the cost of child care for just one infant exceeds 20 percent of the state median income.”²⁶

Our report, *The True Costs of Home Care: The Impact on Working Latino Caregivers*, was written to provide a rich understanding of the costs of care for Latino households, looking beyond purely financial costs. In this report, the costs of care are understood to include financial effects—e.g., the impact on savings and current expenses—but they also include nonfinancial costs, such as the effect of caregiving on career opportunities (e.g., job choice) and, importantly, psychic and quality of life effects (e.g., stress and time constraints). The report is based on qualitative research undertaken in three locations in the United States: Raleigh, NC; Los Angeles, CA; and New York, NY. In each of these locations, in-depth interviews were conducted with Latino adults who work full time or part time for pay outside the home and who are also the primary caregivers for one or more dependent children and/or adults in their home (see Appendix A for full details).²⁷

The Effect of the COVID-19 Pandemic on the Study

When we began planning this project in early 2020, we did not know that a global pandemic was about to hit. As the threat of COVID-19 began to spread throughout the United States and stay-at-home orders and travel restrictions were put in place, we assumed these changes would be short-lived. Our most pressing concern about the impact of COVID-19 on the research process was how to coordinate telephone interviews among interviewers, caregivers, and interpreters.

The effect of COVID-19 on the research process was more extensive than we anticipated. UnidosUS Affiliates—community-based nonprofit organizations in the four cities originally targeted for this study—were our partners in helping recruit local interviewees. These organizations have experienced the same COVID-related shutdowns as other businesses, and recruiting interviewees for a research project took a back seat to their trying to provide services in a time of real crisis.

The confluence of the pandemic-related health and employment crises also created a unique opportunity to understand the competing demands between caregiving and work. In order to capture relevant and timely information, we adjusted the interview guide to include questions on the impact of COVID-19 on caregiving specifically. In addition, we interviewed the staff of Affiliate organizations who were assisting with the research process in order to learn about their operations in the face of the pandemic and any increased demand for their services. We discuss Affiliate staff experiences and our findings in Appendix B of this report.



FINDINGS

The Caregivers in Our Study

The 14 caregivers we interviewed range in age from 27 to 57, with an average age of 41. Thirteen out of the 14 caregivers are women, and the participants were evenly split between rural and urban settings. All but two participants were born outside of the United States. The participants provide care to their children (adult as well as those under the age of 18), grandchildren, adult siblings, nieces and nephews, and elderly parents. Most of the people they care for live in the same home or on the same or an adjacent property; in one instance, the people being cared for live in the same city, though not next door to the caregiver. Seven participants are part of the sandwich generation, caring for both adults and children; six participants are caring solely for children; and one participant is caring for an adult and no children.

Living and care configurations varied greatly across the group of people we spoke with. At the more intensive end of the spectrum, we spoke with **Maria**, a grandmother who, in addition to working outside of the home, is the primary caregiver of two preschool-aged grandchildren with special needs and one adolescent nephew with special needs, all of whom she has adopted. She also helps care for her adult live-in sibling who is recovering from a stroke, pays the expenses of her adult child (who lives elsewhere), and sends money twice a year to help her family in her country of origin. For this caregiver, tending to others is a nearly full-time activity, which she manages in addition to a full-time job.

At the less intensive end of the spectrum is **Margarita**, who works as a paid caregiver for an elderly woman and whose unpaid caregiving is helping her adult brother, who has disabilities and lives next door to her with his wife. For this caregiver, tending to another person's needs is a more occasional task, in part because she shares care of her brother with her family and he also has access to adult day care. Her caretaking happens a few times each week, and she describes the level of care she provides as “not that much.”

Those caring for elderly people—in all cases, their own parents—engage in tasks such as taking their loved ones to medical and other appointments, retrieving prescriptions, dispensing medications, preparing meals, doing laundry, and ensuring that their parents get out of the home for exercise or fun. A few caregivers are responsible for assisting with bathing and dressing their parents, though this was not the norm for the elder caregivers we spoke with. Those whose parents have mobility issues assist with the use of walkers and wheelchairs. Several participants described taking care of nonelderly adults: in one case, this was a sibling with a disability; in another, it was a sibling recovering from drug addiction; and in the final case, it was a sibling recovering from a stroke.

Those caring for children described the hectic set of daily responsibilities that any working parent will recognize; these are particularly burdensome with very young children and ease up as children can take more responsibility for themselves and perhaps even help with their younger siblings. Parents and guardians described getting children up, feeding them, getting them to school or child care centers or sitters, going to work, picking children up after work, taking them to appointments, getting them home, feeding them, doing laundry, cleaning up, assisting with homework, helping with baths and bedtime, and finally going to bed themselves.

For some participants, caregiving is an around-the-clock activity. This is true for Maria; one of her adopted grandchildren was in a phase of waking up for hours each night around the time of our interview.

It is also true for **Juana**, whose elderly mother and adult sibling (who is recovering from addiction) both require medications that Juana controls and dispenses. As she explained, this involves “really monitoring them both all night every night. Because as soon as I get home, I give them their medication, but I have to monitor the medication and how they’re doing. It’s really hard.”

Teresa, who is caring for her parents—one physically dependent, one more independent—has changed where she sleeps to be near them at night. As she explained, “I sleep nearby them so I can hear their bed moving whenever one of them is getting up, and that way if I hear that, then I can get up and I go and see what kind of help they need.”

The networks of care support that participants described were intricate and varied. Those caring for young children benefitted from the support of those children’s aunts, uncles, grandparents, older siblings, and cousins, as well as family friends, babysitters, child care centers, Head Start programs, and after-hours programs. Those caring for adults benefitted from the support of their own siblings, older children, adult day care services, and the assistance of paid attendants. As we discuss later in the report, care arrangements shift over time, requiring reconfiguration as loved ones’ needs change, life circumstances shift, one’s own caregiving capacities change, and external care options either become available or close off.

The purpose of our study is to provide a rich understanding of the true costs of home care for working Latino caregivers. Because of this, we selected participants who were working full time or part time for pay outside the home, or who had been doing so recently but had lost jobs due to the COVID-19 pandemic. At the time of our interviews, 11 of the 14 participants were working outside the home. The caregivers we spoke with are (or were) employed as social service workers, paid caregivers, teachers, fast-food restaurant workers, house cleaners, farmworkers, and factory workers.

A note before we present our findings. As described in the introduction to this report, we conducted the interviews for this study over the summer and into the fall of 2020, when unemployment rates were high, COVID-19 infection rates were soaring, and participants were balancing work and care needs in a significantly altered reality. The interviews revealed that COVID-19 has thoroughly affected people's lives, and the effects of the pandemic on work and care are mentioned frequently in the findings presented here. Because of its significant impact on participants' lives, the effects of the pandemic are also explored in depth in a distinct subsection here.

The Day-to-Day of Caregiving

As mentioned above, living and care configurations varied greatly across the group of people we spoke with. In this section, we present findings about the day-to-day of caregiving in people's lives.

The more people one is caring for, the greater their individual needs, and the more diverse the needs across that group of people, the more complicated caregiving is.

For Maria, caregiving for her special needs' grandchildren and nephew, as well as her adult sibling who is ill, is an around-the-clock activity. Before a family member moved into help with the grandchildren, the care schedule was as follows: she gets up at 6:00 a.m. to get her nephew ready for school, wakes and feeds the two babies, takes the babies to day care for an 8:00 drop-off, works from 9:00 to 4:00, picks up the babies, takes them to any therapy appointments they might need, then heads home with the babies to change diapers, make and serve dinner, oversee homework and bedtime routines, and finally head to bed herself. Her care does not end at that point, however, since she gets up in the night if the younger children need her, which, at the time of our interview, one did for several hours each night.

