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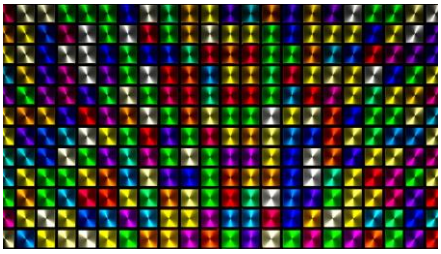
Caregivers & Technology: What They Want and Need

A Guide for Innovators — Research from A Nationally Representative Sample of America's 40 Million Family Caregivers



Editor's note: What follows is an abridged, illustration-rich presentation of research conducted for Project Catalyst (charged with positioning the 50+ consumer the center of innovation) by HITLAB (a healthcare innovation lab dedicated to improving the quality and accessibility of healthcare worldwide). HITLAB helps stakeholders in the public and private sectors technology-based solutions from concept to development and evaluation to meet pressing healthcare challenges.

EXECUTIVE SUMMARY

The goal of this study was to gather information about how caregivers use technology, the functions they are interested in, and the barriers product developers must overcome, HITLAB designed and conducted the study.

From October through December 2015, Project Catalyst and HITLAB conducted a nationally representative survey, ethnographic observations, and semi-structured interviews to better understand how caregivers are using technology, which technology functions they are interested in, and the barriers innovators need to overcome to adequately meet caregivers' needs.

As of late 2014, approximately 40 million Americans provided unpaid care to an adult. This population of caregivers is estimated to reach 45 million by 2020, caring for 117 million people.

The market opportunity includes spending on needs such as health and safety awareness, care coordination, transportation, caregiver quality of life, social well-being, and daily essential activities, which take the lion's share at $53.7 billion (74%). Total spending across these areas for the years 2016 to 2020 is expected to be $279 billion.[1]

Beyond direct spending, the opportunity costs for family caregiving are huge: $533 billion annually, as measured by the RAND Corporation's estimate of income lost during the time that unpaid caregivers spend on eldercare.[2]

The challenge for a caregiver is real. While caregivers' use of technology to aid their duties is scant, their interest in tech is high. Most caregivers care for one adult on their own. For half of caregivers, it's a part- or full-time job.

- 91% of caregivers care for one adult; 81% are the primary caregiver and 68% care without any paid assistance.
- 21% of caregivers perform 21 to 40 hours of care per week, and 30% care for 41 or more hours per week.
- 71% of caregivers are interested in technology to support their caregiving tasks.
- 59% of caregivers say they are likely to use a currently available technology, when asked about their likelihood to use a range of available technologies.
- 7% of caregivers are using or have used technology available in the market.
- Technologies for scheduling, organizing, and medication refill delivery are used most, and those used least are technologies for and sharing motivational content

about caregiving.

Barriers to Technology Adoption

Many caregivers perceive that technology won't be better than traditional methods they already follow. This perception is a product of a lack of awareness.

Younger caregivers use technology twice as much as their aged counterparts; and among those who aren't currently using available technologies, younger caregivers more often say they are likely to use technology in giving care.

- 8.5% of caregivers ages 18-49 years use technology for caregiving, whereas only 4.6% of caregivers ages 50+ use those same technologies.
- 65% of caregivers ages 18-49 years are likely to use available technologies, whereas 56% of caregivers ages 50-64 and only 38% of those ages 65 and up said the same.

Peace of Mind

More than three-quarters are interested in technology that helps them check on or monitor a loved one. Available technologies are used by only 10% of caregivers. Caregivers say these technologies, while attractive in principle, are too costly and complex, and not worth the investment of time and money for technology that is only useful in rare and emergency situations.

