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# Catalyzing Technology to Support Family Caregiving

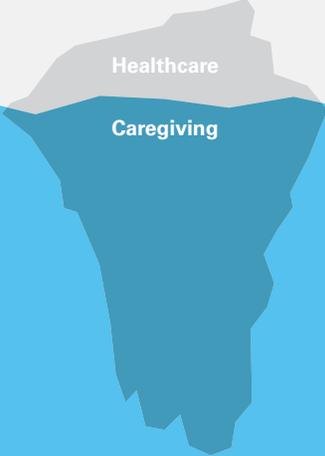
Richard Adler & Rajiv Mehta  
National Alliance for Caregiving



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“The vast majority of health care is actually provided by families, not by healthcare professionals”

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Healthcare

The diagram features a jagged horizontal line representing the water surface. Above the surface is a small, light grey iceberg tip labeled 'Healthcare'. Below the surface is a much larger, dark teal iceberg body labeled 'Caregiving'. The 'Caregiving' section is approximately 10 times larger in volume than the 'Healthcare' section, illustrating that the vast majority of health care is provided by families.

Caregiving

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## Foreword

It's no secret that technology is advancing at a rapid pace. When I began working to support family caregivers, personal computers were only beginning to come into vogue and cell phones were reserved for an elite few. Today, most family caregivers are connected to technologies, whether through the Internet, mobile apps, or telemonitoring devices that can help friends and families support the care of a loved one. The word "technology" barely encompasses the various ways that innovators are reaching across the digital divide to family caregivers and their loved ones who want to age in place.

What can we do to keep families and patients at the center of care, given the rapid changes in the way healthcare is delivered? The 21<sup>st</sup> century is full of digital solutions, but to be effective, these solutions must be tailored to the needs and abilities of the family caregiver. Recent research shows that nearly 40% of people in the U.S. are caring for an adult or child with disabilities, a number that is increasing as the Baby Boomers age. Caregivers increasingly rely on technology to help with medication management and reconciliation, to get information on a treatment

or diagnosis, to find support, and to search for services. In-home technologies offer new means for caregivers to coordinate healthcare services across providers, to manage treatments, and to keep track of the various Activities of Daily Living they may be required to do to care for their friend or family member.

Smart technologies address these needs and meet caregivers where they are. That's why the National Alliance for Caregiving was proud to co-convene the April 2014 roundtable on *Catalyzing Technology to Support Family Caregiving*. With a panel of 22 national experts from Silicon Valley, government agencies, and the non-profit sector, we put our heads together to identify the best next steps for moving the field forward. Following that discussion, co-organizers Richard Adler and Rajiv Mehta have pulled together a report of the roundtable and the panel's recommendations. This report provides a good starting point for innovators who want to better understand a caregiver's needs. I'm looking forward to continuing the conversation, both with caregiving stakeholders and beyond.



Gail Gibson Hunt  
President and Chief Executive Officer  
National Alliance for Caregiving

July 2014

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Richard Adler has been actively involved in the field of technology and aging for several decades. He helped start SeniorNet, a national nonprofit organization that introduced older adults to computers and the Internet. At the Institute for the Future, where he was named as a Distinguished Fellow, he has been involved with several projects exploring the future of aging. Richard served as guest editor of an issue of *Generations*, the journal of the American Society on Aging, on the future of aging, and he has written extensively on the future of broadband, education and institutional innovation. He has taught at Oberlin College, Stanford and UCLA, and is on the board of several nonprofit organizations.

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## About The National Alliance for Caregiving

Established in 1996, The National Alliance for Caregiving is a non-profit coalition of national organizations focusing on advancing family caregiving through research, innovation and advocacy. Alliance members include grassroots organizations, professional associations, service organizations, disease-specific organizations, government agencies, and corporations.

The Alliance conducts research, does policy analysis, develops national best-practice programs, and works to increase public awareness of family caregiving issues. Recognizing that family caregivers make

essential social and financial contributions toward maintaining the well-being of those they care for, the Alliance is dedicated to improving quality of life for families and their care recipients through research, innovation and advocacy.

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## Table of Contents

<b>Foreword</b> .....	<b>III</b>
<b>About the Authors</b> .....	<b>IV</b>
<b>About The National Alliance for Caregiving</b> .....	<b>IV</b>
<b>Sponsors</b> .....	<b>IV</b>
<b>Participants</b> .....	<b>V</b>
<b>Executive Summary</b> .....	<b>VII</b>
<b>Introduction</b> .....	<b>1</b>
<b>Providing Better Support For Caregiving</b> .....	<b>2</b>
Framing the Issues: What We Know About Caregiving .....	2
Technology Solutions: What Exists and What We Envision .....	6
Beyond Technology: Considering and Designing for the Whole System .....	8
<b>Recommendations</b> .....	<b>10</b>
Framing the Issues .....	10
Creating a Fertile Environment .....	11
Maximizing Value of Technologies .....	12
Who Should Do What .....	13
<b>Conclusions</b> .....	<b>14</b>
<b>Recommended Reading</b> .....	<b>15</b>
<b>Appendix</b> .....	<b>16</b>

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## Executive Summary

Millions of Americans are currently providing care for a family member, friend, or neighbor, typically because of illness, injury, or frailty. Their efforts range from providing emotional support and helping with routine household tasks to providing care 24x7 and carrying out complex medical procedures. Though those receiving care are of all ages, the amount of caregiving will certainly rise as our population ages.

Caregiving is also an important social issue. Providing care can be stressful as well as time consuming. The burdens of caregiving have a tremendous impact on the physical and mental health and financial and social situations of caregivers, as well as on their economic productivity.

Until now, technology has made only modest contributions to supporting caregivers. Can technology play a more meaningful role in helping caregivers? And how we can accelerate innovation in developing new applications to support caregivers?

In April 2014, an expert roundtable was convened to explore these questions. Participants were optimistic that new technologies could play a significant role in making caregiving easier and more effective. While developing specific solutions was beyond the scope of a single day's discussion, three ideas got a lot of attention:

- An “Intelligent Family Care Assistant” to help with day-to-day caregiving by helping to coordinate the family's tasks in the context of the family's other activities.
- “Wearable technologies”—devices worn on or placed in the body, with sensors and/or human interfaces—to help monitor a person's health and overall condition.
- Technologies that provide better connections between family caregivers and health professionals, enabling them to work more effectively as a team in providing care.

Participants felt that we have barely scratched the surface of what might be possible. Once sparked, technology innovators are likely to change the nature of caregiving as much as they have so many other facets of modern life.

Participants also noted significant challenges to innovation, particularly a limited understanding of the realities of caregiving among innovators and decision makers and a paucity of good data on caregiving, which contribute to a lack of support for entrepreneurs.

## Recommendations

To catalyze technology innovation to support family caregiving, the roundtable developed several recommendations (Fig 1).

### **Create better “concept maps” and find more appropriate language to describe the varied and complex caregiving landscape.**

Current widely held but simplistic perspectives on caregiving stand in the way of needed innovations. Good models of caregiving, especially visual concept maps, of caregiving and appropriate language are needed to provide a better understanding of caregiving and to catalyze innovation.

