

Caregivers and Digital Health: A Survey of Trends and Attitudes of Massachusetts Family Caregivers



Executive Summary

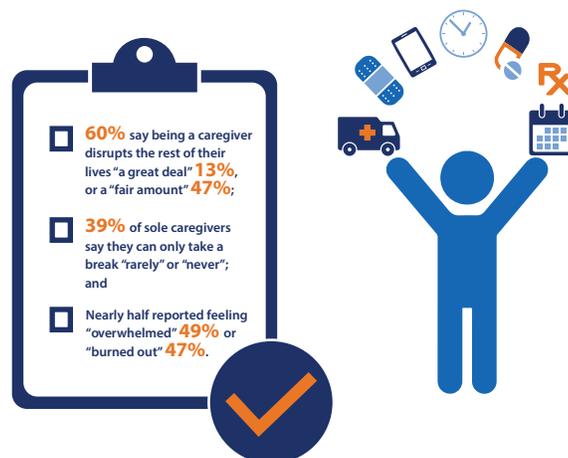
The Massachusetts eHealth Institute at the Massachusetts Technology Collaborative (MeHI/MassTech) is pleased to present this new research report, “Caregivers and Digital Health: A Survey of Trends and Attitudes of Massachusetts Family Caregivers.” Sponsored by MeHI and conducted by the MassINC Polling Group, this report identifies key challenges faced by Massachusetts family caregivers and offers insight to help entrepreneurs develop solutions to address those challenges.

More than 43 million adults in the United States provide unpaid care to another adult or to a child¹, with an overall economic value of more than \$470 billion annually². In addition, as our population ages and life expectancy continues to expand, these totals are only trending upward. While these statistics have been documented by AARP and others over the years, MeHI sponsored this research in order to help identify key opportunities for the Digital Health industry to support Massachusetts family caregivers and address their individual challenges.

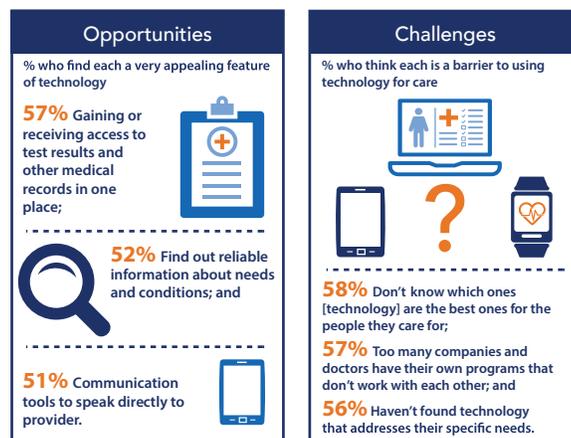
This report highlights focus areas where digital health solutions could benefit family caregivers both practically and emotionally. Key findings from the research include:

- Massachusetts caregivers are overwhelmingly stressed, depressed, and feel isolated due to their constant, “24-7-365” lifestyle.
- The most common challenges for caregivers have nothing to do with the complexities of providing care, according to respondents. More challenging is the time and energy required while trying to balance caregiving with their personal lives and other daily tasks.
- The most appealing technologies for these home-based caregivers are those that can:
 - ▶ Serve as a platform to facilitate peer-to-peer support;
 - ▶ Provide access to medical records and/or resources; or
 - ▶ Manage and/or consolidate tasks and time.
- Caregivers are either unaware of the options available to them - OR - are aware of too many options and do not know how to choose between them.
- Caregivers surveyed showed little fear or lack of understanding of technology, with 96 percent reporting they go online daily.

Common Caregiver Stressors



Caregiver Views on Technology



1 National Alliance for Caregiving and AARP. (2015). Caregiving in the U.S.

2 AARP Public Policy Institute. (2015). Valuing the Invaluable: 2015 Update.

The role of caregiving has a large socio-emotional impact that cannot be ignored. As this impact grows, families are looking for innovative solutions to help them balance the demands of caregiving with the demands of their own lives. Digital health technology can help address the adverse health complications that caregivers face by building communities for peer to peer interaction and support, improving the ability for caregivers to monitor health and medications, and assisting in managing everyday tasks. Innovative technologies also have the potential to help caregivers feel more organized and ultimately more in control.

These are important issues for the Commonwealth. As the Baby Boomer generation ages into retirement, more and more non-professional caregivers will be faced with the challenges and stresses of caring for a loved one. Technology will not be a panacea for all the issues faced, but as these results show, there are large market opportunities for digital health companies interested in helping the demands of these citizens. Policymakers and health professionals can work with entrepreneurs, researchers, caregivers, and patients to support the development of these important solutions.

Through the Massachusetts Digital Health Initiative, we are partnering with industry, academia, and government to accelerate the growth of digital health innovations in Massachusetts, and to leverage technology solutions which have an impact on the health and wellness of the Commonwealth's residents. Among the challenges facing our community in the coming years, supporting our unpaid caregivers is an area worthy of strategic focus from our entrepreneurial ecosystem.

Regards,



Laurance Stuntz
Director
Massachusetts eHealth Institute at the Massachusetts Technology Collaborative

MeHI would like to thank The MassINC Polling Group for their work on this report and Appleseed Consumer Insight for their work on the initial qualitative research. We would also like to thank the many healthcare, technology, and policy leaders that contributed to this report's development, including, but not limited to, executives from Aetna, Beth Israel Deaconess Medical Center, Biogen, Eliza Corporation, the Massachusetts Executive Office of Administration & Finance, Harvard Pilgrim Health Care, the Massachusetts Attorney General's Office, Massachusetts General Hospital, Partners Center for Connected Health, and UMass-Boston. We'd also like to send our sincere thanks to Secretary Marylou Sudders, Executive Office of Health & Human Services (EOHHS), Undersecretary Alice Moore, EOHHS, and Secretary Alice Bonner, Executive Office of Elder Affairs, for their input and the feedback received from their colleagues within numerous divisions including the Department of Mental Health, Massachusetts Commission for the Deaf & Hard of Hearing, Massachusetts Commission for the Blind, Department of Children & Families, Department of Youth Services, and the Massachusetts Rehabilitation Commission.

