

Designing Technology for Caregivers: Understanding What Works and Doesn't



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Acknowledgments

This research was made possible through generous support from the founding members of Project Catalyst.

Project Catalyst fills a gap in the market by putting the 50-plus consumer at the center of innovation. By conducting consumer research of new and emerging products with the 50-plus consumer, we help inform developers about how their products and services are working to improve the lives of Americans as they age.

Research was conducted for Project Catalyst by HITLAB.

HITLAB is a healthcare innovation lab that helps leading organizations with the ideation, creation, evaluation, and diffusion of technology-based solutions to improve the quality and accessibility of healthcare worldwide. Our scientific, multidisciplinary approach allows us to effectively investigate digital health research questions, providing stakeholders from all sectors of the global healthcare system with meaningful ideas and products, as well as an evidence base across numerous therapeutic and geographic areas.

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Executive Summary

To help shape development of the caregiver technology marketplace and stimulate market growth, it is vital to pinpoint and address key areas of need identified by family caregivers. Project Catalyst commissioned HITLAB to conduct three pilot studies that tested technologies in three areas identified as pain points from prior Project Catalyst research: care coordination, emergency alerting, and in-home aide services. By increasing understanding and knowledge among innovators and investors about the caregiver technology market, they can better support the millions of family caregivers, both today and in the future.

Family caregivers tested either a care coordination platform, a personal emergency response (PERS) device, or a home care aide hiring platform for up to 6 weeks. We asked them to assess whether and how technology could address their concerns, determine plusses and minuses of function and design, barriers and opportunities for use, and areas for future improvement. Most caregivers care for one adult on their own. For half of caregivers, it's a part- or full-time job.

The Care Coordination pilot offered several benefits and addressed several caregiver concerns about managing and tracking care recipients' needs. However, room for improvement exists in functionality, complexity, and user-friendliness; additionally, cost remains a barrier for some.

The PERS pilot was well received and benefited caregivers and care recipients. This fostered additional peace of mind as well as some unanticipated benefits. Several features were considered “must have” core components, however, cost was a considerable barrier for some participants. Additionally, flexibility, added functionality, and automated features were highly desired.

The Home Aide pilot addressed several barriers to hiring paid home care aides—cost, vetting/screening, scheduling, and care recipient compatibility in hiring. Its strong success rate demonstrated a clear need for this type of tool, which offers caregivers and care recipients more control and input into the complex and emotional decision-making processes when hiring home care aides.

Background and Context

WHY THIS STUDY

Caregivers are overwhelmed, exhausted, and burnt out¹. Technology can help alleviate some of the stress and burden, but only if it's the right technology, that works for the caregiver and care recipient at the right time, in the right way. As the U.S. population continues to age, more care, not less, will be needed. Savvy tech companies will understand caregiver pain points and stand ready to assist. Consider the data:

The proportion of adults over age 50 is growing rapidly². There were 108.7 million adults age 50+ in 2014 (34.1% of U.S. population). That will jump by a projected 19 million over the next decade, outpacing the projected growth for the population aged 18-49, which AARP expects to increase by 6 million over the same time period².

Longevity is increasing too. In 2014, the average life span for an adult in the United States was 78.8 years, (76.4 years for men and 81.2 years for women)³. By 2030, U.S. women will live to an average age of 83, and men until age 80³.

That's good and bad news. Already, the 80+ population is the fastest growing cohort but it's also the age when people are most likely to have a physical or cognitive impairment. Living longer often means living with health conditions which impact older adults' ability to care for themselves and stay in their homes for as long as possible. According to the U.S. Department of Health and Human Services, as reported by NORC at the University of Chicago, more than two thirds (70 percent) of older adults will need some form of long-term care in their lives for an average of three years⁴.

According to the Journal of the American Medical Association Internal Medicine, almost half of U.S. older adults currently report they either need help or already receive help with routine daily activities, such as shopping, transportation, bathing, meal preparation, or managing medication⁵. Almost 8 million older adults need significant help with basic activities of daily living (ADLs), as well as tasks like getting to physician visits, managing finances, and medical decision-making⁶. About 6.3 million older adults receive a family caregiver's help with household tasks or self-care because of health or functioning and an additional 3.5 million older adults receive help because they have dementia. The longer people live, the more their need for care increases. More than half of adults (58.5%) age 85 to 89 and a majority of those over age 90 (86%) need at least some help^{7,8}.

It's up to family caregivers to pick up the slack.

GROWING SCALE OF UNPAID CAREGIVING IN THE U.S.

Family caregivers—mostly women between ages 45 and 64—find themselves squeezed between caring for an aging parent or spouse and caring for their children. Between 1988 and 2007, one in 10 women in this age group provided significant care for a parent or parent-in-law and financial or housing help to both a parent and an adult child⁹.

Prior research from AARP estimates that 40 million Americans provided unpaid care to an adult in 2014. More than 8 in 10 (81%) were the primary caregiver and over two thirds (68%) had no paid help. More than one-third (36%) of family caregivers care for a parent; 7 out of 10 caregivers care for loved ones over 50 years old¹⁰. About 34.2 million Americans provided unpaid care to an adult age 50 or older in the prior 12 months¹¹.

The Congressional Budget Office estimates the value of family caregiving to older adults in 2011 at \$234 billion in unpaid services¹². Just two years later, that figure more than doubled—in 2013, about 40 million family caregivers provided 37 billion hours of care worth an estimated \$470 billion to their parents, spouses, partners and other adult loved ones, more than total Medicaid spending (\$449 billion) for that year¹³. And, by 2020, some 45 million family caregivers will care for 117 million people. Family caregivers spend an average of five years caring for an older adult with high needs, and they're more likely to suffer negative consequences, from anxiety and depression to financial issues, the longer they do so^{14,15}.

Prior Project Catalyst research showed that 71 percent of caregivers are interested in technology, but significant barriers to adopting new tools remain. A chasm exists between currently available technology to help family caregivers manage their myriad concerns and what they actually want, need, and will use.