### **Continue to collect extensive data about the prevalence, burden, and impact of caregiving and the role of technology.**

There is an ongoing need for research on family caregivers, especially as technology dramatically impacts caregiving. More current, thorough and accurate data is needed about the diversity of caregiver roles and responsibilities, about what caregiving involves day-to-day and the nature of the burden it represents, and how much it impacts those around the caregiver. Such data is necessary to develop business plans and to evaluate the impact of solutions.

### **Spur a broad national conversation on caregiving.**

A national discussion is needed to raise consciousness of the issues related to caregiving and its



**Fig 1. Successful caregiving technologies require three supports.**

social and economic impacts, and to explore what kinds of responses are necessary and feasible. Entrepreneurs will be much more inclined to develop innovations if there is widespread attention on the topic.

**Develop compelling business cases for employers and healthcare providers to support caregiving.**

Employers and healthcare institutions are ideally positioned to help family caregivers. But they require clear business plans to justify their taking action.

**Provide caregiving coaching as an integral component of all solutions.**

Caregivers often lack the time to learn about technologies that may be useful to them. Coaches who are knowledgeable about available technologies and can take the time to understand each family's unique situation would make it possible for caregivers to get the full benefits of technology solutions. Coaches could also teach skills for managing multiple, competing responsibilities.

**Inspire social conversations about caregiving to encourage more learning and support within families and communities.**

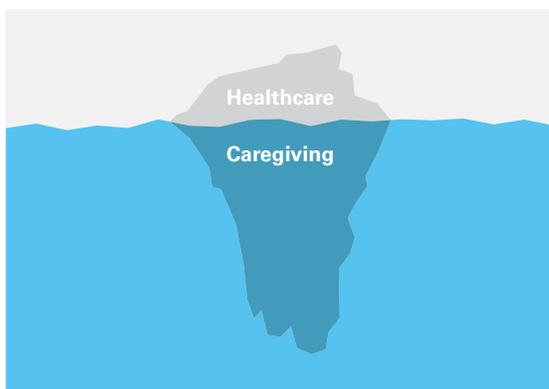
Most caregivers toil in isolation that not only deprives them of emotional support that others could provide, but also means that people do not learn from each other's experiences and knowledge. We need to find ways to make conversations about caregiving more normal and less taboo.

## Conclusions

Technology-based solutions have the potential to lighten the burden that falls on family caregivers, particularly by helping them to coordinate the demanding tasks and the complex networks of relationships involved with caring for others. Technology could also help improve the health of both caregivers and care recipients. All those with an interest in supporting family caregiving—caregiver advocacy and support organizations, employers, entrepreneurs, foundations, healthcare institutions, and the media—should understand this report's recommendations and follow them as they apply to their efforts

## Introduction

Many millions of Americans are currently engaged in providing care for a family member, a friend, or a neighbor who needs assistance, typically because of illness, injury or frailty, as well as in taking care of their own health. Care may range from providing simple assistance with routine household tasks or providing emotional support and company, to carrying out complex medical procedures. Though those receiving care are of all ages, the amount of caregiving will certainly rise as our population ages.



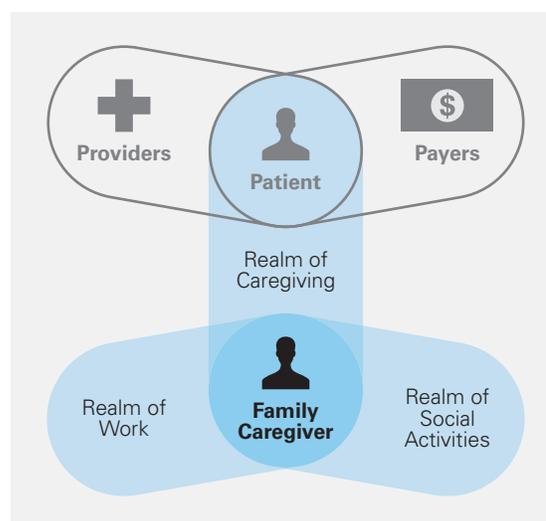
**Fig 2. Care of health is like an iceberg. We see the professional healthcare system, but hidden underneath is a much larger effort provided by family caregivers.**

The vast majority of health care is actually provided by families, not by healthcare professionals (Fig 2). And yet the efforts of family caregivers get little attention. For example, the Affordable Care Act, the biggest government effort in health in decades, barely has anything for family caregivers. (The one provision in the ACA designed to help caregivers, the CLASS Act, was rescinded even before it went into effect.)

More, much more, must be done. Until now, technology has made a relatively modest contribution to supporting caregivers, even though it is playing a big role in many other aspects of life. The Internet has become a useful source of information, particularly on medical issues, for caregivers. But could technology play other, more meaningful, roles to help reduce caregiving burdens? If so, what might be done to accelerate innovation in this field?

These questions were the focus of an expert roundtable held at the Institute for the Future in Palo Alto, California, on April 1, 2014. The twenty two participants included researchers, advocates, designers, entrepreneurs and others interested in improving the lives of caregivers. Sponsors of the roundtable were the California HealthCare Foundation, Kaiser Permanente, Care Innovations, and the Institute for the Future.

The roundtable's focus was very much on the family caregiver, not on the care-recipient (although the day's discussion emphasized that self-care should be included in the idea of "caregiving"), and not the perspective of healthcare professionals (Fig 3).



**Fig 3. The healthcare ecology is complex; the focus of the roundtable was family caregivers, who must simultaneously manage work, social and care responsibilities.**

Participants were encouraged not to limit their thinking to fine-tuning of technologies available today and incremental improvements (e.g. 10%), but rather to think boldly, to loosen their imaginations, to aspire to "10x" improvements.

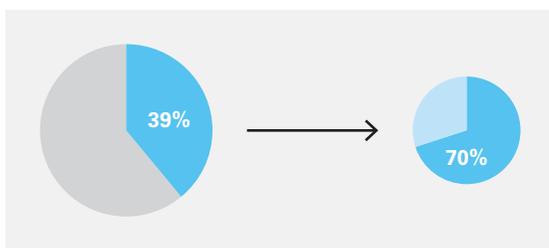
## Providing Better Support For Caregiving

The roundtable began by considering where we are today: what evidence exists on current realities of caregiving, and how we conceive of the role of caregivers and the challenges they face. Second, we reviewed existing technologies focused on the needs of caregivers, and then explored ways in which technology could play a more effective role in supporting caregivers. Third, we identified non-technology initiatives that are needed to catalyze and supplement the value of technology-based solutions. Finally, the group formulated a set of recommendations for steps to accelerate innovation in the field.

### Framing the Issues: What We Know About Caregiving

#### Caregiving is Widespread.

The most recent publicly available data comes from a June, 2013, report from the Pew Research Center titled *Family Caregivers are Wired for Health*<sup>11</sup>, which was presented at the roundtable by Gail Gibson Hunt, President and CEO of the National Alliance for Caregiving. While most of the study is concerned with caregivers' online use, especially for medically related information, the report also provides an overview of the demographics of caregivers.



