



“It’s always something”

The Hidden Costs of Informal Caregiving

Sarah Savage, Katherine Townsend Kiernan and Erin Graves

The American Voices Project (AVP) relies on immersive interviews to deliver a comprehensive portrait of life across the country. The interview protocol blends qualitative, survey, administrative, and experimental approaches to collecting data on such topics as family, living situations, community, health, emotional well-being, living costs, and income. The AVP is a nationally representative sample of hundreds of communities in the United States. Within each of these sites, a representative sample of addresses is selected. In March 2020, recruitment and interviewing began to be carried out remotely (instead of face-to-face), and questions were added on the pandemic, health and health care, race and systemic racism, employment and earnings, schooling and childcare, and safety net usage (including new stimulus programs).

The “Monitoring the Crisis” series—which is co-sponsored by the Stanford Center on Poverty and Inequality, the Federal Reserve Bank of Atlanta, and the Federal Reserve Bank of Boston—uses AVP interviews to report on the impact of the pandemic throughout the country. To protect respondents’ anonymity, quotations have been altered slightly by changing inconsequential details. To learn more about the American Voices Project and its methodology, please visit inequality.stanford.edu/avp/methodology.

The American Voices Project gratefully acknowledges support from the Annie E. Casey Foundation; the Bill & Melinda Gates Foundation; the Center for Research on Child Wellbeing at Princeton University; the Chan Zuckerberg Initiative; the David and Lucile Packard Foundation; the Federal Reserve Banks of Atlanta, Boston, Cleveland, Dallas, New York, Philadelphia, Richmond, and San Francisco; the Ford Foundation; The James Irvine Foundation; the JPB Foundation; the National Science Foundation; the Pritzker Family Foundation; and the Russell Sage Foundation. The Stanford Center on Poverty and Inequality is a program of the Institute for Research in the Social Sciences.

The authors thank Sara Chaganti, Prabal Chakrabarti, Jessica Coria, Ben Horowitz, Karen Leone de Nie, and Bethany Miller for their comments and Brittany Birken, Amanda Edelman, Macario Mateo Garcia, Gracie Griffin, and Jeff Johnson for their contributions since the early stages of this research. The views expressed here are the authors’ and not necessarily those of the Stanford Center on Poverty and Inequality, the Federal Reserve Bank of Atlanta, the Federal Reserve Bank of Boston, the Federal Reserve System and its Board of Governors, or the organizations that supported this research. Any remaining errors are the authors’ responsibility.

Suggested Citation

Savage, Sarah, Katherine Townsend Kiernan, and Erin Graves. 2024. “‘It’s always something’: The Hidden Costs of Informal Caregiving.” In *Monitoring the Crisis: American Voices Project*. Stanford Center on Poverty and Inequality.

Series Editors

Ann Carpenter, Federal Reserve Bank of Atlanta
Vanessa Coleman, Coleman Strategy Group
Peter Cookson, Georgetown University
Kathryn Edin, Princeton University
Corey Fields, Georgetown University
Jonathan Fisher, Stanford University
Stephanie Garlow, Stanford University
David Grusky, Stanford University
Marybeth Mattingly, Federal Reserve Bank of Boston
Michael Schwalbe, Stanford University
C. Matthew Snipp, Stanford University
Charles Varner, Stanford University

Acknowledgements

The American Voices Project extends our sincere gratitude to everyone who shared their story with us. We would also like to thank our researchers and staff: Don Abram, Elias Aceves, Judy Alterado, Kenny Andejas, Karen Armendariz, Trevor Auldridge, Danya Axelrad-Hausman, Haeli Baek Andrew Barney, Kimberly Batdorf, Maddie Baumgart, Courtney Berthiaume, Hannah Bichkoff, Claudia Bobadilla, Kaitlyn Bolin, Sharie Branch, Mackenzie Brown, Rachel Butler, Kathrine Cagat, Mila Camargo, Annabel Campo, Marina Carlucci, Laurel Cartwright, Amy Casselman Hontalas, Kristin Catena, Esha Chatterjee, Ricardo Chavez, Cindy Cho, Alice Chou, Julia Corbett, Grace Corona, Cocoa Costales, Nima Dahir, Madalyn Damato, Amelia Dmowska, Anthony Duarte, Noa Dukler, Cody Eaton, Amanda Edelman, Anke Ehlert, Afroz Emami, Andrew Eslich, Rossana Espinoza, Hannah Factor, Megan Faircloth, Samantha Faul, Alisa Feldman, Priya Fielding-Singh, Jordan Fieulleateau, Alex Fuentes, Nicole Galicia, macario garcia, Raul Garcia Andrea Goepel, Sofia Goodman Arbona, Ayan Goran, Victoria Gorum, Lauren Griffin, Julia Gutierrez, Erin Hardnett, Kristina Harris, Tara Hein, Colleen Heidorn, Madeleine Henner, Daniel Hennessy, Thomas Henri, James Hiebert, Cameron Hill, Carla Ho, Christopher Hopson, Alexa Hui, Lisa Hummel, Lynn Hur, Karla Jimenez- Magdaleno, Nathaniel Johnson, Amy Johnson, Lillian Kahris, Anna Kallschmidt, Nikoo Karbassi, Noa Katz, Charlotte Kaufman, Sehajleen Kaur, Samantha Kern, John Kingsley, Mawuko Kpodo, Rachael Yoon Ah Ku, Paola Langer, Ellie Lapp, Catherine Lechicki, Sarah Lee, Rachel Lee, Tiffany Loh, Janet Martinez, Kaylee Matheny, Isabel Michel, Claire Miller, Bethany Miller, Eliane Mitchell, Pablo Mitnik, Sara Moore, Diana Mora, Paige Morrisey, Hannah Mueller, Aldo Munoz, Sky Myasia Sealey, Yasmeen Namazie, Sharoon Negrete Gonzalez, Bethany Nichols, Bailey Nicolson, Jennifer No, Jacelyn Omusi, Diana Orozco, Taylor Orth, Eleni Padden, Jillian Pak, Bunnard Phan, Rosina Pradhananga, Malena Price, Reginald Quartey, Vanessa Quince, Jocelyn Quintero, Emily Ramirez, Jennifer Reed, Tye Ripma, Karina Roca, Ricky Rodriguez, Karla Rodriguez Beltran, Cat Sanchez, Ximena Sanchez Martinez, Miguel Santiago, Melissa Santos, Liz Schnee, Michael Schwalbe, Grace Scullion, Victoria Shakespeare, Julie Siwicki, Lauren Sluss, Laura Somers, Sydney Sousa, Ingrid Stevens, Erik Strand, Andrew Suarez, Ashley Sunde, Catherine Sweeney, Alexis Takagi, Elizabeth Talbert, Daniel Te, Lucy Thames, Catherine Thomas, Chris Thomsen, Zachariah Tman, Thalia Tom, Marie Toney, Sonia Torres, Naomi Tsegaye, Saul Urbina-Johanson, Alina Utrata, Chaze Vinci, Brandon Wafford, Seth Walensky, Maya Weinberg, Robin Weiss, Rondeline Williams, Gretchen Wright, Katherine Wullert, Jenny Yang, Irina Zaks, Karina Zemel, Jonny Zients, Cassandra Zimmer.

