THE PITTSBURGH REGIONAL CAREGIVERS SURVEY

UNIVERSITY OF PITTSBURGH
HEALTH POLICY INSTITUTE
INFORMING POLICY FOR BETTER HEALTH

PITT University of Pittsburgh Center for Social & Urban Research

SUMMARY REPORT

EXECUTIVE SUMMARY

Nearly 18 million informal caregivers in the United States provide care and support to older adults who because of limitations in their physical, mental or cognitive functioning require assistance.

The population of informal, unpaid caregivers includes relatives, partners, friends and neighbors. They provide a wide spectrum of support, which can include arranging and attending medical appointments, participating in routine and high-stakes treatment decisions, and coordinating care and services. They make sure that needs for food and shelter are met. They help with daily tasks, such as dressing and bathing. They manage medicines, and may be responsible for obtaining and overseeing the use of medical equipment.

Although informal caregiving is a national phenomenon, it is greatly influenced by regional differences in population demographics, health and long-term care resources, and family structures and experiences. Who helps, how much they help and how these acts of caring affect caregivers and their relatives greatly depends on where they live.

The University Center for Social and Urban Research at the University of Pittsburgh and the Health Policy Institute's Stern Center for Evidence Based Policy recently conducted a survey of western Pennsylvania caregivers to better understand informal caregivers and their needs, and help inform regional and state policies.

This executive summary provides highlights of key findings unique to our region in comparison to national data on caregivers:

1. Local care recipients and caregivers are older
   - Census data indicate that Allegheny County has more older adults (18.1 percent 65+ vs. 15.2 percent in U.S.) and more "oldest old" (16.7 percent of 65+ population is 85+ vs. 12.8 percent in U.S.)
   - As a result, local caregivers are much more likely to be caring for the oldest old (48 percent vs. 32 percent)
   - Local caregivers of care recipients age 65+ are also older (84 percent are 50+ vs 73 percent)
2. Local care recipients have higher levels of disability and local caregivers provide higher intensity care
   - Local care recipients need and receive more help with self-care activities of daily living (ADL), chores, and bills / managing money than the national comparison sample
   - More local care recipients meet the Institute of Medicine definition of *high need* (receive help with 2+ ADLs and or have Alzheimer's disease / dementia)
   - Local caregivers are more likely to provide 40+ hours per week of care
3. Local caregivers have larger networks of additional caregivers
   - Local caregivers have larger informal helper networks
   - Local caregivers are more likely to use paid help compared to the national sample
4. Approximately 20 percent of care recipients have at least one unmet need for informal care
5. In addition to helping with instrumental activities of daily living (IADL) / ADL / mobility tasks, local caregivers are performing high levels of medical, nursing, and care coordination tasks
6. Relatively few local caregivers are accessing formal services for caregivers
7. Local caregivers reported more negative impacts of caregiving
   - Local caregivers reported more negative and fewer positive aspects of caregiving
   - Local caregivers were more likely to report caregiving as emotionally difficult, with similar levels of physical and financial difficulties
   - Local caregivers were more likely to report more restriction of valued social activities due to caregiving
8. Local caregivers reported poorer physical and mental health
   - Local caregivers were more likely to report physical symptoms such as pain and low energy
   - Local caregivers were more likely to meet clinical cutoff risk scores for anxiety, but had similar levels of risk for depression
9. While having similar employment rates (about 50 percent of local and national caregivers were employed), local caregivers were more likely to report that caregiving negatively affected their work
10. Local caregivers reported higher out-of-pocket expenses related to caregiving
    - Local caregivers were more likely to report any out-pocket expenses
    - Among those reporting expenses, local caregivers reported higher spending amounts
13. A significant minority of caregivers were not included in discussions about post-hospitalization acute care and feel that they

should have been; and only a little more than half felt very well prepared to take on this care

14. Local caregivers reported a lack of formal discussions with healthcare providers about what they need to care for the care recipient
15. A significant minority of local caregivers reported difficulty locating and arranging for high quality, trustworthy community-based services and in-home paid care
16. Local caregivers were strongly in favor of various caregiver support policies to help integrate them into the care of the care recipients, such as requiring providers and hospitals to keep them informed; and asking the caregiver what is needed to provide high quality care
17. To help financially with caregiving, the majority of caregivers were in favor of being paid directly for caregiving; the second most favored option was an income tax credit to caregivers to offset costs

DISTINCT CAREGIVER PROFILES

Two unique groups of caregivers emerged in our analysis:

At Risk Caregivers Who Need Help: Older, spouses, female, lower income, high intensity caregivers (provide 40+ hours per week of care)

- Less likely to have other unpaid / paid helpers to assist
- Do more medical / nursing / care coordination tasks
- Care recipients more at risk of unmet needs for care
- More negative aspects of care; caregiving seen as financially / physically difficult; More valued social activity restriction due to caregiving
- Poorer caregiver physical and mental health
- More negative impact on work due to caregiving
- Higher out-of-pocket expenses due to caregiving

Emerging Cohort of Future Caregivers: Younger, more educated, shorter duration caregivers

- More likely to have other unpaid / paid helpers to assist
- More family conflict with care coordination for care recipient
- More likely to use respite services; have received caregiver training
- More negative impact on work due to caregiving
- More exclusion from post-hospitalization care discussions
- More difficulty interacting with long-term services and support (LTSS), locating quality services

INTRODUCTION

Nearly 18 million informal caregivers in the United States provide care and support to older adults who because of limitations in their physical, mental or cognitive functioning require assistance. Millions more provide care and support to younger individuals with serious illness and disability.

The population of informal, unpaid caregivers includes relatives, partners, friends and neighbors. They provide a wide spectrum of support, which can include arranging and attending medical appointments, participating in routine and high-stakes treatment decisions, and coordinating care and services. They make sure that needs for food and shelter are met. They help with daily tasks, such as dressing and bathing. They manage medicines, and may be responsible for obtaining and overseeing the use of medical equipment.

Family members have long undertaken such roles with older parents, grandparents and other relatives when they fall ill and when they can no longer function independently. In the last few decades, however, the job of caring for older adults has become more complex, arduous and longer-term due to medical advances, shorter hospital stays and increased longevity.

Although informal caregiving is a national phenomenon, it is greatly influenced by regional differences in population demographics, health and long-term care resources, and family structures and experiences. Who helps, how much they help and how these acts of caring affect caregivers and their relatives greatly depends on where they live.

The University Center for Social and Urban Research at the University of Pittsburgh (UCSUR) and the Health Policy Institute's Stern Center for Evidence Based Policy recently conducted a survey of Pittsburgh region caregivers to better understand informal caregivers and their needs, and help inform regional and state policies.

Survey methodology in brief

The Pittsburgh Regional Caregivers Survey involved telephone interviews with more than 1,000 informal caregivers in the seven-county Pittsburgh Metropolitan Statistical Area, primarily in Allegheny County. About 800 residents interviewed lived in Allegheny County and about 200 lived in Armstrong, Butler, Beaver, Fayette, Washington and Westmoreland counties.

A variety of sampling and recruitment methods were used to capture a broad swath of caregivers. Methods included probability sampling via random digit dialing with screening for caregivers; listed household samples targeting middle-aged and older adults; research registries, primarily the UCSUR Research registry; and recruitment flyers through local service providers.

Because the sample was drawn using a mix of probability and non-probability methods, some caution is warranted in drawing conclusions about the entire population of local caregivers.

The local sample, however, is similar to several national samples of caregivers in many ways.

Moreover, the survey stands as the most comprehensive ever conducted among caregivers in the Pittsburgh region.