**Fig 4. According to a Pew survey, 39% of American adults are family caregivers. Of those, 70% are in the workforce.**

First of all, there are a lot of caregivers: According to the Pew survey nearly four out of ten adult Americans (39%) said that they had “provided

unpaid care to an adult relative or friend 18 years or older to help them take care of themselves” over the previous 12 months. Caregiving is nearly as prevalent among men (37%) as women (40%), and is distributed across income levels, educational levels, race/ethnicity and age, with no less than 30% of the members of any of the sub-groups in these categories involved in caregiving. The survey also found that nearly three-quarters (70%) of caregivers are in the workforce, which means that they have to balance the demands of caregiving with the demands of their jobs (Fig 4). Also, according to an earlier Pew study, nearly half (47%) of adults say that they expect to be a caregiver for an aging parent or other elderly relative at some point in their lives.

#### Caregiving Can Be Complex.

Carol Levine, director of the United Hospital Fund’s Families and Health Care Project, called the attention of the roundtable participants to the special challenges faced by caregivers who are responsible for what she described as “complex medical care,” which was the focus of a 2012 survey reported in *Home Alone: Family Caregivers Providing Complex Chronic Care*. While most caregivers help with household chores and other “activities of daily living,” half or more of all caregivers were called on to perform “medical/nursing tasks for care recipients with multiple chronic physical and cognitive conditions,” which involved such tasks as managing multiple medications, wound care, giving injections or intravenous therapy, incontinence support, and/or serving as care coordinators. Caregivers often find themselves doing these complex tasks with little training or support from medical professionals. As a result, most caregivers have to learn how to perform these tasks on their own, and many reported being frightened or upset about their ability to carry them out properly.

Although the available survey data provides compelling evidence of the magnitude of caregiving in the US, and offers some insights into the challenges

1. All references and additional resources are listed in Recommended Reading at the end of report

that caregivers face, the roundtable participants agreed that much more needs to be known about the range, frequency and intensity of what caregivers do and how they manage their responsibilities.

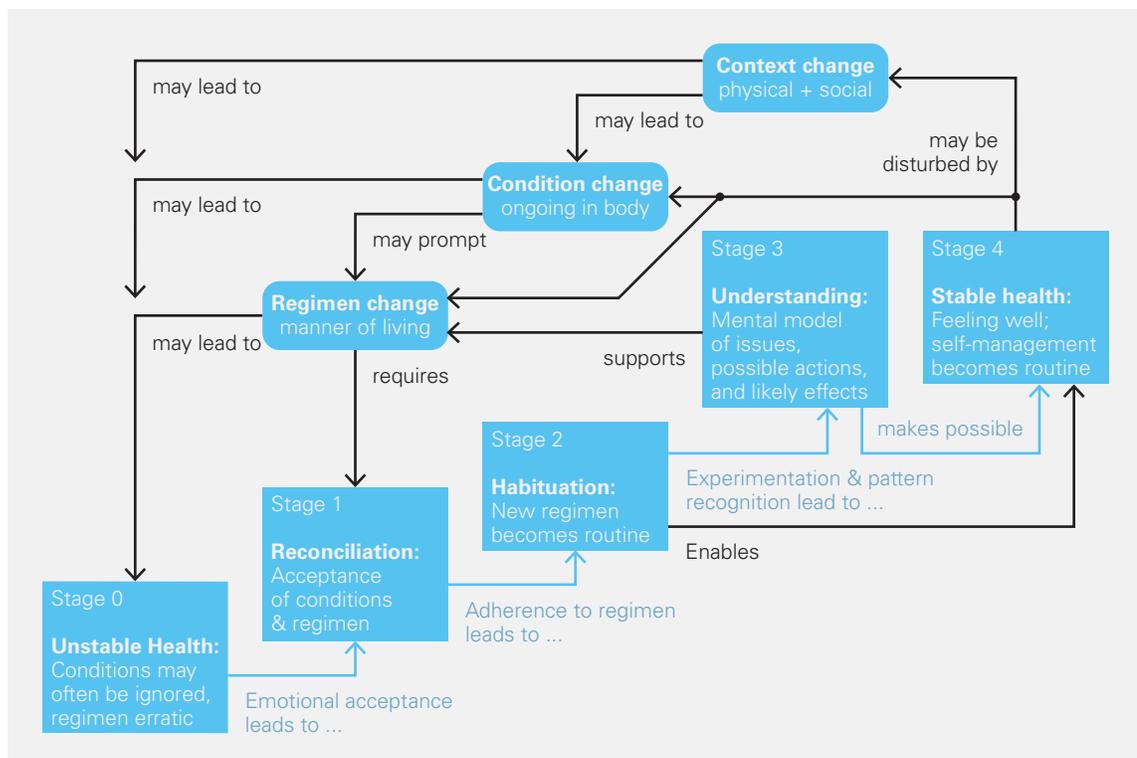
Adam Darkins, head of National Telehealth Programs at the US Department of Veterans Affairs (VA), noted that much of the research on caregiving is done from the perspective of healthcare providers and focuses on health outcomes. In order to identify areas where technology might make a more effective contribution, it is vital that we fully understand and properly frame the challenges that caregivers face.

### How Caregiving is Framed.

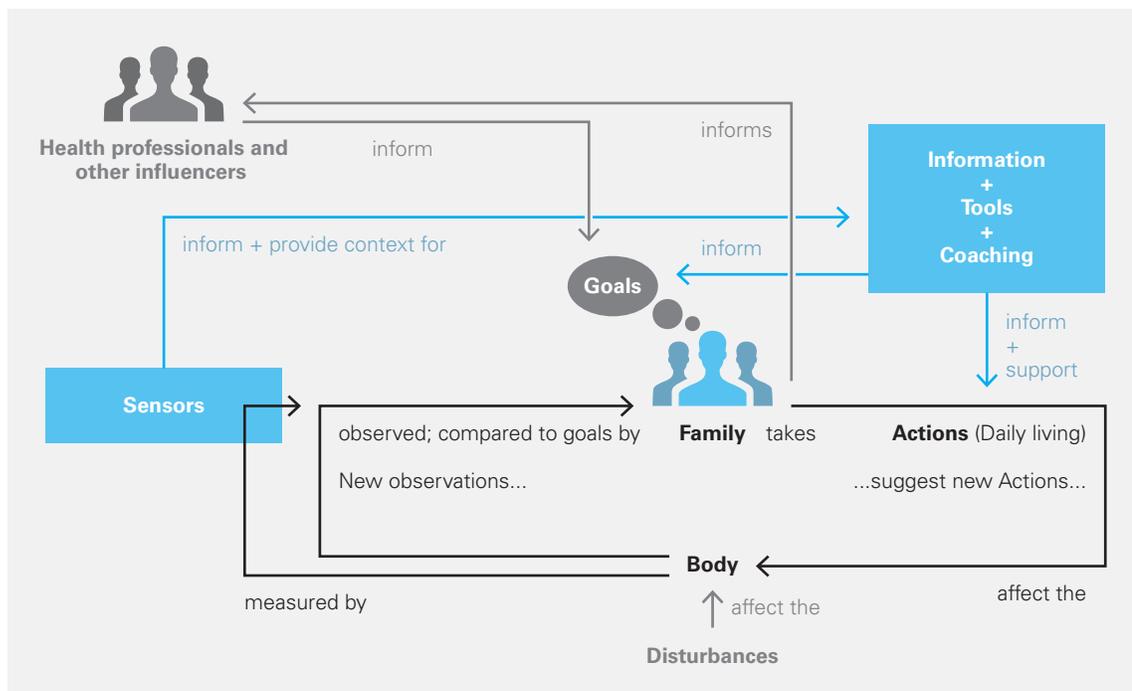
How one frames a problem can have a huge impact on the solutions envisioned. Ethnographers, journalists, and novelists have produced many in-depth narratives describing caregiving (e.g. books by English-Lueck and Lake, and a paper by Dudley), but unfortunately this information is read by few and is not easily accessible to those seeking to develop solutions. Instead, well-designed diagrams, or

“maps,” enable people to more quickly grasp important information. Rajiv Mehta, principal of Bhageera Consulting and co-leader of the roundtable, shared several different conceptual maps that have been used to depict different facets of caregiving.