Pandemic shutdowns brought new attention to caregiving responsibilities.

Many households with paid formal care arrangements shifted to informal sources of care, such as parents and relatives. However, the stories of those already reliant on informal care prior to the pandemic received less attention. Informal care is the norm for many lower income households, so we would expect shutdowns to have different impacts on these households in comparison to those that temporarily lost access to formal care.

Using data from the American Voices Project and its sample of high poverty communities, we examine caregiving needs, usage, and provision with special attention to informal care experiences, whether or not such care was induced by the pandemic. We find that while informal care is often free (or at least unpaid), it is accompanied by significant hidden costs to those seeking care, caregivers, and in some instances, care recipients. For instance, residential moves to be closer to informal caregivers were driven by care needs and accompanied by costs. Our findings are indicative of formal care access challenges and yield policy implications for supporting informal caregivers of children and adults.

Introduction

In the absence of robust public caregiving systems in the United States, working-age adults who need to care for a child or dependent adult must arrange that care themselves. Many who can afford it use formal paid care (i.e. licensed or certified¹ care providers such as child care centers, home health aides or nursing homes) exclusively or as a supplement to familial sources of caregiving. Others, often because they cannot afford formal care, use informal paid and unpaid care – by family mem-

KEY FINDINGS

While some caregiving arrangements during the pandemic were marked by abrupt shifts from formal care (e.g., child care facilities, public schools, home health aides) to free or low cost informal care (e.g., parents themselves, grandparents, relatives, friends), most caregiving arrangements described by respondents were informal even before the pandemic.

Although informal care was typically unpaid, it was often accompanied by less visible costs, whether or not the pandemic induced a change in type of care. Such “hidden” costs have been underappreciated both in the literature and in policy.

One major hidden cost was the interruption or cessation of employment due to caregiving responsibilities by the interviewee or someone in their care system.

There were also concerns over costs to the care recipient when compromised forms of informal care (e.g. technology, screens) were used as a last resort during the pandemic.

Reactive residential moves in pursuit of familial care for children were frequently mentioned by respondents, with implications for household finances and stability.

Additional caregiving demands left some informal caregivers overwhelmed and conflicted. This hidden cost was often expressed as a loss of agency.

bers, friends, or neighbors; and/or reduce their own participation in the workforce to provide the care themselves. Whether formal or informal, care transactions involve multiple actors with benefits and costs that vary depending on one's role as a care recipient, a caregiver, or someone needing care for another person.

Households who gave and received care informally were often outside the realm of policy response.

Families with caregiving responsibilities experienced the pandemic shutdown in vastly different ways, stratified in part by the type of care used. Some experienced an abrupt loss of access to a child care provider or home health aide. Others faced the complicated question of whether and how to continue relying on family, friends, and neighbors as sources of care given the risks of spreading COVID-19. Pandemic response policies, however, assumed engagement with the formal caregiving system. The Coronavirus Aid, Relief, and Economic Security Act (CARES) and the Consolidated Appropriations Act and the American Rescue Plan Act (ARPA) invested more than \$50 billion in child care,² while ARPA also increased funding for home- and community-based services.^{3, 4}

However, those who were already outside the formal caregiving system were less often the subject of pandemic policy or concern. As prior research shows, informal care for young children and adults is more common among low-income families.^{5, 6} Households who gave and received care informally were often outside the realm of policy response even though the pandemic posed significant struggles for them.

In early 2021, the American Voices Project conducted in-depth interviews of mostly low-income households across the United States.⁷ These interviews offer a window into households with care responsibilities. Interviewees from high-poverty communities almost exclusively relied on informal care both before and during the pandemic. While less affected by disruptions in formal care caused by the widespread shutdown, we find significant challenges for families engaged in informal caregiving arrangements. Because this type of care is largely unpaid, the costs that accrue to either the caregiver or the care recipient are often less visible, and as such they have been underappreciated both in the literature and in policy. These “hidden costs” came in many forms, some specific to the pandemic while others are persistent features of reliance on informal care. Because families were mainly left to deal with both ongoing and new caregiving challenges themselves, the pandemic underscored the implications of disparate access to reliable and affordable formal care and highlighted needed supports for informal caregivers.

Background

In the United States, many working age adults are responsible for the care of children or dependent adults. In 2021, 27 percent of households had at least one child under the age of 13,⁸ and increasing numbers of Americans report serving as unpaid caregivers for an adult, up from 17 percent in 2015 to 19 percent in 2020.⁹ Most parents, especially those of young children, need child care in order to obtain and retain employment.¹⁰ Working age adults with caregiving responsibilities for other adults, such as aging relatives and those with functional needs ranging in intensity from picking up grocery items to helping with a myriad of self-care tasks, may find it necessary to juggle work and caregiving or give up work altogether.¹¹

Researchers and advocates have long argued that lack of access to reliable, affordable formal care (such as licensed center-based care or family child care for young children and home health aides or nursing homes for adult care recipients)

adds yet another burden to an already vulnerable set of workers.¹² Studies consistently find that the responsibility for securing or delivering care disproportionately falls on the shoulders of women¹³ making them especially vulnerable to caregiving-induced employment disruptions, which may be accompanied by lost wages, benefits, or Social Security.¹⁴ The disparities in access to formal care have been influenced by systemic sexism and racism, that relegated care to women and in many cases women of color.¹⁵ This has perpetuated an undervaluing and underinvestment in formal care,¹⁶ leaving families to navigate care options in the private market or find informal care outside of it.