To provide context, the findings among local caregivers are compared with the 2011 National Survey of Caregivers (NSOC), the most comprehensive national survey of caregivers of adults aged 65 and older. Although the Pittsburgh Regional Caregivers Survey includes caregivers of adults aged 50 years and older, nearly 85 percent were caring for someone aged 65 and older, which allows for direct comparisons with the national NSOC sample. All graphics shown in the report are for the entire sample of 1,008 caregivers, including those caring for recipients age 50-64.

Interviewers from the UCSUR Survey Research Program conducted the local survey between February and July, 2017 using computer-assisted telephone interviewing. The survey, which took about 45 minutes to complete, was approved by the Institutional Review Board of the University of Pittsburgh.

The responses to the Pittsburgh Regional Survey of Caregivers offer a detailed portrait of caregivers in the region, from who they are, whom they care for and what they do, to how cargiving impacts their lives. The key findings are highlighted in this report.

OLDER ADULTS IN ALLEGHENY COUNTY

Men and women 65 years old or older claim a greater share of the population in western Pennsylvania than in most other metropolitan regions in the United States.

They account for more than 18 percent of the population of Allegheny County, the most populous of the seven counties in the Pittsburgh MSA. Nationally, they make up 15.3 percent of the population, U.S. Census Bureau data suggest.

The demographics of the region's 65-or-older population also stray from national averages. One striking characteristic is that residents 85 years or older make up a relatively large share of the senior population. In Allegheny County, 16.7 percent of seniors are 85 years old or older compared to only 12.8 percent nationally. These oldest older adults are more likely to require a higher level of care than younger seniors.

Racial differences are also seen. In Allegheny County, 88.6 percent of residents 65 or older are white and 9.5 percent are African American. In the U.S., 83.1 percent of the senior population is white and African Americans account for 9.1 percent. More than 58 percent of adults 65 or older in the county are women, a slightly higher share than what is seen in the U.S. population.

Local aging trends were greatly influenced by the economic crisis the region experienced in the 1980s when steel and other heavy manufacturing severely declined. Job loss triggered a short-lived, but significant, exodus of residents, the majority of whom were under the age of 39. The result was the loss of many young adults, as well as their future children.

The share of the region's population older adults account for continues to rise, but at a slower pace than the rest of the nation. UCSUR demographic modeling suggests that more than 1 in 5 residents of Allegheny County will be 65 years or older by 2040, mirroring the national average. And more than 1,000 will reach the age of 100, according to a 2014 UCSUR study, *The State of Aging in Allegheny County*. Such a demographic phenomenon has profound implications for families and care giving.

PREVALENCE OF CAREGIVING

The estimated prevalence of caregiving varies depending on how caregiving is defined and measured, as well as the age range of the caregivers and care recipients included. For example: A 2015 AARP study of caregivers and care recipients of all ages found that 18.2 percent of the adult U.S. population provide care; the same 2015 AARP study found that 14.3 percent of adults in the U.S. provide care to care recipients age 50 and older; and the 2011 NSOC study including care recipients age 65 and older found that 7.7 percent of U.S. adults provide care to that population.

Locally, the best estimate is from 2014, *The State of Aging in Allegheny County* survey conducted by UCSUR researchers, which found a 20.3 percent caregiving prevalence rate among adults age 55 and older, and included care recipients of any age.

These estimates translate to 18 million to 43 million adults providing care nationally and an estimated 80,000 caregivers age 55 and older locally. Including younger caregivers and the entire Pittsburgh MSA would push the local estimate to over 100,000 caregivers.

WHO ARE THE CARE RECIPIENTS?

Just as the region has a greater share of older seniors overall than the rest of the nation, the local senior population who receives help from informal caregivers also tends to be older.

The Pittsburgh Regional Caregivers Survey suggests that more than 48 percent of those who receive care from family and friends in Allegheny County are aged 85 years old or older—and 20 percent of them are at least 90 years old. That's a much higher rate than what is seen in nationally: 32 percent of older adults in the U.S. who receive care from informal caregivers are 85 years old or older.

Similar to seniors nationwide, 43 percent of those in the region who receive care live with their caregivers. Among the rest, more than 7 in 10 continue to live in their own home. And for 9 in 10 local seniors, their informal caregivers are family members, most often their children..

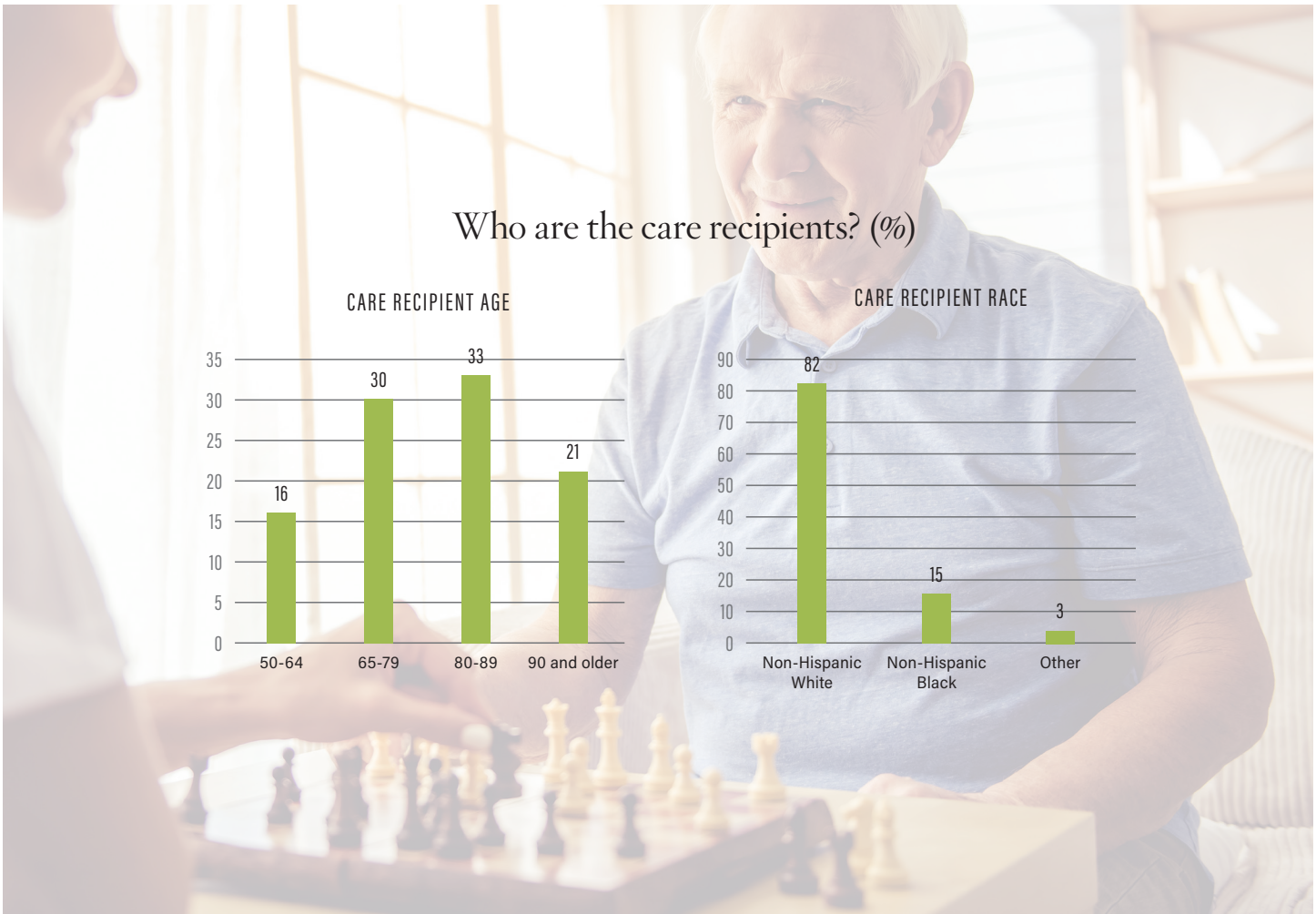
Health issues

Survey findings related to the health of seniors in the region underscore the fact that for many caregivers, helping friends and family often means more than assisting with simple daily chores.