Introduction

The MassINC Polling Group was commissioned by the Massachusetts eHealth Institute (MeHI) to conduct a survey of caregivers in Massachusetts. The goal of the research was to illuminate areas of caregivers' everyday lives where electronic health (eHealth) technologies may be beneficial. To this end, this report describes the challenges, emotions, and daily lives of the Bay State residents providing ongoing care to loved ones with a chronic illness.

In 2014, MeHI commissioned a separate project, summarized in the report “MeHI Provider and Consumer Health IT Research Study.” That project involved two surveys, one of consumers in Massachusetts and one of the state's physicians, and was designed “to provide a snapshot of the ways that eHealth and health information technologies (health IT) are used, and currently perceived, by consumers and healthcare providers in various care settings across the Commonwealth³.”

While refreshing this research in the future may be useful, that is not the intent here. Instead we seek to build on that research, but also to chart a new course. To ensure this research provided original insight, both to MeHI and to stakeholders in the Massachusetts eHealth arena, this research focuses on the lives of caregivers rather than the broader healthcare consumer and provider markets.

The survey and report also focus less than might be expected on the details of the kinds of technologies residents might feel they want. There are other reports that have looked at this specific issue, and often users of technology cannot always anticipate what solutions might be most useful. Instead, the report looks at the often stressful, sometimes overwhelming challenges that come with the everyday tasks of taking care of a loved one. The survey asked some questions about technology, but focused more on the challenges of being a caregiver: the challenges that technical solutions could potentially help to address.

Respondents outlined a variety of anxieties and difficulties associated with being a caregiver, most of which they do not see as challenges calling for a technical solution. Therefore, eHealth companies seeking to create helpful products for this market should be aware that many of their target customers may not be looking for a widget, but they could benefit from technology that helps them manage the problems they are facing. Caregivers are comfortable with technology, but they also report feeling stressed or overwhelmed by their daily tasks. The challenge will be developing technology that is intuitive enough for caregivers to adopt and use, and that addresses concerns which may not feel technical in nature. Anything too difficult or complex to use could be seen as contributing another burden instead of helping matters.

For more detail on how this research was conducted, please see the “Research Methods” section on the following page.

Acknowledgement: *We would like to thank the staff of MeHI for their contributions to the design and execution of this research and for their assistance in assembling this report.*

3 2014 MeHI Provider and Consumer Health IT Research Study
<http://mehi.masstech.org/sites/mehi/files/documents/MeHI-Research-Report-final.pdf>

Research Methods

The findings in this report are based on an online survey of 700 non-professional caregivers who live in Massachusetts. For the purposes of this survey, a caregiver was defined as an adult “partly or fully responsible for the care or the coordination of the medical care of anyone who requires frequent care,” and who spent at least 2 hours a week on care-related tasks. Caregivers for both adults and chronically ill children were included in the survey. Some respondents reported acting as caregivers for both adults and children.

Data collection was conducted via an online survey among an internet panel of Massachusetts residents. The potential respondent pool included residents of Massachusetts who had opted in to participate in the panel and take surveys online. At the beginning of the survey, panelists were screened to ensure they met the definition of caregiver for this survey. Because we started with a panel intended to represent the population of Massachusetts, and chose respondents from this pool, the survey can be thought of as generally representative of the overall population of caregivers. As such, we often refer to respondents as “caregivers” in the report rather than specifically as “respondents.”

In many surveys, the demographics of the respondent group can be matched to the demographics of the group or groups they are intended to represent. In this instance, demographic parameters for the totality of Massachusetts caregivers are not available. Additionally, the survey included two partially overlapping groups of caregivers, with some respondents providing care for adults, children, or both. There are national studies that focus on caregivers for adults that provide estimates of the demographics of this group. There are some less detailed demographic figures available for Massachusetts. We were unable to find reliable demographic estimates for caregivers of chronically ill-children. There were no reliable estimates of the size of the two groups of caregivers, or how much they overlap, and not enough Massachusetts-specific data to create target parameters for all respondents.

As such, we used demographic data from several national and state sources to develop approximations of the likely demographics of the adult caregiver group and applied weights to adult caregivers group to match these estimates. We did not apply weights to the child-only caregiver group, and did not make any estimates of or adjustments to the relative size of the two groups.

The survey was conducted on the internet from October 27 – November 7, 2016, and was sponsored by the Massachusetts eHealth Institute (MeHI), a division of the Massachusetts Technology Collaborative. Survey design was a joint effort between MeHI staff, stakeholders, and The MassINC Polling Group (MPG). Fielding and analysis were conducted by MPG.

Qualitative research: Prior to the survey, in-home, qualitative interviews were conducted with nine healthcare consumers across Massachusetts. The purpose of these interviews was somewhat different than the ultimate aims of the survey, focusing more on the role of technology in the doctor-patient relationship than life as a caregiver. However, some of the issues uncovered during the research are pertinent to acting as a caregiver, so are mentioned in this report.



Life as a caregiver – almost always on

Being a caregiver for someone with a serious or chronic medical condition is a major responsibility. For some caregivers, it can be all-consuming. The tasks caregivers are asked to do run the gamut, from helping administer medicine to completing housework, keeping track of bills and appointments, and helping with basic functions like feeding and toileting.

The AARP described the world of being a caregiver in a recent report.⁴

“More than 40 million family caregivers each year provide unpaid care for aging parents, spouses, aunts, uncles, friends, or other loved ones so they can live independently at home, where they want to be (87 percent). These family caregivers assist with daily tasks—such as eating, dressing, bathing and transportation as well as medical/nursing tasks. The value of this unpaid care is about \$470 billion dollars annually. In addition, about 3.7 million family caregivers provide care to a child under 18 because of a medical, behavioral or other condition or disability.”

The real and social value that caregivers provide is enormous, but it comes at a personal cost. Caregivers are juggling an extraordinary amount of responsibilities, and doing so while trying to keep up with the rest of their day to day lives. The most common challenges cited by respondents have nothing to do with the complexities of providing care, but rather the amount of time and energy required, and the emotional toll that all that work takes. Balancing the daily demands of providing care with a personal life and other daily tasks is the number one challenge cited by respondents in open-ended comments.

Always on call

Being a caregiver is a central part of most respondents' lives, and for many it is the biggest part of all. This level of responsibility colors the responses to many of the other survey questions. Three-quarters of respondents think that providing care is either the most significant (41 percent) or one of the most significant (35 percent) aspects of their lives. A large percentage (45 percent) report they are the only person responsible for providing care. Among the 51 percent who share duties with other friends or family, three-quarters (74 percent) consider themselves the primary caregiver. Even those with help still feel the primary burden on their shoulders.