Francisco is part of the sandwich generation: he lives with his aging mother and shares part-time custody of his two adolescent children. Due the COVID-19 pandemic, he is responsible for supervising his children as they attend school from home. Daily care of his mother involves making meals, helping her get around the house, dispensing her medications and making sure she takes them, taking her to

medical appointments, and helping with her personal care as needed. He says about taking care of his mother, “It’s kind of like having another child.”

For **Silvia**, a mother of four children ranging from infant to young teen, caregiving is complicated by the need to work and the pressure of being the only adult in the home. Her current schedule involves working the midnight to 7:00 a.m. shift in a factory; to do this, she leaves her baby in the care of her cousin’s wife while the older children sleep at home. When she gets home early in the morning, she goes to bed for a few hours, waking at 11:00 to feed and care for the children who are involved in virtual school. The hardest aspect of her caregiving is being solo: the fathers of her older children have been deported and the third father chooses not to be involved in the child’s life.

The stress and actual work of caregiving are reduced when one has a solid support network. It is especially helpful if members of that support network live in the home.

Juana lives with and cares for her elderly mother, her adult sibling (who is recovering from addiction), and her four children, three of them teenagers and one adult. Juana works two jobs and is primarily the one responsible for overseeing medical care for her mother and sibling. When she is working, she is in contact with her mother “by phone all the time,” and she estimates that caregiving takes up “100 percent” of her days off. In addition, she says of her parent and sibling, “I have to monitor them all night.” However, having self-sufficient children who are able to assist with caregiving and household tasks has alleviated the stress of Juana’s caregiving, though she only realized this as a result of the pandemic. To manage the changes in life due to COVID-19, Juana and her children made a plan to divide up the household responsibilities. “Because of this situation,” Juana said, “we’ve actually become a better team.”

For Maria, caregiving is definitely made easier because of the help of family members. Her goddaughter and the goddaughter’s grandmother have provided emergency care when Maria’s grandchildren were sick. She used to pay her sister-in-law to clean her house. Her niece now lives with her and is caring for the two babies instead of paying rent. As Maria describes her niece, “She helps me with the kids completely, 100 percent.” So helpful is her niece that Maria says she’s “like my significant other” and adds, “She can stay [with me] until she gets married.”

Sofia, who is currently not working, cares for her parents, who live in a separate unit on the same property as her, her husband, and their two older children. Sofia is responsible for coordinating her children’s school routine while also caring for her parents, which involves feeding them, taking them to appointments, and generally watching out for them and making sure they are doing well. As she describes her involvement with them, “I spend as much time as I can with them and so I’m kind of in and out all day.” She does this caretaking gladly—as she says, “My blessing is that

they're here with me...and if I'm able to help, then I do it"—but she also expresses gratitude that she doesn't feel alone in these efforts. She has the support of her six siblings. As she described their relationship around caring for their parents, "We all support each other through the good and the bad and we're all in agreement with each other.... They've never left me alone to do it."

For **Adriana**, a strong support network was crucial when she became sick with COVID-19. Her normal routine is to wake up at 5:00 a.m., get her three young children ready for the day, take her oldest child to school, bring her younger children to their care program, work from 8:00 a.m. to 5:00 p.m., take one child to physical therapy, head home, feed the children, bathe them, spend time with them and her husband, put the children to bed, and then clean the house until she herself goes to bed at 10:00 or 11:00. She organizes all this with a calendar on her wall: "If it's not on there, it isn't happening. I'm like, everything has to be on there." Her well-organized routine was thrown completely off kilter, however, when she tested positive for COVID-19. Fortunately, she has a strong family support network nearby, and her sisters stepped in to keep things running. As Adriana described it:

When I got tested positive, the first immediate thing, my sister, she left her job and she was like, "Okay, I'm going to go pick up your kids and I'm taking them to my house. They're not going back home to you, I'm sorry, but I'm going to handle them." I went home, I put gloves on, I packed some of their things, and I took to them, and then my sister washed everything. [My sisters] just took charge. They're not asking me, they just took charge, and they just made sure that the kids were fine. And, thankfully, they were able to handle it. Me, I don't like putting my children on anybody so I was like, "Oh man, I know my kids can be a lot sometimes." But they didn't make it feel like a burden at all. On the contrary, they were very supportive the whole time.



Paid and Unpaid Care Arrangements

The interviews revealed that support networks are crucial to enabling caregivers to work outside the home. In this section, we offer an overview of what caregivers told us about those supporting them in their caregiving activities.

Caregiving arrangements are adaptive and change over time.

Changes in care arrangements occur as loved ones' needs change, life circumstances shift, one's own caregiving capacities change, and external care options either become available or close off. We heard this from all types of caregivers—those providing elder care, those caring for children, and those doing both.

An example of shifts in eldercare arrangements is offered by Francisco, who moved in with his aging mother just before the COVID-19 pandemic began. Seventy-three-year-old Josefina was on her own for years, relying on Francisco and his sister's occasional care and on the support of friends and neighbors in the apartment complex where she lived for 36 years. Over the past few years, Josefina has gotten more infirm, and in one recent year she fell 12 or 13 times. Francisco and his sister moved their mother to a nursing home, but as Francisco describes it, Josefina wasn't happy there: "She still didn't have the independence she had when she was living alone, and she missed her home." The siblings moved their mother back home, and for a time Francisco lived separately and worked as her paid caregiver. Now, he lives with Josefina, providing unpaid care such as meal preparation and assistance with her mobility and her personal care. In addition to the care Francisco provides, a paid caregiver comes into the home for five hours a day, five days a week. For Francisco, the current care arrangement works, although it's not without its disadvantages. In particular, it affects "everything from just having your own personal space and being able to escape, to my dating life." He admits to finding his living situation stressful, although he was also stressed when he lived separate from his mother and she wouldn't answer the phone. "I think living here," he told us, "that's kind of relieved some of that nervousness."

Child care arrangements—especially for preschool-aged children—are also cobbled together as needed and are subject to change as children age and care resources shift. Maria has balanced her child care needs over time from the following sources: private, paid child care, day care, paid or unpaid relatives or friends, and, at the moment, a live-in relative who helps with her two grandchildren in exchange for room and board. She summed up the nature of coordinating care over time:

With all this, you just have to find your norm, what works for you, because it's not always a money issue. It's a lot of other things and you just have to find what makes it work for you. Unless you're in it, I don't know how else to explain it. I've just been really blessed that things have fallen into place for me, that I've got people that are helping me.... Everybody that's helping me has just made this a little easier because I know that it could be a heck of a lot more stressful.



For one participant²⁸ with small children, finding and using care has been a juggling act. She works full time, with one child in elementary school and two in a child care center she likes a lot. Unfortunately, when her youngest was born, there was a waitlist for spots at the center, so this caregiver had to make other arrangements for her baby. Because this participant lives in a rural area, she had difficulty finding care: "It's already hard in the area where I live to actually find babysitters because usually there's not much of them available. Mostly, there's day cares, but my fear was she's so little." Eventually she found a babysitter—whom she described as "more like a grandma"—and this person cared for the baby while the middle child remained at



the care center and the oldest went to school and then to after-hours care, until his mother could leave work at 5:00 to pick him up. At the time of our interview, the baby had just been given a place at the care center. “I don’t have to pay for child care, which is amazing,” this caregiver told us. “And the quality that they give to my kids is great.”