Alzheimer's disease and dementia affect 27 percent of adults 65 years and older who receive care from friends and family.

The most common medical conditions that seniors receiving care must deal with include high blood pressure, which 66 percent have, closely followed by arthritis. Some 55 percent have had a heart attack or other heart disease, 28 percent are diabetic, 23 percent have lung disease, 22 percent have had a stroke and more than 1 in 4 have cancer.

Their conditions have led to a high rate of home modifications to enhance safety. More than 8 in 10 care recipients live in homes that have been modified with features ranging from bathroom grab bars and shower seats to emergency call systems.



WHO ARE THE CAREGIVERS?

Helping out friends and family members 65 years old or older consumes a significant portion of the lives of informal caregivers in the Pittsburgh region. They're more likely to care for seniors 85 and older than caregivers nationwide. And they, themselves, are more likely to be older than the average U.S. caregiver.

More than half of the informal caregivers in the Pittsburgh region are between the ages of 50 and 64 years. Nationally, 40.5 percent of caregivers fall into that age group.

Women account for 74 percent of caregivers locally, which is also high. Nationally, they represent less than 62 percent of informal caregivers.

Caregivers in the Pittsburgh region also tend to have more formal education. Some 46 percent, for example, have a bachelor's degree or higher, while only 27 percent of all U.S. caregivers have that level of education.

Length and duration of care

A smaller percentage of local caregivers have been helping older adult friends and relatives for at least five years than U.S. caregivers as a whole. But those providing care today to local older adults are much more likely to spend a significant number of hours every week doing so, survey findings indicate.

Nearly half of local informal caregivers spend at least 9 hours a week helping older adults. And 17 percent of them overall report that caring for relatives and friends over 65 years of age is a job that consumes 40 hours a week or more. Only 12 percent of U.S. caregivers devote such long hours to caring for older adults.

CARE NEEDS OF OLDER ADULTS

Older adults need help with a range of chores and personal and medical care. The type of help they require is an indicator of the role informal caretakers assume in helping to keep them safe and healthy.

The level of care they need varies. Older adults may need help with basic self-care, or activities of daily living (ADL), such as help with bathing, eating and using the toilet. They may need higher levels of care to navigate "instrumental" activities of daily living (IADL), which include household chores, managing money, paying bills, shopping and preparing meals.

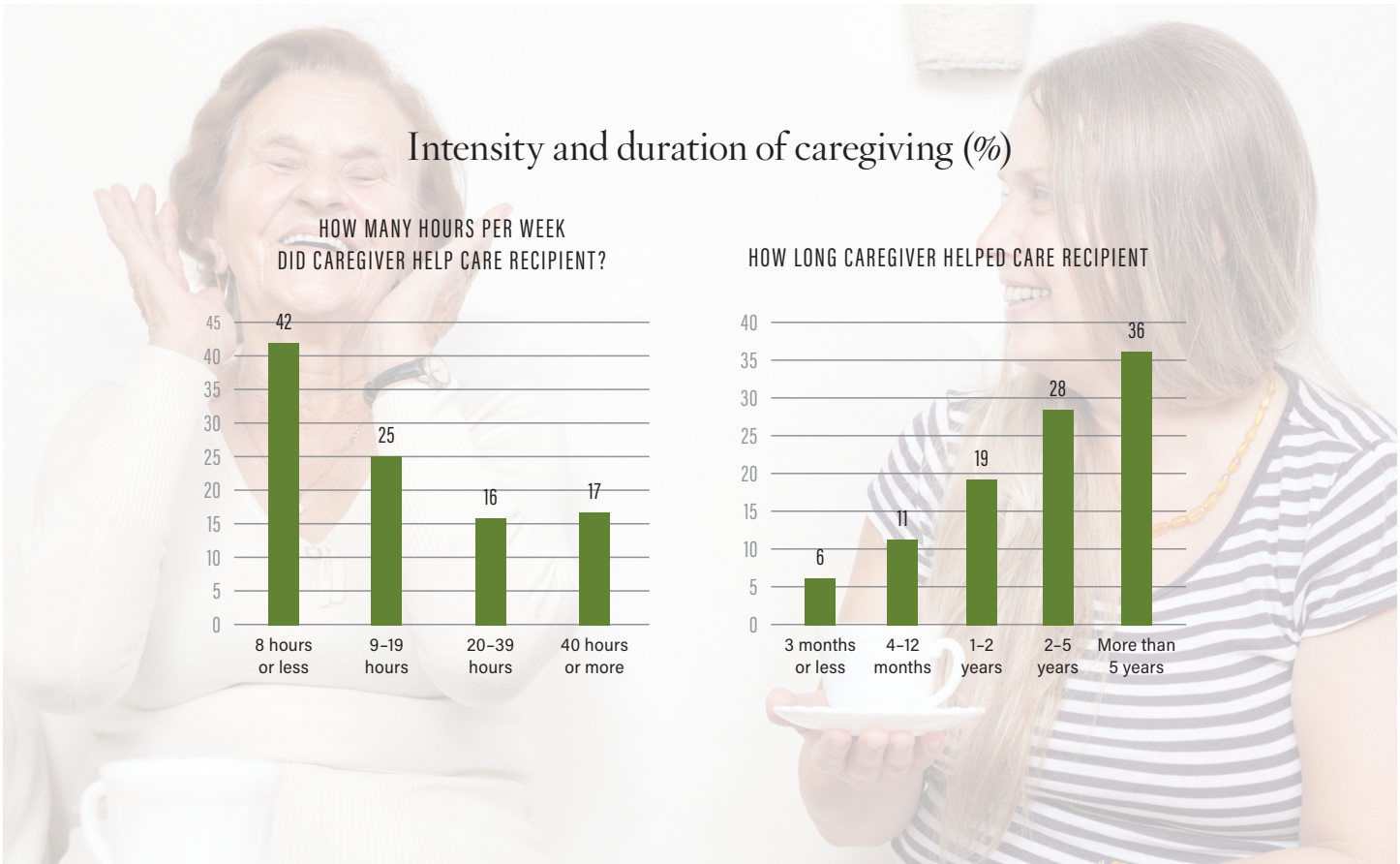
Greater need seen in region

Care recipients in the region who are 65 years old or older need and receive more help with both basic self-care and higher-level activities compared to the U.S. care recipients in general.

Local care recipients, for example, are much more likely to need help with basic self-care, paying bills and managing money. And the percentage of care recipients who need help with at least three basic self-care activities is much higher in the region than across the nation.

A greater share of local care recipients also receive help with two or more self-care activities and/or have Alzheimer's disease or dementia and therefore meet the Institute of Medicine definition of a "high need care recipient."

However, relatives and friends who care for them are more likely to have outside help. The survey suggests local care recipients tend to have larger informal caregiver networks and are more likely to hire paid help to supplement informal care than the national sample of U.S. adults aged 65 years and older who receive care.



Intensity and duration of caregiving (%)

CARE RECIPIENT NEEDS	REGION (%) Care recipient age 65+	NATION (%) Care recipient age 65+
CARE RECIPIENT HELP RECEIVED, SUMMARY		
Household activities only	24.2	31.1
Self-care or mobility	75.8	68.9
1 – 2 need	29.8	38.0
3 or more needs	45.9	30.9
HELP RECEIVED, SPECIFIC TASKS		
Mobility (Any)	67.1	71.6
Self-care (Any)	59.1	49.2
Shopping	89.0	89.5
Chores (laundry, housework, meals)	89.3	79.2
Help with bills, money	68.1	58.3
HIGH NEED CARE RECIPIENT		
None	44.7	51.8
Alzheimer's / Dementia (AD) only	9.3	16.7
Help with 2+ ADL only	28.4	15.7
Both AD + help with 2+ ADL	17.6	15.8
Care recipient meets "high need" criteria	55.3	48.2
ADDITIONAL UNPAID CAREGIVERS		
One additional caregiver	21.0	51.0
Two	27.0	21.0
Three or more	52.0	28.0
HAS PAID CAREGIVER	32.3	20.0

WHO MEETS THOSE NEEDS?