**Journey Maps.** One of the most common framing images is of a journey that typically involves moving through different stages, emotions, and/or responsibilities (Fig 5). These are meant to convey an average person’s experience, usually with a particular disease, using the metaphors of a map, a landscape, and a path. Usually these are created from the perspective of the “patient” rather than that of a caregiver. Such maps gloss over a lot of complexity. For example, a person may have multiple concurrent health issues, or be caring for multiple family members. The reality is that people are often on multiple journeys simultaneously. Despite these limitations, these simple journey maps are valuable, as they provide families and patients some sense of what to expect.



**Fig 5. An example of a journey model, showing how a person may move through stages from the start of an illness to stable health, and possible regressions.**



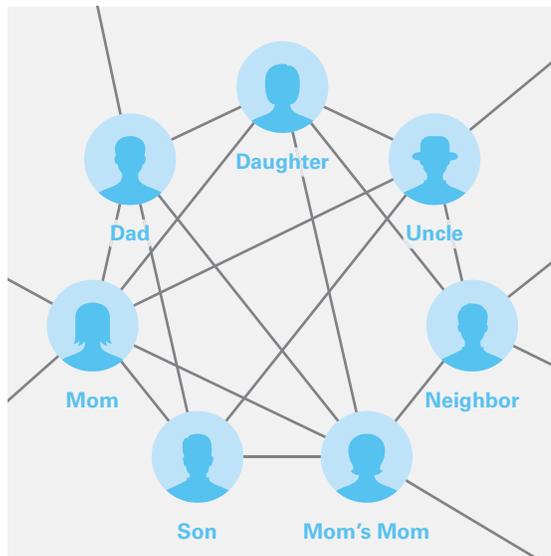
**Fig 6.** Example of a dynamic system model, showing different elements of the caregiving ecosystem and how they interact.

**Dynamic System Maps.** A different approach is to think of a person's care situation (his and his family's health and wellbeing and related activities) as a dynamic system. Such maps show how an ecosystem works, how the different actors, actions, and technologies interact with each other. In this example (Fig 6), simplified from *Health Technology for the Other 99%*, the caregiver and his family have certain goals and action plans for their health. Many people outside the family, including healthcare professionals, the media, neighbors and colleagues, influence these goals and plans. The family carries out their planned tasks, though not always successfully or as planned. Other aspects of life sometimes take precedence, and many external factors impact health. As family members observe their actual health and compare it to their goals, they may alter their plans.

Diagramming the family's care process in this way also highlights the different ways that technology could help: to enable more successful task execution; to measure health and activities; to analyze this data, and to inform new goals and plans; and

to support conversations both within the family and with outside influencers. Such maps, though complex at first glance, provide a more nuanced view of the most important elements of an ecosystem, helping innovators and other decision makers to keep the whole picture in mind.

**Identity vs. Activity.** Caregiving is often viewed as a simple, asymmetric relationship of two people: one exclusively providing care (the caregiver) and one exclusively receiving care (the care recipient). This leads to defining caregivers as an identity—e.g. [a caregiver is an unpaid individual \(a spouse, partner, family member, friend or neighbor\) involved in assisting others with activities of daily living and/or medical tasks](#). However, many people who are engaged in caregiving activities do not necessarily identify themselves as “caregivers.” Rather, they may see themselves as just doing the sorts of things that “anyone” would do for an aging parent, spouse, child, or friend who needs help. Also a person may be responsible for providing care to one person at the same time that he or she is receiving



**Fig 7. Example of a caregiving network diagram, showing that people often live within interwoven networks of mutual caregiving.**

care from another. People often live within interwoven networks of mutual caregiving (Fig 7). In light of these complexities, it may be more useful to define caregiving as an activity—e.g. caregiving is everything we do to assist a friend or relative due to that person’s illness or disability, and that we do for our own health.

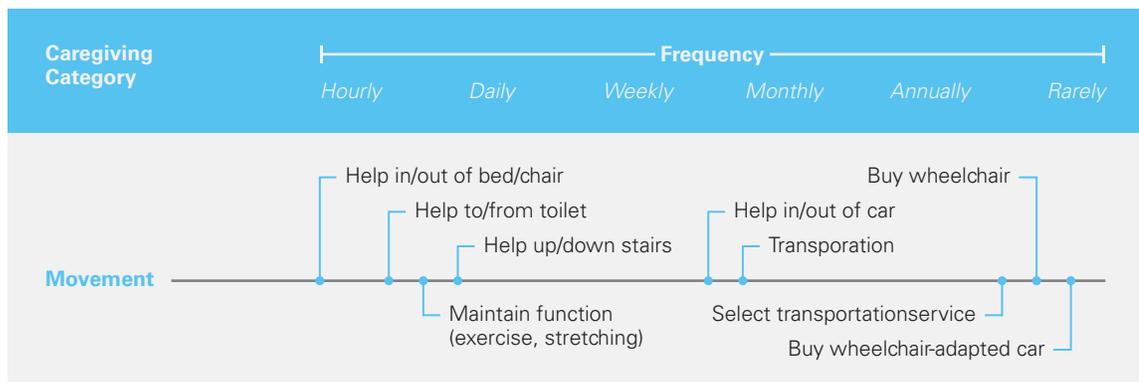
**Task Matrix.** To explore the range of caregiver tasks in greater depth, the roundtable participants were invited to fill in a matrix that identifies different realms for activities on the horizontal axis (e.g., medical, movement, home, social, finance), and frequency from hourly to rarely (Fig 8) on the vertical axis. In a

very short period of time, the participants had filled the matrix, using “sticky notes,” with a wealth of activities that occur across the spectrum in terms of focus and frequency (Appendix).

One striking finding from the exercise was that the densest cluster of items appeared in the lower right hand corner of the chart around “emotional” issues that arise on a daily basis. Denise Brown, founder of CareGiving.com, noted that people who are developing technologies to support caregiving often fail to recognize that much of the challenge of caregiving is emotional, not functional. It is also possible that the overwhelming functional burden makes caregivers emotionally more vulnerable and less resilient.

**Language**

Participants discussed the need to find better language (vocabulary) to describe the caregiving situation from the perspective of individuals and families. Current language, including the problematic term “caregiver,” comes from medical research, and can get in the way of properly understanding the realities of caregiving from the perspective of families. Terms such as “informal caregiver” and “unpaid/free caregiver” disrespect caregivers by creating an impression that the efforts of family caregivers play only a minor role in society’s health, whereas the reality is that families do almost all of the work. Technical terms such as ADLs (Activities of Daily Living), IADLs (Instrumental Activities of Daily Living), etc. also do not capture the full range of caregiving activities, and give no flavor for the importance or difficulty of many activities. New language, a better vocabulary, is needed.