Reliable, quality child care is hard to find in rural areas.

While participants living in large cities certainly spoke about the effort involved in finding caregivers one feels comfortable with, participants in rural areas spoke about the limited options available to them.

For example, Adriana said when describing her search for child care for her three young children in her rural area, “I see on TV care.com is offered, but not where I live. I live in a very, very country area and that’s not really offered.”

Gabriela, a farmworker with four children ranging in age from baby to older teen, explained that it was hard to find someone to help her elementary school-aged child get on and off the school bus each day, because in her neighborhood, “It’s all Americans.” She eventually found a neighbor to help with this activity—for pay—but the neighbor only speaks English, “So I’m having to use my kids to interpret.”

Thirty-five-year-old **Elizabeth**, living in a rural area with children who range in age from baby to adult, told us that finding care for her youngest was “a little difficult, because we all have to work.” She eventually arranged for an acquaintance to watch her younger children. This person charges less than others, and Elizabeth would watch the woman’s children in return when she wasn’t working. However, because the woman has her own children, her ability to watch Elizabeth’s children isn’t consistent. “It was difficult, because she also has her own kids, and so they might have had a medical appointment or something that came up all of a sudden.” As Elizabeth described her child care situation, “A person that’s always there, I don’t really have that.”

Isabel, who lives in a rural area, takes her three-year-old son to a Head Start program. When asked about options for child care in her area, she explained:

If I needed day care, it would be a problem. First of all, because there aren't any day cares near me, and the closest [is] 30 minutes away, so I'd have to take him there, and I can't do that. Plus, the prices they charge is higher, and I think, in fact, I'm not sure of this, but I think that at those type of centers, you have to enroll, and you pay for whatever the enrollment is. I couldn't bring him one day on and one day off.

Trust is a key component in the search for nonfamilial care providers.

When we asked participants about their search for care, we learned that no matter where one lives—in a rural or urban area—trust is a crucial factor in the search.

When Maria began to look for care for her young charges, trust was a major issue. As she told us:

I'm not going to just let anybody take care of [my grandchildren]. It's like, I don't know what they're doing in this house. I don't know any of that, so I had to pay out of my pocket at the beginning for my day care. I was paying \$650 a month for day care for these babies when I first had them...because I couldn't just trust, like I say, I don't know who these people are, and I'm not just going to drop my babies off and say, "Oh, let's hope for the best." I couldn't do that.



Francisco told us that he was able to find good caregivers for his elderly mother because many people in his mother's housing complex use them, so most of his mother's caregivers have come via community referrals. Because he is currently home full time, he "monitors" caregivers closely and says his mother has accused him of "running off" some of her paid caregivers. For his mother, he wants "somebody who's an advocate. Dealing with doctors and doctors' offices, especially in low-income communities, is a maze. You just need somebody who's able to advocate for her."

Adriana, in her search for trustworthy care for her children in a rural area, discovered that, "Finding somebody was very difficult, and then finding somebody who you could trust. Knowing how their household is, knowing how they do certain things, that was really, really hard. I had to ask a friend who I knew and just ask her what she thought and ask for recommendations."

The Intersection of Work and Caregiving

As mentioned earlier, 11 of the 14 people we spoke with are currently working for pay, though some have experienced reduced hours or have been through periods of furlough due to the pandemic. The people we spoke with are employed as social service workers, paid caregivers, teachers, fast-food restaurant workers, house cleaners, farmworkers, and factory workers. We look in this section at how the people we spoke with balance the competing demands of work and caregiving.

The need to provide care for loved ones inevitably crosses into the workday.

It was fairly common for the people we spoke with to receive phone calls at work either from their loved ones or, if they have children, from the schools or day care centers or sitters in charge of their children's care. Juana, who holds two jobs, is in contact with her mother "by phone all the time."

Isabel, whose son is in a Head Start program, takes calls from the program "often" when she's at work. "There are interviews that they have to do. For example, sometimes they call and they want to know how my son is doing or if there is anything that we need.... And so it takes about 15 to 20 minutes, and even though I'm at work, I have to take the time to answer those calls."

One interviewee, whose four children are now home full days due to the pandemic, takes time from her workday to call home regularly and check in. As she explained, "You just don't know what might be happening or where they might be. I call every little bit to check on them." Another interviewee handles care-related doctor calls at work, though it requires juggling. As she explains, "Sometimes I have to clock out or try to talk to them in my lunchtime or get lunch around when they are able to talk, so that [if] they can't talk until 2:00 p.m., I don't get my lunch until 2:00 p.m., so I can be able to talk to them comfortably."

The need to take loved ones to medical appointments or pick them up from school if they are sick, is another way that caregiving overlaps with work. Since the closure of her children's child care center due to COVID-19, Maria has to leave work to take her special needs grandchildren for therapy appointments; these used to take place in the child care center during care hours, and now it falls to Maria to ensure that they receive the therapy they need elsewhere.

Alejandra, who works on a farm and lives with her mother, preschool-age daughter, five-year-old son, and boyfriend, must leave work if her son is sick at school. While her mother helps care for Alejandra's children, she does not drive, so it falls to Alejandra to take both of the children and her mother to any medical appointments they need, which normally occur during her work hours.

Given the overlap between care and work, a flexible workplace makes a big difference to those providing care.

For the most part, the people we spoke with can take time off work to care for sick loved ones or to take children or elders to medical or therapy appointments. Some of the people we spoke with are able to make up the hours they miss—and in that case, they do not lose pay—but most of the people we spoke with are not paid for their time off. As one interviewee described about her job in the service industry, “The manager allows me the time off, but I don’t get paid.”

Not all workplaces make room for care activities, however. For Elizabeth, a seasonal farmworker, her ability to take care of the unanticipated needs of her children depends heavily on whichever farmer she is working for. “Not all of the farms are the same,” she told us. “Some of them understand, some of the other ones, if you miss two or three days then they’ll let you go.” The farmer she was working for at the time of our interview was more understanding than some, and this matters to her. As she explained, “He understands us better. But there are some farms that they don’t understand.” At her current job, she says, “It’s less hours, and the pay is less. But it’s easier, because he lets me go if I need to go for an emergency, and he doesn’t say anything. He just says, ‘Okay, I’ll see you tomorrow.’”

This is also the experience of **Luz**, who works cleaning houses (independently, not for a company). For the most part, when Luz needs time off to care for her children, her employers are understanding: “My bosses, they understand if I have to take care of my kids, and I’ll get the work done, and they know that. I mean, they’re my kids, and I have to take care of them.”

Participants revealed that personal sick leave is a rarity in the jobs they hold.

What happens when caregivers themselves get sick and need time off? When it comes to receiving paid time off while sick, most participants do not receive this benefit. In fact, only two of the people we spoke with receive paid leave as part of their benefits packages, although at the time of our interviews, one of them had not worked at her job long enough to qualify for it. One of these interviewees explained that she receives a set number of hours of paid leave each year at her job; she can take leave beyond this, but she will not be paid for those hours.

In the absence of workplace support for caregiving activities, knowing the law and your rights helps a lot.