Medications Management

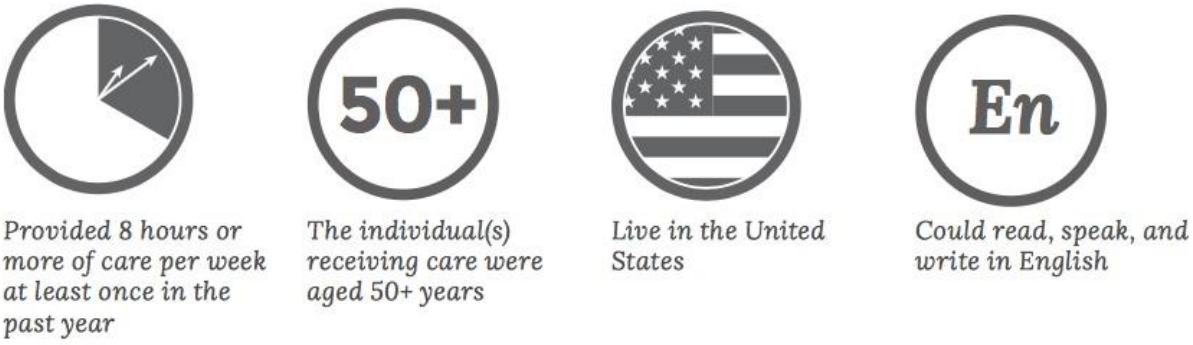
More than three-quarters are interested in technologies that help with medication refills, delivery, and adherence. Only 11% use refill and delivery tools, while and 8% use adherence tools. Caregivers said awareness of the best management tools is a significant barrier, as well as the perception that medication tools lack total interoperability. If a tool helps them obtain all available providers, but does not provide refills for all medications at all available providers, they'd rather not use the tool at all.

Caregivers Seek Integrated, Multifaceted Platforms

Among caregivers, 20% currently use technology for calendars and scheduling, and 13% use it for tracking tasks. They want organizational tools that allow them to communicate with other members of their care team, including informal and professional caregivers. They want tools that engage them, and they are tired of using many single-point solutions. They want one platform that can be adjusted to their individual (and changing) needs.

STUDY METHODOLOGY

Guided by known demographics of the national caregiver population, survey recruitment followed quotas according to gender, income level, education level, race and ethnicity, and age.



There were 1,028 caregivers who completed online surveys from October through December 2015 and answered questions about their experiences and needs as caregivers. There were 15 survey respondents who agreed to in-home interviews. Respondents from the New York Metropolitan area, where HITLAB is located, were selected to participate in this study component.

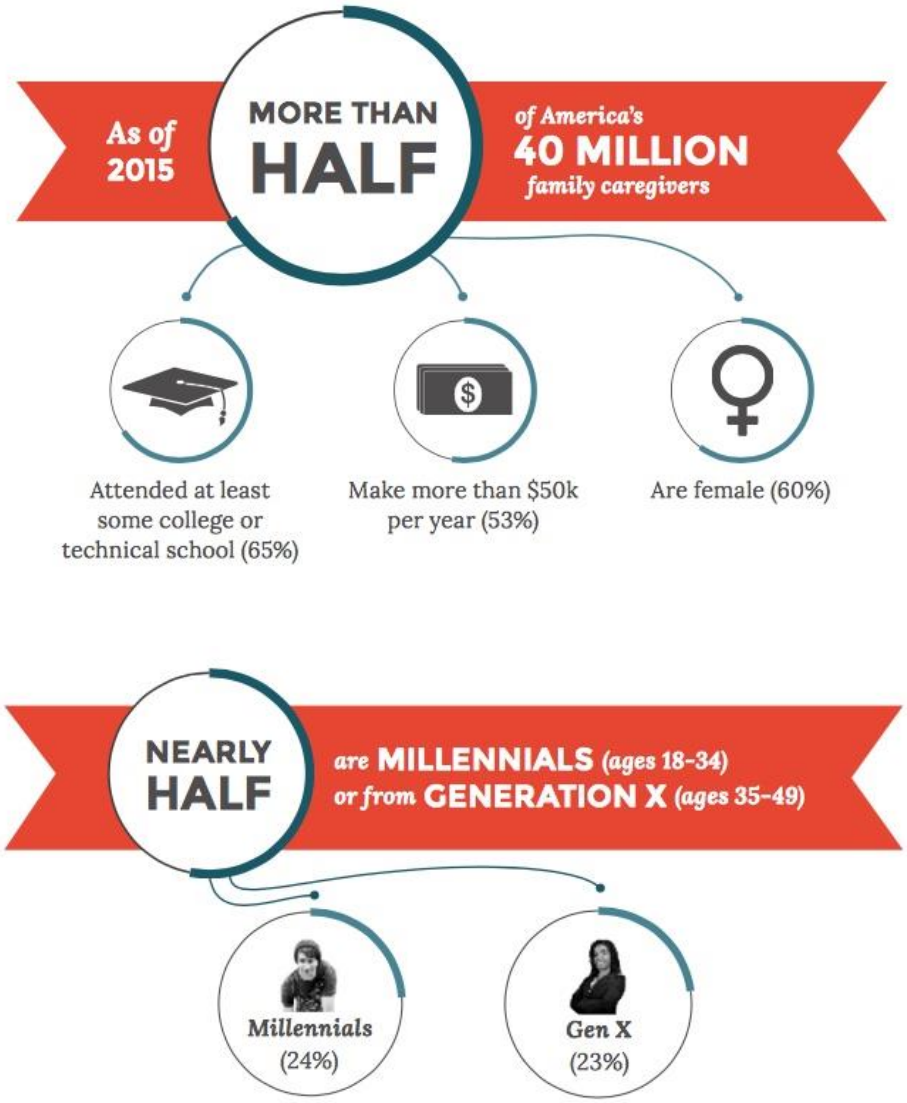
Analysis of qualitative and quantitative data was performed by HITLAB researchers. Descriptive statistics were generated for percentages for categorical variables and measures of central tendency for continuous variables.