Informal caregivers take on the largest share of the work meeting the ADL needs of older adults who need help with basic self-care, such as bathing and eating. In fact, informal caregivers alone or with other unpaid helpers meet most the needs of older adults who rely on their care for help, including higher level needs and help with mobility issues.

Paid caregivers are most often used for ADL tasks, with bathing assistance being the most common.

Unmet needs

But not all needs are being met, regardless of whether care recipients have paid help. The degree that caregiver needs go unmet is an indicator of potential risk.

The survey found 1 in 5 informal caregivers say the older adults they care for have at least one need that is not being met by the caregiver or any of the other people who help them, a rate similar to national estimates. Unmet needs are most often reported for higher-level, IADL tasks, including shopping and household chores.

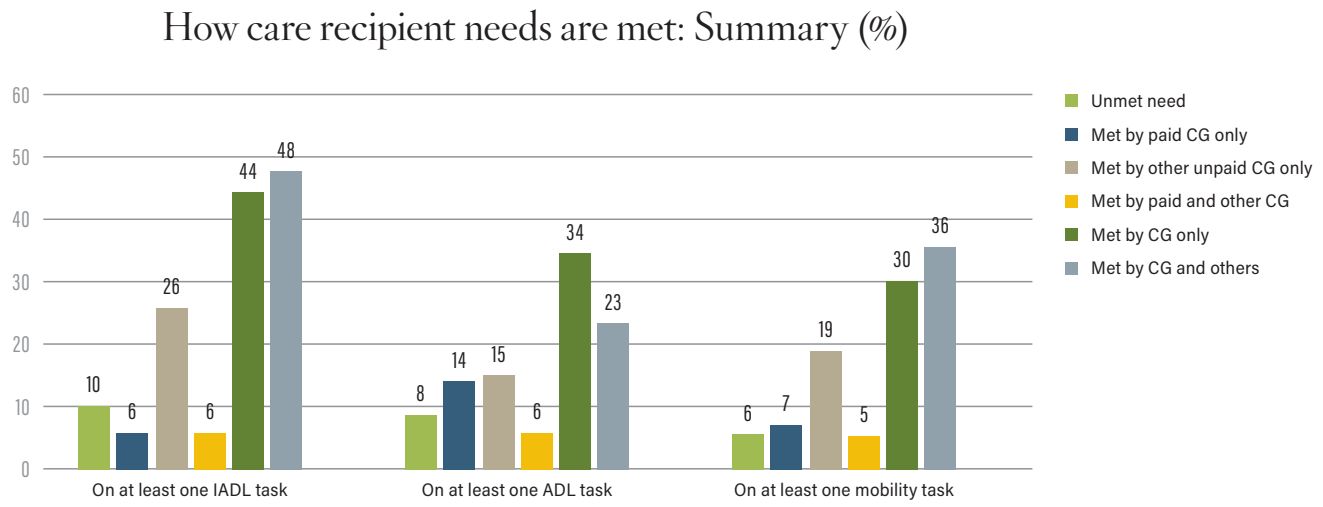
HELPING WITH HEALTH CARE

Survey findings among the region's informal caregivers make clear that the breadth of the help they provide extends well beyond routine personal care and household chores to include performing a significant share of medical and nursing tasks and coordinating health care.

Giving medicine and helping older adults with exercises, special diets, and caring for feet and teeth are the most common medical tasks the region's informal caregivers report performing.

The most commonly performed nursing tasks include helping with incontinence equipment, meters/monitors, such as glucometers or blood pressure monitors, and durable medical equipment.

The survey suggests that the more hours a week informal caregivers spend helping older adults the more likely they are to find themselves responsible for medical and nursing tasks. The most likely caregivers to perform a medical task of some kind include women, those who are caring for a spouse and those with less formal education. Informal caregivers most likely to perform some type of nursing task include spouses, women and those caring for Alzheimer's disease and dementia patients.



Coordinating medical care

Coordinating the medical care of older adults is a common challenge for all caregivers. In Pittsburgh region, for example, nearly two-thirds of caregivers surveyed make doctor appointments and 85 percent say they accompany older adults when they visit the doctor—rates similar to those reported among U.S. caregivers.

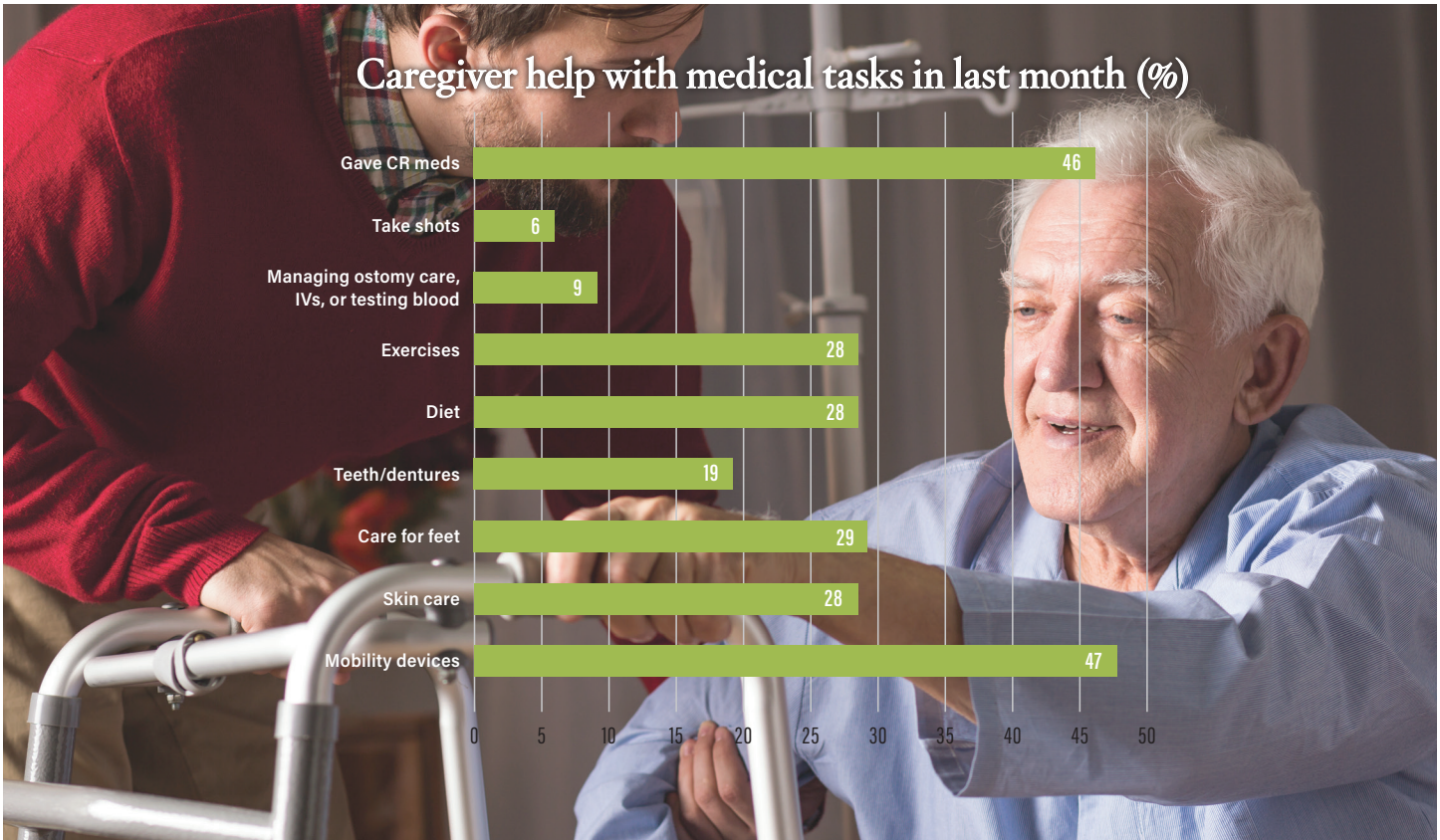
One difference noted in the survey is that local caregivers report a higher rate of engaging with health care providers on behalf of the older adults they care for. In the region, 67 percent of caregivers say they speak with doctors about the care recipient's conditions, something 58 percent of U.S. caregivers report doing.