Only one person raised the issue of the Family and Medical Leave Act (FMLA) during our discussions. Juana provides care for her elderly mother by phone during the workday. As she explained to us, she applied under FMLA to be designated as “the person in charge of taking care of the health of [an] immediate family member,” her mother. She has in her work files that she must have access to her

phone at all times and that she might have to leave work for appointments. She is careful to talk with her managers about the need to provide care, and she always brings documentation back to work from any doctor visits on her mother's behalf. One of Juana's two jobs brings her in contact with people who know a lot about social services, and she credits this with giving her information about resources for her mother, as well as her brother. As she says:

I've been able to learn a lot through my work, how to manage working with somebody who has disabilities like my brother, and my mom as a senior, and they've given me training and understanding, so that not everything falls on me. The programs, they help [my mother and brother] with their own care, and they're part of a group, and [so] it's not just one person taking 100% of the responsibility. So that helped me to have my own life, but still to help them. And I'm thankful to have that work, to be able to learn.



The greatest cohesion between working and providing care occurs when one is paid to take care of those one loves.

Several of the people we spoke with were paid to care for their loved ones. This is the case for Teresa, who is being paid to care for her elderly parents. She described her situation to us:

I went to [a caregiving] agency...and there I received some classes. I took those classes. I was able to pass the classes and then they came and evaluated my parents. They are paying me for the care that I give to my parents. For my father, they're paying me for 15 hours a week...and for care of my mother, they pay me four hours a week.... [The] classes were things like the rules that I needed to take into consideration if I was taking care of them, orientations around all of that. And skills like how to manage a wheelchair, how to have the emergency contact information available with the telephone numbers, for example, of social workers and doctors and transportation... those kinds of things.



Working as a paid caregiver for their loved ones is not for everyone, however. Francisco worked as his mother's paid caregiver, but he is happier now that someone else is doing this work. As he put it, "Stepping away from that role as the paid provider, I think, has really helped me out a lot. I think that was good.... Knowing that her needs are going to be attended to by somebody. It's pretty good."



The Costs of Care

When we asked caregivers specifically about the costs of care, our questions concentrated on several areas of life that might be impacted by caregiving: finances, relationships, social life, and mental and physical health, including any stress experienced as a result of care. In this section, we share what interviewees told us about the full costs of caring for their loved ones.

The financial costs of care varied widely across our interviews and were experienced differently across households, depending on the predictability and amount of household income.

For example, Maria estimates her monthly costs of care at \$800: she spends \$400 on her adult child's rent and expenses, another \$200 for extra care if her grandchildren need to stay home, and approximately \$50 per week for her nephew to be transported to and from school. As she explained, the costs are lower than they might be, because the state covers the babies' day care center costs and because Medi-Cal covers the children's medical expenses. As Maria put it, "I don't have a lot of those out-of-pocket expenses, thank goodness." She manages the costs of care by working full time and with money the state provides for caring for the children.

Juana estimates her monthly costs of care for her mother, sibling, and four children at \$600. While her mother is insured under Medi-Cal, her sibling is not, and despite working two jobs, Juana finds the costs of caring for all these people difficult. She always makes sure she's "managing the priorities, and organizing my money so that I can cover the basic costs of the household, and that we don't run out of money." She finds managing everyone's needs stressful. "I'm able to manage it, but it does affect me. I mean, I do get stressed."

Teresa, who lives with and cares for both of her elderly parents, wasn't able to give us a specific estimate of the amount she spends on care each month. She works as her parents' paid care provider, and said about her income and care expenses, "What little bit I earn for caring for my parents, I use that to buy food and the things that I need to take care of them.... What little I earn, I am having to reinvest in the cost of the household." Teresa was able to give specific examples of her parents' care costs: medicine, medical equipment, and new clothing when the seasons change. "Right now, we're not able to save anything," she told us. In fact, her household has had to cut back on expenses in order to make ends meet, stopping their DirectTV subscription, no longer going out for street food, hamburgers, or ice cream, and eating meat only two or three times each week "if we have money to pay for it."

For Alejandra, paying the care expenses of two young children and her aging mother requires strategizing. "I can't save anything," she told us about the money she earns working on a produce farm. "Everything that I earn gets dedicated to the cost of the house and care and those kinds of things. There's nothing left over for saving." Alejandra manages these costs by cutting expenses where she can. For example, she purchases her children's clothing out of season, when the items are on sale, and purchases clothing one size larger than needed, so it will fit them when the right season comes around.

One caregiver, who works on a farm, puts the costs of caring for her five children at between \$800 and \$1,000 per month. The children have Medicaid, which cuts down on some expenses, but the costs of caring for five children on a single parent's salary is difficult. As she explained, "To be able to save, I don't have anything. Because I'm just trying to take care of the kids." This participant's hours were impacted by the COVID-19 pandemic because she had to be home to provide child care while school was closed, but her work hours can also be reduced due to weather. In addition, her work is seasonal: she moves from tobacco farms to blueberry farms to vineyards. Speaking about her work in the vineyards at the time of the interview, she explained, "It's very few hours, and we still have the same expenses in the house. Sometimes it's not possible to do."

Gabriela currently works full time harvesting grapes, but if it rains or if her children have appointments, she can't work. The \$800 she earns each month—sometimes less, depending on her hours—is her only income. Gabriela's four children are all insured, and she receives a monthly check for her son, who was born with a condition that requires regular visits to the hospital. At the moment, Gabriela estimates that she spends her entire income on her children's care each month, "Because when the kids don't go to school, I have to pay for somewhere for them to be. And with everything I have to buy, I really spend the whole \$800."

Before one caregiver was able to move her baby to a free child care program, the costs of child care alone could run as high as \$600 per month. This included \$400

for a babysitter and \$200 each month for her oldest child's after-school program. When her baby was able to join the middle child at the free child care program, costs dropped significantly. However, this caregiver still estimates the costs of caring for her family at "maybe \$400 [for] probably all of us, in case my kids need something or I need something. Maybe a little bit more, but on the range of maybe \$400." When this caregiver contracted COVID-19 and was sick for two weeks, she lost income for that time and her husband lost income as well, since he had to take care of their children. This disruption affected the family's financial well-being significantly. "We've had to live paycheck by paycheck and see our savings go lower and lower and lower. And as much as I try to save, it just comes down...it's been coming down, down, down. I'm just like, God, please don't give me an emergency because I don't know how I'm going to do it."

The most prevalent nonfinancial cost of caregiving is stress.

In addition to questions about the financial costs of caregiving, we asked participants about the nonfinancial costs, and especially about any effect on their relationships, social life, and mental and physical health. From what the caregivers we spoke with shared about their lives, it is clear that stress is the primary nonfinancial cost of care.

For one participant, who cares for four children on her own and also works full time to support her family, caregiving itself is not stressful. The main stress she experiences is due to the effort of trying to balance work and care obligations. "Just when I'm working and I have to be running around," she told us, "That's when I get stressed."

Silvia, who works the night shift in a factory, feels much stress in being a working caregiver and single parent of four children. For this caregiver, the main stress in her life comes from having too much on her plate. Her life as a solo parent is hard, she told us, because everything falls to her—the cooking, cleaning, helping with homework, everything. She explained that she's always doing a lot of things at once, and in fact she undertook our telephone interview from a laundromat, where she was doing her family's laundry. Because of the need for a better support network, Silvia recently moved to another state to be closer to family.

