The vast majority of health care is actually provided by families, not by healthcare professionals. They need help, to make caregiving both easier and more effective. Unfortunately there exists too little of the type of data needed to create great solutions.

The Atlas of Caregiving Pilot explored new methods to study family caregiving, to understand day-to-day care in detail.
Foreword

Family Caregiver Alliance is pleased to be a partner on the Atlas of Caregiving Pilot. This project tests the boundaries of collecting data about the lived experiences of family caregivers across the spectrum of ages, health conditions and family configurations. It offers a unique opportunity to appreciate the dedication, love and effort by which families find their “new normal” as caregivers.

There are several lessons worth sharing from our vantage point of 40 years of experience in the field of supporting unpaid family caregivers.

First, each family is unique, with unique dynamics, strengths, capacities, and resources. Care mapping provides the opportunity for caregivers to increase awareness of their own care system and illuminate where additional assistance may be needed.

Second, while there are plenty of surveys on time spent on caregiving on a daily or weekly basis, they can be misleading. That is, surveys measure the time spent in independent care transactions such as dressing, bathing, medications, assisting with mobility and other life activities. These transactions disguise the overall need for family members to just be there, onsite in the home, sometimes on a 24 hours basis for those family members who have more complex health conditions and/or cognitive impairments.

And last, when you view the daily activities, one begins to understand how fractured and interrupted a day can be, and how quickly attention moves from one activity to another, whether medical or all the activities that surround keeping a home in order. One may view this as running a personal assistive living facility with the caregiver doing all the roles and having all the responsibilities.

We hope this report inspires you to create services and products that can fit into a busy daily schedule, be practical and useful, and can create true value and assistance to family caregivers.

Kathleen Kelly, Executive Director
kkelly@caregiver.org
April 2016

About Family Caregiver Alliance

Family Caregiver Alliance (FCA), a public voice for caregivers, was the first community-based nonprofit organization in the country to address the needs of caregivers providing long-term support for family members and friends. For 40 years, FCA has shed light on the challenges caregivers face nationally and provides the assistance they need and deserve. FCA champions their cause through education, services, research, and advocacy.

These are some of FCAs key national, state, and local programs and resources: CareCompass is an online pathway to tailored information, support and services; National Center on Caregiving unites research, policy, and practice, to advance programs and policies nationwide; Family Care Navigator helps caregivers locate support services by state; and the Bay Area Caregiver Resource Center provides direct caregiver services for the six-county San Francisco Bay Area.

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Dubberly Design Office
Dubberly Design Office is a San Francisco based consultancy founded in 2000. The office focuses on software and service design, especially integrated systems of hardware, networked software applications, and human services. Much of the office’s work is in the domain of health and well-being with clients ranging from large corporations, such as Amgen, IBM Watson Health, and Johnson & Johnson, to start-ups, including some engaged in adaptive vision testing, using phase energy to measure heart health, and patient population management. The Internet of Things and machine learning are increasingly components of the work. The office is also known for modeling and concept mapping, including maps of “Heart Attack” and “Alzheimer’s.”

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In addition to the project’s formal advisors, many contributed to the project’s success, some providing guidance and advice, and some doing considerably more.

Most importantly, though they remain anonymous, we are deeply grateful to the families who participated in this research. This effort would not have been possible without their generosity in time and openness, and their willingness to learn with us and to trust us.

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Katie Anthony assisted with some participant interviews.

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Sapient graciously provided access to their in-house data analysis tool, DataDeer, along with substantial assistance in set-up and debugging.

For data analysis, we were assisted by: Aniket Bhatnagar, Peter Binggeser, John Cain, Robert Goldberg, Elliott Hedman, Patch Kessler, Rosalind Picard, Pasindu Wevegama, and Anne Wright and the participants of Georgia Tech’s “Humanities Data Visualization Workshop.”

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Phylene Wiggins, Celine Takatsuno, and Mary Sheridan played leading roles for the care map workshops conducted in Santa Barbara. Carol Levine, Rebecca Madigan, and Lisa Riolio also assisted.