RESULTS

Who are America's Caregivers?

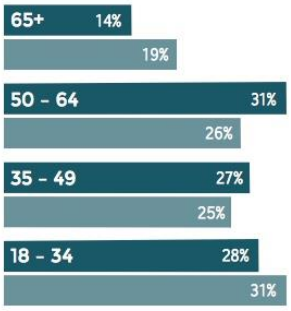
About half of all family caregivers are 50+ years old—the age at which many people

begin receiving care. Caregivers are found in every demographic and resemble the average U.S. adult population, albeit with a few exceptions.



Demographics of our sample (dark green) were similar to the general U.S. population (light green).[3]

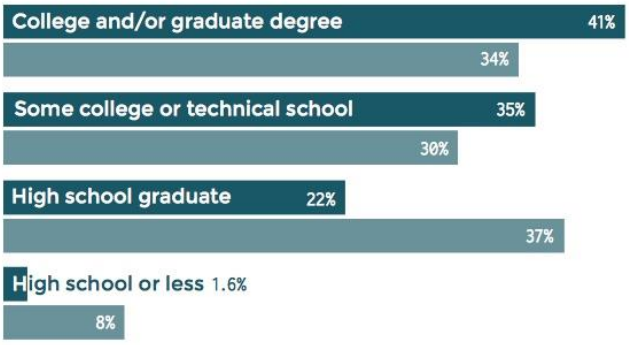
Age[4]



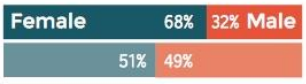
Average: 46.4 years
Median: 37.7 years

Ethnicity[5]

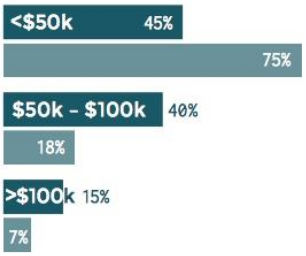
Education[6]



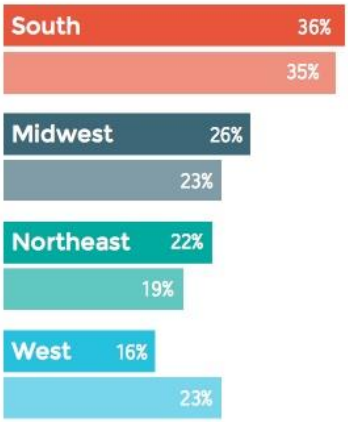
Gender[7]