While Francisco denied finding caregiving itself stressful, when he reflected on the effects of caregiving on his life, he identified several areas of stress. He finds it hard to juggle care of his mother and the two children who live with him part-time. Speaking about his mother, he explained that he finds it difficult that he can't leave home for more than a few hours at a time: "It's difficult. If I want to take my kids out, it's not that much of a concern if I'm going to be out for an hour or two, but if I do plan to leave for three days [for a weekend vacation], then I have to make sure I set something up." Upon reflection, he admitted, "I'm definitely a little more stressed," though he identified the main stressor as moving back in with a parent, where he's still seen and treated like a child. Worry about his mother's well-being is another

source of stress for him, and he concluded our interview by talking about the worry involved when the person you're caring for is someone you love, which is not at all like caring for a stranger, where you can detach: "It's stressful. When they're not eating or when they don't want to take their medication, you don't understand the stress. If it's a stranger, that's fine."

Adriana sacrifices sleep in order to balance the demands of a full-time job and the needs of her family. She takes care of her home "after they go to sleep...it's easier for me that way," and so generally only sleeps from 11:00 p.m. to 5:00 a.m. As she explained her weekly routine to us, she said, "My mind is constantly thinking, okay, today is Wednesday, what's today?" and said that she is able to stay organized and on top of her life only by using a calendar on her wall. For Adriana, the current main stressor in her life is the threat of her three children contracting COVID-19 at their child care center. "That's my fear, okay, I brought them here because I need to work and I need child care, but because of that need, now I'm exposing my children.... Mentally, it's extremely stressful."

Another cost of caregiving is the time spent doing it.

The caregivers we spoke with provided an estimate of the amount of time they spend each week providing care to their relatives. Answers ranged from a low of nine hours for one caregiver, who helps care for her adult sibling living next door, to a high of 128 hours for another caregiver who is working and raising three young children. The second estimate may sound high (and the actual number of hours may be lower if her children do not need her in the night), but this is an accurate depiction of caregiving in the life of this mother of three, whose only break happens when she's at work. It is not surprising that this caregiver expressed some ambivalence about the possibility of being a stay-at-home mother. As she explained to us, "If I could stay home...I wanted to.... [But] I honestly felt too that for my mental health, I could not be able to handle two little babies and handle [my older child] with school and all that."

Caregiving factors into what jobs people apply for and accept.

The final cost of caregiving is the effect that the obligation to provide care has on one's job choices. One caregiver explained that she had recently finished her bachelor's degree in the hopes of getting a "better job." The hitch is that her children's child care center closes for several months each year: "Child care-wise, I don't know if I'm going to have it year-round." Right now, this isn't a problem because her current job is flexible enough that she can fill in the caregiving gap. "Maybe once they get older," she said, referring to getting a different job, "Then maybe."

Silvia didn't choose the factory night shift job for its schedule: she took it because she couldn't find other work. But the schedule has turned out to work well for her, because her kids are sleeping while she's at work "and not doing any activity." With

the kids attending school virtually due to COVID-19, the schedule has turned out to have the added benefit that she's home and available during their school hours. As she told us, she is very grateful for her job. It's hard work, but she can also be home with her kids during the day and take care of them.

Francisco isn't working right now because his job as a substitute teacher ended when the schools closed due to COVID-19. When he thinks of getting another job, his caregiving duties affect what jobs he'll apply for or take, because he needs the flexibility to take his mother to doctor appointments and oversee his children's schooling. As he described the conflict he sees between the current caregiving demands in his life and the possibility of working, he said, "Right now...based on kids and homeschooling, if I wanted to get a job, I'd have to worry about child care costs, or pay somebody to come in.... If I worked nights, when the provider's not here, then I'd have to find somebody to kind of be here with my mom. It's a restriction or a constraint that I have to work around, and it might only get worse." Given his need for flexibility to take his mother to doctor appointments, he said, "I generally tend to stick to gig economies and stuff like that."

The Effect of COVID-19 on Work and Caregiving

The COVID-19 pandemic is a "perfect storm," hitting working caregivers hard. It has affected jobs and income streams, changed caregivers' ability to rely upon informal support networks, closed schools and child care centers and brought children home full time, and threatened people's elderly loved ones. We didn't anticipate that the effects of the pandemic would run so prevalently throughout the interviews we conducted, but they did. We present here what people shared about the extensive effect of this public health and economic crisis upon their lives.

COVID-19 has had economic impacts on the lives of the caregivers we spoke with.

Because of the pandemic, jobs have been lost or hours have been cut, and incomes are down. The restaurant where one caregiver works shut down when several employees tested positive for COVID-19. This participant explained that she was able to apply for unemployment to help cover the disruption in income, and her second job was unaffected by the pandemic. But with an elderly mother, a recovering brother, and four older children in her home, it's not surprising that she told us, "I can't save any money." Another participant, who is paid to care for her elderly parents, has maintained her employment during the pandemic, but her husband was out of work for five months. They had to use their savings to weather his unemployment, as well as cut back on expenses: "The little bit that I earn," she told us, "I've had to be turning it all toward things that have to be taken care of in the house, the care for my parents, [making] the rent, paying the bills, those kinds of things."

Patricia, a mother of five boys ages adult down to toddler, not only experienced a disruption to household income as a result of the pandemic, but she also noticed an

increase in expenses since COVID-19 hit. Before the pandemic, Patricia's husband and oldest son worked, which added to the income she earned working on a turkey farm. Unfortunately, her husband and son both lost their jobs due to the pandemic and her hours have been cut. In addition to this reduction in income, Patricia has noticed that the costs of caregiving are "very high" right now: "Things like food are definitely higher, meat is extremely high, and anything related to the children also is higher." As a result, she is not able to save any money. In fact, she and her family are having to do with less: "Everything that we used to buy I've had to cut back on now and try to find things that are less expensive."

Before COVID-19 hit, Alejandra was working on a blueberry farm, but that changed when the schools closed: "Initially, I stopped working because of COVID. It was because the [two] children were no longer in school." Months later, she still isn't working, because "the schools were supposedly going to provide computers so that the children could do virtual work, but so far they haven't provided any kind of apparatuses for us." Because of the lack of computer equipment, Alejandra was given the option of having her five-year-old son in school four days per week, but with school buses not running, transporting her son to and from school fell to her. "I have not been looking for work, because I have to take care of the kids and everybody."

Before COVID-19, the \$200 per month that Sofia estimates she spends on her parents' care was not prohibitive, because she and her six siblings "split everything between all of us." However, with her two children home full time now due to the pandemic, food expenses have increased as her children aren't getting breakfast at school anymore. In addition, because of a reduction in her husband's hours in the construction industry and the resulting loss of income, they have had to cut back on things. "Life has changed," she told us. "We don't spend anything on what we don't need, because there's no work. It's changed everything."

Those who have been sick with COVID-19 find the stigma of the disease itself can have economic consequences.

When Luz, her three children, her husband, and her parents contracted COVID-19, they likely didn't expect long-term financial consequences. Once Luz and her family recovered from the illness, however, she discovered that her business as an independent house cleaner was decimated: "The households, they didn't want me to be there, and so we had to start over, looking for work."

For another participant, being sick with COVID-19 resulted in both emotional and financial impacts. In addition to being separated from her husband and children for their safety—a situation that was hard for her mentally and emotionally because she "had a lot of mom guilt"—she and her husband subsequently had to manage with two weeks of lost income. She couldn't work while sick, and her husband lost work as a result of needing to provide care for the children. Her workplace had to close

temporarily as a result of her diagnosis, and she discovered afterward that everyone else was paid during the closure, though she herself was not. As she described this situation, “It’s unfair sometimes when you realize other people were paid and you were the one that tested positive and then you were the one that don’t get paid.... I was just like, I didn’t mean to get this, I didn’t mean for other people to be exposed...I didn’t want that ever to happen.”