Several people provided opportunities to present and discuss work-in-progress at appropriate meetings and conferences: Richard Anderson, Tim O’Reilly, Kathy Raffel, Madeleine Starr, and Gary Wolf.

Many have contributed to our analysis of the implications of our findings and recommendations for next steps, including: Joan Barlow, Sadia Kalam, Josephine Kalipeni, Elly Kugler, Bill Portelli, and Cali Yost.

Susan Williams and Brian Hutchinson helped edit the final report.

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Executive Summary

We live in an era of unprecedented amounts of data, collected by rapidly improving sensors and analyzed by ever more powerful computers. Shopping habits, traffic patterns, environmental changes, even the variation in grape growth in a vineyard, are far better understood today. Everything from the nation’s power grid to hospital operating rooms, and from financial trading to automobile dashboards, relies upon extensive data for normal operation. In theory, continued data collection and analysis is supposed to lead to a virtuous cycle of better and better solutions.

The Atlas of Caregiving Pilot set out to answer one fundamental question: Can this technological revolution be used to understand the crisis of family caregiving, one of the less explored major issues associated with modern living?

If care is thought of as an iceberg, professional healthcare might be considered to be the tip. Family caregiving is the huge, unseen portion underwater. Through surveys, we know that family caregiving is widespread. Tens of millions of Americans care for ill family members, without pay and often with little to no support. This occurs at an annual cost of hundreds of billions of dollars in lost wages and direct expenses. Because family caregivers, not professionals, perform the vast majority of care activities, the success of healthcare is highly dependent on what family caregivers do. Caregiver’s concerns, however, are all too often invisible in debates about healthcare.

Surveys only tell us that the hidden iceberg is huge. They do not provide a deep understanding of who is involved in family caregiving. Nor do they provide details on what exactly caregivers do, the kinds of difficulties they face, or what their concerns are. Innovations in data collection, so widely used elsewhere, raise the prospect of studying the hidden iceberg in new ways. They may enable a deeper understanding of each family and its unique situation, so that it becomes possible to identify the kind of help that truly matters.

As evidenced in our study, today, family caregivers are already overwhelmed by burdens, and unfortunately society’s demands on family caregivers are going to increase dramatically in the coming decade as the baby boom generation continues to age. Family caregivers need solutions — products, services, and policies — to make it easier (and possible) for them to do more. Without detailed knowledge, it is highly unlikely there will be great solutions.

Technology alone, however, is not enough. Humans and families are complex, and today’s sensors and analytics, as amazing as they are, are still in their infancy. Sensors often do not measure what we really want to know. Even seemingly simple metrics such as steps and heart rate are often based on data that are only rough proxies for the stated measurement. Results are often inaccurate, and sometimes altogether wrong. Usable measurements of more complex things, like mood and stress, are only on the horizon.

Today’s technology still only provides vague, shadowy measurements of what it means to be fully human. But when we think about electronically collected data as clues instead of fully complete stories, new possibilities for analysis open up. In this manner of thinking, technology can form one piece of the puzzle, while human analysis, particularly by the individual involved, can form the complementary piece used to make sense of the data collected about that person.

Approach

The Atlas of Caregiving Pilot sought to assess whether it was possible to learn more about family caregiving by combining “off the shelf” consumer technology with ethnographic interviewing. To our knowledge, this combination is a unique and groundbreaking approach to the study of day-to-day family caregiving.

Fourteen diverse families, all within two hours of San Francisco, participated in the research. Caregivers ranged in age from 30 to 73. Care recipients ranged from 3 to 101. They held diverse conditions including, but not limited to Alzheimer’s, cancer, cerebral palsy, diabetes, and Parkinson’s.
Care contexts also varied widely. In some instances, parents cared for young or adult children. In others, young, middle-aged and older adults cared for each other and/or cared for their parents.

Data was collected by several means. Participants were interviewed, and kept a log of their activities and stress levels. They wore an Empatica E4 wrist sensor (to record body metrics such as heart rate and movement) and a Narrative Clip camera. Environmental sensors, a Netatmo Weather Station and SmartThings Motion Sensors, were placed around their home. The data was then analyzed, and visualizations of the data were reviewed with the participants.