We identified three key pain points caregivers face, which have the potential to be addressed by technology¹⁶:



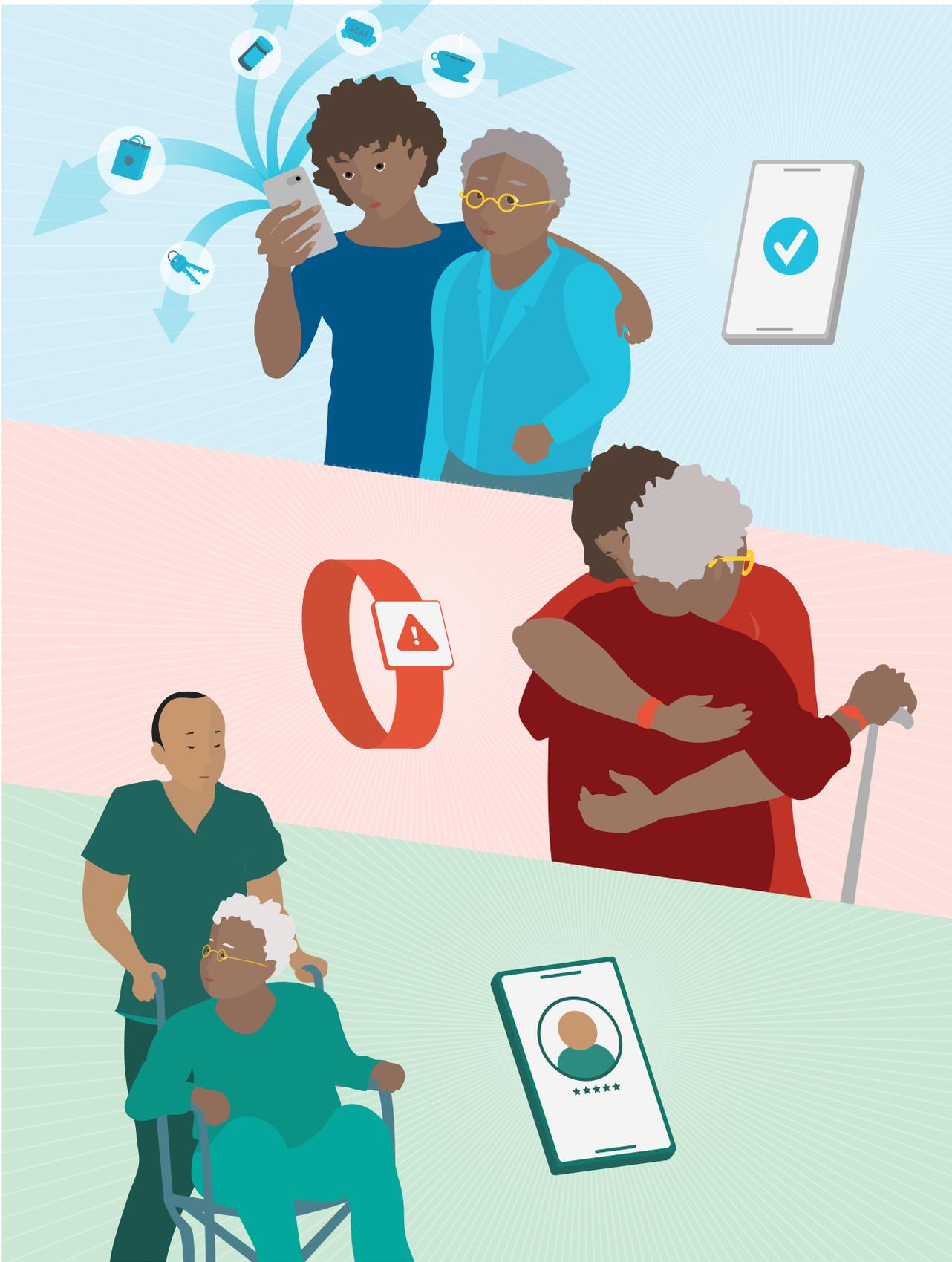
Coordinating
and organizing
caregiving activities



Emergency
monitoring of care
recipients



Finding and
securing in-home
services



WHAT WE HOPE TO ACHIEVE

This report provides further evidence to shape the development of the caregiver technology marketplace and to stimulate growth for caregiver technology products by pinpointing which aspects of technology caregivers find most useful, desirable, and necessary.

Additionally, increased understanding and knowledge among innovators and investors about the caregiver technology market will aid in determining how their products can support caregivers. Pilot testing is an important step in gathering quantifiable evidence when determining solutions to key questions, including:

- **How can technology help?**
- **How can it be improved?**
- **What are the unique needs that caregivers have when it comes to technology?**
- **How should technology be designed in order to best meet caregiver needs?**
- **What barriers and opportunities exist for technology use among caregivers?**

WHAT WE DID

HITLAB conducted three pilot studies that tested technologies in three key areas identified as pain points: care coordination, emergency alerting, and in-home aide services.



**Study 1: The Care
Coordination Pilot**



**Study 2:
The PERS Pilot**



**Study 3: The
Home Aide Pilot**

We recruited caregivers and their care recipients from across the U.S. to participate in the research. We asked them to use a technology product for up to 6 weeks to understand how it helped and what it could do better. Caregivers assessed either a care coordination platform, a personal emergency response device (PERS), or an online screening tool for hiring paid caregivers between May 2016–Jan 2017.



Study 1: The Care Coordination Pilot

Piloting a smartphone app for coordinating and organizing caregiving activities

OBJECTIVES AND OUTCOMES OF INTEREST

We asked caregivers to pilot a multifaceted organizational tool delivered through the [smartphone application and accompanying website](#). The goal was to determine the challenges caregivers face in coordinating care, and how a care coordination platform can best alleviate them. The platform was designed to improve caregivers' organizational processes and the ease with which caregivers coordinate the various aspects of care, including task and medication management, health status tracking, and care network communication.

In our prior caregiver study¹⁷, caregivers voiced a strong need for tools to improve their organization and coordination of care. Specifically, they articulated a desire for tools to provide:

To further probe into this, we designed a pilot study of a care coordination platform to answer three questions:

- **Better communication with other family members to coordinate caregiving tasks**
- **Scheduling prompts and appointment reminders to guide them through appropriate care routines and keep appointments top-of-mind**
- **Flexibility and integration of tools that allow them to organize a variety of caregiving tasks in one platform**

- **What challenges do caregivers face in coordinating care, and how can a care coordination platform best remedy them?**
- **What components should a care coordination product include to be useful, usable and acceptable to caregivers?**
- **Can a care coordination platform alleviate caregiver stress?**

STUDY METHODOLOGY

Twenty caregivers were asked to use a care coordination platform for 30 days for all of their care coordination activities. The platform allowed caregivers to track medications, appointments, and tasks pertaining to their loved one's care. It also permitted communication and task delegation to other members of their care team.

HOW WE DID THIS STUDY:

20 caregivers were asked to use a smartphone-based care coordination platform to manage caregiving activities for 30 days.



CAREGIVERS WHO PARTICIPATED:

provided unpaid care to a person aged 50+ for 20 hours a week, owned an iPhone, spoke English, and lived in the New York Metropolitan Area.



DATA COLLECTED:

user interviews, surveys, and device analytics.