The intensity of child care has increased as a result of COVID-19.

From overseeing children with school and homework, to keeping an eye on preschoolers full time, to helping teenagers stay entertained and upbeat, none of these are easy for parents who are working outside the home.

Teresa’s teenaged son is home full time due to COVID-19. This has caused a serious uptick in her caregiving duties. As she explained:

I have him all day and all night. So, each day we go out and play with the football that he has, an American football, and we’ll spend 15 or 30 minutes outside with that. And yesterday he got a piece of equipment that he can do exercises with. It’s a step-type of machine. So we spent some time setting it up and I was helping him figure out how to make it work and how to use all the different features of it. When he was in school, I didn’t have to do a lot of meal preparation for him. I would just fix food for him in the morning and then he’d come home later on in the day. But now I have to fix breakfast, lunch, and dinner, and there’s a whole lot more related to that.



Francisco lives in a one-bedroom apartment with his mother and children (on the days he has custody). Four people (and one part-time paid caregiver) in the small space hasn’t been easy: “Just being here together and being in a living situation where room is kind of tight, it does get difficult to live here, and just having our own personal space.” In addition, he oversees his children’s schooling when they’re living with him. As he described it, “I still have to watch my kids and make sure they’re on their homework, or they’re on their assignments that they have to do. I’m fortunate. I’m blessed that our kids are pretty good at being on task.”

For Patricia, the hardest part about COVID-19 was that it used to be easier for the family to do things together, but now she, her husband, and their five boys don’t go out at all and don’t have gatherings with others. “The truth is,” she told us, “the situation is pretty hard right now, because we can’t go out at all.” She is being very cautious, she explained, because she doesn’t want anyone in her home to get sick. “The kids want to go out and do fun things, but we’re just here, always in the house and we don’t go out at all.... It’s easier to explain to the kids who can understand why we can’t go out, but the little one is always asking....”

The experience of needing to stay home with energetic young children who cannot understand what is happening was raised by other parents. Elizabeth, who is caring for five children from baby to adult, said her family used to “go out and hang out with people or go to parks.” They can do neither now; while her older children are okay with the situation, she told us, “I really struggle with the young ones.”

Confinement due to the pandemic is having negative effects on elders and their caregivers.

Staying home full time has affected the elderly family members of the caregivers we spoke with. The need to protect the elderly from COVID-19 is also impacting the routines of those who provide elder care.

Juana is very concerned that she will bring COVID-19 home from one of her two jobs and give it to her aging mother. So great is this concern that Juana has divided up and is using her living space differently: she now lives and sleeps in the den, which she can enter by a separate door. She is also cleaning vigorously. As Juana describes her current living situation,

There’s definitely a lot more cleaning, to maintain safety in the house. Because [my mother] doesn’t go out at all, she’s in total isolation. But it is a level of stress, and the cleaning is more work. I’m in the same house, but I have my own space. Fortunately, the house has two floors. And so I’m in the den. I set up my bed and my own space, and then I come in through a door on the side, and I take my shower and I change my clothes. So every time I come in the house, I change. It’s lucky that in my house that I have that option to be in the same house and have my own space.



When Sofia’s aging mother contracted COVID-19, she and her siblings had to move their elderly father from the parents’ home (adjacent to Sofia’s) and into Sofia’s brother’s home. “[COVID] was being passed around a lot in the places where we are,” Sofia explained, “and we didn’t realize it.” During the time of her mother’s isolation, Sofia cared for her at a distance. As she explained, “When my mom was sick with COVID, I couldn’t even go in. I just brought the meals to the door and left them there for her and I would talk to her and just try and encourage her and tell her that my dad was okay, and everything would be okay. She’s not going to die. But it worried me that I just had to drop off the food.” Both of Sofia’s parents are fine now, but she worries about the impact of the stay-at-home confinement on their physical health, and especially on their mobility. “With this pandemic we can’t go out into the street, and they really can’t go out, even less than us. And so, my brother brought a treadmill and I put videos on for them and get them to be active.”

Francisco is also concerned about the effect of COVID-19 on his mother's health and mobility. His mother was in poor health and had mobility issues before, but things have gotten worse: "Now with corona[virus], she really has no chance to go out and walk as much as we'd like to, so that's affecting her." He is also concerned about the effect of the stay-at-home confinement on her mental health, telling us his mother is more socially isolated now: "She has friends that come around, just pre-COVID. She used to entertain a lot of folks, just a conversation and stuff, but slowly that's going away."

Caregivers are worried about passing COVID-19 on to those they care for.

"There are times when it's very stressful," Alejandra told us in reference to her 65-year-old mother, who has diabetes. She describes her mother as "very, very cautious" and explained that now her mother "doesn't go to the store, doesn't go out at all, because of the diabetes." At the same time, Alejandra's young children are eager to go out to the park, an activity they can't currently enjoy. Says Alejandra, "We don't go out. And so all of it can be kind of stressful."

Another caregiver is uneasy about going to her job on a farm, because she is "always afraid that there's going to be a contagion. And I have to take care of my kids," she explained, "so it has affected me because sometimes I'm afraid to go to work."

Caregivers have experienced disruptions to their external care networks.

In the midst of school closures, child care center closures, and adult day care and senior center closures, some caregivers have managed these disruptions by paying for private child care, though this can be an expensive option. For example, Maria has remained employed throughout the pandemic, but her grandchildren's day care center closed, and she had to pay \$300 per week for her goddaughter to watch them.

Other caregivers, too afraid of exposing their children to people outside the home, are managing as best they can with the resources in their homes. Elizabeth, who is caring for five children from baby to young adult told us, "I'm afraid to send them to somebody else's house because I don't want them to get sick in another house. Because I've taken the precautions in my house." Her children are now home full time, and she calls frequently during the workday to check in on them.

The importance of a support network is especially apparent during the COVID-19 pandemic.

The interviews revealed that pandemic-related disruptions to care routines have been eased somewhat for those who can rely upon help from older children or adults. While Maria, discussed just above, originally had to pay \$300 per week for her goddaughter to watch her grandchildren, this task was taken over by Maria's niece, who lost her job and now lives with Maria and watches the children rather than paying rent.

Patricia used to pay a friend for occasional care of her boys, but now that her husband is out of work, he has assumed this responsibility. As she told us, “[My husband] pretty much is the person who focuses on our two kids who have to do their classes online, he’s the one who makes sure that they get help with that. He also handles cleaning of the house and the yard for the moment. He’s cooking and handling washing the clothes and folding the clothes....”

Elizabeth has been relying on her oldest son to assist with the care of his younger brothers and sister: “My oldest son, the one that’s 19, he’s helping me with the younger ones. He just went back to school, and he is only there for two hours. Then he doesn’t work until the evening. He helps me with the three youngest.... He’s the one that’s helping me get through.”

Caregivers’ Needs

We asked the caregivers we spoke with, “If you could change anything at all to make your life easier, what would you change?” The answers varied, and we report here what caregivers told us.