Findings

The Atlas of Caregiving study provided rich insights into individual family lives, including things about participating families that would not have been possible to know through traditional approaches, or via ethnography or technology alone. Participation also helped families to better understand their own situations. For example:

- Hanna and Gaston care for her brother, who requires 24×7 care due to several issues. Gaston also has extensive self-care needs. Reviewing motion data from the E4, Hanna and Gaston better understood how different their sleep patterns are, and how poorly Gaston sleeps.

- Nadine cares for her teenage son, who has Type 1 diabetes. Discussing a moment of stress in her log, while also reviewing the contemporaneous E4 data and Narrative Clip images, Nadine came to understand what was at the root of her stress.

- Sally cares for an adult son with major emotional and behavioral difficulties, and manages her own health needs. When Sally reviewed her log and saw the extent of her caregiving and other activities, how fragmented her day was, and how she was always “on edge,” she was able to better understand her tiredness.

As we look across the 14 families, we see some common patterns:

- Caregivers are not fully aware of the extent of their caregiving activities. As in the examples above, participants learned something about their own activities, challenges and opportunities from the self-reflection enabled by the research tools and methods.

- There are almost always more people involved than “a caregiver, a care recipient, and doctors”, sometimes a lot of people. For example, the care map in Figure 1, based on interview data, shows the key people involved in Fernando and Laura’s caregiving situation: who they care for, who else cares for those people, and who provides them support.

- The complex choreography of care (juggling numerous care and life activities) plus contextual knowledge (likes, wants, limitations, histories, and interdependencies) makes respite difficult. The diagram of Gaston’s activities in Figure 2 shows how 24 hours of caregiving, self-care, and other life activities are intertwined. The diagram also shows the self-reported stress of caregiving activities, and how stress does not necessarily coincide with a particular kind of activity.

- Caregiving experiences vary day-to-day, sometimes dramatically. During the brief period of their participation, some participants had easier than expected caregiving days, while for others, the situation was much worse than expected.

- Defining the caregiving experience solely by disease, condition, or age can be myopic, missing major features of what caregivers do. Caregiving is always about more than just medical tasks.

- Caregiver stress involves a complex interplay of in-the-moment stress and long-term burnout. In addition, even downtime or other seemingly stress-free moments can be times when the caregiver is “on call.” Therefore, time to truly recover from the stress of caregiving is limited.
Caregivers are often too overwhelmed to avail themselves of potential assistance. Seeing how busy participating caregivers were, even on “good” days, it is easy to understand the difficulty they face in discovering, evaluating, acquiring, learning and using potentially helpful services and products.

Rich learning, about individual families and broad caregiving themes, confirmed the value of a multi-modal research approach and the use of sensor technologies. While specific tools like interviews or wearable sensors were valuable in and of themselves, combining and analyzing results from them together was what led to critical new findings. The whole was definitely more than the sum of the parts.

Though this approach has enormous potential, collecting, analyzing and visualizing the data was laborious, and current data-analysis technologies were inadequate. The study was originally designed to see what researchers with basic quantitative skills could do. But, without specialist technical knowledge of sensor systems or data wrangling, the reality is that future efforts will require more technology development for efficient analysis. The sensors used in the study also had limitations; but, they show great promise and these technologies are advancing rapidly.

**Recommendations**

Most importantly, this pilot has made clear that research of this type should be expanded significantly, potentially in a variety of contexts. Despite the constraints that we found, the method is feasible for—and can be adapted to—research conducted by individuals, academics, and non-profit and for-profit organizations.

In addition, this research opens up opportunities for immediately empowering family caregivers. One of the key findings of the study was that the caregivers directly benefitted from participation. Most found value from the effort of self-observation, learning about themselves and their situations. Many found that it provided greater clarity about the forms of help that would truly improve their caregiving situation, and that it did not significantly add to their burden (a very real risk in this situation). Self-learning tools, based on the project’s findings, could help caregivers better understand their own needs, leading to experimentation to improve their situations and to better advocacy for themselves and their families. Indeed, workshops, led by the Atlas team, that teach family caregivers and social workers how to draw and learn from care maps have received enthusiastic feedback.