Once enrolled in the study, caregivers were granted access to a care coordination platform. The platform enables caregivers to manage their calendars and tasks, communicate with other members in their care team, track and record health data and review reports on their loved one's progress. It is accessible through the web and smartphone application. Key features of the platform included a personalized task checklist, allowing them to track a loved one's health data and biometrics; an educational component, which recommended tasks based on their loved one's medical conditions and behaviors; capacity

for adding medications and tracking the care recipient's adherence; and a coordination and engagement element with other caregivers and family members for task delegation and progress review.

All caregivers (n=20) reported at least a moderate comfort level with technology and a strong belief that technology can solve their needs.

This was an IRB-approved study that used a single arm pre-post study design. Caregivers were assessed at baseline and end line with questionnaires and semi-structured interviews performed by trained HITLAB research staff.

Study Results

UNDERSTANDING THE NEED FOR A CARE COORDINATION PLATFORM

Do caregivers perceive a need for a product that serves this purpose?

Caregivers in the study reported that they find it challenging to keep track of the many components of their loved ones' care, especially remembering key details such as juggling medical appointments, transportation, medication schedules, and health metrics. They feel technology is necessary to help them coordinate care. Caregivers who lived with their loved one were especially interested in exploring technology options to help them improve care coordination.



89% agree that care coordination technology is an important need for their caregiving situation



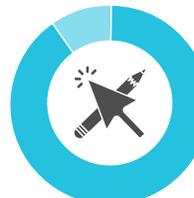
83%, the majority of caregivers in the study, report a strong interest in using care coordination technology to support their caregiving activities.

How are caregivers currently organizing their care?

Before joining the study, most caregivers relied on simple organizational systems, using tools that are not intended for coordinating or organizing care.

“My mom’s doctor is like ‘How do you remember?’... to remind her to take her meds, to set up automatic refills, to call the pharmacy to change the date...”

Most notably, none of the study participants used a product designed specifically for caregiving prior to the study. In fact, only 20% had heard of an app specifically for caregiving, **indicating that the current reach of technology products designed for caregivers is low.**



90% of participants had some method of coordinating care prior to the study (paper-based and/or electronic).



65% of caregivers used a paper-based method (i.e., sticky notes, physical calendar, or writing reminders in a notebook).



85% used a computer program or mobile tool (i.e., spreadsheet, digital calendar [iCal, Google], reminders on phone).

What challenges do caregivers face in organizing care?

Caregivers face unique challenges in coordinating care for older adults. Products should be designed with awareness of the specific needs and experience of coordinating care in mind.

When asked about the biggest problems encountered, four trends emerged as most common reported among caregivers participating in the study:

Juggling their own schedule along with their loved one's.

Caregivers report that they struggle to balance the multi-faceted needs of their loved one with the demands and activities of their own lives.

“*Appointments are the most challenging to coordinate because I have to make it fit on my own calendar. I'll have to move some work hours or something to make her appointments work.*”

Communicating and delegating across caregivers, paid aides and loved one.

Caregivers must often share information and manage activities across an entire care team consisting of other family members, their care recipient, paid aides, medical teams, and others. Caregivers report that communication and information management are the major challenges when it comes to coordinating care.

“*My brother and I take care of my dad. We need a better way of communication to learn how to make him feel independent and in control of his own life, but be able to monitor and ensure his safety.*”

Coordinating a loved one's care while supporting their independence.

Caregivers report being concerned about helping their loved ones maintain independence, but occasionally find that very independence to be a challenge to their ability to efficiently coordinate care. Caregivers find it difficult when their loved ones' actions and strong opinions results in sudden changes to plans or activities the caregiver has arranged.

“*I arrange a car service for her, but sometimes she gets mad at them if it's a car she doesn't like, and she won't get in. She hates small cars.*”

Accounting for sudden changes in planned activities due to health needs.

Caregivers' plans often change suddenly due to their loved one's illness or other health-related situations. When a care recipient is too sick to attend a scheduled appointment, it creates a ripple effect of often-tedious rescheduling needs for the caregiver to manage.

“*Some days she's in so much pain. So, she wakes up and she's just like 'I can't go in [to the doctor], book it for tomorrow.'”*

STATE OF THE CURRENT PRODUCT

How does the care coordination platform tested in our study impact caregivers?

Caregivers felt neutral about the overall impact of the care coordination product on their caregiving activities. About half of the caregivers (53%) felt that the platform had benefits for their caregiving tasks. However, nearly all study participants reported that product was not designed in a manner that met their care coordination needs, and that critical design and functionality limitations were the main hindrance to caregivers feeling the full benefits of the product.

Caregivers felt the product design didn't adequately acknowledge their need to coordinate personal duties in addition to caring for their loved ones, deterring them from fully embracing the platform.

Major complaints included the inability to incorporate their own schedules and activities into the coordination tool, limited ability to use the tool to communicate with other members of their care team (paid aides, family members), lack of interoperability with existing calendars (iCal, GCal), and arduous processes to add scheduled appointments.

95% of participants reverted to their former means of care coordination.

Nearly all (95%) of study participants reverted to former means of care coordination during the study period to supplement perceived product shortcomings. Yet, study participants remained optimistic that a product would soon emerge that

better meets their need while addressing the current usability and design challenges.

Current products don't fully meet caregivers' needs, but there's optimism that coordination tools can be helpful if improvements are made.

Although reception for the platform could be qualified as lukewarm, 68% of caregivers reported they would continue using the product solely to retain access to the stored information on their loved one's medications and medical information. This indicates it is a highly valuable function for caregivers and an area of opportunity for such products to be impactful on caregiving practices.

Additionally, caregivers displayed a slight (10%) improvement in their perceived stress score* from baseline to end line of the 30-day study period. This suggests that the product has potential to improve their caregiving-related stress. Prior research by JAMA Internal Medicine and AARP confirms that family caregivers experience significant stress and emotional difficulty, yet few take advantage of supportive services^{18,19}. This further substantiates the opportunity that care coordination platforms may fill in supporting caregivers.

*The Perceived Stress Scale (PSS) is the most widely used psychological instrument for measuring the perception of stress. Items were designed to tap into how unpredictable, uncontrollable, and overloaded respondents find their lives. This questionnaire was administered to caregivers to assign a stress score with regard to their caregiving activities.

ESSENTIAL ASPECTS OF THE PRODUCT

What functionalities are necessary for a care coordination product to provide value to caregivers?

Caregivers in the study encountered challenges identifying value-adds that the care coordination platform offered over their previous methods of coordinating care.

In this process, five key areas emerged as those that caregivers felt were opportunity areas for a platform to deliver value. Innovators designing products for caregivers should consider incorporating the following concepts:



1. Ease the balancing act between caregiving and personal lives.

Caregivers report that they struggle to balance the multi-faceted needs of their loved ones with the demands and activities of their own lives.