**Fig 8. Example of a task matrix, showing the wide range of frequencies of caregiving tasks.**

## Technology Solutions: What Exists and What We Envision

### Current State of the Art

To provide a baseline for envisioning new technology solutions, Rajiv Mehta presented a brief review of the current state of the art (Fig 9). There are already quite a few commercial solutions that use technology in a variety of different ways to offer various kinds of help for caregivers. Some solutions are

specifically designed for the needs of caregivers, while others are more general-purpose applications that have proved to be useful for caregivers. Many information-oriented services are web-based, while many personal assistance products come in the form of mobile apps.

Category	Examples
<b>Information/Education for Caregivers</b>	
Broad information	Family Caregiver Alliance
Disease-specific	National Alzheimer’s Association
Online Communities	MedHelp
<b>Assistance/Access to Resources</b>	
Finding Facilities	Caring.com
Finding Home Care	CareLinx
Guidance	CarePlanners
<b>Family Coordination/Communication</b>	
Caregiver-Specific	Lotsa Helping Hands, CareZone
General Purpose	Google Calendar, Google Docs, Evernote
Low Tech	Notebooks, Binders
<b>Supporting Day-to-Day Care</b>	
Task Management Apps	Unfrazzle, Elder911, Making Care Easier
Assistive Technologies	DME (walkers, canes, tub assists)
General Purpose	Smartphones, Ride sharing, Online shopping and delivery
<b>Remote Monitoring</b>	
Home Activity Tracking	QuietCare, Lively, Healthsense
Personal Emergency Response	Philips Lifeline
Geo-tracking	Life360

**Fig 9. Some of the tools available to caregivers today.**

In terms of providing useful information, the Family Caregiver Alliance offers a range of practical educational materials on caregiving while the Caregiver Teleconnection provides free telephone-based “tele-learning sessions” on topics such as “Coping with Caregiver Stress,” “Outsmarting Investment Fraud for Caregivers and their Families,” and “Ideas for Increased Family Involvement.” Sites such as

CareLinx and CarePlanners offer directories of resources for caregivers. Other sites focus on providing social support: Lotsa Helping Hands facilitates the creation of online “caring communities” that “organize daily life during times of medical crisis or caregiver exhaustion in neighborhoods and communities worldwide.” CareGiving.com includes blogs by caregivers and interactive forums on topics

such as caring for a parent, caring for a spouse, and dementia care. Mobile apps such as Unfrazzle and Elder911 are specifically intended to help caregivers organize their activities and get access to support services. Other apps, such as Google Calendar and Evernote, provide caregivers with general-purpose tools to help manage their lives.

Several companies, including large corporations such as Intel, GE and Phillips as well as small start-ups such as Lively, have created remote home monitoring systems that help caregivers keep track of the activities of care recipients who live independently. And a range of products and services, including web sites and mobile apps, are designed to help individuals and families to coordinate the activities involved with caregiving.

Adam Darkins described the VAs use of remote monitoring technology, which is now enabling 100,000 sick, frail or disabled veterans to live independently. A big challenge with remote monitoring is to identify the data that is actually useful to track; too much data can be counterproductive. The VA's experience has also shown that the most important aspect of the technology is not the ability to track vital signs remotely but to help families and patients with tools for self-management and targeted education.

### **Wearables**

Mark Francis, Venture Development Lead and Wearable Product Innovator, New Business Initiative Group, Intel, provided an overview of the current state of "wearable technologies"—devices worn on or placed in the body, with sensors and/or human interfaces—a category that has emerged in just the past few years as sensors and processors have continued to get smaller, cheaper and more powerful. An important recent development is the emergence of the cloud, which means that it is no longer necessary to "cram" all functionality into a small wearable device. Rather it is now possible to offload much of the burden of data capture and processing to the cloud. Devices like Google Glass are also demonstrating the power of wearables to deliver information to people when and where they need it. Francis spoke of the immense promise of

these new technologies, but also cautioned against overly complex or poorly designed solutions that actually create more burdens for caregivers. Done well, these technologies could help families in their day-to-day care management, while also helping healthcare professionals better understand and monitor their patients.

### **An Intelligent Family Care Assistant**

Roundtable participants engaged in a "futures" exercise to brainstorm new technology-based approaches over the next decade. One sub-group explored how technology might help in-person caregivers, while a second focused on the needs of long-distance caregivers, and a third considered how technology might be applied to the needs of those caregiving for multiple people.

Interestingly, all three groups independently came up with a very similar solution: an "Intelligent Family Care Assistant"—a device or system that keeps track of the family's care metrics and tasks, as well as the overall context of the family's other activities, and automatically notifies appropriate family members about upcoming activities, important preventative measures, and alerts to current or impending crises. Such a system would automatically integrate all available data streams and use powerful analytical and decision-support algorithms to help each individual and each family with their unique situations.

The first group described their solution as an advanced version of "Google Now for Caregivers." The second group labeled their concept as a "Person Centered Concierge/Executive Assistant/ Circle-Keeper/Siri" that can learn what is needed, make useful suggestions, and provide a simple dashboard for keeping track of important tasks. The third group envisioned a "Care Coordinator" that tracks task status and manages communications among all parties in a support network which they described as a "Base Camp-like" collaborative project manager for caregivers.

Participants also noted that we are now living in an age of "combinatorial innovation". Rather than having to rely on fundamental breakthroughs in

new technologies, there are many opportunities to solve problems and create new products by simply making use of existing technology capabilities combined in new ways. Among the emerging technology capabilities that will enhance the power of future caregiving solutions are: Pro-active Computing (systems that learn our needs and change their behaviors accordingly); Pervasive Connectivity (devices that have continuous access to computational and data storage capabilities in the cloud); High-resolution Sensing (cheaper, smaller and more sensitive sensors arranged in “body area networks”); and Orchestrated Devices (devices that automatically interconnect and work cooperatively). Such novel approaches will find their way into future caregiving solutions.

### Beyond Technology: Considering and Designing for the Whole System

Hugh Dubberly, Partner, Dubberly Design Office, observed that while we often think about things in isolation, in the real world things are “connected.” For example, the healthcare system is beginning to understand that patients are not merely individuals but are part of families. Doctors don’t practice alone but are members of caregiving teams. We need to adopt what Dubberly described as a “whole systems approach to designing products.” Patients rely on a network of formal and informal health care providers; caregivers are part of a support network that may include multiple social networks; care recipients have complex lives that encompass many types of tasks and relationships. To properly understand these challenges, we need to shift our thinking from mechanical models, with neatly designed cause-and-effect relationships, to a biological perspective that looks at whole ecosystems.

In designing new products, Dubberly urged developers to aspire beyond simple usability (Fig 10). We need to move from focusing narrowly on what is being sold to a broader viewpoint that considers what is being done for the customer. This shift implies taking on a larger challenge of designing not single products but more comprehensive systems that help caregivers and care recipients where help is needed.



Fig 10. Usability is necessary but not sufficient.