The insights we have gained from this pilot also have major implications for those who hope to develop and offer great solutions for family caregivers, such as entrepreneurs, employers, and health and social service organizations.
For example:

- For entrepreneurs, the pilot suggests that certain approaches to product design and development may gain more traction than others given the fragmented, yet largely non-medical nature of caregiving. These include deeper need-finding than surveys or focus groups permit, measuring success by usefulness rather than usage, and including coaching as a fundamental product feature.

- For employers, the pilot found that working caregivers need significant day-to-day flexibility, even for "light" caregiving situations. In addition, caregiving does not just pertain to those who care for elders. It can affect all employees—those with parents, spouses, or children who suffer from diseases. At the same time, employers are well positioned to help caregivers be much better informed and empowered.

- For health and social service organizations, we recommend assisting caregivers in developing self-knowledge, and redesigning service delivery in ways that assume the presence of multiple caregivers, not a single primary caregiver. In addition, healthcare institutions also must be more sensitive to realities of how often various healthcare protocols conflict with caregiving activities and compete for caregiver time and attention.

**Conclusion**

The Atlas of Caregiving Pilot shows that it is possible to look at family caregiving in detail. And yet, it is only a tiny glimpse of what needs to be known. The pilot studied 14 families, each for roughly a day. To truly address the family caregiving crisis, the world needs to learn from thousands, even millions of caregiving families, and to better understand how things change over time. Fortunately, the path forward is clearer.

The hidden iceberg of family caregiving can be made visible. We can begin to understand the complexity of what is currently hidden from view by devoting resources to a major effort to: improve and expand research efforts (better technology, more participants, over a longer time period); develop and deploy tools that empower family caregivers through self-learning, and; bring actionable insights to entrepreneurs, policy makers, healthcare institutions, and all others seeking to support family caregivers.
Team

Project Leadership

Rajiv Mehta (principal investigator)
Principal, Bhageera Inc.
Rajiv provided overall project leadership. He also led the selection of data collection methods and tools, design of the research protocol, participant outreach and selection, participant interviews, data collection, analysis of results, and project reports and presentations.

Hugh Dubberly (co-principal investigator)
Partner, Dubberly Design Office
Hugh’s office led the data visualization effort, as well as designing, producing, and coding the project web site and reports. Hugh also contributed to the selection of data collection methods and tools, and design of the research protocol.

Dawn Nafus,
Anthropologist, Intel Labs
Dawn contributed significantly to the selection of data collection methods and tools, design of the research protocol, participant interviews, analysis of results, and the project report.

Kathy Kelly
Executive Director, Family Caregiver Alliance
Kathy assisted with participant outreach, and provided guidance to project design, execution, and analysis of results.

Carol Levine
Director, Families and Health Care Project,
United Hospital Fund
Carol helped ensure ethical practices with respect to research protocol, participant outreach and selection, and reporting of participant results. She also provided guidance to project design and execution, and analysis of results.

Core Team Members

Robin Bahr, Paul Souza, Ryan Reposar, Knut Synstad and Cody Wackerman, all of Dubberly Design Office, were deeply involved in all project elements led by Hugh Dubberly. In addition, Paul participated in a few of the family interviews.

Shalin Mehta and Kavi Mehta, interns at Bhageera Inc., were deeply involved in research preparation and data analysis. Shalin wrote Python code to process sensor data for analysis, and created Tableau templates for viewing the data. Kavi beta-tested the activities that participants were asked to do, and helped develop and test the workflow for handling logs.
Research methodology

Overview

We used a mixed method approach, emphasizing ethnographic interviewing in combination with off-the-shelf sensing devices that did not require specialist knowledge to use. Several tools and techniques were used to collect data from participating families. Here, we provide a brief description of these tools and the flow of their use in the overall approach. For readers interested in the methodological considerations and the usability of individual tools in a research setting, the Research Methodology Appendix provides more details about each method or tool, including how data was analyzed and processed.