“I added activities to my daily plan that were outside of my caregiving, but were related to my own [personal] life.”



2. Offer easy, reliable access to loved one’s health information.

Caregivers reported that they felt a sense of ease knowing their loved one’s essential medical information was stored safely in their smartphone when using the care coordination platform. Many caregivers said this was the primary reason they would continue use of a care coordination tool.

“It feels like a safety net to know information is recorded accurately somewhere I can check.”



3. Provide a sense of accomplishment and positive messaging.

Caregivers reported that marking and tracking completed tasks in the platform made them feel that they were making progress and accounting for their caregiving responsibilities. They responded positively to receiving this sense of accomplishment and positive reinforcement of their hard work.

“The app made me realize ‘hey you’re a caregiver and you have responsibility,’ and it helped me see what [activities] I had to do specifically. I looked forward to seeing what I had completed in the evening and see what I had to do ahead of time.”



4. Include options for learning and developing skills.

As many caregivers are not trained health professionals, they reported finding value in receiving educational material on providing quality care. Educational prompts provided by the platform also serve to differentiate the care coordination tool when compared with traditional organization tools used by caregivers (iCal, Excel), adding to its value.

A handful of caregivers (20%) found the educational material unnecessary and overly simplistic, and reported a preference that viewing this material be optional.

“It helps remind me to do healthy, positive things. sometimes I wouldn’t even think about stuff like her mood, her diet, her exercise. Tracking her mood made me think more about it. It helped me understand her better.”



5. Facilitate information-sharing with others in the care network.

Caregivers reported that they felt the product must allow them to communicate with and delegate tasks to their loved one, paid aides, and other family caregivers. Think about the needs that different users who may not be tech savvy, speak English, or have smartphones, will require and use.

“Better communication with medical professionals would be infinitely helpful. Sometimes if I can’t be with my dad, I won’t know what tests he had done or what the results were—it would be good to be able to check up on this.”

USABILITY CONSIDERATIONS FOR DESIGNING A TOOL THAT WORKS

Caregivers in the study encountered a number of usability and design limitations that hindered their ability to experience the full benefits of the platform. The following feedback surfaced as the most important considerations for designing a tool with high usability for caregivers:

Provide options for caring for multiple loved ones. Some caregivers coordinate care for several loved ones, and voiced a need to be able to clearly distinguish between each loved one’s information, navigate across profiles, and aggregate schedules.

Acknowledge the design needs of different roles within the care team. Caregivers in the study faced challenges when using the software to communicate with care recipients or paid aides who had lower technological literacy, limited English language skills, or lacked a smartphone. Different members of the care team (paid aides, care recipients, secondary caregivers) may have different interface design needs.

Avoid duplicating entry of info available elsewhere. Caregivers reported frustration at having to re-enter information that was already stored in other calendars, emails or lists. They voiced an expectation that technology products should be sophisticated enough to auto-populate information from other programs whenever possible. Many also

reported the sentiment that their own personal schedules should integrate into the platform to facilitate more complete decision-making.

Help caregivers recall what’s been completed. Caregivers voiced a need to use the platform as a record-keeping tool. They felt it was necessary that the product allowed for adding data retrospectively, checking back on accomplishments, and sharing this information with health providers. Many found it essential that the platform allow them to access information about past activities, completed or not. The checklist feature was considered valuable and reinforced caregiving progress.

See schedules at a glance. Caregivers felt that the platform interface must be designed in a way that lets users easily see future (and past) weeks and months at a glance, in addition to what’s on their plate for the current day. To support this, notifications of upcoming tasks such as medication reminders or doctor appointments were identified as means to help them stay on top of numerous

CONCLUSION

Care coordination products have promising potential, but need to expand functionality to best suit the needs of the caregivers.

Despite experiencing shortcomings with the status-quo of care coordination technology, caregivers voiced optimism that such products could be useful to their caregiving if these functionalities are improved.

Innovators should consider ways to incorporate caregivers' feedback into the design of such products, but with caution: while caregivers voiced that communication and health data storage functions would make care coordination tools more useful to their caregiving, these are complex features that are challenging and expensive to build. This may create challenges for innovators if caregivers also expect such complex products to be priced in the range of the existing digital organization and coordination tools they are familiar with, such as iCal, Evernote, WhatsApp, and Excel. Innovators should carefully consider the price that caregivers would be willing to pay for their products, and do further research to understand caregivers' perception of the costs vs. benefits of coordination products that offer more robust healthcare communication and information storage components.



Study 2: The PERS Pilot

Piloting emergency response systems for caregivers and their care recipients



OBJECTIVES AND OUTCOMES OF INTEREST

PERS, or Personal Emergency Response System, often brings to mind the old Life Alert television ad, “I’ve fallen and I can’t get up!” The device is perceived by some caregivers and recipients as something “for old people,” and proposed use is frequently met with resistance.

Prior research confirms that PERS can be highly valuable in maintaining a care recipient’s independence. In a study published by Research on Nursing & Health, older adults found fallen on the floor and unable to get up, 72% survived, but only 38% of survivors were able to return home. Those who received help quickly were more likely to survive. Researcher recommendations included increased use of PERS devices²⁰.

Originally designed as a remote, accessible means to contact 911 or a family member at the push of a button, PERS have evolved to include more robust, interactive features, offering caregivers more peace of mind and fostering improved independence in the home for care recipients.

In our last study, caregivers voiced a strong need for tools that can improve their peace of mind when caring for loved ones²¹:

This indicates a high level of need, but barriers to entry exist for using such tools.

To further probe into this, we designed a pilot study of two Personal Emergency Response systems to answer three questions:

- **How effective is a PERS product at alleviating caregiver worry and keeping caregivers informed about the safety and wellbeing of their care recipient?**
- **Can a PERS product improve care recipients sense of personal safety?**
- **What components should a PERS product include to be useful, usable and acceptable to caregivers and care recipients?**



77.5% of caregivers were interested in an emergency alerting tool, but only 9.7% are already using such tools

STUDY METHODOLOGY

Twenty pairs of caregivers and their recipients were randomized to use one of two PERS devices and accompanying caregiver platform for 6 weeks.

EACH OF THE DEVICES CONTAINED A DIFFERENT ARRAY OF FUNCTIONS AND FEATURES, INCLUDING:



emergency alerting capabilities,



GPS tracking,



intercom communication,



and mobile alerts to caregivers.

CAREGIVERS WHO PARTICIPATED:

50+

Provided unpaid care to a person aged 50+...

8-40+

for 8-40 hours a week,



owned an iPhone,

En

spoke English, and...



lived in the New York metropolitan area.

Care recipients were carefully screened to ensure they had relevant product need and cognitive awareness to ethically participate in research, including completion of tests to assess cognitive ability, the Barthel Index independence test, and TICs-30 Cognitive Status test.