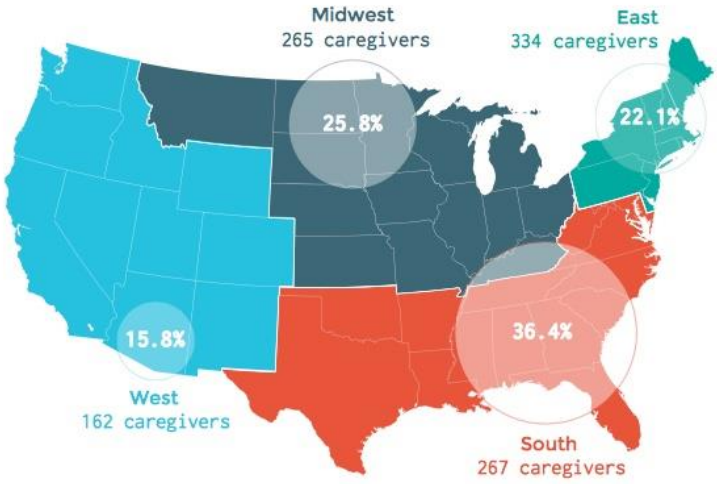


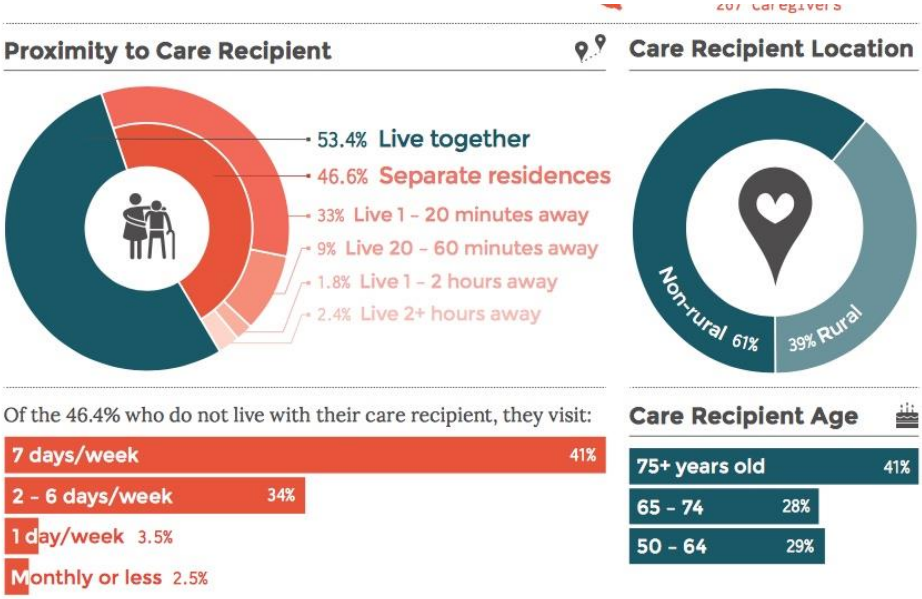
Income[6]



Geography







Caregivers and Technology

Caregivers are technologically literate, comfortable using a variety of devices, and already use technology in their caregiving. As data were collected via an online survey, we expect that technology literacy, comfort, and use to be slightly higher than the general caregiver population. However, general internet access rates in caregivers tends to be high: a 2013 study by the Pew Research Center indicates that approximately 86% of caregivers have internet access, compared with 78% of non-caregivers.[10]

While comfort with computers was high across all groups, the 65+ population reported the lowest levels of technology comfort for smartphones, tablets, and devices.

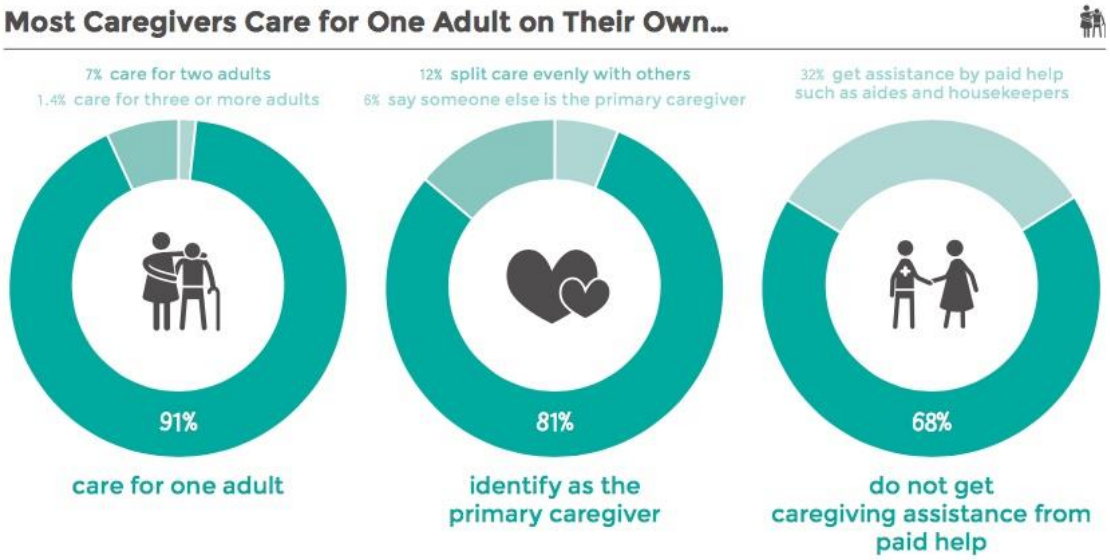
While many caregivers (43%) currently use technology less than weekly to provide care, a large share of them want to use technology, especially when asked about technological solutions for specific activities they perform.