Data collection methods and tools included:

- Surveys — Two brief online surveys.
- Interviews — Two interviews with each participant.
- Caregiving Activity Log — Participants kept a hand-written log of their caregiving and other activities for the duration (24-30 hours) of their participation.
- Empatica E4 — Participants wore the E4, a wristwatch-like device that collected data about their movement, heart rate, and skin conductivity.
- Narrative Clip — Participants wore a small camera, clipped to their shirt, which automatically took photos at roughly 30-second intervals.
- Netatmo Weather Station — This device, which captured data about sound, temperature, humidity, and CO2 levels, was placed in participants’ homes.
- SmartThings Motion Sensors — These devices, which collect data on movement, were placed throughout participants’ homes.

Flow of Methods and Tools Usage

Participant Screening

People who expressed interest in participating in the Atlas of Caregiving research were asked to fill out an online survey, providing basic information about their caregiving situation.

Participants also had brief phone calls or email exchanges with the research team to have their questions and concerns addressed about the research, and to schedule their participation.

Pre-Visit Survey

Those selected to participate were asked to fill out a second online survey, which asked about the people involved in caregiving — family, friends, professionals—and services used. Researchers used this information to prepare for the interviews.

First Interview

Participation began with a 90-minute first interview in the participant’s home. This interview focused on family history, caregiving history, and the current caregiving situation. Near the end of the interview, participants were shown how to use the log, and E4 and Clip sensors. The Netatmo and SmartThings sensors were placed around the home.
Data Collection
For 24-30 hours following the first interview, participants made entries in their logs, and wore the E4 and Clip sensors. They were free to remove the sensors when they needed to (for example, to take a bath) or if they did not want data collected (for privacy). The Netatmo and SmartThings devices collected data without participant intervention. At the end of this period, the researchers visited briefly to collect the materials.

Preparation for Second Interview
In the hours immediately following the Data Collection period, much of the collected data was analyzed quickly to prepare for the second interview. Logs were read, and items flagged for discussion. E4 data was plotted and printed, and certain periods were flagged for discussion with participants. Clip images were downloaded to a laptop computer and reviewed. Plots of the Netatmo data were also printed and flagged. SmartThings data, however, was analyzed at a later stage.

Second Interview
The 60-minute second interview usually took place on the day after the logs and sensors were collected (two days after the first interview). In a few instances, due to busy calendars, the second interview was delayed by a few days. This interview sought to engage the participant to self-reflect on the study experience. In addition, researchers reviewed and discussed captured data with participants. Care networks were the final topic discussed, an effort to build on information provided in the Pre-Visit Survey.

Data Analysis & Processing
In the months following a family’s participation, the research team conducted in-depth analysis and processing of the collected data. The specifics of this process are described in Appendix: Research Methodology.
Research participants

Recruiting Process

Goals for Recruitment
The project’s goal was to recruit at least 12 currently active, adult family caregivers. Emphasis was placed on recruiting a body of participants from diverse caregiving situations. Only caregivers located within two hours of San Francisco were eligible for the study, and “long-distance” caregivers were excluded from consideration.

Below, we provide a further breakdown of why we chose these goals.

“At least 12” — Given that a study such as this one had not been done before, we did not know how easy or difficult the research would be. As such, we aimed for a modest number of participants. In addition, 12 participants were felt to be adequate for the fundamental project goal: to understand whether this new, multi-modal research methodology was a useful way to study caregiving. For the future, gaining deep insights into a wide range of family caregiving situations will likely require many more participants.

“Currently active” — To record caregiving activities using logs and sensors, it was necessary that the participants were active during the time of their participation. This methodology would not work for those who had been caregiving in the past, but were not currently. We defined “active” as spending at least two or more hours per day in self-defined caregiving activities. From experience, we know that caregivers often underestimate how much they do, and were thus comfortable with participants’ self-categorization as active.

“Adults” — Although there are many youth caregivers, they were excluded from this initial research to avoid age-related ethics complexities related to their participation and also complications of their lives (such as wearing sensors in school).