This was an IRB-approved study that used a randomized two-arm pre-post study design. Caregivers and care recipients were assessed at baseline and end line with questionnaires and semi-structured interviews performed by trained HITLAB research staff. Data on the usage of the devices' emergency alerting capabilities was also collected and analyzed.

Study Results

UNDERSTANDING THE NEED FOR AN EMERGENCY RESPONSE SYSTEM

How are caregivers currently monitoring for emergencies, and what challenges do they face?

Nearly all caregivers reported strong worries about their care recipient's safety—75% said they worried about leaving their care recipient alone **every time** they go out or leave the home. Despite this, none of the caregivers in the study reported having an emergency plan or using any type of emergency monitoring/alerting tool.

Many challenges exist in monitoring care recipients. Among the key issues cited was the need for diversity and flexibility. Monitoring needs are different for every care situation, have a range of levels and intensity (24/7 monitoring vs. emergency-only alerts) and type of monitoring (air quality, eating habits, balance/falls). And, needs are not static—they evolve over time as the care recipient's health changes.

Additionally, caregivers struggle with monitoring loved ones while preserving independence and privacy. Some caregivers, while desiring more access to information about their loved one's safety, feel a tension between the growing need to monitor their loved one and helping them feel independent.

Despite a widely documented need for PERS, utilization is low. When asked why they did not use a PERS device, caregivers pointed to three main reasons. Innovators developing products for caregivers should think strategically about how their product can address the barrier to adoption identified in this study.

1. Cost of device and subscription

Cost was a commonly cited barrier among caregivers using PERS. Many caregivers hoped that insurance coverage, such as Medicare, might alleviate the cost burden of PERS.

“We have tried to get an emergency alert system but insurance won't pay for it.”

2. Lack of awareness of market options

Few caregiver-care recipient dyads were familiar with PERS available on the market today, other than Life Alert. Furthermore, there was little awareness of the greater sophistication and wider set of functions of PERS technologies available today.

“We have seen Life Alert commercials. That's the only one I know about.”

3. Perception that PERS is for “old people.”

Some caregiver-care recipient dyads thought PERS did not apply to them because it was for “much older citizens” or “90 year-olds.” Overcoming the stigma of PERS is important to increase adoption of the technology.

“I joined this study because I was interested to see if there are more alternatives than the traditional devices that my brother and I know about. They show 90-year old people with necklaces and medallions around their neck, which basically label themselves as like ‘Hi, I am someone that may need help.’”

“I thought [PERS] was for people who are crippled. I never thought this is something I, well we, would qualify for.”

STATE OF THE CURRENT PRODUCT

How did the PERS device tested in our study impact caregivers and care recipients?

While many barriers limited caregivers and care recipients from deciding to start using a PERS device, the study found promising benefits experienced by users once they began using the device.

Importantly, PERS positively impacted level of caregiver peace of mind and care recipient independence reported by study participants. Among caregivers, most (85%) felt their peace of mind improved as a result of using the PERS device. Self-reported worry levels were cut by more than half (57%)* over the 6-week study period.

85% of caregivers felt their peace of mind improved as a result of using the PERS

Among care recipients, almost all (90%) felt more independent in terms of their safety and well-being with PERS use. Care recipients reported that they felt more confident leaving their homes due to the sense of security provided by the PERS system. Care recipients noted that they felt glad the device helped their caregivers worry less about their safety.

Both caregivers and care recipients found the device to be helpful in emergencies. An average of 3.5 emergency calls were made per user over the 6-week study period.

90% of care recipients felt more independent in terms of their safety and well-being.

“Thank goodness she had the device. She fell when my brother was not home. My husband and I had to run over and help her up...She did not have the phone reachable when she fell, but she had the lanyard around her neck. Thank goodness!”
–Caregiver

“I’m happy to know [via the device] that he was able to get to the hospital, if I hadn’t known that I would have gone into extra panic, extra panic mode [laughs].” –Caregiver

“Yeah I fell and [the wearable] was right on me, and I pressed it and then my daughter was right on the phone, it was very easy.” –Care recipient

Nearly all study participants (80% of caregivers and 100% of care recipients) would recommend the PERS device to others in similar situations, indicating that they perceived a high level of value and comfort with the product.

The 7-item worry measure used in the study was comprised of adapted items from the C.A.R.E. Tool: An Assessment of Caregivers' Aspirations, Realities, and Expectations and the Family Caregiving Inventory Role Strain Worry Subscale. The adapted instrument is intended to measure the extent to which caregivers worry about things related to their care recipients' safety and well-being. Items were designed to understand key areas related to PERS use, such as sudden illness, accidents, wandering, or having enough information about safety.

ESSENTIAL ASPECTS OF THE PRODUCT

What functionalities are necessary for a care coordination product to provide value to caregivers?



1. PERS devices that facilitate a direct line of communication between the caregiver and care recipient had an unforeseen benefit for caregiving.

We saw unexpected improvements in the frequency and ease of general communication between caregiver and care recipient. PERS intercom buttons were conveniently placed in locations accessible to care recipients throughout the home, and proved to be more convenient than using the telephone for many. Users also found it helpful to hear their loved one's voice in emergencies.

80% of participants felt the PERS device improved overall communication with their caregiver

Care recipients saw benefits in having a PERS device that did more than just detect emergencies. Care recipients reported this feature helped the product integrate more seamlessly into their day-to-day life.

“He uses the device to let me know even as far as if he needs food or something.” –Caregiver



2. Caregivers recognized that some features, even if not necessary in their current care situation, might be needed later as their loved one aged.

Caregivers anticipated the need for features in the PERS device to be deployed or turned off later as their loved ones aged. Medication reminders and camera were noted as features one might need with complex medications or cognitive decline.

Adjusting features over time may fight stigma reported with using PERS. Independent care recipients can benefit from some features of PERS without feeling like an “old person,” but also permit use of more comprehensive monitoring features when the time comes.

“I think, only because he's able to move around OK, that I don't need [camera monitoring]... but I don't think that's something that should be taken away from the system because maybe someday he will need it.” –Caregiver



3. Dashboards designed to provide monitoring data to caregivers were reported by nearly all participants as essential components to easing caregiver peace of mind.

Some caregivers found value in having PERS work passively in the background, knowing that it was available in emergency. Others actively checked in with the system to gain a more detailed view into their loved one's activities.

“I wanted it more as an emergency preparedness device as a caregiver... so I'd have no reason to access [the caregiver dashboard]... there were times I didn't even realize it was here, so it worked perfectly, I thought that was a plus.” –Caregiver

“I liked that I can see activity levels...It makes me feel more secure knowing where she is and what she's doing.” –Caregiver



4. Non-PERS functions, such as clock or radio features, helped care recipients feel more comfortable with the device.

Participants reported that non-emergency features allowed care recipients to gradually become more comfortable with the PERS technology and its presence in the home.