Many American families lack access to high quality formal paid caregiving. Private market options can be difficult to afford and require information and time to navigate.¹⁷ Subsidies, such as the Child Care and Development Fund, are limited. Only about 15 percent of federally eligible children receive subsidies, and not all providers accept them.¹⁸ Dependent adult care is similarly labor intensive. While Medicaid defrays some of these costs, formal care remains unaffordable for many, especially since Medicaid will not cover the cost of long-term services unless the care recipient is financially impoverished.¹⁹

Caregiving strategies are a function of family and community contexts from which caregiving preferences emerge; which options are affordable and available; and employment and familial needs.²⁰ Some families may have little option but to endure lower quality care; to engage informal sources of caregiving support through friends, families or neighbors; or to provide the care themselves, regardless of preferences.²¹

Child Care

The U.S. lacks a robust child care system, with higher income families being twice as likely to use licensed care than lower income families.²² Just over half of children with household incomes of \$100,000 or less had at least one weekly nonparental care arrangement, as compared to 74

Providing informal care can be stressful and constraining, with negative effects for both children and caregivers.

percent of children with household incomes above \$100,000.²³ However, the type of nonparental care varied considerably. Of those children receiving any nonparental care, over 42 percent of those in lower-income households received that care from a relative, as compared to just 29 percent of children with household incomes above \$100,000.²⁴ Often unregulated and unlicensed,²⁵ informal child care such as relative care may offer benefits to lower income families because it is low- or no-cost as well as potentially more flexible to accommodate nontraditional work schedules.

Family needs, resources, cultural norms, and preferences, as well as child care supply all affect child care decision-making.²⁶ While preference may drive some child care decision-making, the choice to use informal care is often borne of necessity. Higher income families are more likely to pay for licensed care and lower income families are more likely to use informal care.²⁷ Access challenges play a significant role in the reliance on informal care.²⁸ Providing informal care can be stressful and constraining, with negative effects for both children (e.g., lower test scores as they enter school) and caregivers (e.g., burdens on relationships or care needs interfering with work).^{29, 30}

As formal child care facilities closed to stop the spread of disease, the pandemic highlighted just how essential child care is to the overall economy. For working parents, and especially mothers, pandemic-related child care closures significantly increased the burden of child care,³¹ leading U.S. parents to extensively rely on informal child care during COVID-19. In one study, approximately 60

percent of parents in 2020 used informal child care.³²

Despite the increase in informal child care during the pandemic, the literature has been limited. A few case-based studies focus on parents who temporarily pivoted from formal to informal care as a strategy for enduring shutdowns.³³ Yet, given the pre-pandemic prevalence of informal child care support, particularly among lower-SES parents and parents of color,³⁴ a very large number of families and their caregivers experienced the shock of the pandemic in ways that differed profoundly from the experience of economically advantaged families.

Adult Care

Those with adult caregiving responsibilities also have both formal and informal options. Social Security and Medicaid may be used to cover care costs for adults who cannot work due to advanced age or disability.³⁵ However, the under-supply of home health aides, the high costs of long term care services and more general supports, and the aging of the U.S. population have increased the prevalence of informal caregiving for adults.³⁶ About 42 million Americans engage in some form of unpaid care for an adult age 50 or older, forming a “shadow workforce.”³⁷ Like child care, the burden of informal adult caregiving work disproportionately falls on the shoulders of women,³⁸ and this work provides a huge societal benefit. The economic value of unpaid family caregiving was estimated to be \$600 billion in 2021.³⁹

The evidence on the impacts of informal adult caregiving on the caregiver is mixed. Some research indicates positive outcomes such as increased confidence and closeness with the care recipient.⁴⁰ Yet other research finds informal caregiving is associated with poorer overall health⁴¹ and a reduction in preventive health behaviors among caregivers.⁴² There is an increased risk of depression (when caring for adults with dementia),⁴³ caregiver burnout,⁴⁴ and decreased social

participation.⁴⁵ Caregiving also tends to disrupt employment.⁴⁶ The longer one serves as an unpaid caregiver for adults, the more they are at risk for negative consequences such as stress, anxiety, and health problems.⁴⁷ And low income caregivers are likely to care for recipients longer than higher income caregivers do.⁴⁸

There is a relatively large body of research on informal adult caregiving in the United States during the COVID-19 pandemic. These mostly quantitative studies have considered caregiver’s stress, mental health status, and access to supports.⁴⁹ One study on informal adult caregiving during the pandemic finds that it had a net negative impact on the health and quality of life of informal caregivers, and that impact varied by numerous sociodemographic factors.⁵⁰

About 42 million Americans engage in some form of unpaid care for an adult age 50 or older.

During the pandemic, public interest grew regarding the difficulties working age adults encountered in arranging care for their dependents. Much of this interest focused on those who had lost formal care during the pandemic. Yet many working age and low income households had informal care arrangements to begin with. By talking with individuals residing in high poverty communities during the pandemic, the American Voices Project provided an opportunity to gather the recollections of the experience of informal caregiving both before and during the pandemic in order to develop a grounded perspective on informal caregiving.

Methodology and Limitations

The American Voices Project offers a window into the lives of individuals, most of whom reside in high poverty communities. The AVP began collecting qualitative data through interviews from a nationally representative sample of Americans on their day-to-day life and activities in 2019. Researchers drew respondents from a stratified sample of communities that represent a wide range of regions and community types. The sample was randomly drawn with an oversample of low-income households.

In 2020, as the pandemic took hold, AVP interviews switched from face to face to telephone conversations, and questions were added on the pandemic, health and health care, race and systemic racism, employment and earnings, schooling and child care, and safety net usage to monitor how people were faring during the pandemic and into the recovery. This report leverages interviews conducted from January 2021 to March 2021. A team of researchers devised a caregiving codebook for the transcribed interviews that revealed the caregiving responsibilities of respondents. 198 transcripts from this period mentioned caregiving. We read through these transcripts and conducted a content analysis, identifying patterns of frequent themes.

To understand how participants described their family's caregiving needs, we identified all cases coded as having any mention of care recipients. We found a subset of 105 cases, where 52 (26.3 percent of the total sample) had situations that were currently or recently impacted by the need to care for others. The subset included cases of caregivers, persons with caregiving responsibilities, or someone who had sufficient information about the care situation. The remaining 53 cases did not have recent needs for caregiving (e.g., older interviewees who recounted caregiving responsibilities more than 30 years ago) or did not have enough information on the caregiving situation to provide insight for the analysis (e.g., just one or two lines of the transcript coded for caregiving).

Appendix Table 1 shows the demographic breakdown of our analytic subset along with a

breakdown for the total sample. The subset with caregiving needs had a lower average and median income, which is consistent with the literature, but only a slightly younger age. The full sample of 198 cases had an oversampling of females (58 percent), but 80 percent of the subset with caregiving needs were female.⁵¹ Though there was an overrepresentation of low income (annual household income under \$30,000, 51%) in our subset, we did not exclude middle (\$30,000-\$85,000, 27%) and high income (\$85,000 and above, 22%) respondents.