Local caregivers most likely to coordinate medical care include women, adult children, spouses, those who are middle-income earners and caregivers 50 years old or older. And the more hours per week they spend helping the care recipients, the more likely the help they provide includes coordinating medical care.

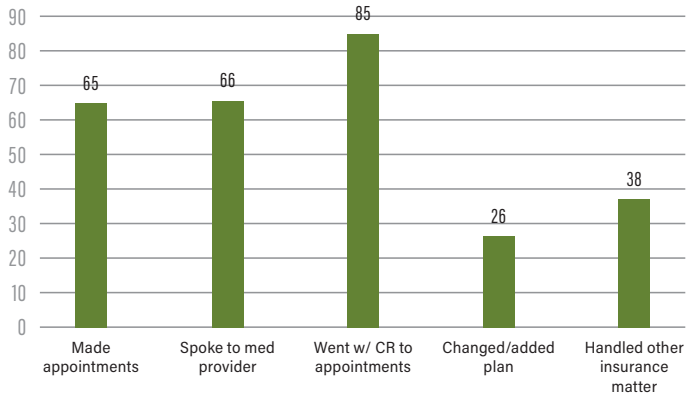
Family conflict over coordination

Coordinating medical care for older adults is not without the stress of family conflict for many informal caregivers in the region. While 60 percent report no family conflict arising from coordinating care, 37 percent report some degree of conflict over care-giving matters.

Younger informal caregivers aged 20–49 years, and those who care for Alzheimer's disease and dementia patients are the most likely to say they've encountered family conflict around the issue of coordinating medical care.



Caregiver involvement with care recipient's medical care in last year (%)



CAREGIVER SUPPORT AND TRAINING

Formal care-giving services, support groups and training can ease an informal caregiver's burden of caring for older adults, particularly when those older adults have higher-level needs and conditions such as dementia. But in western Pennsylvania, informal caregivers tend not to get that kind of help.

While nearly 9 in 10 say they talk to friends about aspects of caring for older adults, 94 percent have not gone to support groups for people who give care. Only 10 percent get training to help them provide the care they give older relatives and friends. And fewer than 1 in 5 say they have used a service that allowed them to take time away from their care-giving duties.

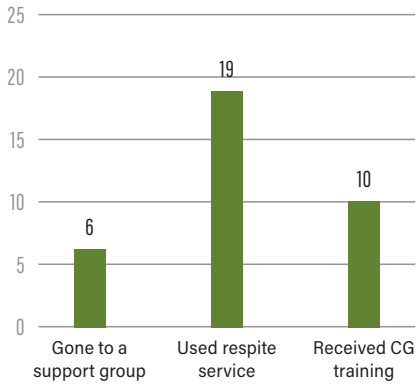
Most local caregivers who say they don't receive support don't seek it out, the survey suggests. More than 8 in 10 local caregivers who don't get support say they have not looked for a respite service, sought training or looked for a support group for caregivers like themselves.

Caregivers who provide help 40 or more hours a week and those who care for Alzheimer's and dementia patients are the most like to have attended caregiver support groups. Caregivers most likely to use respite services include adult children, more highly educated and higher income caregivers and those who care for Alzheimer's and dementia patients. Women and more highly educated caregivers are the most likely to have received formal caregiver training.

IMPACTS OF CAREGIVING

Survey findings suggest that informal caregivers in the Pittsburgh region are more likely than caregivers nationwide to care for seniors 85 and older, whose care needs can be challenging to relatives and friends who help them. At the same time, local caregivers themselves are more likely to be older than caregivers elsewhere.

Support services used by caregiver in last year (%)



Positive and negative impacts

Perhaps it's not surprising that local caregivers tend to report fewer positive aspects of care giving and more negative aspects than what is seen among caregivers nationwide. For example, 53 percent of local caregivers of those 65 and older report "substantial" positive aspects of helping older adults compared to 67.5 percent nationwide. At the same time, 20 percent of local caregivers report substantial negative aspects compared to 10 percent of caregivers nationwide.

Local caregivers most likely to report substantial positive aspects include African-American caregivers, less educated caregivers, lower income caregivers, those who provide care 40 or more hours per week and those who have been providing care the longest.

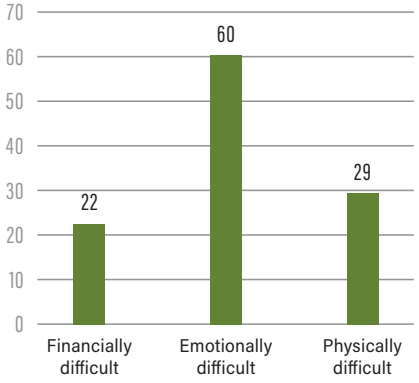
Local caregivers most likely to report substantial negative aspects of care giving include spouses, women, white caregivers, those with the highest education levels, those who provide care 40 or more hours per week and those who care for Alzheimer's and dementia patients.

Physical, financial, emotional difficulties

Local caregivers report levels of financial and physical difficulty associated with care giving that are similar to the national caregiver sample. However, they are much more likely to find it emotionally draining. Among local caregivers, 60 percent say helping older adults is emotionally difficult compared to 45 percent of U.S. caregivers.

Local caregivers most likely to find it emotionally difficult include adult children and spouses, women, white caregivers, caregivers with higher levels of education, those providing care for at least 9 hours per

Perceived difficulty of caregiving (%)



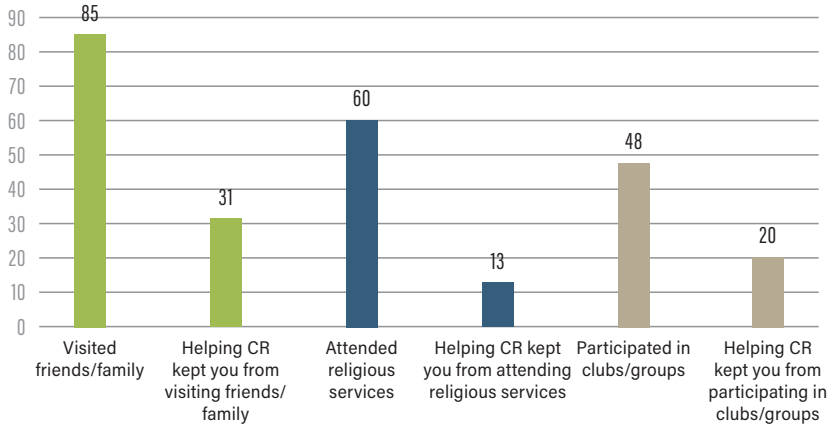
week and those who care for Alzheimer's and dementia patients. Local caregivers are more likely to report physical and financial difficulty include spouses, women, lower income caregivers, and those providing more hours of care. Caregivers of AD patients were also more likely to report financial difficulty.