“Family caregivers” — The intention of this project was to study family caregivers, that is, people who are not acting as health care professionals but supporting a family member. Studying professional caregivers in a similar way is important for the future. In addition, the intention of this project is to study family caregivers, that is, people caring for someone else, rather than those who are care-recipients or those only doing self-care. Of course, many participants were indeed caring for themselves while also caring for a family member.

“Diverse” — Within our limited sample size (about twelve participants), we sought as much diversity as possible. By diversity we mean a variety of ages of caregivers and care recipients, health conditions, economic status, cultural backgrounds, and geographical context (urban–rural). Ideally, we wanted some participants who had limited-to-no assistance, and others who had many co-caregivers.

“Within two hours of San Francisco” — This limitation was imposed by practical, logistical issues. Given the research methodology, which involved two interviews, and the provision, installation and collection of several sensors, several in-person visits were required per participant. Since much of the research team lives in the San Francisco area, we limited participants to those within a roughly two-hour drive of San Francisco. This still permitted a range of physical locations, from urban settings to fairly isolated, semi-rural communities.

“Excluding long-distance caregivers” — Given the limited sample size, we wanted to maximize the possibility of capturing as wide a range of caregiving activities as possible. By definition, long-distance caregivers do not provide hands-on assistance. Studying such caregivers in a similar way is important for the future.

Outreach
To recruit research participants, we relied on direct outreach to potential participants from project team members and others, as well as mass communication (newsletter and email blasts) from Family Caregiver Alliance (FCA) and other organizations. Our expectation was that direct outreach would be more effective than mass communication.
While FCA exists to serve all kinds of family caregivers, those who contact and are known to the organization are primarily caregivers for the elderly. To help achieve our goal of participant diversity, we contacted other organizations and individuals who might potentially reach other types of caregivers. In all cases, the organizations and individuals we contacted were enthusiastic about the project, and eager to help.

The organizations contacted were: California Sibling Leadership Network (Julie Payne-Neward), Carb DM (Tamar Sofer-Geri), Caring for Military Families / Elizabeth Dole Foundation (Carol Harlow), Parents Helping Parents (Mary Ellen Peterson), and RespirTech (Jenna Christensen and Pam Mertz).

Several individuals who are active in certain disease communities also reached out to their networks: Jamia Crockett (MS), Judy Feezer (autism), Kevin Krejci (Parkinson’s), Roy Nierenberg (Huntington’s), Avni Shah (diabetes), and Roni Zeiger (cancer).

Project team members and several FCA staff members also contacted family caregivers personally known to them.

Results
To everyone’s surprise, recruitment was far more difficult than expected.

In the beginning, most of those asked to help with outreach expressed disappointment that only one or two members of their community could be included in the study (to meet diversity goals) as they felt that they would be able to find plenty of people for the study. In practice, however, only 17 individuals responded and expressed interest in participating in the study.

There is no obvious answer to why there was such a large gap between expectations and results. Perhaps the communication materials could have been better. Perhaps July-August is a particularly bad time for recruitment. Perhaps people’s hesitancy to participate in research is very high, even when contacted by a trusted person. Perhaps those who lead advocacy organizations or are community activists are far more enthusiastic than their community members.

Of the 17 people who responded, 11 learned about the project via the FCA Connections newsletter. They were either newsletter subscribers themselves, or had been forwarded the information by a subscriber. Three people were known to—and directly contacted by—members of the project team. Three others learned about the study through the efforts of other organizations or individuals.

After having their questions answered, all 17 individuals chose to participate. Three later dropped out: one because the care recipient changed his mind about participating, one because his care burden increased such that he felt he couldn’t take the time to participate, and one because of scheduling difficulties. The 14 that did participate were sometimes joined by their spouses, resulting in a total of 19 caregivers in 14 families.