We focused on a time period a year into the pandemic to determine how people were faring at that time. The number of cases relevant for this report was smaller than expected, and thus our findings are in some ways circumscribed and limited to generating hypotheses worthy of testing in future research. For example, the 52 interviews we analyzed did not reveal differential patterns by demographic group. However, we cannot rule out that such differences might be observed given a larger sample.

The Hidden Costs of “Free” Care

More than half of the caregiving accounts we analyzed described informal care for children or adults. This included the use of friends or family or, in many instances, respondents or their partners caregiving themselves as parents, sons, daughters, or granddaughters. With few having formal care, it was uncommon for interviewees to confront facility closures or gaps in home health aide availability, a conventional story during the pandemic. Although some reported COVID-induced disruptions in care, in general the continuity of informal care indicated a resilience to the pandemic. We found that interviewees made some associations between care demands and pandemic related financial constraints, yet these too were minimal. This may be due to the continuity of unpaid or low cost informal care arrangements through friends or family.

However, we did find that interviewees frequently reported how the pandemic exacerbated other caregiving constraints. In effect, informal “free” care was accompanied by an array of alter-

native costs to caregivers, both prior to and during COVID. As this partnered father of two young children shared, his family's norm was a significant reliance on his children's grandmothers, particularly to facilitate his nontraditional schedule.

"...I drop them off at grandmothers before I go to work and pick them up once I get off. It's daily like that or my mother will come over and spend a night while I go to work so I won't have to like, get up early just to drop them off or stay out late picking them up going home or bring them out in the cold. She will need to come over and watch them and then she'll just leave when I get off work. She'll spend the night or I'll drop them off."

Interviewees also described ways in which informal care presented benefits, such as not having to worry about trusting strangers to provide care, particularly given public health risks; greater continuity of care during COVID, and not having to pay for care. However, we found that as interviewees described their routines both before and during COVID, these benefits were accompanied by costs to caregivers or to the care recipients. While policy makers have long recognized costs of informal caregiving, particularly for adult care recipients,⁵² we find that such costs are often "hidden": Respondents were not necessarily cognizant of the costs of a particular arrangement, particularly if it was low cost or free.

Four types of hidden costs emerged from our analysis. These costs are primarily to the caregiver but at times also to the care recipient or person needing care for another. Below we detail the forms these hidden costs took – including suspended career plans; concerns that care may be compromised; the familial sacrifices of relocating, combining households, and sometimes even moving apart; and strained relationships and feelings of reduced agency – and describe how some respondents mitigated them.

1. Career Disruptions

The use of informal caregiving affected employment and career advancement for two types of

caregivers. The first were caregivers who cared for their own children or related adults, and the second were caregivers to other people's children or to unrelated or less closely related adults. Respondents discussed reduced hours and workforce departures and revealed the difficulty of balancing work and caregiving. Reducing time or exiting the formal workforce affected economic security and was a source of stress. Not being in the labor force carried meaning beyond lost income and benefits, especially for women, as some recalled experiencing paid work as a source of fulfillment and identity. Others discussed the sense of loss that accompanied leaving the workforce to provide care. The pandemic added to the stresses for some informal caregivers, causing them to shift and reduce work and sometimes suspend their own educational plans and development.

A very typical caregiving strategy among interviewees in two parent households who care for their own children was for one parent, typically a female partner, to significantly reduce or suspend workforce engagement. For example, one interviewee explained he and his partner's division of labor which preceded the pandemic. He shared the following:

"We made a plan... I said 'I'm going to take care of everything [financially]. All I want you to do to is to take care of my daughter.'"

This arrangement was common among interviewees and begs the question of what these arrangements meant for the parent in the caregiving role when that parent was not the one interviewed for the study. Some cases better aligned with the stories prevalent in public media, such as among respondents who had a combination of public school options for children and informal care. This was particularly problematic for those respondents who had no remote work options. The loss of in-person school reduced their incomes and increased their stress. One mother who was the primary and sole caregiver for her children continued to work outside the home

while her children participated in virtual schooling. She reduced her hours in order to minimize the amount of time they were home alone. She explained:

“I have the kids and I can’t leave them unattended for extended periods.”

This approach left her managing both the stress of leaving them at home and of lost income. In another case, a married father who was the primary caregiver of two school aged boys left his part time job early in the pandemic, “in March when they ended school. So, I could make sure I was taking care of my kids.”

Several parents reported having left the workforce prior to COVID-19 to care for their own children. Many detailed the mental costs of leaving paid work. Finding the routine monotonous, one mother shared:

“It’s boring. It’s terrible... I do feel like there’s a lot more that I could be doing that I’m not doing... That’s why I wanna go back to work so badly... I just feel like I’ve kind of lost my mojo. ...Probably a lot of women are going through this too where we kinda need to get back out there especially if you’ve been home with kids.”

Many detailed the mental costs of leaving paid work.

Another married mother who left the workforce described her difficulty with this decision.

“I think, right now, the most difficult decision was to not go back to work. It’s something I never imagined myself doing. It was not something we initially planned for. We had daycare all set up and I was supposed to come back from maternity leave. So, that was a really big decision for me.”

This case exemplifies how even though the mother prefers to provide care herself, the decision was at the expense of another part of her life. Thus,

even though these interviewees were able to provide continuity of care through the pandemic, they remained mindful of the long-term career costs.

While most interviewees described informal care usage pre- and post-pandemic, one mother who had subsidized child care described disrupting her own education when COVID-19 limited her options.

“The daycare is constantly shutting down...I need that free time to study without having a two-year-old and a four-year-old screaming, you could probably hear them in the background now, without them screaming my head off.”

Another partnered mother, whose children were home when schools shut down, reported that she stopped her own education when the pandemic started. These parents suspended their own development since balancing education and caregiving was not possible during COVID-19.

Those who used informal caregiving for adult care recipients also described job disruptions they experienced as primary caregivers. For several respondents, health issues for adult dependents affected their ability to work. One man with older children had been in business for himself. After his father had a stroke, he had to transition to caring for his father, which reduced his ability to generate income.

“I’m having to take care of him a lot now, so I haven’t been able to really do any of my business...that kind of just got left to the wayside, and now I’m just kind of helping my dad.”

Another woman experienced disruption in her work as a substitute teacher when her partner had a stroke.

“I haven’t done it since [partner name] had a stroke.”

Some other interviewees with adult caregiving responsibilities shared a different type of employment disruption, owing to the risks of exposure that interfered with their caregiving responsibilities. One woman described her decision to leave her job where she interacted with high-risk popula-

tions to protect her father from the risk of exposure to COVID-19.

