Caregivers: Executive Summary

Family Caregivers are America’s largest volunteer army on the frontlines of health care. 2020 will be a watershed year for Caregiving, with 117 million people needing care and less than 50 million available family members to provide it – the lowest ratio in history. Caregiving affects four generations of adults in the US. At the oldest end of the age continuum is the Silent Generation, primarily caring for spouses or significant others. The emerging story at the other end of the continuum is that Gen Xers are now providing care for their parents. Meanwhile, Boomers are providing care, mostly for parents and in-laws, but a full quarter are doing so for spouses.

Caregivers believe that they are called to their role, which comes with a delicate balance of gratitude, grief, and guilt. Fully half of Caregivers describe their lives as fulfilled, which highly correlates to having daily assistance in their Caregiving role. The story of two types of Caregivers begins to emerge: 1) those caring for parents; and 2) those caring for spouses/partners. While their attitudes toward the role are similar, their approaches to care differ. For example, those caring for parents or in-laws are more likely than spousal Caregivers to use paid care assistance.

Overall fewer than one in five Caregivers use outside help. The negative impacts of not having help include emotional and mental-health concerns, loneliness, isolation, and little time for self care. In spite of the weight of their responsibilities, Caregivers describe their lives in positive terms and are often happy to care for their loved ones.
Providing care is spread across a wide range of responsibilities in both the Activities of Daily Living (ADLs) (feeding, mobility, dressing/bathing, etc.) and Instrumental Activities of Daily Living (IADLs) (meal preparation, shopping, transportation, companionship, etc.). Spousal caregiving and those who live with the person they care for tend to be more involved (11.3 activities) and provide more emotional support and companionship. Food preparation is the most common activity reported, followed by transportation, cleaning, and emotional support. Many caregivers are also performing tasks that nurses typically perform. These skilled activities include tasks such as wound care, injections and other skilled activities.

Caregiving exacerbates concerns about emotional and social health for most Caregivers. A smaller, but sizable, percentage report that their physical health has been directly impacted by their Caregiving role. Qualitative data suggests that this Life Shift is a wake-up call to pay attention to Caregivers’ own health needs, including weight control, smoking, and healthy eating. Many worry about their mental state, including depression, but aren’t exactly sure how to help themselves through these issues. In spite of overall fairly positive feelings about the care they are providing, more than half describe feeling overwhelmed, guilty, and conflicted.

Nearly 40% of Caregivers report being under at least some financial strain as a result of their role. This strain is greater among those living with their care recipient than those who aren’t. Younger Caregivers also feel the strain and show lower levels of fulfillment. Caregivers report they typically pay out of pocket for everything from co-pays and prescriptions to food and gas, further straining their already volatile financial situation. Most cope with financial strain by cutting their own expenses or seeking different employment. More than half report that their current employer is supportive of their Caregiving responsibilities, with a little less than half of employers providing flex time. But Caregivers report that they use up their vacation days and personal leave for Caregiving and worry about the impact their role has on their career potential, which is a different type of financial impact.

Resources for Caregiving

Most Caregivers are aware of products and services that can help their recipient relative to this experience, but fewer are aware of what’s available to help them manage their role and their lives. Resources related to physical health are top of mind. Yet, even less than half of Caregivers who are aware of a resource actually have accessed it. The one exception: resources to help with the physical health of their care recipient.

Most Caregivers say they “sometimes” or “rarely” seek out information or resources to help navigate their Caregiving challenges. Medical professionals (for physical or mental health) are the most sought out, followed by magazine articles, newspapers, and blogs. Younger caregivers turn to medical professionals first but more often seek information through digital media. Older Caregivers are more likely to look to organizations such as AARP. In fact, information-seeking behavior divides along generational lines with Gen Xers preferring to search online, Silents looking for face-to-face contact, and Boomers split between the two. Speaking with people via phone to find information is the least desire method by every generation.
More than 70% of Caregivers have or plan to make a purchase to assist with their caregiving role. Practical items like grab bars and mobility aids top the list, followed by smart devices and monitoring technology. Other than insurance and other financial products purchased by Silents, the generational differences when it comes to purchases are not remarkable. Interestingly, within the technology category, the Silents are the biggest purchasers of computers/laptops/tablets at 18%, double that of younger generations.

Some of these Silents are “late to the table” in all things tech and are playing a bit of “catch-up,” understanding that having these tools can support their Caregiving role. Additionally, we’ve found qualitatively that Silents particularly like the size and convenience of tablets.

Caregivers have the highest percentage of Technology Wizards in their ranks and the lowest percentage of Technology Novices yet most are not using the newer technology available to help with their caregiving. Wizards tend to rely heavily on technology and new gadgets to navigate their lives. So, there’s a clear opportunity to provide a range of digital products and resources to help this Life Shift. Caregivers are most likely to use their phones for the basics and have the lowest penetration of Social Connectors, where a phone acts as a social bridge and is central to their lives.

Caregivers believe they have a responsibility to the person for whom they provide care, regardless of their familial relationship. While they attribute positive feelings to the experience, they often place their own well-being at risk. They feel guilt over not being able to be everything to everyone. This tradeoff of their own interests in service to the person they’re caring for extends to their consumer behavior as well.
About: The Five Life Shifts

This new “Hacking Life Shifts” study dives deeply into five of the most provocative changes that can take place during the aging journey:

- **Caregiving** – providing ongoing informal care (usually for a spouse or parent)
- **Recent Singles** – moving to the next stage of life after a divorce or widowhood
- **Grandparenting** – becoming a grandparent
- **Career Encoring** – starting a new career or focusing on volunteering after ending life’s work
- **Changing Living Situation** – relocating from one’s current home to another location

None of these shifts takes place in a vacuum. Consumers frequently experience one or more at the same time. Moreover, this study focuses on recency of the shift. We recruited participants who are either immersed in the shift right now or have recently navigated through it, ensuring that the insights are fresh and the stories compelling.

Methodology

Hacking Life Shifts is a four phase research project combining secondary research, an online quantitative survey (n=2003, ages 45-91), qualitative interviews and exercises, and behavioral data integration. For full methodology information, please see the *Hacking Life Shifts: Methodology* document. Caregivers are defined as those who provide 5 or more hours of unpaid care or assistance to an adult friend or family member who needs assistance due to aging, as disability due to health-related issue.