“I wouldn't let my son put on AC unless it was a certain temperature! I could point to [PERS device] and say it's only 72 degrees!... The device had everything I needed, time, date, weather.” –Care recipient



5. Many caregivers fear emergency situations, where their loved one is unable to press the emergency call button, and lamented that there was not a way to automate the fall detection process.

Caregivers expressed concern that their care recipient could be in a situation where they were incapable of pressing the emergency button and feared the system wouldn't be of use for these emergencies.

“He knew how to push the button, but I'm worried about what will happen if he's kind of out of it or faints.” –Caregiver

USABILITY CONSIDERATIONS FOR DESIGNING A TOOL THAT WORKS

The following feedback surfaced as the most important considerations for designing a PERS tool with high usability for caregivers:

Plan around situations that may create worrisome misleading alerts. “Low activity alerts” indicated the care recipient was immobile when the care recipient had simply taken off their PERS device. Caregivers reported experiencing unnecessary worry in such situations.

Ensure the communications pathway in emergencies is efficient so caregivers are not stuck in automated systems in times of high need and stress.

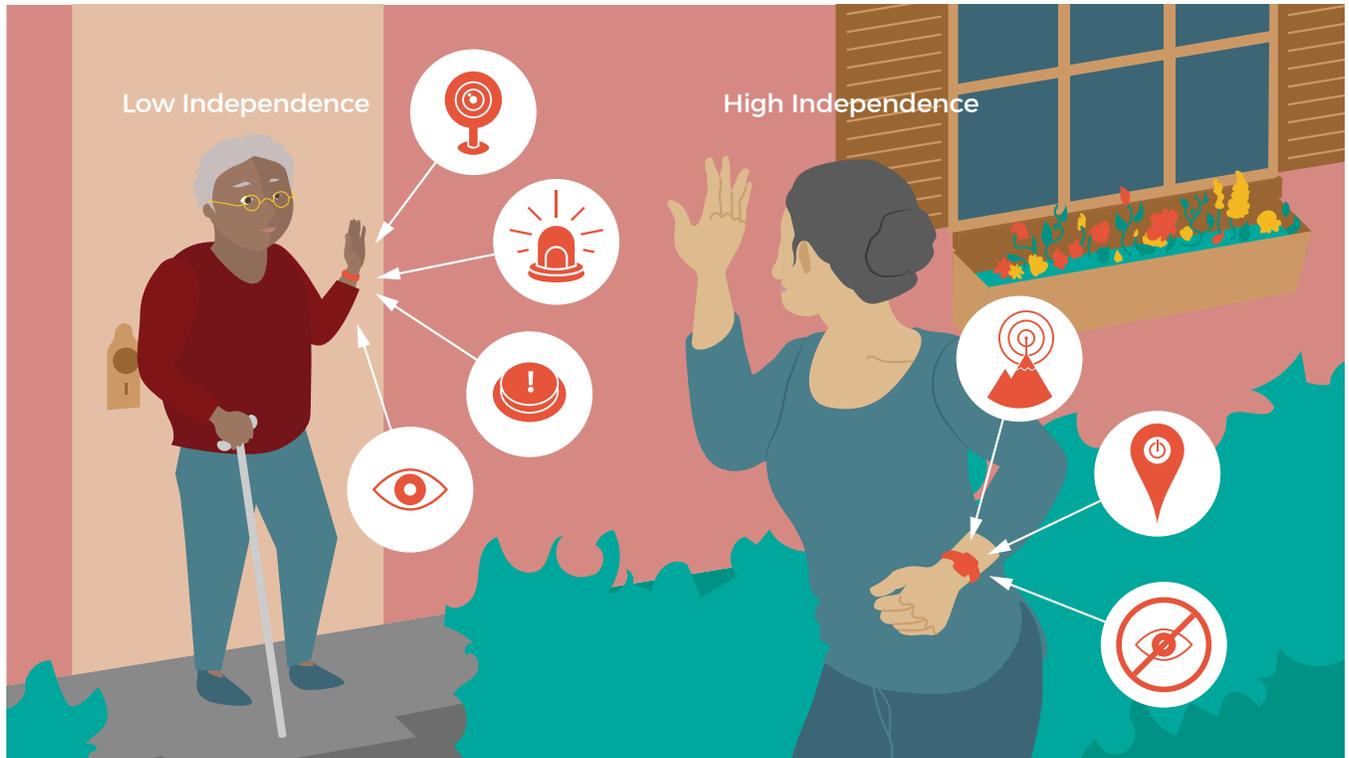
Make sure caregivers know how emergencies will actually play out. Many dyads reported that they did not have a clear understanding of what would happen when the button was activated.

Let users control who the device contacts in emergencies. Some caregivers reported frustration that they were unable to choose who would be contacted when the emergency button was activated based on situational needs. Caregivers voiced a preference for emergency calls to go to family members or the care teams or direct to emergency services on a case-by-case basis.

Give caregivers the option to manage their care recipient account details. In some cases, care recipients can't or don't want to manage the details of the account and device set-up. The inability for caregivers to manage the product accounts creates avoidable logistical challenges in getting going with the device.

NEED FOR AN EMERGENCY ALERTING PRODUCT THE CARE RECIPIENT CAN AGE WITH

Caregivers reported that different product features are needed at different stages of the aging process.



Low Independence

-  Precise location tracking or visualization within the home (e.g., camera)
-  Automatic fall detection (no button-press required)
-  Emergency buttons around the home
-  Additional monitoring components (e.g., medication monitoring)

High Independence

-  Network connection with a large geographic radius outside of the home
-  Location monitoring that can be turned off and on
-  Discreet options for wearing the device in public

CONCLUSION

Results of this study indicate that caregivers and care recipients benefit when given access to a PERS device. While there is no “one size fits all” scenario, several concerns were top of mind for caregivers and care recipients:

Caregivers saw high value in core functions that include a suite of adaptable, need-dependent features:

- **multiple communication pathways**
- **smartphone-friendly dashboards**
- **easy setup/use**
- **automatic fall detection**
- **affordability**

However, room exists for improving and enhancing current technology:

- **improved emergency functions**
- **live vs. automated systems to field emergency calls**
- **enhanced caregiver education on what will happen in possible emergency scenarios**
- **more choice and customization of emergency contacts**
- **greater caregiver control and access to dashboards and accounts**

Innovators should think about how they can best reach caregivers and care recipients to overcome the barriers to entry in using PERS devices. Innovators should also consider the fluidity of aging; products must serve evolving needs, requiring different functions, as the user ages. This may help to address the “old age stigma” barrier that prevents people from using a PERS device.