“I really cut down on my hours there because I wasn’t able to pick up any shifts because of my dad. And we’ve had outbreaks of corona at [work], so I just decided to, you know, not do anything for a couple months.”

2. Care Compromises

Some participants described how the pandemic led to more gaps in care and greater concerns about the care that was available. With school closures keeping some children home, some working parents had to scramble to meet sudden caregiving needs, leading to a reliance on technology.

One low-income mother who needed to continue working outside the home but who did not have a non-school caregiving arrangement for her children used technology to aid in remote supervision. She adapted her job to be more flexible so her children could contact her any time of the day, and she remotely supervised her children. She shared, “I have a camera at home.” While usually used to monitor a human care provider, in this case, the “nanny cam” itself was a substitute care provider. Although this gave the interviewee some piece of mind, remotely supervising her children involved compromising.

Similarly, another woman whose live-in grandmother’s home health aide was discontinued due to the pandemic, had to leave the grandmother unattended while she worked. The interviewee explained that the grandmother had a Life Alert – a device worn around a user’s neck with a call button that connects the individual to an emergency call center when pressed. While it was not the respondent’s preference to substitute a necklace for a nurse, the women reasoned, “she should be OK.” These methods were employed only because a person was not available to provide care for their loved ones. Having to make these technology substitutions was concerning to both women.

In addition to surveillance, some parents used technology as a supplement or “babysitter.” One

grandmother described how her grandchildren were instructed to call her and her husband when the grandchildren’s parents were working:

“Sometimes their parents are both on important calls, so they need to be quiet, and so they’re sent to one of their bedrooms, and they call us”.

Similarly, an older father with young children described a freedom he gave his boys with technology during the pandemic mixed with concerns over their usage.

“Well, last summer it was the pandemic. ... they had all YouTube and video games as they would like.” “I’ll think they’ve gone to sleep and when I wake up at 11:30, 12 o’clock, they’re still looking at the monitors.” “... I told them the other day that they had to set the alarm on their phones, but we’ll see how that works.”

While technology helped alleviate the need for an in-person caregiver, it was generally considered a last resort. Technology was an aid that allowed the caregiver to continue working. These situations reflect how low-income families needed to cope with the loss of formal care during the pandemic. While reducing labor market participation is often a route chosen by families, that option was off the table for many caregivers who needed to provide a paycheck for their families. It may not have met their preferences, but it helped fulfill a need.

3. Reactive Residential Mobility

Informal caregiving, while generally more affordable, can be challenging to access. Participants frequently facilitated access by moving to meet their care needs, which at times had the dual benefit of lowering their living expenses. AVP participants described three distinct forms of mobility, with some caregivers moving closer to friends and family, others moving in with friends and family, and others moving their dependents out of the household to be cared for by other family members. Most participants had adopted these strategies before the pandemic, though some moved due to pandemic disruptions.

One single mother who had two jobs opted to move in with a friend so she could quit one of her jobs. Her friend described the reasoning in her interview saying, “she just was never around for her kids wasn’t able to see them or anything just lived at work.” The very low-cost care from the mother’s friend combined with more care by the mother herself enabled her to spend more time with her children and leave her second job which she presumably worked to pay for someone to watch her children.

Other caregivers opted to give up the primary caregiving role and instead move their children in with alternative informal caregivers. One mother reported moving her son into his aunt’s house that was in a better neighborhood. The mother implied she was unhappy with the situation.

“My oldest sister helped me with raising my son. My son lived with...her, but rest assured I had gone over their house every day to make sure he did his homework.”

Another partnered mother moved her children in with her mother.

“...my mom can help them with their homework because of COVID-19 and their schoolwork on the laptop at home. ...so she’s been helping a lot with that and then I take a week off of work every time they come over.”

While moving in with family or moving dependents in with family was an effective strategy, it was also disruptive. These situations reflect how families must make choices given limited options. While one of the mothers was glad to spend more time with her children, she changed her household composition by moving in with a roommate. Similarly, the second mother was happy to have her son in a safer neighborhood, but wished she had more time to spend with him. Throughout these conversations, interviewees indicated that these were not ideal circumstances for their households, but rather choices made out of necessity. Furthermore, we do not know how these circumstances affected the caregivers – the grandmother, the aunt, and the friend.

While moving was an effective strategy, it was also disruptive.

4. Loss of Agency

Informal caregiving was at times stressful and all-consuming. Interviewees shared that caregiving left them little time for relationships and for themselves. The examples to follow did not seem induced by the pandemic but were described as interviewees’ normal caregiving arrangements, though they could have been related with added intensity given the timing of the interviews during the pandemic.

Two different married fathers involved in the caregiving of their children described facing long days between work and caregiving. A married father of two described his schedule, which involved late nights, early mornings, and long workdays.

“Well, since I got kids I’m always up early and go to sleep late, and when I work, I go to work at four o’clock in the morning, to about six o’clock at night.”

While parental care often eliminates the need for paid care, it may prove challenging for family time as described by another married father of two. He described how he and his wife tag team by working opposite shifts as a strategy to ensure care coverage for their two children. He noted that this affords him little time with his spouse. This situation was not the ideal family dynamic, but rather a choice made out of necessity and limited affordable and accessible options.

A grandfather, who lived with his wife, son, and granddaughter significantly altered his daily and nightly routines to be a primary caregiver. Both he and his wife performed round the clock caregiving to their granddaughter which displaced the grandfather from his bed and disrupted his sleep

routine. He described his days involving “waking up about 5:00 in the morning, going out in the living room, and getting on the recliner to sleep.” He described doing this so after his son left for work his granddaughter could move into his bedroom with her grandmother. The grandparents were responsible for getting their granddaughter ready for school and later feeding her supper and entertaining her, which took until around 7:30 each evening.

Respondents engaged in informal caregiving for adults also described the demands of their care responsibilities, that although free to care recipients, cost the caregivers their personal time and perhaps their sense of self. One father of older children and son of two elderly parents expressed feeling overwhelmed by the significant amounts of time helping his children and his parents.

“Like I just don’t have the money to do it, mostly I’m helping them, you know, pick something all the time. It’s like my daughter, Dad, can you fix my car? Yeah. Can you change my oil Dad? My car’s not running right Dad, could you take a look at it. Dad, can you, you know, re-stain my kitchen table? Dad, can you fix the door in my house and my mom and dad are the same way. They’re like, hey, son, you know, we need you to fix our sliding door. We need you to fix our bathroom sink, it’s always something.”