Being a caregiver is a central part of most respondents' lives, and for many it is the biggest part of all.

Caregivers for children feel this even more acutely; 49 percent of caregivers for children say it is the most significant part of their lives, compared to 33 percent of those caring for adults. This may be due to the fact that caregivers for children are more likely to be performing everyday parenting tasks, like feeding, dressing and bathing, alongside the added responsibility of medical care. They are also more likely to be doing all of this alone; 53 percent report they are the only person responsible for the child's care, and 84 percent of those who are sharing that responsibility with others report they are nonetheless the primary caregiver. Those caring for adults are still taking on major responsibilities, but many share at least some of the burden.

Being the primary or one of the primary caregivers is both time consuming and emotionally draining. We asked respondents to describe, in their own words, the hardest part of being a caregiver, and then coded the re-

⁴ 2015 AARP National Caregiving Survey of Registered Voters Age 40 and Older
<http://www.aarp.org/research/topics/care/info-2015/national-survey-family-caregivers.html>

sponses into categories. Two of the top three responses involved the amount of time that providing care consumes. One frequent complaint (28 percent of responses) was that providing care meant being constantly available, with little or no opportunity for breaks.

“You have to be there on time all the time because people are counting on you,” wrote one caregiver. In all, 20 percent of respondents noted the challenges of balancing caregiving with a personal life. “Balancing family, work and providing 24 hour care for 2 family members and doing nothing for myself,” was how one respondent summarized the challenge. These two categories overlapped, with many responses mentioning some version of both ideas. The overall impression is of a lack of time, both to get done everything needed to provide care, and to maintain personal and professional lives.

Disrupting life

Other results in the survey point to this concern. A majority (59 percent) reports that being a caregiver disrupts the rest of their life “a great deal” (13 percent) or “a fair amount” (47 percent). Two-thirds (66 percent) of

caregivers who are employed full time feel this way, as do 71 percent of those caring for one of their parents. As the number of hours providing medical care increases, so does the level of disruption; 26 percent of those providing 20 or more hours of medical care a week say doing so disrupts the rest of their life “a great deal.” It’s worth noting here that the question on the number of hours specifies the hours spent on medical care. Given the many varied other tasks involved in providing care, it is likely that the figures on the hours per week understate the actual daily responsibilities.

Breaks are not always possible

The level of responsibility also shows up in the lack of downtime and the inability of many respondents to take time off. Only one-third of caregivers report that they feel they could take a break either “whenever I need it” (14 percent) or “most of the time” (19 percent). The rest say they could take a break “only some of the time” (39 percent) or “rarely or never” (27 percent). In other words, about two-thirds of caregivers feel they are on-call most or all of the time.

Who’s caring for whom?

Two of the demarcations in the survey were the age of both the respondents and the people for whom they provide care. About half (48 percent) of respondents were caring for a child and 64 percent were caring for an adult. These add up to more than 100 percent because some were caring for both adults and children. Among adult caregivers, 15 percent were caring for a child as well. Among caregivers for children, 22 percent were also caring for an adult.

In many respects, survey responses show similar demographic profiles for caregivers of children vs adults. On race, income, and education, there was a great deal of similarity. Even in terms of many (though not all) of caregivers’ daily activities and attitudes, the two groups were similar.

The major exception to this is in the age of the caregivers. We can see from the survey data the natural life progression of who cares for whom and when. Respondents under 40 were more likely to be caring for children (many presumably their own). Those in their 40s were about evenly split between caring for children and adults. Those age 50 or more were much more likely to be caring for parents or other aged relatives.

These demarcations will also play a role in a caregiver’s interest in technology: younger people were more interested in technological solutions to their challenges than were older caregivers.

This sentiment ran across all demographics, including whether the caregiver was taking care of a child or adult. Just a third of caregivers for adults said they could take regular breaks, nearly identical to the 35 percent of caregivers for children who said the same.

Nearly a third (32 percent) of caregivers for children said they rarely or never take breaks, slightly higher than the 25 percent of those caring for adults, suggesting there are more parents who feel they can never get away.

Figure 1: Acting as a caregiver places major demands on time and energy
Responses to questions on time required to act as a caregiver

Which best describes your situation? Acting as a caregiver is...	
The most significant thing in my life right now	41%
One of several significant things in my life right now, but not the most significant	35%
A moderately significant part of my life right now	20%
A minor part of my life right now	4%
Don't Know / Prefer not to answer	<1%
Are you the only person responsible for their care, or do you share the responsibility with others (not counting medical personnel)?	
I am the only person responsible	45%
Share with other friends or family members	51%
Yes I am the primary caregiver	37%
No I am not	12%
Don't Know / Prefer not to answer	2%
Share with paid home caregivers	4%
Don't Know / Prefer not to answer	<1%
Are you the person most responsible for their care, or not?	
Yes I am the primary caregiver	74%
No I am not	24%
Don't Know / Prefer not to answer	2%
Would you say that you could take a break from providing or coordinating care if you needed one?	
Yes, whenever I need it	14%
Yes, most of the time	19%
Yes, but only some of the time	39%
Rarely or never	27%
Don't Know / Prefer not to answer	<1%
To what extent does acting as a caregiver disrupt your life?	
A great deal	13%
A fair amount	47%
Not very much	27%
Not at all	13%
Don't Know / Prefer not to answer	1%

Being a sole caregiver also makes a difference; 39 percent say they can only take a break “rarely” or “never,” compared to 17 percent of those who share the responsibility who are similarly limited.