Roundtable participants explored the prospects and challenges for new technology-based solutions for caregiving from three different perspectives: *caregivers themselves*, *product developers*, and *supporters* (i.e., employers, foundations and other institutions). Some useful insights emerged from these discussions about key elements of the caregiving ecosystem.

### The Value of Coaching

As appealing and useful as the envisioned technologies might be, they will probably not be enough, by themselves, to have a significant impact on the quality of caregivers’ lives and the quality of care that they are able to provide. Cali Yost, founder of the Flex/Strategy Group, noted that the situation caregivers find themselves in is often chaotic and confusing, which makes it difficult for them to think systematically about what kinds of help or support they needed. Yet the ability to devise and to adopt effective technology solutions depends on being able to clearly define and understand a problem to be addressed.

The roundtable participants agreed that knowledgeable and empathetic, human coaches are required to help families find and leverage available technologies. Such coaching is common in the workplace. New technologies for workers are not simply tossed out. Employers make sure that they seek out and evaluate useful technologies, and then take the trouble to introduce these to appropriate employees, coach them on proper use, and support their ongoing usage. Employers do this because they know such support is required to get the potential benefits. It is no different for technologies for families.

### Linking Families and the Healthcare System

One specific challenge for caregivers, especially for those who are responsible for supporting recipients with significant medical problems (which includes

post-acute patients with immediate needs for care and people with serious chronic health problems who need ongoing care) is providing useful linkages between caregivers and the healthcare system. Carol Levine pointed out that [caregivers are often “invisible” to health care professionals and therefore are not included in planning for patients’ home care.](#) Matthew Holt, Co-Chairman of Health 2.0, noted that the next stage of “meaningful use” standards for electronic health records will require the ability for patients to get access to their medical data, but does not clearly grant similar access to caregivers. Jodi Daniel, Director, Office of the National Coordinator for Health Information Technology, added that current health information systems are beginning to focus more on getting information from healthcare out to patients, but have not seriously addressed how best to get information from patients and caregivers into the systems, or how to support health conversations rather than directives.

### **Better Healthcare Support for Family Caregivers**

In fact, [health professionals require the cooperation of family caregivers to be successful in caring for their patients.](#) While families are dependent on health professionals for high-quality diagnosis and treatment and for access to various services, professionals are dependent on families for both information about patients’ health status and living experience, and for properly carrying out professional advice. These facts provide reasons why the healthcare system should be more engaged with developing technology-based solutions to link them with caregivers. However, for healthcare institutions to do much more for family caregivers than they do today, they will need convincing business cases that show a clear return on investment (ROI).

### **Mobilizing Employer Support for Family Caregivers**

Similarly, employers need clear business cases to expand their support of caregiving employees. While employers are not directly involved in family caregiving, they are impacted by the caregiving needs of their employees. The phrase “work-life balance” evokes an image of two very separate things (work and life) at far ends of a balance. However, roundtable participants noted that work and life are inseparably intertwined in today’s world.

Caregiving responsibilities, and certainly emergencies, occur throughout the day and have no respect for 9-5 work boundaries. And for many current jobs, work responsibilities themselves do not respect 9-5 boundaries, with emails, phone calls, etc. occurring at all hours. Families have no choice but to accommodate work demands into their lives. Similarly, whether employers like it or not, their employees must also accommodate life demands within their work schedules. For fundamental business reasons, such as workplace productivity and employee retention, employers must do more to help their employees with caregiving responsibilities to be more efficient and effective caregivers and to be less distracted by their care activities.

### **What Developers Need**

Given the lack of clear market delineation, developers face a number of challenges in identifying viable opportunities for designing new products, and in then gaining enough market awareness and sales for business success. Developers are stymied by both a lack of clear understanding of caregivers needs, and by an unsupportive market environment.

Participants also noted that consumers have shown that they are willing to pay out of pocket for solutions that promise to ease or improve their lives, which suggests that a viable consumer market could develop if the right products were created. However, there have been no “blockbuster” products to date, which also suggests the difficulty of developing exactly the right products and finding the right distribution channels to reach this market.

### **International Cooperation**

Participants also agreed about the importance of looking at what is happening in other countries (e.g., Sweden, Singapore, Australia, UK) to learn from their experiences. The challenges of family caregivers are universal. More international dialog would help everyone.

## Recommendations

After a full day of group discussion, the participants were asked to spend some time thinking quietly and to write a personal “manifesto”: What did they believe was most critically important about caregiving? What was their vision for future caregiving

technology? What needs to be better understood about caregiving? And what are the most important, actionable steps to support caregiving in the future? Though each participant’s response was unique, several common themes emerged.



**Fig 11. Successful caregiving technologies require three supports.**

There is great optimism that new *caregiving technologies* could play a significant role in making family caregiving easier and more effective. Technology has had a huge impact on many aspects of life, from the esoteric (confirming the Higgs-Boson particle) to the mundane (intelligent home thermostats). Given that caregiving has a major presence in the human condition—it requires so much time and effort, plays such a large role in people’s lives, and has such a major impact on the well being and productivity of society as a whole—there was a strong consensus that greater investment in technologies to support family caregiving is likely to have significant impact. While developing specific technology solutions was beyond the scope of a single day’s wide-ranging discussion, three ideas got a lot of attention: an “Intelligent Family Care Assistant,” wearable technologies, and better family caregiver(s)–health professional connectivity.

What can be done to catalyze innovation? Roundtable participants honed in on four major, complementary recommendations (Fig 11). Two to “frame the issues”: better *maps & language* to describe the rich, complex, and dynamic caregiving landscape, and more current, thorough, accurate *data*. And two to “create a fertile environment”: spurring a *national conversation* to reframe

conversations about caregiving, and building *business cases* to gain the active support of healthcare institutions and employers.

In addition participants noted the importance of two requirements to “maximizing the value of technology”: *coaching* to help families discover and leverage available technologies, and *social conversations* to provide more learning and support within communities.

### Framing the Issues

#### **Create rich *maps* and appropriate *language* of the varied and complex caregiving landscape.**

The development of good and widely-shared models of caregiving and appropriate language is critical for catalyzing innovation.

We need to find better ways of helping everyone properly frame and understand the reality and challenges of caregiving. Without clear understanding, with only simplistic assumptions about caregivers’ needs, it is unlikely we will see the technology innovations we hope for.

It is critical to develop better and widely-shared models of caregiving illustrated in “concept maps.”

No single diagram is likely to capture all the important elements; a small collection of maps is required. Such maps will help innovators design and develop useful technologies. They are also necessary for families and caregivers to understand their own situations and to have a sense of what lies ahead. In addition, such maps are critical for policy makers, healthcare professionals, employers, and others in their efforts to help and accommodate caregivers.

It is also clear that we need better language (vocabulary) to describe the caregiving situation from the perspective of individuals and families, to replace today's medical-oriented vocabulary.

**Continue to collect extensive *data* about the prevalence, burden, and impact of caregiving and the role of technology.**

There is an ongoing need for research on family caregivers, especially as technology dramatically impacts caregiving. The currently available research provides evidence of the large magnitude of caregiving. However, we need to have a better understanding of: the day-to-day realities of the caregiving process; the diversity of caregivers' roles and responsibilities and how they carry them out in the context of their overall lives; the ways in which caregiving responsibilities change over time in response to both care recipients' needs and the circumstances of the caregivers; and the impact of family caregivers' activities on the lives of others around them (colleagues, neighbors, etc.).