Care responsibilities cost caregivers personal time and perhaps their sense of self.

In summary, raising children and caring for ailing adults is often hard work with little or no remuneration that also involves lost personal time and other opportunity costs. These costs can be overlooked but difficult to bear. Pandemic-related challenges typically exacerbated these hidden costs

of caring. Consider, for example, the son who cared for his father before the pandemic but whose father was unable to get needed surgery when hospitals were at capacity, or the mother who relied on her mother to care for her children after school but who moved her children in with their grandmother during the pandemic so the grandmother could attend to their virtual schooling needs. Even before the pandemic, accounts of caregiving revealed hidden costs, which signals a greater need to understand informal care arrangements, both in terms of its utilization and provision, whether provided by parents, friends, family, or neighbors.

Mitigating Hidden Costs

Some interviewees provided examples of ways to mitigate the costs. Two examples are particularly noteworthy given their intentional efforts to decrease caregiver burdens. The first is from a married father who described his family’s reliance on his wife’s mother for care. The family chose this option because formal paid care was unaffordable, but also for the schedule flexibility the grandmother could accommodate. This family worked to minimize what might amount to hidden costs to the grandmother by paying her to watch her grandchildren.

“I work roughly first and part of second shift every single day of the week. So, we’ve got to be able to drop them off before school. And so, in turn, [wife’s] mother actually watches them. She went and got certified for daycare and all that stuff. But we still pay her [each] month,... and it’s roughly about \$400 cheaper than we would pay anywhere. Because she’s got to watch the baby all day long, and she’s got to watch the older ones just before school and after school when they get back.”

In the second case, a mother was able to retain employment while her employer allowed caregiving to be a permissible reason to be absent from work. Her employer safeguarded her from employment disruptions during this time.

“[Employer name] fortunately had given us a lot of support, like in terms of if we had children, you can use this pay code on your timesheets, so that way, you’re not shorted any pay, because you’re stuck at home with a bunch of kids during the pandemic. But that benefit is no longer available to us as of this January, so I quickly took her back to a full time daycare provider that I was familiar with from my previous daughter that’s a little bit of a relief, but then it adds up household costs again.”

While the employer policy did not persist, it helped this mother bridge her need to rely on informal caregiving while sparing her some of the hidden costs.

Discussion and Policy Implications

Many working age adults with caregiving responsibilities in the United States, especially low-income ones, rely on informal care, yet their stories were often missed in pandemic care discussions. Their reliance on informal care occurs for many reasons, with the prohibitive expense of high-quality formal care being one of the most salient.⁵³ The pandemic-induced closure of schools and daycares, and the heightened risks surrounding elderly adults or adults with health conditions, created novel and acute problems for consumers of formal care and received significant public attention. Concerns arose about widespread challenges for parents—mothers in particular—due to school and daycare closures⁵⁴ as well as for adults needing long-term care services. We argue that the challenges faced by those who entered into the pandemic reliant on informal care, though less researched, are of equal concern.

Analyzing a set of in-depth interviews conducted in primarily low-income households offered insight into experiences with informal care. Interviewees described their attempts to meet their caregiving responsibilities, maintain financial and family stability, and meet other life goals and demands. The interviews took place during the pandemic, which framed longstanding issues in sharp relief and provided additional insight into

new problems and improvisations. Low-income families described their care challenges during the pandemic as exacerbated relative to pre-pandemic times. Their need and access to care may not have changed in the conventional way, but the hidden costs of care were amplified.

Informal care took many forms, with some interviewees providing the care themselves as parents, grandparents, sons, daughters, or granddaughters; and others relying on friends or family, almost always uncompensated. Given these arrangements, interviewees reported few care-related financial expenses. However, their descriptions revealed other tolls these arrangements took on working adults with caregiving needs, caregivers themselves and, in some instances, care recipients. Thus, while these respondents lowered the financial cost of caregiving, free or low-cost care appeared to have other consequences that are deserving of future research.

The pandemic revealed the various challenges that families face when formal care is too costly.

Additionally, these tradeoffs were not presented as interviewees’ ideal circumstances. Many times, respondents detailed what they were missing by making a choice to use a particular kind of informal care, but accepted it as the better option given their circumstances and family needs.

The disruptions to work and school during COVID-19 may have additionally burdened informal caregivers, who became even more essential to household functioning during that time. These significant safety nets provided in kind by family are not without consequence. Informal care can be accompanied by variable reliability and interpersonal tension, which can be stressful for the

working adult with caregiving needs, and can also pose variable burdens on the caregivers.

Past studies suggest informal care has benefits and consequences for caregivers, partially dependent on whether the care is reciprocated in some way.⁵⁵ Further research on the effects of unpaid caregiving on those providing care could help reveal its true economic and social cost, not just to individuals but to family systems as well. The pandemic offered a unique lens to observe these effects. Understanding whether additional costs are accrued might strengthen the case for policies increasing the availability of affordable formal care as well as the support for informal caregivers.

Researchers have studied the costs to informal caregivers of adults⁵⁶ but aside from attention to stay-at-home mothers, have paid less attention to the costs to other, informal caregivers of children, an area largely ignored by policy.⁵⁷ What can we learn from studying caregivers of children and adults in a more parallel fashion? Would access to formal caregiving allow those in informal caregiving roles to pursue more employment outside the caregiving role? Would such employment enhance household well-being, both financially and overall? Or in contrast, could remuneration for the provision of informal caregiving enhance family economic security in more equitable ways? These are open questions. However, the tendency for higher income families to use paid formal caregiving offers some clues.⁵⁸ These families pay these costs both in an effort to achieve higher quality care and possibly to facilitate their own labor force

engagement and advancement. Those using formal care are also paying for a caregiving agreement and reliability, which for most the pandemic significantly disrupted.

Many of the interviews we examined offer a window into the stories of those who shifted to informal care due to pandemic-induced closures, service interruptions, and the accompanying challenges. The sample also included experiences of families using informal care before and during the pandemic, which often allowed households to enjoy an essential continuity of care during the pandemic for little to no money. At the same time, the interviews detailed how these arrangements can be burdensome and costly to caregivers and those who need care. The shock of the pandemic revealed the various dimensions of challenges that many low-income families face when forced to rely on informal care when formal care is too costly. Our findings signal a need to close access gaps to formal caregiving and better support informal caregivers, who are disproportionately women. Leaving parents, children, adults, and informal caregivers to deal with hidden costs on their own may perpetuate inequality and economic exclusion.