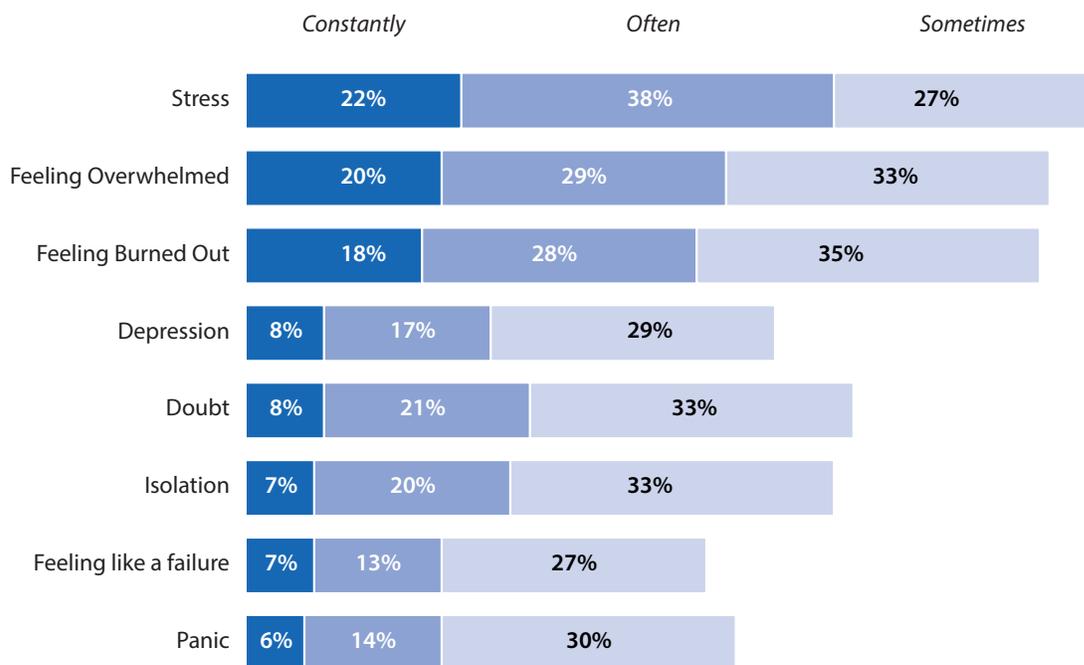
The emotional toll: stress, burn-out

The long hours, lack of breaks and personal time, and sheer number of different tasks caregivers must do take an emotional toll. The survey also explored how often respondents felt a range of emotions (Figure 2). “Stress” was the top emotion, with a majority of caregivers reporting feeling stress “constantly” (22 percent) or “often” (38 percent). Nearly half reported feeling “overwhelmed” (49 percent) or “burned out” (47 percent). Caregivers for children were slightly more likely to feel stressed,

overwhelmed, and burned out than those taking care of adult patients, but their responses on other emotions were largely similar.

“The stress of remembering everything that needs to be done and feeling overwhelmed and alone,” was how one caregiver described the hardest part of providing care in an open-ended question. “The stress and emotional drain it puts on you,” wrote another. Adding to this stress is the fact that many are caring for a loved one. One respondent wrote: “The hardest aspect is watching my mother go downhill, knowing that she won’t be getting any better. It’s a feeling of helplessness.” Another wrote: “Watching someone you love deteriorate; having to readjust your relationship with the individual being cared for.” Comments like these were less common than

Figure 2: Caregivers report frequent stress, and feelings of being overwhelmed, burned out
 Q: In your life as a caregiver, how often do you feel each of the following?



ones citing a lack of time and balance, but they were frequent enough to offer insight into the emotions that even the most well-equipped caregivers must feel on occasion.

While many issues in polling and marketing research focus only on finding the biggest group, most appealing message, or winning candidate, this is not one of those issues. The number of caregivers grappling with all these emotions is considerable, and the needs they are expressing are very real. Thus, solutions that help address these issues, whether human or technical, will have an audience and a sizable one.

“The hardest aspect is watching my mother go downhill, knowing that she won’t be getting any better. It’s a feeling of helplessness.”

Daily Tasks: Medical care is just the tip of the iceberg

Caregivers’ days and weeks are long, and they are made longer by the sheer number of different tasks they are forced to balance. Some of those are medical (administering medicine, dressing, feeding, diapering), but many are logistical. These range from negotiating the web of health care providers and insurers to more basic tasks, like shopping for groceries or driving to and from appointments. Balancing all of these tasks while trying to maintain a personal life helps illustrate why many caregivers are feeling stressed or overwhelmed.

Varieties of tasks

The variety of different tasks individual caregivers report performing is impressive. Of the 18 medical and non-medical tasks included in the survey, majorities of respondents reported participating in 16 of them in recent months. With so many different tasks, time management and organization becomes a feat in and of itself.

The most basic tasks were also the most universal: Nine in ten caregivers (90 percent) have gone grocery shopping for the person under their care; 88 percent have provided transportation or given medicine; 87 percent have communicated with health care providers, done

housework, and prepared meals; 81 percent have provided companionship; 71 percent have handled financial matters and insurance or Medicare; and around two-thirds have dealt with other medical tasks like dressing and undressing (68 percent), helping a patient in and out of bed or chairs (66 percent), and feeding (64 percent).

Perhaps not surprisingly, the tasks vary in some ways based on whether respondents were caring for a child

or for an aging parent or other adult. Children were less likely to need help getting in and out of bed and chairs. Adult patients were less likely to need help with feeding, bathing, or dressing. Here it should be noted that many of the tasks caregivers for children are performing are similar to those that might be done by any parent. Even without a chronic medical condition in the picture, parents feed and bathe younger children. However when combined with the tasks that are specific to caregiving, even these routine parenting duties add to the burden.

Figure 3: Caregivers for adults and children perform many similar tasks on a day to day basis, though some diverge

Q: Which of the following tasks have you performed in the last 6 months for the person (people) under your care?

% saying they have performed each task in the last 6 months

	Overall	Any Adult	Child
Grocery Shopping	90%	89%	91%
Transportation	88%	87%	90%
Giving Medicine	88%	87%	90%
Communicating with health care providers	87%	89%	85%
Housework	87%	87%	87%
Preparing meals	87%	83%	91%
Companionship in social activity	81%	83%	79%
Tracking daily activities	75%	75%	74%
Managing Finances	71%	75%	69%
Working with insurance or Medicare	71%	71%	72%
Dressing and undressing	68%	62%	77%
Assisting with getting in and out of bed and chairs	66%	76%	57%
Feeding	64%	59%	73%
Arranging paid services	59%	62%	56%
Bathing	57%	46%	72%
Attending to wounds	56%	52%	64%
Toileting	47%	42%	57%
Dealing with incontinence or diapers	42%	39%	49%

Interest in Technology: Information, organization over connection

The daily lives of caregivers and their emotions help explain their preferences for technology. The ideas that caregivers found the most appealing tended to focus on reducing stress by easing communication, reducing complexity, and improving organization (Figure 4). Ideas that addressed depression or isolation by connecting to other caregivers were less favored. The number of caregivers who do feel depression and isolation is still significant, so there will likely be some interest in products aimed at these challenges; they were just not the most common challenges identified by respondents.