Maria told us that she needs more time, “more hours in the day.” Isabel needs for external care resources to be available more consistently; she said of the Head Start program where her son receives care, “If the Head Start were open more, that would be great.... It would help a lot.” Juana wishes she had a partner to help her in these efforts:

I would like to not be alone with such a big responsibility, to have a partner.... Mostly to be able to share the financial responsibility. That’s what I would change, to have someone who was a team member, you know, being a team together, so that I can spend more time at home. Because I love my house, and I would like to spend more time with my loved ones. Because you never know, tomorrow they might not be there.



Some of the caregivers we spoke with wanted changes to either their jobs or their income. Luz, who cleans houses for a living, said that “being able to have more work and more continuous work would help...to be able to have more money.” Elizabeth’s answer to what would make her life better was, “looking for another job where they’ll pay me better.” Adriana said the best thing would be “if I could win the lottery and I didn’t have to work.” Almost immediately, however, she admitted that she loves her job, so she amended her answer: “This year has been a little bit [of a struggle] because of management. If management could be a little bit more supportive here, I think I could come more happier to work.”

The effects of COVID-19 ran prominently through the discussions we had with Latino caregivers, even though we only asked a few questions about the pandemic. It is not surprising, therefore, that when we asked people about what they would change to make their lives easier, they raised issues directly related to the pandemic.

Teresa only wants for her parents to be able to go out again: “I think it would be great if we could go out. For example, if I could take them to the park or just to take walks around the block or the neighborhood.” Patricia longs for schools to be open again: “Right now, to be honest, I think that the school that my children go to will be very helpful, if they were open. The school that my kids go to helps them a lot and when they’re there, that means that I don’t have to spend money to have somebody take care of them.”

This sentiment was echoed by Luz: “Well, if we could finish this COVID thing, and if the kids were able to go back to school and not be by themselves at home.” Elizabeth spoke for most of us when asked what she would change: “I would really like for them to be able to get a vaccine for this virus, so that we didn’t have to be afraid anymore.”

DISCUSSION AND RECOMMENDATIONS

As this report highlights, care—regardless of whom it is provided to—is time-intensive, financially challenging, and in most cases requires full-time attention. Securing safe, reliable, and appropriate care is a top priority for Latino caregivers in our study. This influences nearly all of their decisions, impacting personal employment choices, lifestyle, and schedule. For many workers who provide care—especially those in low-wage industries—working within the confines of providing care also hinders their economic mobility. Lacking the necessary support or financial resources to meet the care needs of their family members, caregivers in this study were apt to stay in jobs that do not provide them with the financial compensation or benefits they deserve or need. Many of the caregivers we spoke with described informal agreements with managers at work, who allow them to take care-related calls during work hours or unpaid time off to meet their caregiving responsibilities, while others work in jobs simply because the work schedule is aligned with that of their caregiving.

The Brookings Institution has noted that unemployment insurance only covers workers who have lost employment or wages due to instances outside of their control.²⁹ Unfortunately, that does not cover people who consider that risk of contracting COVID-19—or passing it on to someone they care for—is a legitimate reason to stop working, leaving them with little options other than to continue exposing themselves. For some in our study, their caregiving responsibilities take priority in their life, both with their time and finances. They reported not being able to save money for their futures in order to meet the needs of those they provide care for.



Employers also play a critical role supporting working caregivers. Given the focus and time that caregiving requires, caregivers place a premium on jobs and managers that provide them with flexibility. However, there is a stark difference between an accommodation and true support. Not getting fired from a job for meeting caregiving responsibilities at home represents a failure by employers and the government to value the critical role of caregivers in our communities and economy. When a worker must take unpaid time off or stay in a job that pays too little or provides no opportunity for upward mobility in order to continue giving care, it presents an economic hardship. Employer-employee agreements that provide bare minimum benefits have long-term impacts on families. Formal support programs that provide workers with the flexibility and time necessary to meet their home responsibilities would allow workers the opportunity to further themselves because forcing workers to choose between their loved ones and their economic futures creates a lose-lose situation for families and the economy.

The COVID-19 pandemic with its ensuing economic crisis and industry closures has only amplified the existing burden for caregivers and demonstrated a lack of appreciation for caregivers. Eight months after closures first began, jobs have changed and many of the caregivers in our study reported a disruption to their household income, forcing them to live on their savings and make cuts to their regular expenses. Millions of other workers have lost their jobs or have dropped out altogether in response to increased caregiving needs and less access to care providers and networks. This means that workers have less access to jobs while still facing the same responsibilities—financial- and care-related—at home.

Latinos disproportionately face job and income loss as well as barriers in accessing economic supports such as unemployment insurance benefits. This has forced many to turn to their savings, an asset that many of the Latino caregivers in our study admitted they struggle to build or protect. For working caregivers, COVID-19 has upended many of the services they depend on to keep their families safe and financially stable, raising similar challenges for those still working and those unemployed.

To improve the systems that support workers with caregiving responsibilities, policymakers should consider the following:

- **Expand access to paid family leave to reduce the burden of caregiving on workers.** We must ensure that caregivers have the support and financial resources to care for their family members. Paid family leave is especially critical for Latino workers, who are disproportionately represented in low-wage industries where access to any type of paid leave is rare and hourly work means that time spent caring for others or oneself has a direct impact on earnings. The “Family and Medical Insurance Leave (FAMILY) Act” would offer a permanent solution to many of the issues that caregivers face, providing them with access to earned paid and sick leave. This legislation not only will support workers providing day-to-day care, but would also address their needs in times of economic crisis.
- **Ensure better access to home and community-based care, especially in rural areas, and to address the increasing cost of care, especially child care.** COVID-19 has exemplified the failures of our existing care networks, including the lack of access and rising costs that exist in many communities across the nation. These not only prevent families from building wealth, but in many cases keep parents out of the workforce who would otherwise be contributing to the economy. Workers need access to safe, reliable, and appropriate care for their loved ones in order to lessen the economic impact of caregiving on individuals and the economy.
- **We must understand the true “costs of caregiving” to ensure a full and equitable recovery from the health and economic crisis.** The twin crises have forced millions of workers to drop out of the workforce in order to meet the care needs of their families. Several Latino caregivers we spoke with alluded to the jobs or opportunities that might be available to them if they did not have significant caregiving responsibilities at home. While our report focused on the overall costs of care, it is important that future research focus specifically on the financial and economic costs to caregivers who choose to stay in a job because of those responsibilities, despite the job not matching their income needs or qualifications. Only when we have a strong understanding of the purely economic motivators and costs associated with caregiving can policies meant to support workers be as comprehensive as they must be. This report provides a strong basis and understanding for this future research.

Like millions of workers throughout the country, the Latino workers we spoke with in our study face significant challenges in balancing their jobs and at-home caregiving responsibilities, putting their own financial futures and economic mobility on hold in order to care for their loved ones. Without widespread availability of trusted care providers, access to paid leave, scheduling flexibility, and the implementation of policies that ensure employer and government recognition of the challenges that working caregivers face, workers who provide care at home will continue to be held back from securing their families’ futures and contributing to our growing economy.

APPENDIX A: INTERVIEW METHODOLOGY

Data Collection

Information about the impacts of home care on working Latino caregivers was collected through one-on-one telephone interviews. Staff from the UNC Center for Community Capital conducted a total of 14 interviews in three locations identified by UnidosUS: Raleigh, NC (7); Los Angeles, CA (6); and New York, NY (1). UNC Center for Community Capital staff sought to recruit individuals who would represent diversity along the following lines: geographic location (urban and rural); age (younger and older caregivers); and type of person cared for (children, adults, or both).