Impact on social life

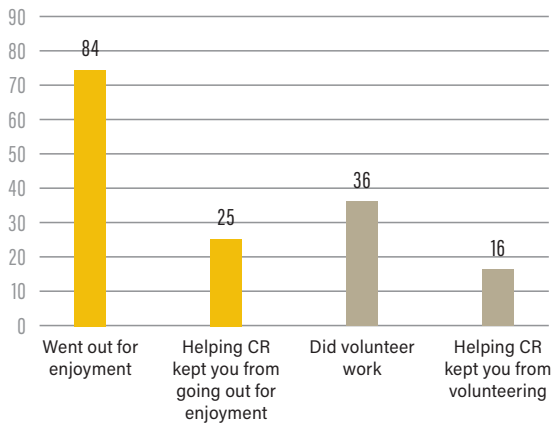
The act of caring for older adults tends to restrict the social lives of caregivers in the region more than what U.S. caregivers nationally. Nearly one-third of local caregivers, for example, say that their care-giving duties have kept them from visiting friends and family compared to 19 percent of informal caregivers nationally.

Local caregivers most likely to report their social activities have been restricted due to caregiving include spouses, women, white caregivers, more educated caregivers, those who provide 20 or more hours of care per week and those who care for Alzheimer's and dementia patients.

Caregiver participation/restriction in social activities (%)



Caregiver participation/ restriction in social activities (%)



CAREGIVER PHYSICAL AND MENTAL HEALTH

Survey data on the health conditions of informal caregivers cannot determine whether the self-reported conditions are directly related to the caregiving duties they perform for older adults. However, the data offer an indication of their physical and mental health, which can influence their ability to provide quality care.

Some 23 percent of western Pennsylvania caregivers surveyed described their general health as only fair or poor. The most likely to do so include caretakers who are spouses, non-white caregivers, less educated caregivers and lower-income caregivers.

In some cases, responses from informal caregivers in western Pennsylvania about their health raise concerns.

Physical health symptoms

Local caregivers are more likely to report severe physical health symptoms than U.S. caregivers. For example, 62 percent of local caregivers of older adults (age 65+) report being bothered by pain compared to 51 percent of U.S. caregivers. And 51 percent of these local caregivers are bothered by low energy while only 38 percent of U.S. caregivers report having that problem.

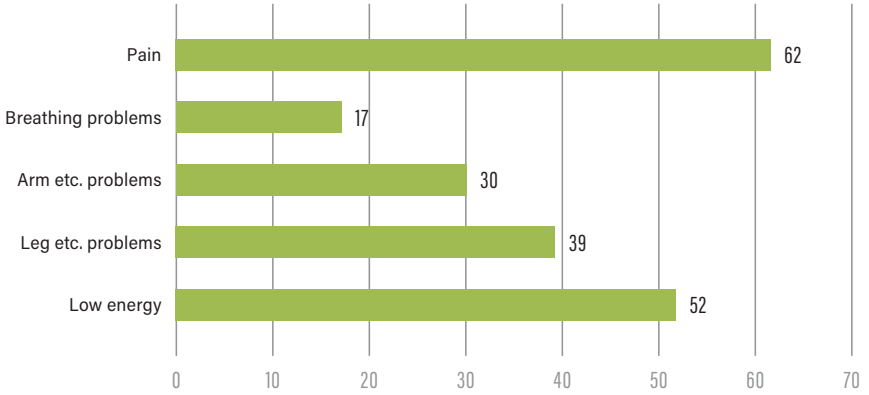
Local caregivers most likely to report physical health symptoms include spouses, women, white caregivers, caregivers aged 65 years or older, less-educated caregivers, lower income caregivers and those providing 40 or more hours of care per week.

Mental health

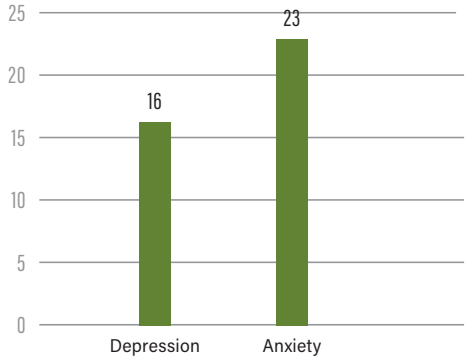
Informal caregivers of adults aged 65 years or older also report higher rates of meeting the at-risk score criteria for anxiety than caregivers across the nation. The scores of 23 percent of local caregivers meet the criteria for anxiety compared to only 13 percent of U.S. caregivers. In addition, 16% of local caregivers met at risk criteria for depression, which is similar to national estimates.

Local caregivers most likely to report anxiety include women, caregivers aged 20-49 years, white caregivers, lower income caregivers and those who provide 20 or more hours of care per week. Local caregivers most likely to report depression include spouses, women, lower income caregivers and those providing 40 or more hours of care per week.

Caregiver physical health symptoms (%)



Caregiver depression & anxiety (meeting defined cutoff scores)(%)



HOW CARE-GIVING IMPACTS EMPLOYMENT

Providing care for adults aged 65 or older can take a toll on the working lives of relatives and friends who serve as their informal caregivers. The survey suggests that in the Pittsburgh region, these informal caregivers struggle to balance jobs with their role of caring for older adults.

Slightly less than half (47 percent) of the caregivers were employed, similar to national figures. Slightly less than one-third (31 percent) of local caregivers are retired compared to 22 percent of U.S. caregivers.

The majority of local caregivers with jobs work full time. Of the employed informal caregivers surveyed, 59 percent report having jobs that require them to work 40 or more hours a week and another 25 percent work 21-39 hours a week.

Negative impacts of caregiving on work

Informal caregivers in the region are more likely to report that helping older adults makes it difficult for them at work.

In the region, 26 percent of local caregivers of those 65 and older who are employed say caregiving makes their work life more difficult compared to 14 percent of U.S. caregivers. Also, 46 percent of these local caregivers reported taking time off work for caregiving compared to 33 percent nationally.

Their duties caring for older adults have led a significant share of local caregivers to cut back their hours at work or leave their jobs altogether. More than 40 percent of local caregivers say they've either gone part time, retired early or simply given up trying to hold down a job.

One in 4 local informal caregivers who are employed report that caring for an older adult negatively affects them at work.

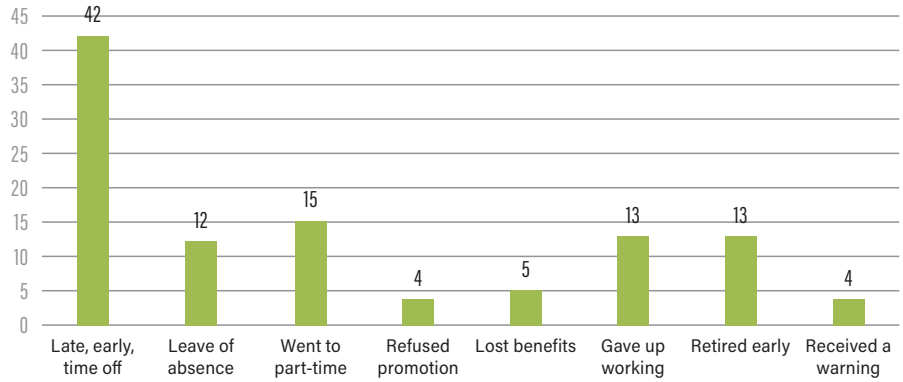
Local caregivers most likely to report that their caregiving currently has a negative affect on their work include women, white caregivers, more educated caregivers, those providing more hours of care per week and those who care for Alzheimer's and dementia patients.

Local caregivers most likely to report that their caregiving has at some time negatively affected their work or career include spouses, women, caregivers aged 50 years or older, lower income caregivers, those providing more hours of care per week and those who have provided care for longer durations.