All of the ideas that a majority of caregivers found “very appealing” involved gaining or giving access to medical information. These included technology that provides “access to test results and other medical records in one place” (57 percent); reliable information about the needs and conditions of patients (52 percent); and tools to communicate directly with doctors and other care providers and coordinators (51 percent). These were followed by technology to help with insurance (49 percent), to help manage disparate aspects of care (48 percent), and to balance caregiving and the rest of life (44 percent).

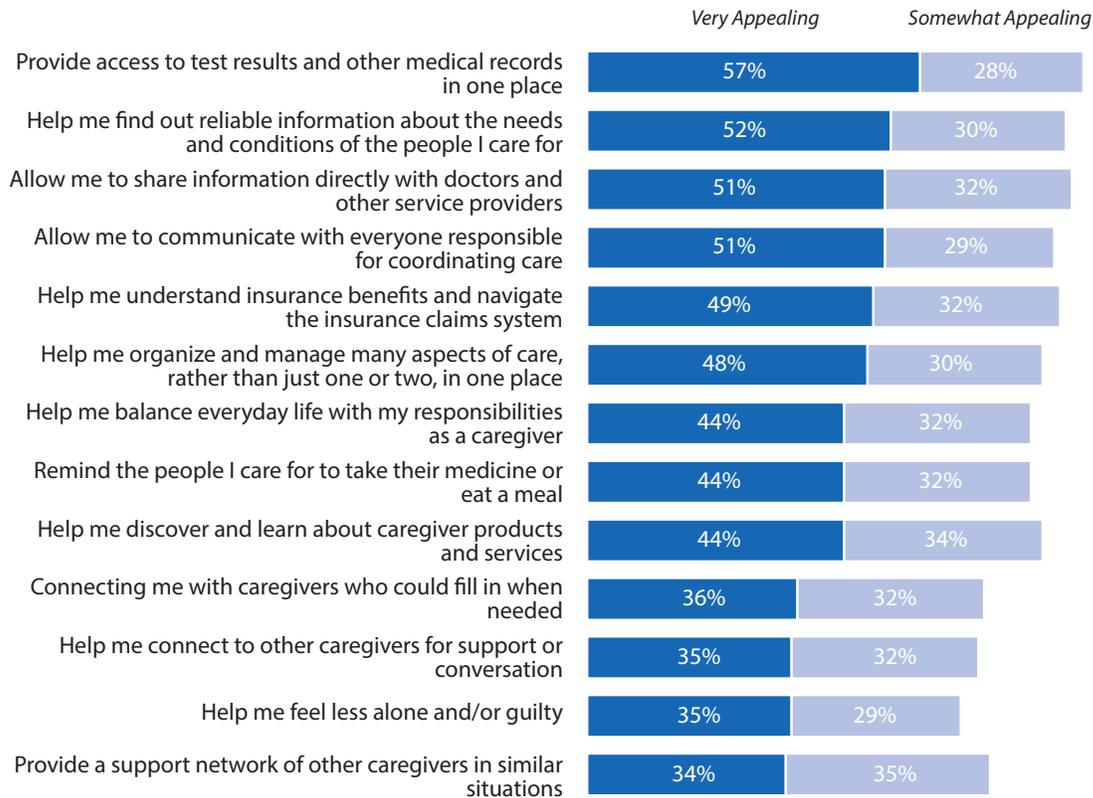
All these ideas address the key problems and emotions identified elsewhere in the survey: a lack of time, a lack of balance, and feeling stressed and overwhelmed by the number of tasks at hand. Ideas that dealt with interpersonal connections, such as providing a network of other caregivers for emotional support, were less favored. Still, even the least favored technology was viewed as at least “somewhat appealing” by 64 percent of respondents, and there is still an audience for technologies centered on connections and community. For instance, 47 percent of caregivers who felt isolation “constantly” or “often” found technology that could connect them to other caregivers very appealing, and 59 percent of those feeling doubt felt the same about a tool to help them balance caregiving and the rest of life.

All these ideas address the key problems and emotions identified elsewhere in the survey: a lack of time, a lack of balance, and feeling stressed and overwhelmed by the number of tasks at hand.

“I don’t know of any technology that would help with the day to day needs I’m responsible for”

Figure 4: Most appealing tech options and solutions help organize tasks and information and reduce complexity

Q: Thinking about technology in providing care, how appealing would technology be that could do each of the following?



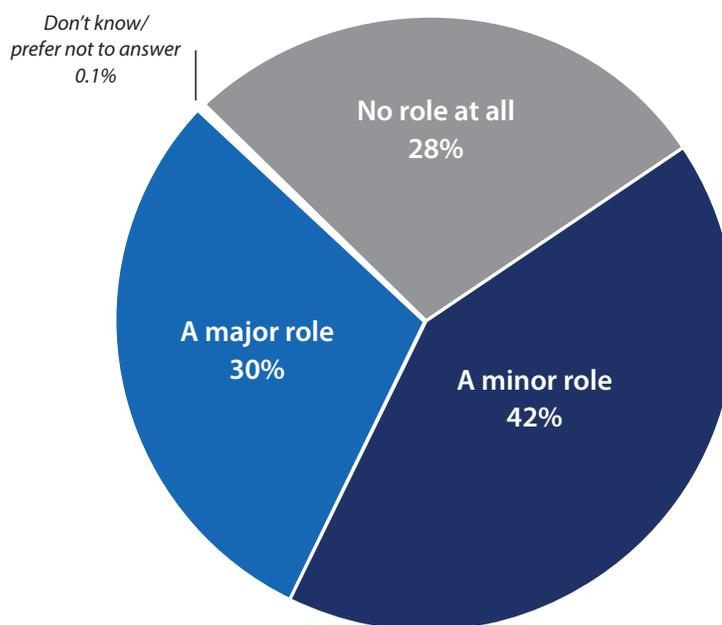
These figures, as well as the open ended-responses, suggest the greatest opportunity lies in helping overworked caregivers better manage the many different kinds of tasks facing them. The biggest challenge for developers to overcome is that many of those individual tasks are not technological in nature, so caregivers may not perceive the need for a technology-based solution.