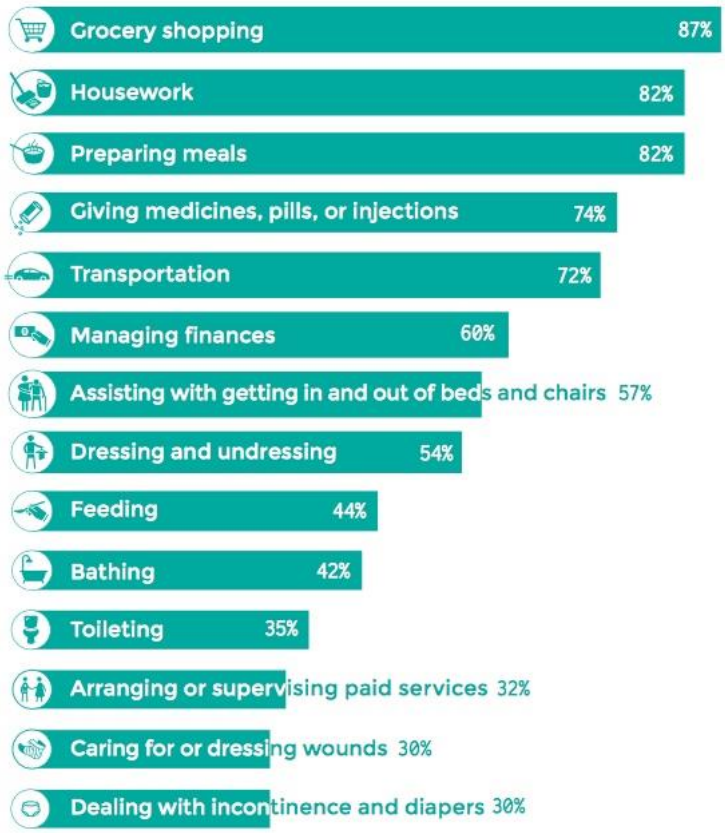
Before looking at their interest in specific technologies, it is useful to understand what caregivers are doing when we say broadly that they are “providing care.”

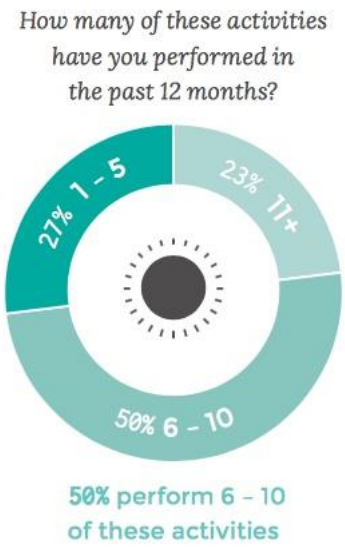
Services Provided by America’s Caregivers

The following quantitative data are national-level data on the spread of duties caregivers perform: groceries and medication pickups, help with bathing and dressing, managing financial affairs, and appointments.

These are categorized as Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs). ADLs are the tasks an individual does when they get up in the morning and go to bed, and involve basic personal care such as bathing, dressing, toileting, brushing teeth, and eating. IADLs are the tasks an individual does during the day, including cooking, driving, shopping, managing finances, and managing medication.







Areas of Opportunity for Innovators

A majority of America's caregivers are interested in using technology to assist their caregiving duties, but current use of available caregiving technology is low.