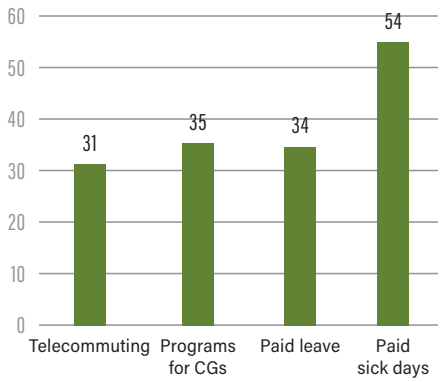
Employer support

In most cases, local caregivers say their supervisor is aware their off-hours include caring for an older relative or friend. Only 22 percent of those surveyed say their supervisors are unaware they assume that role after hours.

Caregiving career impacts (% ever experienced)



Caregiver employer benefits (among employed) (%)



More than half of local caregivers who are working say their employers offer some type of benefit that helps them cope with their caregiving duties. Such benefits range from sick days to offering caregiver assistance programs, such as information, referrals and counseling.

About 35 percent of local caregivers report their employer offers assistance programs for those who help care for older adults. Those caregivers most likely to have such programs at work include adult children caring for a parent, women, younger caregivers, more educated caregivers, higher income caregivers and those providing fewer hours of care per week.

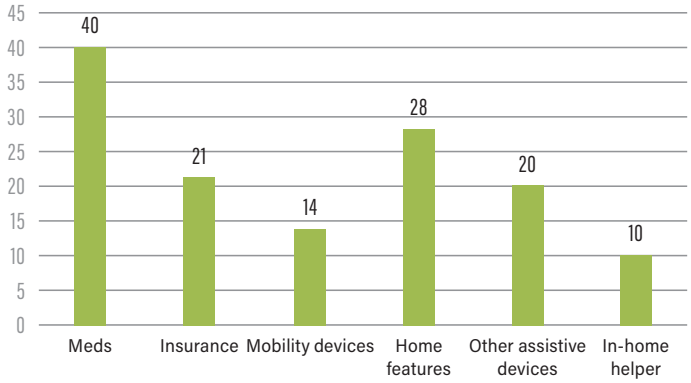
CAREGIVER OUT-OF-POCKET EXPENSES

Informal caregivers helping adults aged 65 or older in western Pennsylvania are more likely than their counterparts nationally to finance some of their care from their own pockets. Four in 10 local caregivers say they do so compared to 22 percent nationally.

They also report spending higher amounts of their money on caregiving expenses. In the region, 43 percent of informal caregivers report having out-of-pocket expenses of $1,000 or more during the past year and 27 percent say they spent more than $2,000.

Local caregivers most likely to report out-of-pocket expenses of more than $2,000 include spouses, caregivers aged 65 years or older, white caregivers, more educated caregivers, those providing 40 or more hours of care per week, those who provide care for longer durations and those who care for Alzheimer's and dementia patients.

Caregiver out-of-pocket expenses in past year in caring for CR (%)



CAREGIVING FOLLOWING HOSPITALIZATION

Older adults typically need higher-level care at home following hospitalization. More and more often, informal caregivers are finding it necessary to perform complex medical tasks that can strain their capabilities, particularly if they receive little or no training.

Local caregivers report that 56 percent of the older adults they care for had been hospitalized at least once during the past year and 19 percent had been in the hospital three or more times.

For 55 percent of local caregivers, performing post-hospitalization medical and nursing tasks was not found to be difficult. But 26 percent reported some level of difficulty.

Local caregivers who provide 20 or more hours of care per week are the most likely to report moderate to high difficulty performing medical and nursing tasks.

Preparation

Among local caregivers, 78 percent report receiving clear instructions regarding post-hospitalization medical and nursing care for the older adults under their care. But more than 1 in 5 say they didn't.

Those most likely not to have received instructions include adult children caring for a parent, younger caregivers, lower income caregivers and caregivers who have provided care for a shorter period of time.

Although most say they received care instructions from the hospital, only 54 percent of local caregivers report that they felt well prepared for the medical and nursing tasks ahead.

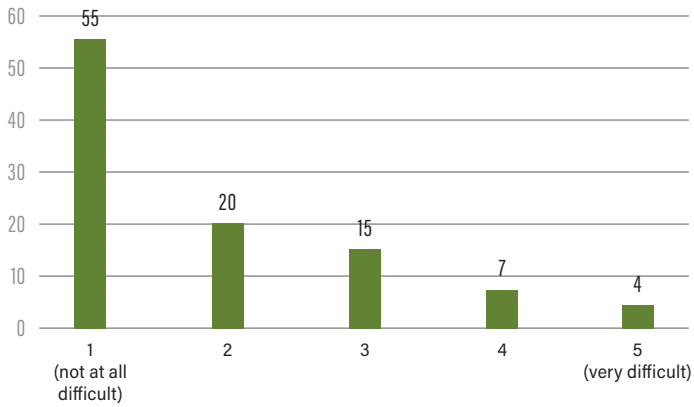
And only 25 percent of local caregivers report that someone trained them to handle the post-hospitalization care they needed to perform. Among informal caregivers, women were the most likely to say they received training to perform post-hospitalization medical and nursing tasks for the older adult they cared for.