Some needs, like communicating with health care providers or insurers, could clearly be aided by technology, and caregivers showed more interest in those. But most of a caregiver’s tasks require physical work or presence. As a result, many caregivers simply don’t think technology can do very much to help them with many of their

tasks. In some cases, they think it only complicates things further and adds another layer of stress to an already difficult situation. Still, the burden of these unavoidable tasks may feel lighter if caregivers feel more organized and less overwhelmed.

When we asked respondents an open-ended question about what prevented them from using technology to provide or coordinate care, the most common response was that they felt there was no need to do so (24 percent of responses). “I need to be more hands-on in my care and [technology] takes too much time to work,” wrote one respondent. Another 17 percent said they were unaware of any technology that would help them in their

Figure 5: Growth Opportunity: Less than a third say technology plays “a major role” in providing care
 Q: How much of a role, if any, does technology such as apps, devices like smartphones or tablets, or computer programs play for you in providing and coordinating care?



work, or were unsure which kind to use. “I don’t know of any technology that would help with the day to day needs I’m responsible for,” wrote another.

These comments are supported by other responses in the survey. Only 30 percent say that technology plays “a major role” in the care they currently provide (Figure 5); nearly as many say it plays no role at all (28 percent), while the remaining 42 percent say it has a minor role to play. There is some variation by age; 38 percent of caregivers under age 40 say technology plays a major role, compared to only 21 percent of those aged 40 or older. Still, technology is not the first thing that comes to mind for caregivers when they think about getting their work done.

Another problem is a lack of familiarity with the technology available. The single largest barrier to using technology to provide or coordinate care is that caregivers don’t know which technology is best for the people they

care for (Figure 6). A quarter (26 percent) considers this a major barrier, and another third (33 percent) a minor barrier. This is followed closely by a related problem: that “too many companies and doctors have their own programs that don’t work with each other” (57 percent total barrier). This is particularly poignant since caregivers are looking for ways to reduce complexity, and many appear to believe technology would do the opposite. The third and fourth biggest hurdles are variations on this theme; caregivers haven’t found technology that addresses their needs (56 percent), and they don’t know where to start or what is available (54 percent).

Caregivers are either unaware of the options available to them, or are aware of too many options and do not know how to choose between them. Without clear guidance, choosing an app, device, or software platform risks becoming one more burdensome task, instead of a tool to help simplify other aspects of care.

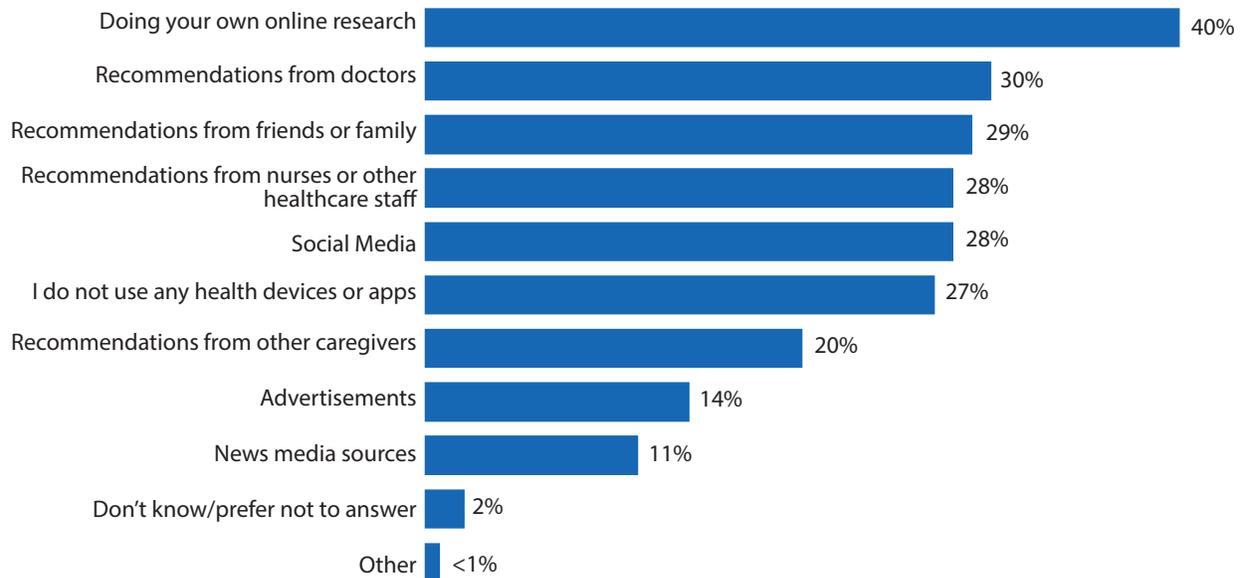
Figure 6: Growth Opportunity: Biggest barriers are unfamiliarity and complexity of finding the right product for the specific situation

Q: When it comes to using technology to provide and coordinate care, how much of a barrier is each of the following to using technology more?

	Major barrier	Minor barrier	Total "barrier"	Not a barrier	Don't know/ prefer not to answer
I don't know which ones are best for the people I care for	26%	33%	58%	34%	7%
Too many companies and doctors have their own programs that don't work with each other	29%	29%	57%	31%	12%
I haven't found technology that addresses my specific needs	28%	29%	56%	35%	9%
I don't know where to start or what technology is available	26%	28%	54%	40%	6%
The options I know about are too expensive	25%	25%	50%	36%	14%
There are too many different programs and devices to learn	20%	29%	49%	41%	9%
The programs and devices are too hard to learn and use	13%	28%	41%	51%	8%
Doing things with paper and pencil is easier	15%	23%	39%	55%	6%
I don't like technology. I'm against it.	5%	15%	20%	72%	8%

Figure 7: Caregivers rely on online research, recommendations when selecting technology

Q: How have you mostly heard about the health devices or apps you decided to use in providing care?