Data needs to be presented in a way that will support entrepreneurs and other organizations. Entrepreneurs need such data to develop business plans, to know which markets they can profitably target. Policy makers, healthcare professionals, employers, and others need such data to understand the impact of caregiving on their actions, and the potential ramifications of their actions on caregivers.

A key objective for caregiving technologies is to make family caregiving easier (less burdensome), as well as more effective (better managed health for both caregivers and care recipients). However, today we lack good measurements for caregiver burden and for thinking about and measuring health per

the goals of the family. We won't know if technologies, services, and policies are actually helping family caregivers unless we have a way to measure caregiver burden. Therefore developing metrics of caregiver burden, and gathering data on current caregiver burdens is an urgent objective. Similarly we need to develop metrics for health based on the family's goals.

The data we collect—what we choose to measure, how we choose to measure it, and how often we gather the data—is strongly influenced by our understanding of what caregiving is. Hence great maps and language are critical to data collection.

## Creating a Fertile Environment

**Spur a broad *national conversation* on caregiving to inform and involve all major parties.**

Despite the millions of Americans who are involved with caregiving, the large amount of time that is devoted to caregiving, and the vital importance of caregiving in maintaining the health and independence of millions of Americans who need care, these issues have not been widely recognized or addressed by business or government. Cali Yost noted that [caregiving simply is “not on the radar of corporate America” as a strategic priority. And there has been little progress enacting public policies to support caregiving](#), despite many years of efforts by advocates.

While large-scale government support for caregiving is not likely in the foreseeable future, at least in the US, a new national discussion is needed to raise consciousness of the issues and explore what kinds of responses are necessary and feasible. Entrepreneurs are much more likely to take on the risks of developing innovative products for family caregivers if there is a national stage for their offerings, if they know that their efforts will be covered in the national media and considered by decision makers.

So we need to spur a national conversation about family caregiving to inform all major public and private decision makers and to create the broadest possible net for innovation, reaching out to experts

in many fields and to innovators in other nations. We want to raise issues and opportunities to the surface, and reframe conversations about caregiving.

**Develop compelling *business cases* for employers and healthcare institutions to support caregiving.**

Institutions that could benefit from more effective and efficient family caregiving—healthcare organizations and employers—could significantly accelerate innovation by supporting development of solutions and channels for their deployment. The nature of the ROI and the business cases will be different for healthcare providers and for employers: health professionals require the cooperation of family caregivers to achieve optimal health outcomes, whereas employers must accommodate the caregiving needs of their employees.

There are plenty of high-powered consulting firms that already focus on healthcare and on employers. Armed with clear models and language about caregiving and rich data, and spurred by a national conversation on the issues, such firms are likely to develop appropriate business models as a normal part of their activities.

## Maximizing Value of Technologies

**Provide personalized caregiving *coaching services* as an integral component of all solutions.**

Coaches who are deeply knowledgeable about available technologies, and who take the time to understand each family's unique situation, would make it possible for caregivers to get the full benefits of technology solutions. Such coaching should also focus on teaching caregivers skills for managing their multiple, competing responsibilities. Technology developers, as well as all parties with an interest in supporting family caregivers, should include coaching as a critical part in a whole systems approach to caregiving solutions.

**Inspire *social conversations* about caregiving to encourage more learning and support within families and communities.**

Despite caregiving being relatively commonplace, most caregivers feel that they toil in isolation. This isolation not only deprives them of emotional support that others could provide, but it also means that people do not learn from each other's experiences and knowledge. Few caregivers are prepared for the burdens that fall on them or have the ability to find others who share similar challenges.

Caregivers could learn a lot from each other and would be less socially isolated if conversations about caregiving were more commonplace. We should find ways to make peer-to-peer conversations about caregiving more normal and less taboo. A prominent national conversation about caregiving, with significant media coverage, would likely spur this, as would coaching that encourages people to learn from their friends.

## Who Should Do What

### Family Caregivers

- Support one another, and learn from friends and family through participation in *social conversations*.
- Not blame themselves for exhaustion, frustration or mistakes, as *data* shows that caregiving is often difficult and overwhelming for many.

### Caregiver Advocacy Organizations

- More deeply understand the richness, complexity, and universality of caregiving (*maps* and *language*) rather than viewing the issue through a narrow lens (by disease or demographic).
- Advocate for whole-system solutions, including *coaching*.

### Caregiver Support Organizations

- Leverage better *maps*, *language*, and *data*, and a *national conversation* to gain support for and improve services.
- Offer *coaching* services to help caregivers fully benefit from available technologies.
- Stay current on *caregiving technologies*, and recommend appropriate solutions to the families you serve.

### Employers

- Support the development of better *maps*, *language* and *data* to understand employees' caregiving needs and the business impact of their activities.
- Direct strategists and consultants to develop *business plans* to support employee caregiving.

### Entrepreneurs and Innovators (and their backers)

- More deeply understand caregiving (*maps* and *language*) rather than relying on simplistic stereotypes.
- Include *coaching* as a critical part of the whole solution.
- Encourage *social conversation* among users.

### Foundations and Philanthropists

- Support research and other projects to address foundational needs (*maps* and *language*; *data*; *national conversation*; *social conversation*) necessary to spark innovation, in addition to extending existing caregiver services.

### Government Agencies & Policy Makers

- Support the development of better *maps*, *language* and *data* to fully understand this major societal issue and its impact on a wide range of other issues (productivity, healthcare expenses, etc.).
- Better support own caregiving employees.

### Healthcare Providers

- Support the development of better *maps*, *language* and *data* to understand your patients' needs and the impact of caregiving activities on health and financial outcomes.
- Work with strategists and consultants to develop *business plans* to support patient/family caregiving.
- Develop procedures and technologies to more fully engage with family caregivers, realizing that bi-directional conversation with all key family caregivers is critical to success.
- Better support own caregiving employees.

### Media

- More deeply understand caregiving (*maps* and *language*) and reflect this in coverage, rather than doing stories that simply confirm current simplistic stereotypes.
- Encourage *social conversations* by making stories about everyday caregiving as commonplace as stories about fitness, nutrition, child-rearing, etc.

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## Conclusions

It is clear that technology has a significant role to play in supporting caregivers. Technology-based solutions have the potential to lighten the burden that falls on caregivers by helping them to coordinate the demanding tasks and the complex networks of relationships involved with caring for others. But technology-based products are not likely, by themselves, to be a complete solution. Other social support systems are needed to ensure adoption and use and to alleviate the isolation that many caregivers experience.

To catalyze greater innovation, a number of things need to happen, including generating better information about the realities of caregiving and developing business cases that identify what kinds of returns on investment new technology-based applications can provide. Researchers can help

deepen our understanding of caregiver needs, while foundations, employers and public agencies can provide the support needed to carry out this research. Once this knowledge is available, we are confident that entrepreneurs and application developers will step forward to devise new ways of meeting these needs.