Tech Interest Is High

When asked about interest in using technology to support caregiving activities

15% Neutral
14% Not interested

Activities of Daily Living (ADLs)

Routine tasks done with waking up and going to bed to manage one's body. Examples:

- Bathing
- Dressing
- Toileting
- Brushing teeth
- Eating

Instrumental Activities of Daily Living (IADLs)

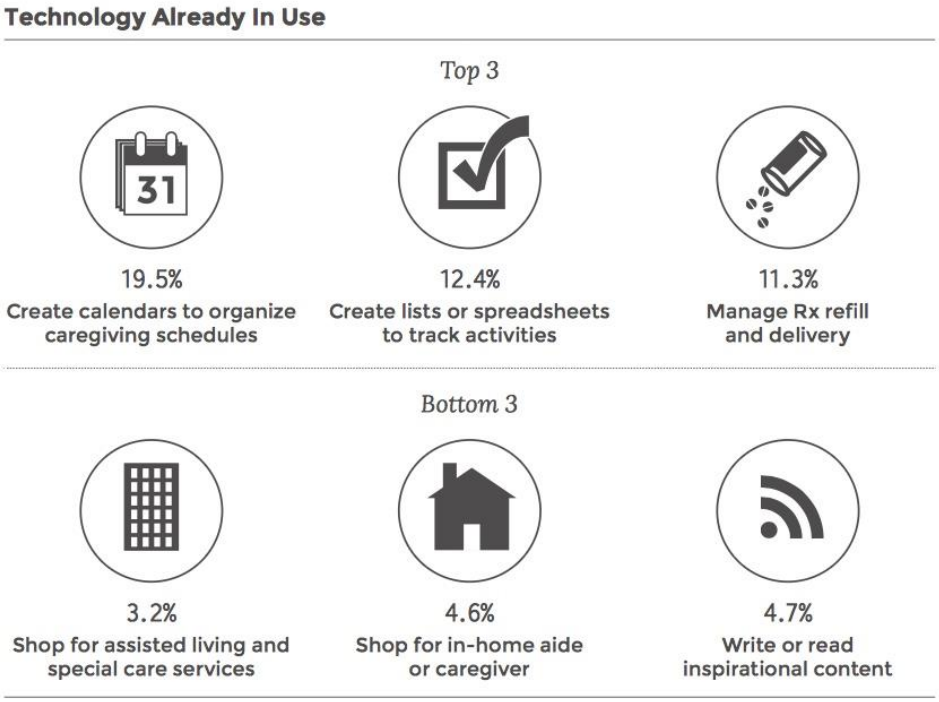
Varied tasks done during the day to manage one's life. Examples:

- Cooking
- Driving
- Shopping
- Managing finances
- Managing medication

Top 10 areas of interested in technology by task include the following.

Interest in Technology, by Task	Interested	Neutral	Uninterested
Rx refill + pickup	79%	10%	10%
Making and supervising medical appointments	78%	10%	11%
Assessing health needs and conditions	78%	12%	10%
Ensuring home safety	78%	12%	10%
Monitoring Rx adherence	77%	11%	12%
Checking in on care recipient	76%	12%	12%
Managing stress and emotional challenges (of caregiver)	74%	14%	13%
Grocery and other shopping	72%	13%	15%
Transportation, providing and arranging	71%	15%	14%
Managing finances	70%	16%	14%

An average of 6.9% of caregivers currently or previously used a caregiving technology function (range: 3.2% to 19.5%; median: 6%).

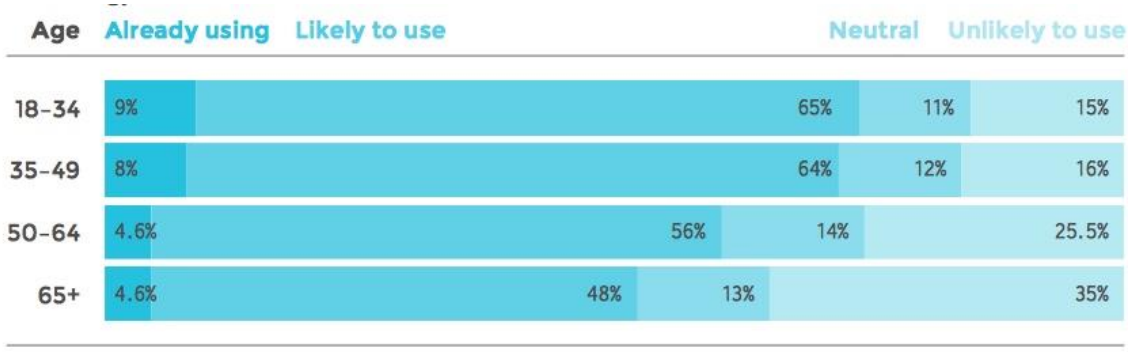


Barriers to Using Available Technology**□□□□□**

- Lack of awareness
- High cost
- Perception that technology will not produce improvement
- Lack of time to learn or select new technologies

A Hopeful Outlook

Tomorrow's generation of caregivers have higher rates of use of available technology: median 9% for millennials and 8% for Generation Y vs. 4.6% for caregivers 50+. Further, greater portions of millennials and Generation Y said they were 'likely to use' available technology vs. those 50+.