One barrier that is less of a concern, at least for respondents to this survey⁵, is a fear or lack of understanding of technology. Only 20 percent of respondents say that they don't like or are against technology. Virtually all (96 percent) respondents go online at least daily; 40 percent say they are online "nearly constantly." Nine in ten say they have a laptop, a smartphone, and broadband internet at home, and when asked how they heard about health technology they use currently to provide care, 57 percent said they did their own research online (Figure 7). Recommendations from friends or family, doctors, and other medical staff were also rated highly. This is not a technophobic group of consumers. The challenge, instead, is to educate them about products that can help them coordinate a distinctly analog set of tasks, and to aid them in finding the right product for them with a minimum of stress and frustration.

The single largest barrier to using technology to provide or coordinate care is that caregivers don't know which technology is best for the people they care for

⁵ Because it was an online survey, respondents were internet users, by definition. According to recent research, 13 percent of Americans still do not use the internet at all, which would exclude them from this survey. We do not know the exact demographic parameter for internet usage frequency among caregivers in Massachusetts. Even so, the intent of the project was intended to explore issues of care giving in the context of potential technology enabled solutions, so the survey's focus on at least periodic internet users is appropriate.

Conclusion

Non-professional caregivers play an important and underappreciated role in society's healthcare system, juggling tasks both medical and mundane, and dealing with stress and burn out while doing it. Most are not using technology to help with their work, not because they are technophobic, but because they are not aware of solutions that would make their lives less, rather than more, complicated. There is a market opportunity not only to create eHealth technologies tailored to the needs of caregivers, but also to help inform caregivers about existing technologies, and to help take the stress out of choosing and using health tech.

In some cases, technology already exists: doctors have patient portals and eHealth records; insurance companies have websites; there are even apps like Uber, Peapod, and TaskRabbit to aid in non-medical tasks like transportation, shopping, and housework, respectively. The challenge is one of simplicity and outreach; to introduce consumers to potentially useful solutions, and to show how they can bring simplicity rather than adding complexity.

For developers and technology companies, the first rule, as in medicine, is to do no harm. Caregivers are working under considerable stress as it is. They are unlikely to adopt and use technology that isn't simple and instantly relatable to their daily tasks. Anything else will likely add to their stress levels and ultimately fall into disuse. Many of the tasks caregivers manage are ordinary, but done with extraordinary care under extraordinary circumstances. The goal should be to make the most complex of these as simple as possible, so that caregivers can focus on the important aspects of their work that require compassion and a human touch.

Massachusetts eHealth Institute Survey: Topline Results

Statewide Survey of 700 Caregivers in Massachusetts

Field Dates: October 27 – November 7, 2016

Are you 18 years old and a resident of Massachusetts?

Yes	100%
No → TERMINATE	0%
Don't Know / Prefer not to answer → TERMINATE	0%

Are you a home nurse or other professional responsible for providing medical care outside a doctor's office or hospital?

Yes I am → TERMINATE	0%
No, I am not	100%
Don't Know / Prefer not to answer → TERMINATE	0%

Are you partly or fully responsible for the care or the coordination of the medical care of anyone who requires frequent care? Coordinating care includes tasks like arranging medical appointments, transportation, and payments. SELECT ALL THAT APPLY

Yes, a child	48%
Yes, a parent	31%
Yes, an older relative	17%
Yes, someone else (please specify): _____	15%
No, I am not → TERMINATE	0%
Don't Know / Prefer not to answer → TERMINATE	0%

On average, how many hours per week do you personally spend providing or arranging for medical care for the person (people) under your care?

Less than 2 → TERMINATE	0%
2 to 6	46%
7 to 10	19%
11 to 20	14%
21 to 40	9%
More than 40	12%
Don't Know / Prefer not to answer → TERMINATE	0%

Which best describes your situation? Acting as a caregiver is...

The most significant thing in my life right now	41%
One of several significant things in my life right now, but not the most significant	35%
Moderately significant	20%
A minor part of my life right now	4%
Don't Know / Prefer not to answer	<1%

Are you the only person responsible for their care, or do you share the responsibility with others (not counting medical personnel)?

I am the only person responsible	45%
Share with other friends or family members	51%
Share with paid home caregivers	4%
Don't Know / Prefer not to answer	<1%

IF SHARE CARE WITH OTHERS, ASK...

Are you the person most responsible for their care, or not?

Yes I am the primary caregiver	74%
No I am not	24%
Don't Know / Prefer not to answer	2%

Would you say that you could take a break from providing or coordinating care if you needed one?

Yes, whenever I need it	14%
Yes, most of the time	19%
Yes, but only some of the time	39%
Rarely or never	27%
Don't Know / Prefer not to answer	<1%

To what extent does acting as a caregiver disrupt your life?

A great deal	13%
A fair amount	47%
Not very much	27%
Not at all	13%
Don't Know / Prefer not to answer	1%

Do you get to connect with other caregivers on a regular basis?

Yes I do	36%
No I do not	64%
Don't Know / Prefer not to answer	1%

IF NO TO PREVIOUS QUESTION, ASK:

Would you like to connect with other caregivers on a regular basis?

Yes I would	38%
No I would not	41%
Don't Know / Prefer not to answer	21%

How well do you think others understand the work you do as a caregiver?

Very well	21%
Somewhat well	39%
Not too well	30%
Not at all	9%
Don't Know / Prefer not to answer	1%

Which of the following caregiving tasks have you performed in the last 6 months for the person (people) under your care?

	Yes	No	Don't know/ Prefer not to answer
<i>Order rotated, sorted for display.</i>			
Giving medicine	88%	11%	1%
Dressing and undressing	68%	31%	1%
Assisting with getting in and out of bed and chairs	66%	32%	2%
Feeding	64%	35%	1%
Bathing	57%	42%	2%
Attending to wounds	56%	42%	2%
Toileting	47%	50%	2%
Dealing with incontinence or diapers	42%	56%	2%

Which of the following tasks have you performed in the last 6 months for the person (people) under your care?

	Yes	No	Don't know/ Prefer not to answer
<i>Order rotated, sorted for display.</i>			
Grocery shopping	90%	10%	1%
Transportation	88%	12%	<1%
Communicating with health care providers	87%	12%	1%
Housework	87%	13%	<1%
Preparing meals	87%	13%	<1%
Companionship in social activity	81%	17%	1%
Tracking daily activities	75%	24%	2%
Managing finances	71%	27%	1%
Working with insurance or Medicare	71%	28%	1%
Arranging paid services	59%	39%	3%

The next few questions are about the use of technology like apps, software or websites on smartphones, tablets or computers to help provide or coordinate care. Please note we are not asking about assistive or adaptive technology that someone under your care might use to communicate or get around.