Recruitment

The sample of interviewees was intended to provide a rich understanding of the true costs of home care for Latino caregivers. The sampling process was therefore purposeful, with the goal of yielding “insights and in-depth understanding rather than empirical generalizations.”³⁰

In each site of interest, UNC Center for Community Capital staff contacted UnidosUS Affiliates, who helped with interviewee recruitment. Affiliates were given criteria for recruiting and screening potential participants from among their client pools. The sample was limited to individuals who were 1) Latino/a; 2) over the age of 18; 3) working full time or part time for pay outside the home (or had been working recently, but had been laid off due to the COVID-19 pandemic); 4) the current caregivers of one or more individuals in their home who were dependent children (under the age of 13) or dependent adults (over the age of 18); and 5) willing and able to be interviewed by phone on a specified date and time.

Interview Methods

The interview guide consisted of a standardized set of open-ended questions that were asked of each interviewee. Where appropriate, the interviewer asked follow-up questions to probe for additional information or to clarify the information being offered. In addition to asking basic demographic questions, the interview guide addressed a range of topics related to the costs of home care, including:

- The effect of the COVID-19 pandemic on caregiving and employment
- The intersection of caregiving and employment before COVID-19
- The financial, social, emotional, health, and career costs of caregiving
- The availability and cost of nonfamilial care
- What changes would help improve caregivers’ lives

Interviewees were offered the option of conducting their interviews in English or Spanish. Where interviewees chose Spanish, a professional interpreter joined the call to assist with the process. Eleven out of 14 interviews were conducted in Spanish.

Interview length ranged from 52 to 79 minutes, with an average interview time of 62 minutes. Where participants gave permission, the interviews were recorded: in total, 12 out of 14 interviews were recorded. The interviewer took notes during each interview session for several reasons: to provide backup if the audio failed and to make note of anything particularly striking that an interview transcript might fail to convey.

Data Analysis

Of the 14 interviews conducted, 12 were digitally recorded and professionally transcribed to allow for in-depth analysis; transcripts were checked against audio recordings for accuracy. Where interviewees wouldn't allow recording, the interviewer took extensive notes, and these served as data for the analysis. Transcripts or notes were summarized in a matrix of key domains based on the interview guide; the matrix was reviewed jointly by the project's analysts to ensure accuracy of analysis and to discuss emerging themes. Interview transcripts or notes were then linked to ATLAS.ti, where they were coded. Coding focused on two types of themes: 1) those arising from the specific questions asked in the interview guide (these were also summarized in the matrix), and 2) consistent, unanticipated themes that arose that were not specifically asked about in the interview guide.

Where interview data are included in the report, all interviewees are referred to by a pseudonym in keeping with our promise not to identify interviewees by name. At times, to ensure interviewees' anonymity, we refer to participants without a pseudonym. We do this so that no one person's story can be traced through this report.

Interview quotes are verbatim, though tics of speech like "I think" or "you know" or "um" or "uh" have been removed. Similarly, repeated words or phrases and partial sentences have been removed while maintaining the speakers' meaning and intent. At times, longer passages have been removed to facilitate smoother conveyance of people's thoughts, though the integrity of their meaning has been maintained; in these instances, ellipses have been inserted to signify the deletion.

APPENDIX B: COVID-19 PANDEMIC IMPACT ON UNIDOS US AFFILIATES

When we began planning this research project in early 2020, UnidosUS Affiliates were designated to help at the local level in each of the four sites chosen for this study: Los Angeles, New York, Houston, and Raleigh/Durham. These community-based, nonprofit organizations were to partner in the research by helping recruit participants for interviews from among their clients.

Unfortunately, these organizations have been affected by the pandemic as most businesses have, experiencing short- or long-term closures, either due to local government requirements or in response to staff members becoming ill with COVID-19. These agencies have also seen increased demand for their services as their clients have lost jobs and income, and they've had to figure out how to continue to offer assistance while minimizing the risk of contracting or spreading COVID-19.

When we realized that the pressures on these organizations had increased, we decided it would be valuable to capture information on how they were operating in the midst of a global health crisis. We wanted to document this because insofar as these organizations play a part in caregivers' support networks, disruptions to the services they offer affect the caregivers they support. We therefore spoke with willing Affiliates by phone to ask about the following in relation to the pandemic: changes to their operation and staffing; whether staff members had been out for reasons related to COVID-19 (e.g., illness or school closures); whether they'd seen an increased demand for their services; and whether they'd added new services as a result of the pandemic. We report here what we heard from two of the organizations we spoke with, concealing details about each agency to protect their identities.

The first organization we spoke with came under new leadership just before the pandemic started. They opened under a new director in mid-March and closed immediately after that. This agency describes their work as "very grassroots" and tied into the community, and so they found working remotely daunting. Further complicating the transition to remote service provision was that they had no IT department to help staff move online. To ensure smooth operation and provision of services, this Affiliate got a grant from UnidosUS to help with their technological and phone issues. Because of this, they've been able to stay connected with the people they serve. At the time we spoke with this organization's staff, their staff were doing a mix of remote and on-site work.

When this Affiliate was ready to reopen their doors, they did so slowly, first with a one-day-per-week distribution of food, toiletries, cleaning supplies, diapers, pet food, shoes, and clothes. They made sure to distribute items safely, encouraging younger relatives to pick up for the elderly and making deliveries if needed. As is the case for many organizations in the United States, the transition back to

providing in-person services has not been smooth for this Affiliate: a few staff and volunteers have tested positive for COVID-19, and when this has happened, they've needed to shut down again.

When asked if they've seen an increase in demand for their services as a result of the pandemic, Affiliate staff answered with a resounding "yes." They are very much community-based and are easily accessible to the people who live in their neighborhood. Since the pandemic started, in particular they have experienced a rise in requests for assistance from community members in their 20s and 30s. The staff said that young children are coming in to seek assistance for family members who may not have needed assistance in the past. Affiliate staff attribute this increased demand to COVID-related job losses in their community.

The second organization we spoke with had to close for a much longer period than the first. They were shut from March through August in compliance with local government requirements for nonessential businesses. During this time period, they remained open for emergencies and certain appointments only, with many of their services transferred to online offerings (for example, the one-on-one financial coaching they offer went virtual). Fortunately, they were able to pivot quickly to offering online services, and they say they will continue to offer some of their assistance in this manner going forward, even after the pandemic is over. Since reopening, this Affiliate has continued to adjust operations in order to reduce the risk posed by COVID-19: they are practicing physical distancing and they are still using an appointment-based service model rather than allowing walk-in service requests.

When asked about the demand for their services during the pandemic, this Affiliate explained that early in the pandemic, requests for their services increased markedly, especially requests for financial support. As was the case with the first Affiliate, this increase was attributed to COVID-related job loss in their community. To meet this demand, this second Affiliate increased the resources they could provide and offered referrals for services they could not provide themselves (e.g., utility support or rental assistance).

The second Affiliate had difficulty recruiting participants for our research study. When asked why this might be the case, staff members explained that they and their clients are "just in survival mode." They told us that while their clients' benefits are running out, their bills remain the same, which has increased demand for this agency's services. Like so many who have had to adjust during the time of COVID-19, this Affiliate has had to focus on providing essential services, and has not been able to prioritize anything that isn't essential. As staff have put it, they just "can't think about extras" right now.

ENDNOTES

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