Additionally, the desire to have a more fashionable, unobtrusive device that reduces perceived embarrassment when carrying it is significant to care recipients. Recent research indicates that design of such devices is increasingly important, and may open up new market opportunities for PERS device makers²².



Study 3: The Home Aide Pilot

Piloting an online service for selecting and hiring a paid in-home aide



OBJECTIVES AND OUTCOMES OF INTEREST

Finding and screening home care aides or personal care assistants (PCAs) is a process often fraught with anxiety and stress. Medicare, Medicaid, and private insurance have strict requirements that may not cover the basic ADL or IADL care needed by many care recipients. Agency, personnel, and scheduling options may be limited. Out-of-pocket costs can be significant²³.

Such restrictions place family caregivers in a bind—fostering uncertainty and doubt, and making traditional paid home care options inaccessible. Finding, screening, and interviewing in-home help based on personal criteria, then monitoring their loved one's care, is a scenario many caregivers desire. An online, vetted “caregiver marketplace” could be the ideal solution.

In our last study, caregivers expressed an interest in hiring aides online, but reported that they were unlikely to use such a service because they felt they could not trust in-home services procured through the Internet.²⁵ Reliability of the person hired to help care for their loved ones is a key concern, especially since they will provide unsupervised care. Non-

traditional, online agencies are perceived as riskier than traditional ones.

To further probe into this, we designed a pilot study of a home aide platform to answer three questions:

- **What challenges do caregivers face in selecting and hiring a home aide, and how can an online platform best alleviate them?**
- **What components does an online home aide service need to include to be useful, usable and acceptable to caregivers?**
- **Will caregivers feel a sense of trust and comfort with services obtained through an online home platform?**

STUDY METHODOLOGY

This study contained a two-part methodology to best understand 1) the factors that contribute to caregivers making the decision to hire a home aide using an online platform, and 2) their experience using services procured through an online platform.

Part 1: Two focus groups were conducted with 16 caregivers (8 per group). One group included caregivers who currently had the help of a paid home aide; the other group was comprised of caregivers who were contemplating or seeking to hire a home aide. The goal was to understand the challenges caregivers face in hiring home aides,

and factors that may influence their decision to use an online service to hire a home aide. As no intervention was delivered, this was an IRB-exempt study.

Part 2: 14 caregivers were asked to use an online platform to select a home aide for their loved one and complete four visits with their selected aide. Caregivers could search for home aides meeting their personal criteria, interview them, and select an aide for hire. After hiring the aide, caregivers used a smartphone app to monitor the progress and activities of each home aide visit with their loved ones.

CAREGIVERS IN BOTH PARTS OF THE STUDY WERE REQUIRED TO...

#1

identify as the primary caregiver

50+

for a family member or friend aged 50+,

En

and speak English.



Caregivers were recruited from across the United States.

This was an IRB-approved study that used a single arm pre-post study design. Caregivers were assessed at baseline and end line with questionnaires and semi-structured interviews performed by trained HITLAB research staff.

Study Results

UNDERSTANDING THE NEED FOR AN ONLINE SERVICE FOR SELECTING AND HIRING HOME AIDES

What challenges do caregivers encounter when identifying and hiring home aides?

To understand the opportunity for technology products to improve the process for hiring and selecting home aides, research was first undertaken to understand what challenges caregivers face with the status-quo of hiring paid support. The following themes emerged as key challenges from caregivers in both Part 1 and Part 2 of the study.

Caregivers are deeply unhappy with the current state of home care.

Almost all caregivers reported a negative experience or view of aides provided by the public sector or traditional agencies covered by their insurance. This indicates a significant opportunity for disruption.

“Most of the time these agencies are just looking at a number, not the person they’re caring for. I don’t feel that these agencies [that are covered by Medicare] really care.”

Cost is the biggest factor in choosing a home aide, limiting use of new online services. Affordable, quality care is hard to find.

Among caregivers who have previously hired an aide, financial considerations were the biggest factor in selecting someone. Nearly all caregivers in both parts of the study depended on Medicare, Medicaid or other insurance for their home aide services. Because of this, caregivers voiced the sentiment that they lack real choice. There are few affordable options for care, particularly companion care, which is not covered under public insurance benefits.

In focus groups, nearly all caregivers (94%) expressed a desire to use online services for selecting a home aide, perceiving that the quality

of care delivered by such a service would be higher than that currently available to them. A third (33%) reported looking at home aide online services when the first began seeking an aide, but none found it to be a financially viable option.

33% of caregivers interviewed in focus groups had previously looked into using an online service to hire an aide, but none found it to be an affordable option.

“I tried a website to find an aide for my dad when he came home from a nursing home, when the process was new to me. It looked great. Then we realized you have to pay out of pocket for these services. Medicare kicked in and we got assigned an aide from an agency. The first couple of weeks were horrible...The aide was terrible. The other [home aide] sites and the aides there looked fabulous.”

Caregivers feel unprepared and under-supported in the process of finding a home aide.

Caregivers who have hired home aides reporting feeling caught off guard by the sudden need to hire someone, and were unprepared for the selection process. In this time of need, caregivers found they lacked accurate, clear information, and the necessary support to determine which agencies and aides were trustworthy and meet their requirements.

In focus groups, approximately 50% of all participants used websites to learn more about home aides in general, and 100% of participants felt there is no easily accessible information about home aides available.

It [the process of finding an aide] has been rough...

“no one prepares you for this and it’s been really horrible.”

“When I first realized I needed a home aide, I was trying to decide which agency to choose, and why, based on my insurance. No one could tell me. No one could say which was a better agency.”

Family member and care recipient resistance adds complexity to the initial hiring process.

Hiring a home aide is a family decision, yet many caregivers reported that they had clashed with other family when deciding whether the time was right to hire in-home help, or encountered resistance from care recipients wanting to maintain independence.

Caregivers have limited ability to personally vet home aide candidates and ensure fit before hiring, contributing to dissatisfaction with the hire.

Caregivers who had previously hired a home aide reported that they felt traditional agencies offer limited choice or ability to select a home aide that

best meets their needs, and that no effort is taken to ensure compatibility with their loved one.

While caregivers feel technology can improve the ease of searching for a home aide, they believe that ensuring the human element of their loved one’s care is the greater priority.

A personal touch is needed to make caregivers feel that online hires are trustworthy.

Caregivers were somewhat apprehensive about the concept of finding home aides online—particularly about trusting the information provided or an ability to get the kind of information they want. Caregivers describe selecting home aides strictly based on online or mobile profiles as impersonal, and consistently express the need to supplement the information online with some kind of meeting with the candidate prior to making the hiring decision.