How much of a role, if any, does technology such as apps, devices like smartphone or tablets, or computer programs play for you in providing and coordinating care?

A major role	30%
A minor role	42%
No role at all	28%
Don't Know / Prefer not to answer	<1%

What prevents you from making more use of technology in providing and coordinating care? OPEN END, RESPONSES CODED

<i>Order rotated, sorted for display</i>	
No need; Not necessary	24%
Nothing; already utilizing technology	20%
Availability, lack of; unaware of useful technology, apps, etc.	17%
Dislike/distrust technology; does not understand how to use; prefers not to use	13%
Time constraints to use or learn about; inconvenience	12%
Cost; inaccessible; lack of physical resources (eg. no smartphone)	10%
Other	7%
Don't know	5%
Refuse; N/A	1%

When it comes to using technology to provide and coordinate care, how much of a barrier is each of the following to using technology more?

<i>Order rotated, sorted for display.</i>	Major barrier	Minor barrier	Not a barrier	Don't know / Prefer not to answer
Too many companies and doctors have their own programs that don't work with each other	29%	29%	31%	12%
I haven't found technology that addresses my specific needs	28%	29%	35%	9%
I don't know which ones are best for the people I care for	26%	33%	34%	7%
I don't know where to start or what technology is available.	26%	28%	40%	6%
The options I know about are too expensive	25%	25%	36%	14%
There are too many different programs and devices to learn	20%	29%	41%	9%
Doing things with paper and pencil is easier	15%	23%	55%	6%
The programs and devices are too hard to learn and use	13%	28%	51%	8%
I don't like technology. I'm against it.	5%	15%	72%	8%

Thinking about technology that could help in providing care, how appealing would technology be that could do each of the following?

<i>Order rotated, sorted for display.</i>	Very Appealing	Somewhat Appealing	Not too Appealing	Not at All Appealing	Don't know / Prefer not to answer
Provide access to test results and other medical records in one place	57%	28%	7%	5%	4%
Help me find out reliable information about the needs and conditions of the people I care for	52%	30%	8%	6%	3%
Allow me to communicate with everyone responsible for coordinating care	51%	29%	9%	7%	4%
Allow me to share information directly with doctors and other service providers	51%	32%	9%	4%	3%
Help me understand insurance benefits and navigate the insurance claims system	49%	32%	9%	6%	4%
Help me organize and manage many aspects of care, rather than just one or two, in one place	48%	30%	10%	7%	4%
Remind the people I care for to take their medications or eat a meal	44%	32%	12%	7%	5%
Help me discover and learn about caregiver products and services	44%	34%	13%	7%	3%
Help me balance everyday life with my responsibilities as a caregiver	44%	32%	10%	9%	4%
Connecting me with care givers who could fill in when needed	36%	32%	17%	11%	4%
Help me connect to other caregivers for support or conversation	35%	32%	17%	12%	4%
Help me feel less alone and/or guilty	35%	29%	17%	14%	5%
Provide a support network of other caregivers in similar situations	34%	35%	15%	11%	5%

ASKED ONLY TO THOSE WHO SAID THEY USE ANY APPS OR DEVICES.

How have you mostly heard about the health devices or apps you decided to use in providing care? SELECT ALL THAT APPLY,

<i>Order rotated, sorted for display</i>	
Doing your own online research	40%
Recommendations from doctors	30%
Recommendations from friends or family	29%
Recommendations from nurses or other healthcare staff	28%
Social media	28%
I do not use any health devices or apps	27%
Recommendations from other caregivers	20%
Advertisements	14%
News media sources	11%
Don't Know / Prefer not to answer	2%
Other (please specify): _____	<1%

In your experience, what is the hardest aspect of being a caregiver? OPEN END, RESPONSE CODED.

<i>Order rotated, sorted for display</i>	
Time, constant availability, no breaks	28%
Sadness, sorrow, guilt, helplessness, loneliness/isolation, emotional drain	21%
Balancing personal life (time for family, self-care, or career)	20%
Stress, responsibility, worry, mental or physical drain	16%
Patience, thankless, dealing with patient	11%
Other	8%
Organization, coordination, care management	6%
Nothing	4%
Refusal; N/A	1%
Don't know	1%

In your life as a caregiver, how often do you feel each of the following?

<i>Order rotated, sorted for display.</i>	Constantly	Often	Sometimes	Rarely	Never	Don't know/ Prefer not to answer
Stress	22%	38%	27%	8%	5%	1%
Feeling overwhelmed	20%	29%	33%	12%	5%	1%
Feeling burned out	18%	28%	35%	11%	7%	1%
Depression	8%	17%	29%	21%	22%	1%
Doubt	8%	21%	33%	21%	16%	1%
Isolation	7%	20%	33%	17%	21%	1%
Feeling like a failure	7%	13%	27%	25%	26%	2%
Panic	6%	14%	30%	27%	22%	1%

These next few questions are about your use technology in general.

How frequently do you use the internet either on a computer, tablet, or mobile device?

I am online nearly constantly	40%
More than once a day	42%
Daily	14%
A few times a week	2%
Weekly	1%
Less than weekly	<1%
Rarely	1%
Never	<1%
Don't Know / Prefer not to answer	<1%

Which of the following technologies do you own?

<i>Order rotated, sorted for display.</i>	Yes	No	Don't know/ prefer not to answer
A personal computer (desktop or laptop)	90%	9%	1%
Hi-speed internet access in your home	90%	8%	1%
A smartphone	88%	11%	1%
A tablet	68%	31%	1%
A device that streams TV shows and other content to your television (Apple TV, Roku, Chromecast, etc)	44%	55%	2%
A "smart" television that can access the internet	39%	60%	2%

DEMOGRAPHICS

Gender

Male	28%
Female	72%

Age

18-29	20%
30-39	30%
40-49	21%
50-59	10%
60+	19%
Don't know / Refused	<1%

Race

White / Caucasian	74%
All others	25%
Don't Know / Refused	1%

Education

High School or less	20%
Some college, no degree	36%
College graduate (BA/BS)	33%
Advanced degree	10%
Don't know / Refused	0%

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