Notes

1. Childcare.gov. What is Child Care Licensing? <https://childcare.gov/consumer-education/child-care-licensing-and-regulations>. Gallagher, M. (2018). The Truth Behind Home Health Aide Certification Requirements. O'Neill Institute for National & Global Health Law. Georgetown Law.
2. Hardy, A. & K. G. Robbins. (2021). Child Care Relief Funding in American Rescue Plan: State-by-State Estimates. CLASP. (March).
3. Home- and community-based services can include services and supports provided at home such as personal/home care, home health services, home modifications; and in the community such as transportation, meal services, and adult day services.
4. Department of Health Care Finance – DHCF. (2022). American Rescue Plan Act Enhanced Funding for Home and Community-Based Services.
5. Rachidi, A. (2019). How Do Low-income Families Pay for Child Care? American Enterprise Institute – AEI. (October).
6. National Alliance for Caregiving and AARP. (2020). Caregiving in the US: 2020 Report. Research Report. May. Retrieved on 11/7/2024 from: <https://www.aarp.org/pri/topics/ltss/family-caregiving/caregiving-in-the-united-states/?msockid=3ebbr15dcee9c683d2e4f1a45ef05695d>
7. The American Voices Project began in 2019 collecting qualitative data through interviews from a nationally representative sample of Americans on their day-to-day life and activities. We focus on interviews conducted from January to March 2021.
8. Weighted percentages using IPUMS USA sample: Steven Ruggles, Sarah Flood, Matthew Sobek, Danika Brockman, Grace Cooper, Stephanie Richards, and Megan Schouweiler. IPUMS USA: Version 13.0 [dataset]. Minneapolis, MN: IPUMS, 2023. <https://doi.org/10.18128/DOI0.V13.0>.
9. NAC and AARP. (2020).
10. Erdal Tekin, “An Overview of the Child Care Market in the United States,” National Bureau of Economic Research, 2021, https://www.nber.org/sites/default/files/2021-10/White%20Paper-Tekin-101.06.21_revised.pdf
11. Maetas, N., Messel, M. & Y. Truskinovsky. (2021). Caregiving and Labor Force Participation: New Evidence from the Survey of Income and Program Participation. Center for Financial Security, University of Wisconsin-Madison.
12. Bauer JM, Sousa-Poza A. Impacts of informal caregiving on caregiver employment, health, and family. *J Popul Ageing*. 2015;8(3): 113-145. Morrissey, T.W. Child care and parent labor force participation: a review of the research literature. *Rev Econ Household* 15, 1–24 (2017). <https://doi.org/10.1007/s11150-016-9331-3>. Wolters, B., Jerrett, D., Bagley, A., & L. K. Smith. (2021). The economic impact of America's child care gap: The cost of the child care gap to parents, businesses, and taxpayers. Bipartisan Policy Center. Committee on Family Caregiving for Older Adults; Board on Health Care Services; Health and Medicine Division; National Academies of Sciences, Engineering, and Medicine; Schulz R, Eden J, editors. *Families Caring for an Aging America*. Washington (DC): National Academies Press (US); 2016 Nov 8. 6, Family Caregivers' Interactions with Health Care and Long-Term Services and Supports. Available from: <https://www.ncbi.nlm.nih.gov/books/NBK396396/>
13. Schulz, R., and Martire, L.M. (2009). Caregiving and employment. In S.J. Czaja, editor; and J. Sharit, editor. (Eds.), *Aging and work: Implications in a changing landscape*. Baltimore: Johns Hopkins University Press. National Alliance for Caregiving and AARP. (2020).
14. Arno, P. S., Levine, C., & M. M. Memmott. (1999). The Economic Value of Informal Caregiving. *Health Affairs*. Volume 18, No. 2. DataWatch.
15. Amott, T., & J. Matthaei. (1996). *Race, Gender, and Work: A Multicultural Economic History of Women in the U.S.* (Boston: South End Press). Jones, J. (1985). *Labor of Love, Labor of Sorrow: Black Women, Work, and the Family from Slavery to the Present* (New York: Basic Books).
16. McLean, C., Austin, L.J.E., Whitebook, M., & Olson, K.L. (2021). Early Childhood Workforce Index – 2020. Berkeley, CA: Center for the Study of Child Care Employment, University of California, Berkeley. Retrieved from <https://cscce.berkeley.edu/workforce-index-2020/report-pdf/>
17. Grunewald, R., & L. Stepick. (2022). What drives the cost of high-quality early care and education? High quality costs more but produces higher returns. Federal Reserve Bank of Minneapolis. January.
18. Office of Child Care. An Office of the Administration for Children & Families. (2021). *Priorities Report: 2021*.
19. Committee on Family Caregiving for Older Adults; Board on Health Care Services; Health and Medicine Division; National Academies of Sciences, Engineering, and Medicine; Schulz R, Eden J, editors. *Families Caring for an Aging America*. Washington (DC): National Academies Press (US); 2016 Nov 8. Available from: <https://www.ncbi.nlm.nih.gov/books/NBK396401/> NAC and AARP 2020.