We recommend that efforts be put forth immediately to develop better maps and language about caregiving, followed closely by development of better data. In addition we can begin to lay the groundwork for a national conversation informed by the initial work, and for educating the major consulting firms serving healthcare institutions and employers. We believe these steps will result in caregivers benefiting from the full potential of technologies to ease their lives and improve their health.

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## Recommended Reading

These are books, papers, and other materials that were preparatory materials for the roundtable and/or referenced during the discussion.

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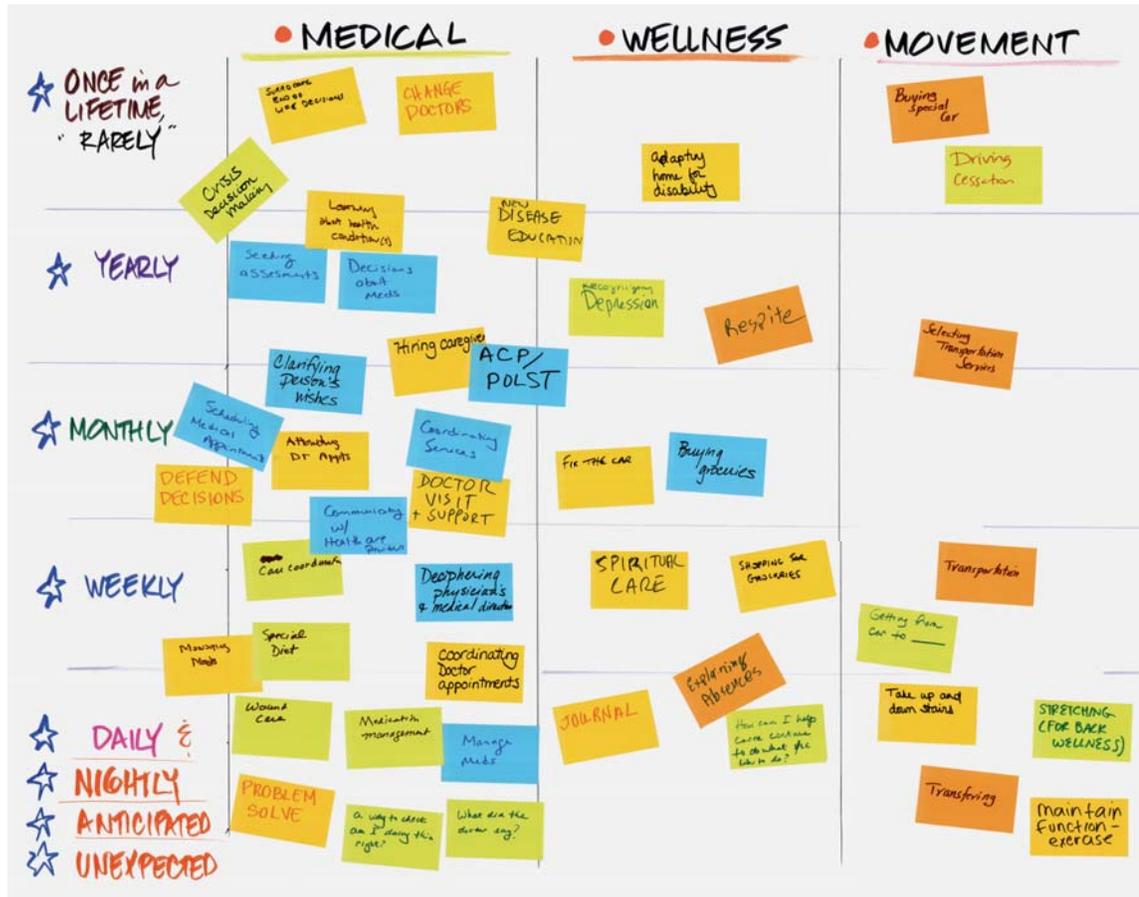
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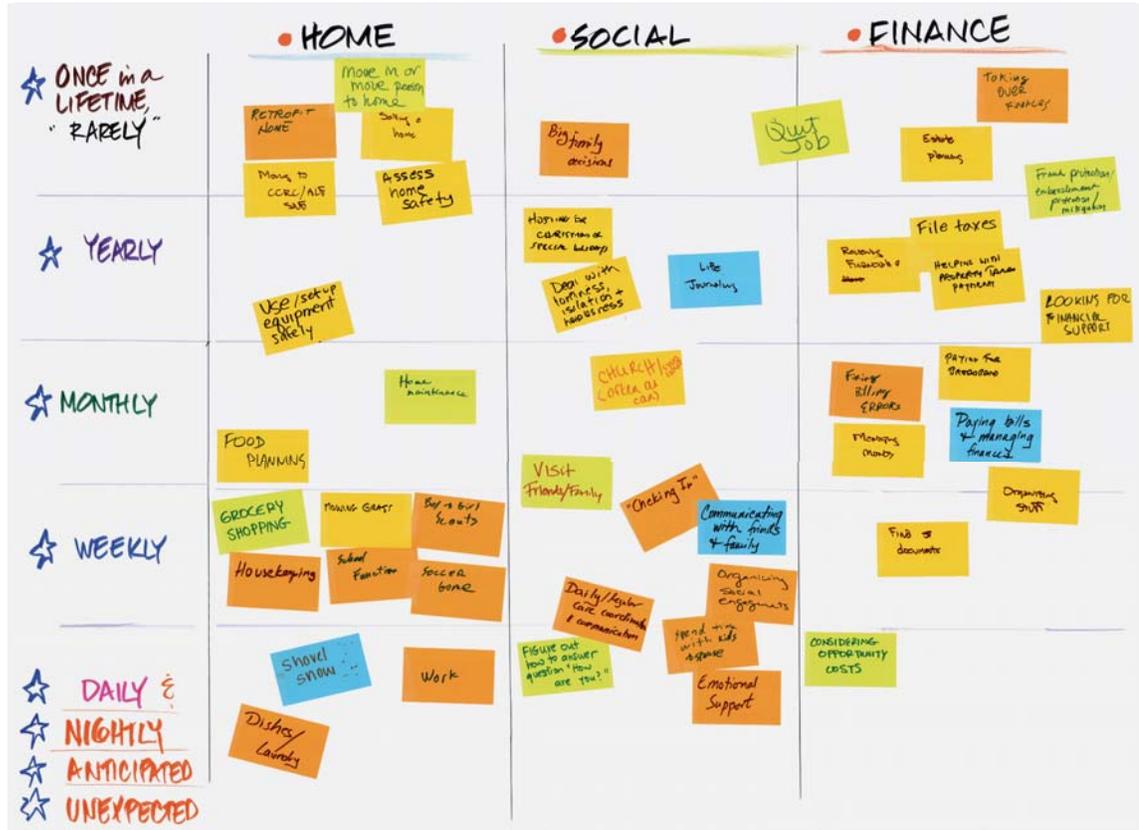
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## Appendix



Caregiving task matrix. Result of an exercise by roundtable participants noting common caregiving activities by focus and frequency (Part 1 of 3).

Appendix Continued



Caregiving task matrix. Result of an exercise by roundtable participants noting common caregiving activities by focus and frequency (Part 2 of 3).

## Appendix Continued



Caregiving task matrix. Result of an exercise by roundtable participants noting common caregiving activities by focus and frequency (Part 3 of 3).