DISCUSSION

Caregivers are highly interested in technologies that provide peace of mind. They want technologies that offer assurance of their loved one's well-being even when apart, access to their vital signs, and access to resources for immediate care and intervention.

Caregivers want the ability to detect emergency events. But they aren't willing to purchase, setup, or use bulky and expensive technology (especially if it requires upkeep) just to get alerted for a rare event. They want near-invisible or barely-there solutions that they don't have to think about until they need it.

Top reported needs to improve caregiver organizational tools include the following.

1. Seamless communication with other family members to coordinate caregiving tasks
2. Scheduling prompts and appointment reminders to guide the caregiver through appropriate care routines and keep appointments top-of-mind
3. Flexible integration tools that allow them to organize a variety of caregiving task
4. Clear structures to follow that are condition and authored or approved by a trusted source
5. Active reminders and prompts in technologies so caregivers are assured that if they forget, their technology won't

To succeed in this area, innovators will need their technologies to communicate a high level of credibility in the platform and the available service providers, as well as build an adequate screening process into the user experience. Additionally, the added

convenience must outweigh both the real and perceived costs of giving up control and introducing additional variability to the overall picture of giving care.

These decisions are complex and come with large and binding material commitments. Innovators should consider their role as aggregators of information that improve the discovery and research process for caregivers rather than as providers or brokers of such technologies.

To succeed with technologies that enable caregivers to manage their personal quality of life or seek and receive social, emotional, and mental support from others, whether peers or professionals, innovators will need their technologies to create environments where caregivers feel safe and validated in their caregiving experiences. Even to the extent of persuading caregivers that taking care of themselves is not only acceptable, but is a critical component of the overall well-being of their care recipient.

Caregivers expressed interest the following functions, among others:

- Medication reminders
- Appointment reminders
- Rx refills
- Doctor appointment scheduling
- Financial, medical and legal information
- Calendars
- Monitoring and alerting systems

Findings from qualitative interviews indicate that using technology could be prohibitive if caregivers are offered a separate technology solution for each individual caregiving activity or recipient need.

CONCLUSIONS

Caregiving is uncharted territory for most caregivers. They didn’t go to school for it. They haven’t received formal training. There are no standards of care to which they can look or aspire to know that they are doing a good job.

In a few cases, they may have seen their parents provide care to grandparents, but otherwise they have no models to follow. On top of that, the needs of their care recipient are many and come with high stakes of health outcomes, most of which go above and beyond their level of knowledge and skill. For these reasons, having the feeling that a resource or a provider is an expert and can be trusted are paramount.

Where individuals might embrace risk in a decision for themselves, they are more risk averse in the same decision in caregiving because the recipient is a loved one to whom they feel responsible for making the right choice. These factors may explain the preference for access to experts and reviews from experienced caregivers.

The majority of technology functions that caregivers are most “likely to use” relate to access to professionals, personalized guidance from trusted sources, or access to ratings and reviews of providers.

Rank	Function	Likely to Use
2	Get immediate professional healthcare information or second opinions at any hour or day	71%
3	Receive personalized information on the resources you need to provide care to your loved one	70%
5	Personalized reminders or guidance about care based on your loved one's health condition	67%
6	View directories with professional reviews of caregiving services (e.g. ratings from state inspection reports, seals of approvals, etc.)	67%
7	Personalized advice that considers your loved one's condition to produce a personalized plan to prepare for their discharge from a health facility	66%
9	Read other caregivers' ratings and reviews for various caregiving services, facilities and companies	65%
10	Checklists and information to help you prepare for your loved one's discharge from the hospital or care facility	65%

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Tags

barriers to technology, caregivers, *HITLAB,* innovators, market opportunity, medications management, *Project Catalyst,* technology, telemedicine process improvement, telemedicine program implementation, telemedicine remote health, what is telemedicine and how does it work