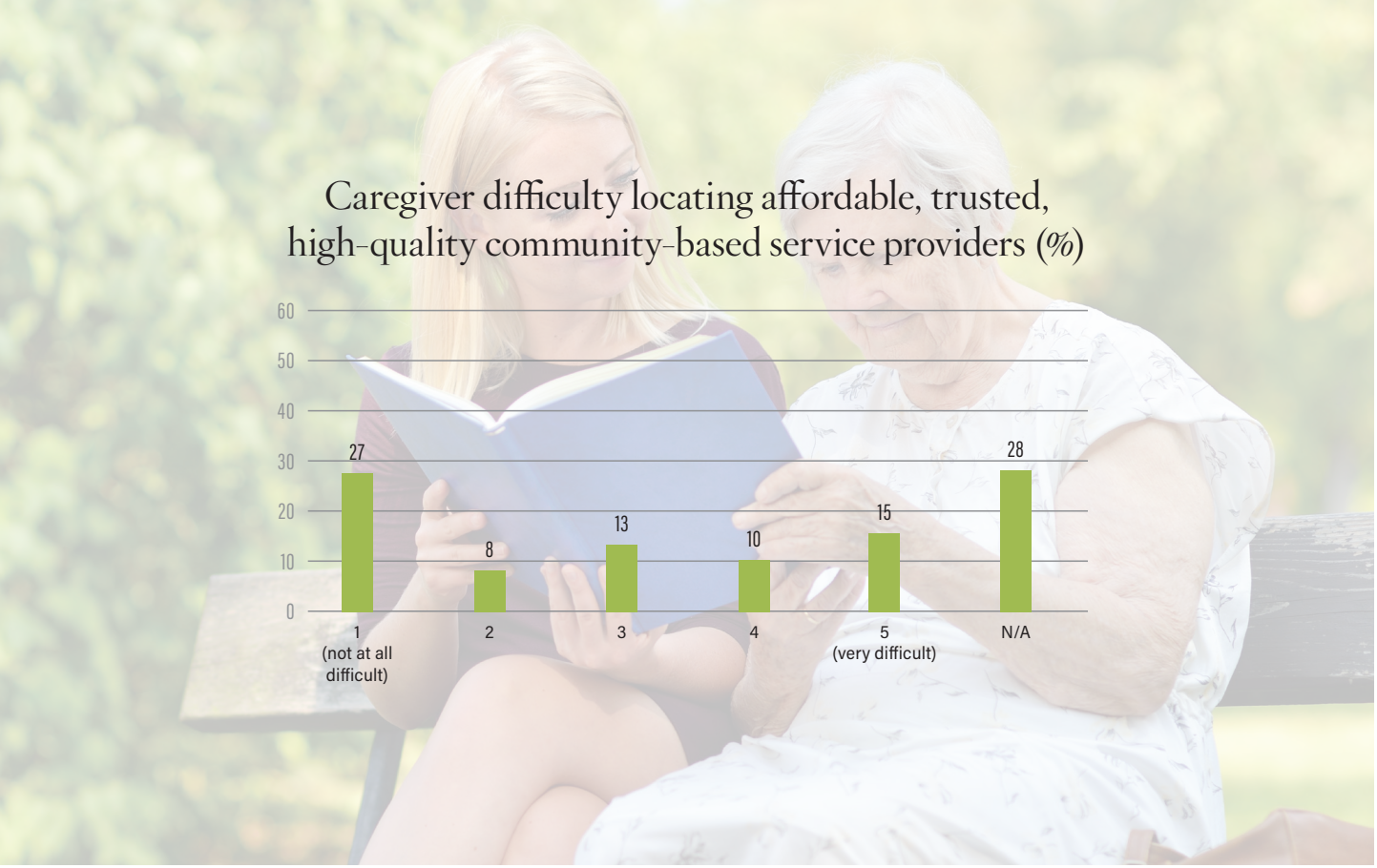
Inclusion

Most local caregivers say they were included in at least some of the discussions around the care recipient's medical and nursing care needs. For 58 percent, that meant being included all of the time, while 24 percent of local caregivers report they were included only some of the time.

Local caregivers most likely to report being excluded from discussions about post-hospitalization care include caregivers who have provided care for shorter durations and those caring for older adults who do not suffer from Alzheimer's or dementia.

Caregiver level of difficulty performing medical/nursing tasks (among those performing these tasks) (%)





INTERACTIONS WITH LONG-TERM SERVICES, SUPPORTS

A significant number of local caregivers have some difficulty finding quality services for the older adults they care for. And survey findings suggest gaps exist in communication between caregivers and healthcare professionals and social workers.

Local caregivers are most likely to report having difficulty finding and arranging for affordable, trustworthy, high-quality community-based service providers for the older adults they care for. About 46 percent of the caregivers surveyed reported this type of difficulty.

Those caregivers who are most likely to report difficulty finding affordable, trustworthy, high quality services include white caregivers, more educated caregivers, higher income caregivers and those who care for Alzheimer's and dementia patients.

About 30 percent of local caregivers reported difficulty locating and arranging for in-home personal care. The most likely to report difficulty include white caregivers, more educated caregivers, higher income caregivers and those who care for Alzheimer's and dementia patients.

Local caregivers are least likely to report difficulty in finding affordable community-based services, with 27 percent reporting such difficulty. Those most likely to encounter difficulty include caregivers aged 20-49 years, white caregivers, more educated caregivers and higher income caregivers.

Communication gap

Survey results suggest formal discussion is lacking between local caregivers and healthcare providers around what they need to do to care for older adults. That shortcoming is also seen in discussions about the needs of informal caregivers.

Only 37 percent say doctors, nurses and social workers ask them about the needs of care recipients.

Discussions about caregiver needs are even more limited: Only 18 percent of caregivers report that doctors, nurses and social workers ask them what they need to take care of themselves.

ATTITUDES ABOUT CAREGIVER POLICY IDEAS

Caregivers in the Pittsburgh region strongly favor caregiver support policies to help them care for older adults, such as requiring providers and hospitals to keep them informed.

More than 8 in 10 caregivers favor such a policy. A similar percentage favor providing caregiver training to help them perform medical and nursing tasks care recipients may need.

Financial assistance

Local caregivers were asked to choose a preferred policy to help offset the cost of caregiving.

The most popular is having a program that pays caregivers for at least some of the time they spend caring for an older adult, a concept that draws the support of 48 percent of caregivers. About 1 in three local caregivers favor a tax credit to help offset their caregiving costs. Less than 1 in 5 favor a partially paid leave of absence to accommodate caregiving.

Older caregivers, men, spouses, white caregivers, more educated caregivers and higher income caregivers are more likely to favor income tax credits. Those more likely to favor being paid directly for caregiving include adult children, women, African American caregivers, younger caregivers, less educated caregivers and lower income caregivers.

SUMMARY PART 1

LOCAL VERSUS NATIONAL CAREGIVERS OF OLDER ADULTS (AGE 65+)

Local caregivers differ in the following important ways from national caregivers:

- Local care recipients and caregivers are older
- Local care recipients have higher levels of disability and local caregivers provide higher intensity care
- Local caregivers have larger networks of additional caregivers
- Local caregivers reported more negative impacts of caregiving
- Local caregivers reported poorer physical and mental health
- Local caregivers were more likely to report that caregiving negatively affected their work
- Local caregivers reported higher out-of-pocket expenses related to caregiving

These findings highlight the unique challenges for local caregivers and have crucial implications for local caregiver support policies and coordination of services.

SUMMARY PART 2
DISTINCT CAREGIVER PROFILES

As a way to succinctly summarize key caregiver group differences, the following table highlights three distinct groups of caregivers based on a synthesis of findings across the entire survey.

The first group is the traditional "at risk" caregiver group consisting of older, spouse, female, lower income, high intensity caregivers who seem to suffer the greatest negative caregiving impacts.

The third group—Alzheimer's disease / dementia caregivers—is of great interest due to the devastating impact of the disease and the growing numbers of older adults who will be diagnosed with AD in the future. Note that this group has some overlap with the traditional "at risk" group.

Lastly, and most interesting, is the younger, more educated, shorter duration caregivers. This group is more engaged with informal care networks and uses more services, but is more likely to report family conflict and difficulties interacting with the LTSS system. This group has not been previously discussed in the caregiving literature, and there are important policy implications for helping these caregivers.

CAREGIVER GROUP	KEY CHARACTERISTICS / PROFILE
■ Older ■ Spouse ■ Female ■ Lower income ■ High intensity (*provides care for 40 or more hours per week*)	■ Less likely to have other unpaid / paid helpers to assist ■ Do more medical / nursing / care coordination tasks ■ CR more at risk of unmet needs for care ■ More negative aspects of care ■ CG seen as financially / physically difficult ■ More valued social activity restriction due to caregiving ■ Poorer CG physical and mental health ■ More negative impact on work due to caregiving ■ Higher out-of-pocket expenses due to caregiving ■ Most "at risk"
■ Younger ■ More educated ■ Shorter duration caregiver	■ More likely to have other unpaid / paid helpers to assist ■ More family conflict with care coordination for CR ■ More likely to use respite services; have received CG training ■ More negative impact on work due to caregiving ■ More exclusion from post-hospitalization care discussions ■ More difficulty interacting with LTSS, locating quality services
■ Caregiver of Alzheimer's / dementia patient	■ More likely to have other unpaid / paid helpers to assist ■ Do more nursing tasks ■ More family conflict with care coordination for CR ■ More likely to attend support groups; use respite services ■ More negative aspects of care ■ CG seen as financially / emotionally difficult ■ More valued activity restriction due to caregiving ■ More negative impact on work due to caregiving ■ Higher out-of-pocket expenses due to caregiving

THE PITTSBURGH REGIONAL CAREGIVERS SURVEY

Contributors

This report was prepared by the University Center for Social & Urban Research (UCSUR) at the University of Pittsburgh in collaboration with the Pitt Health Policy Institute.

Acknowledgments

The survey was funded by the Stern Family Foundation and the Emily Kelly Roseburgh Memorial Fund of The Pittsburgh Foundation.

We would like to acknowledge the staff members and telephone interviewers from the Survey Research Program at UCSUR, who supervised and conducted the phone calls with caregivers.

Jeffery Fraser of Pittsburgh Today wrote the report, and it was edited and produced by Bending Oak Publishing.