20. Weber, R. (2011). Understanding Parents' Child Care Decision-Making: A Foundation for Policy Making, OPRE Research-to-Policy, Research-to-Practice Brief OPRE 2011-12. Washington, DC: Office of Planning, Research and Evaluation, Administration for Children and Families, U.S. Department of Health and Human Services.
21. National Alliance for Caregiving and AARP. (2020). Radey M, McWey LM. Informal Networks of Low-Income Mothers: Support, Burden, and Change. *J Marriage Fam.* 2019 Aug;81(4):953-967. <https://doi.org/10.1111/jomf.12573>. Epub 2019 Apr 8. PMID: 31749503; PMCID: PMC6867802.
22. Rasheed Malik, "Working Families Are Spending Big Money on Child Care" (Washington: Center for American Progress, 2019), available at <https://americanprogress.org/issues/early-childhood/reports/2019/06/20/471141/working-families-spending-big-money-child-care/>.
23. Cui, J., and Natzke, L. (2021). Early Childhood Program Participation: 2019 (NCES 2020-075REV), National Center for Education Statistics, Institute of Education Sciences, U.S. Department of Education. Washington, DC. Retrieved June 18, 2024 from <https://nces.ed.gov/pubsearch/pubsinfo.asp?pubid=2020075REV>
24. Ibid.
25. Administration for Children & Families Office of Child Care. (2015). Supporting License-Exempt Family Child Care. (November). https://childcareta.acf.hhs.gov/sites/default/files/public/supporting_exempt_fcc.pdf
26. Coley, R. L., Votruba-Drzal, E., Collins, M. A., & Miller, P. (2014). Selection into early education and care settings: Differences by developmental period. *Early Childhood Research Quarterly*, 29(3), 319-332.
27. Malik (2019).
28. Zang, E., Yang, Y. M., & Calarco, J. M. (2022). Patterns in Receiving Informal Help with child care Among U.S. Parents During the COVID-19 Pandemic. Available at SSRN 4108245.
29. Raquel Bernal and Michael P. Keane, "Child Care Choices and Children's Cognitive Achievement: The Case of Single Mothers." *Journal of Labor Economics* 29:3 (July 2011); Radey and McWey (2020).
30. Gordon JR, Pruchno RA, Wilson-Genderson M, Murphy WM, Rose M. Balancing Caregiving and Work: Role Conflict and Role Strain Dynamics. *J Fam Issues.* 2012 May;33(5):662-689. <https://doi.org/10.1177/0192513X11425322>. Epub 2011 Oct 21. PMID: 32123460; PMCID: PMC7050936.
31. Collins, C., Landivar, L. C., Ruppanner, L., & Scarborough, W. J. (2021). COVID-19 and the gender gap in work hours. *Gender, Work & Organization*, 28, 101-112.
32. Zang, E., Yang, Y. M., & Calarco, J. M. (2022). Patterns in Receiving Informal Help with child care Among U.S. Parents During the COVID-19 Pandemic. Available at SSRN 4108245.
33. Zang
34. Ackert, E., Ressler, R., Ansari, A., & Crosnoe, R. (2018). Maternal Employment, Community Contexts, and the Child-Care Arrangements of Diverse Groups. *Journal of Marriage and Family*, 80(5), 1210-1224. <https://doi.org/10.1111/jomf.12501>
35. <https://www.medicaidplanningassistance.org/in-home-care/>
36. Tsai, Y. (2015). Social security income and the utilization of home care: Evidence from the social security notch. *Journal of Health Economics*, 43, 45-55. Retrieved from <https://pmc.ncbi.nlm.nih.gov/articles/PMC5784430/>
37. Archer J, Reiboldt W, Claver M, Fay J. Caregiving in Quarantine: Evaluating the Impact of the Covid-19 Pandemic on Adult Child Informal Caregivers of a Parent. *Gerontology and Geriatric Medicine.* 2021;7. <https://journals.sagepub.com/doi/10.1177/2333721421990150>
38. NAC and AARP. 2020.
39. Reinhard, SC, Caldera, S, Houser, A., & RB Choula. (2023). Valuing the Invaluable: 2023 Update: Strengthening Supports for Family Caregivers. AARP. Public Policy Institute. March.
40. Committee on Family Caregiving for Older Adults; Board on Health Care Services; Health and Medicine Division; National Academies of Sciences, Engineering, and Medicine; Schulz R, Eden J, editors. Families Caring for an Aging America. Washington (DC): National Academies Press (US); 2016 Nov 8. Summary. Available from: <https://www.ncbi.nlm.nih.gov/books/NBK396392/>
41. Bauer JM, Sousa-Poza A. Impacts of informal caregiving on caregiver employment, health, and family. *J Popul Ageing.* 2015;8(3): 113-145. Legg L, Weir CJ, Langhorne P, Smith LN, Stott DJ. Is informal caregiving independently associated with poor health? A population-based study. *J Epidemiol Commun H.* 2013;67(1):95-97.
42. Reeves K, Bacon K, Fredman L. Caregiving associated with selected cancer risk behaviors and screening utilization among women: cross-sectional results of the 2009 BRFSS. *BMC Public Health.* 2012;12(1):685.
43. Etters L, Goodall D, Harrison BE. Caregiver burden among dementia patient caregivers: a review of the literature. *J Am Acad Nurse Pract.* 2008;20(8):423-428.
44. Gérardin P, Zech E. Informal caregiver burnout? Development of a theoretical framework to understand the impact of caregiving. *Front Psychol.* 2019;10:1748.

45. Hajek A, König HH. Impact of informal caregiving on loneliness and satisfaction with leisure-time activities. Findings of a population-based longitudinal study in Germany. *Aging Ment Health*. 2019;23(11):1539-154
46. Committee on Family Caregiving for Older Adults. (2016).
47. Ibid.
48. NAC and AARP (2020).
49. Altieri & Santangelo, 2021; Cohen et al., 2020; Gallagher & Wetherell, 2020; Park, 2020; Savla et al., 2020.
50. Cohen, S. A., Nash, C. C., & Greaney, M. L. (2021). Informal Caregiving during the COVID-19 Pandemic in the US: Background, Challenges, and Opportunities. *American Journal of Health Promotion*, 35(7), 1032-1036.
51. See Appendix for descriptive data on the sample.
52. CBO (Congressional Budget Office). Rising demand for long-term services and supports for elderly people. Washington, DC: Congressional Budget Office; 2013.
53. Barrie Thorne, The Crisis of Care, in *Work-Family Challenges for Low-Income Parents and Their Children* 165, 168 (Ann C. Crouter & Alan Booth eds., 2004)
54. Furman, J., Kearney, M. S., & Powell, W. (2021). *The role of child care challenges in the U.S. jobs market recovery during the COVID-19 pandemic* (No. w28934). National Bureau of Economic Research.
55. Gordon et al. (2012).
56. Committee on Family Caregiving for Older Adults. (2016).
57. Loeb, S. (2016). Missing the target: We need to focus on informal care rather than preschool. Brookings. <https://www.brookings.edu/articles/missing-the-target-we-need-to-focus-on-informal-care-rather-than-preschool/>
58. NAC and AARP. (2020); Rachidi. (2019).

Appendix

Table 1. Respondent Demographics*

Subset of cases with situations currently or recently impacted by the need to care for others			All cases with any mention of caregiving		
Count	52		Count	198	
Gender			Gender		
Female	41	78.8%	Female	115	58.1%
Male	11	21.2%	Male	81	40.9%
Race			Race		
White	25	48.1%	White	112	56.6%
Black	17	32.7%	Black	47	23.7%
			Latinx	13	6.6%
Education			Education		
High school / GED degree	22	43.1%	Less than high school degree	12	6.1%
College degree	16	31.4%	High school / GED degree	85	42.9%
			Associate degree	20	10.1%
			College degree	76	38.4%
Income			Income		
Household Income (average reported)	\$34,955		Household Income (average reported)	\$ 39,071	
Household Income (median reported)	\$19,500		Household Income (median reported)	\$ 25,900	
Age			Age		
Age (average)	45.3		Age (average)	45.5	
Age (median)	44.5		Age (median)	46	

* Categories with cell sizes <11 are not shown to protect the confidentiality of respondents.