“You can’t just Uber caregiving.”

What do caregivers look for in a home aide?

Participants in both parts of the study reported two key criteria for making a hiring decision. Interpersonal dynamics and the bond between the care recipient and aide are primary considerations in hiring someone the caregiver also feels comfortable with. Notably, this key consideration is not a factor in the home aide selection process employed by traditional agencies.

1. Compatibility

An aide that has a good rapport and interpersonal bond with the care recipient. This was identified as the most important feature.

“What’s required for this job isn’t only experience.... I could get someone with experience, but if my mom doesn’t like them or feel comfortable with them,

experience doesn’t matter.”

2. Credentials

A single home aide that meets specific care needs and is reliable.

“The hardest thing is having a stranger come into your house. You see their credentials on paper, but sometimes the reality doesn’t match.”

STATE OF THE CURRENT PRODUCT

How does the online home aide service tested in our study impact caregivers?

In Part 2 of the study, 14 caregivers were asked to use a home aide online service to identify and hire an aide, then complete four visits with the home aide of their choice. The product was successful in meeting caregivers needs for home care (this is in stark contrast to the low level of satisfaction caregivers voiced regarding their experience with traditional agencies).



82% of caregivers found a suitable home aide using the platform

18% of caregivers were unable to find a suitable aide, citing the following reasons:

- **Family members were not ready to have any paid help**
- **Concerns about trusting an aide they don't know personally**
- **Inability to find aide with suitable schedule for their unique needs**

Following the completion of the home aide visits, caregivers voiced a high level of comfort and satisfaction with the care provided, indicating that aides selected through the online service met their needs. 100% of caregivers felt comfortable leaving their loved one with the home aide they selected.

100% reported being highly satisfied with the quality of care, and all (100%) said they would continue using their home aide after the study ended.

While the study paid for the four home aide visits, caregivers reported that they found the cost of care (\$20h/hr) to be fair. However, some expressed concerns about their ability to pay this rate perpetually and for increasing frequency/duration of visits as their loved ones aged.

ESSENTIAL ASPECTS OF THE PRODUCT

What functionalities are necessary for a home aide product to provide value to caregivers?

A number of product design components emerged as being particularly useful for caregivers in the study. Innovators designing products for caregivers should consider product design that incorporates the following concepts:



1. Online profiles with details on home aide candidates allowed caregivers to easily vet and narrow down candidates based on credentials.

Caregivers in the study viewed home aides' resume, references, photos, and background check information, and reported that this information helped caregivers feel comfortable with the aides under consideration. Caregivers appreciated having choice and control over the selection process. Most looked at 11-25 profiles before selecting home aides to interview.



2. In-person interview with aide candidates prior to hiring allowed caregivers to assess compatibility.

Caregivers reported that they were highly satisfied by the ability to meet the aides in person, and use intuition to assess interpersonal compatibility with the home aide. This helps caregivers feel more at ease. Caregivers said the “gut feeling” they received from the in-person interview was more important than other credentials and information on the home aide.

Caregivers interviewed 1-3 aides before making a selection.

90% reported that the interview was the most important factor in their hiring decision.

USABILITY CONSIDERATIONS FOR DESIGNING A TOOL THAT WORKS

The following feedback surfaced as the most important considerations for designing a tool with high usability for caregivers:

Automate the process of vetting and recommending home aide profiles as much as possible.

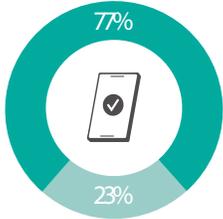
Many caregivers cited an expectation that they would be recommended profiles as if on “Match.com” and cited disappointment that they did not receive tailored recommendations.

Allow caregivers to easily compare credentials and other aspects of home aides.

When viewing numerous online profiles to select home aides to interview, caregivers felt the review process could be streamlined by allowing side-by-side comparisons between profiles.

Apps and dashboards for monitoring hired home aides: are these features essential?

Once a home aide was hired, caregivers were offered access to apps or online dashboards to monitor and communicate with their aides. Such products were found to not have a huge appeal to the majority of caregivers assessed in the study.



77% of caregivers, when offered a mobile app to monitor their home aide, did not use the application, citing that it was not useful.

Redundant Purpose

Many caregivers felt that the mobile application for communicating with their home aide served no purpose, as they already had other means to communicate with their aide.

“I think a conversation every few days, or a call or a text, would be fine.... That’s all you need. A text or phone call, not a whole app.”

Information Overload

Caregivers articulated the opinion that they do not need constant information updates from their home aides, but instead want updates of only the most pertinent information.

“I don’t need to hear from the home aide all the time – only in emergencies, or if they have questions about something.”

23% of caregivers found the app to be useful

Peace of Mind

Caregivers who found the app to be useful cited that they enjoyed being able to track and monitor their aide remotely

“I can put down tasks and goals that I have for her with my mom. She can communicate back to me what she has done. It’s a ‘paper trail’ document; she tells me exactly what she did.”

USABILITY CONSIDERATIONS

Prominently display details on certifications and credentials. Caregivers felt the need to be assured that all aides are certified (or offer a simple training or certificate) and have undergone a background check. Make this information prominent on the website.

Create a sense of transparency with upfront and flexible pricing listed online. Caregivers reported that they felt a greater sense of trust in the service because they could clearly note the cost and pay rates for aides on the online platform.

Create a sense of security by providing liability insurance.

Caregivers reported that the offer of liability insurance contributed to a sense of credibility and security in the service.

CONCLUSION

Online platforms for hiring a home aide have demonstrated the potential to address a serious pain point for caregivers. Providing increased caregiver control in vetting, interviewing, hiring, and scheduling, while incorporating professional guidance in these processes, significantly boosted peace of mind, satisfaction, and success. The “human element” in the home aide selection process was fundamental to the success caregivers experienced with the product. The ability to meet home aides in-person prior to making a hire and the support of a “care advisor” throughout the selection process emerged as essential factors to overcoming challenges traditionally faced by caregivers in hiring aides.

The costs for the non-traditional agencies like the one tested are actually lower than those reimbursed by Medicare. The home aides used in our study cost an average of \$25/hr, compared to ~\$40/hr for traditional agencies, primarily due to lower administrative overhead. Caregivers in the study noted that they were surprised at how much more affordable this service was compared to those covered by their insurance. However, for many caregivers and care recipients, cost and insurance coverage remain major barriers to the widespread use of such services²⁴.

Innovators should think about how to improve upon existing home aide services by including product components identified in our study. It clearly demonstrates that non-traditional agencies can improve the quality of care delivered by more traditional agencies reimbursed by Medicare/Medicaid or private insurance. Stakeholders should consider how to drive reimbursement expansion to include non-traditional agencies.

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