Summary of Participants
Fourteen families participated in the project:

- Caregivers ranged in age from 30 to 73. Thirteen female; six male.
- Care recipients ranged in age from 3 to 101. Six female; ten male.
- Care recipients had a wide range of medical conditions, including Alzheimer’s and other dementias, autism, cancer, cerebral palsy, cystic fibrosis, epilepsy, MS, Parkinson’s, Type 1 diabetes, and many others.
- Home locations varied from cities in the greater San Francisco Bay Area, to suburbs and semi-rural communities.
- Some caregivers had very little support, essentially providing 24×7 care by themselves, while others were assisted by several family and professional caregivers.
- In two families, paid domestic care workers played a significant role.
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<th>Name</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ana</td>
<td>Ana, a woman in her 50s, has cystic fibrosis and is the primary caregiver for her own needs. She also cares for her son Albert, who suffers from depression.</td>
</tr>
<tr>
<td>Chantal</td>
<td>Chantal (50s) has left work to care for her mother Debby (80s), who is in very poor health. A paid home aide provides significant assistance. Chantal's brothers also help.</td>
</tr>
<tr>
<td>Fay</td>
<td>Only-child Fay (30s) cares for her mother Josephine (70s), who has Alzheimer's. With no one to help her, she has put her career on hold to provide 24×7 care.</td>
</tr>
<tr>
<td>Fernando</td>
<td>Fernando (50s) lives with his wife Laura (50s). They are the primary caregivers for his mother Maria (80s). Maria lives next door and was diagnosed with Alzheimer's last year. They have built up a support network to help.</td>
</tr>
<tr>
<td>Gabrielle</td>
<td>Gabrielle (60s) is the primary caregiver for her mother, Karen (101), who has Alzheimer's and other conditions. Gabrielle also has health issues of her own.</td>
</tr>
<tr>
<td>Hanna</td>
<td>Hanna and husband Gaston (both in their 50s) care for her brother Harvey (50s), who has many major health issues. Gaston also cares for his mother, while managing his own chronic pain and edema. Both Hanna and Gaston work.</td>
</tr>
<tr>
<td>Ida</td>
<td>Ida cares for her husband Ian (both in their 70s), who has Lewy body dementia and dysautonomia, during a calm period in an otherwise difficult year.</td>
</tr>
<tr>
<td>Nadine</td>
<td>Nadine (50s) lives with her husband Larry and two teenage sons Jerry and Karl. Karl has Type 1 diabetes and Nadine is his primary caregiver.</td>
</tr>
<tr>
<td>Nate</td>
<td>Nate and Patty (both in their 30s) care for each other. Nate has glioblastoma, and Patty has multiple sclerosis.</td>
</tr>
<tr>
<td>Odette</td>
<td>Odette and her husband Marco (both in their 70s) share their home with many other people: their son and son-in-law, and several tenants. Marco has Parkinson's disease and other conditions. Odette is his primary caregiver, though several others are involved.</td>
</tr>
<tr>
<td>Omar</td>
<td>Omar and his separated wife Cindy (both in their 40s) share a home with their pre-teen son Bob who has Aspergers.</td>
</tr>
<tr>
<td>Sally</td>
<td>Sally (50s) cares for her son Pablo (20s), who has behavioral and emotional difficulties stemming from XYY chromosome disorder and related conditions.</td>
</tr>
<tr>
<td>Tammy</td>
<td>Tammy (40s) and Rafael (50s) care for their pre-teen children Wanda and Sam. Wanda has severe epilepsy and cerebral palsy. She is effectively quadriplegic. Sam has severe autism.</td>
</tr>
<tr>
<td>Teddy</td>
<td>Teddy (40s) and his wife are the primary caregivers for their two young sons, Van and Walter. Van has Aspergers, and Walter has cyclical vomiting syndrome.</td>
</tr>
</tbody>
</table>

Table 1: Brief descriptions of the families (all names are pseudonyms).
Economic circumstances ranged from those “just getting by” to those who were economically comfortable or prosperous. (Participants were not asked to disclose their finances. This judgment is based on what participants said during interviews and on the researchers’ observations of the condition of the home.)

Details about each family’s situation, the data collected, and analysis can be found in the Appendix: Case Studies.

**Ethics, Consent and Privacy**

While conducting this research, the Atlas team was guided by the American Sociological Association’s Code of Ethics, as well as by the team’s own long-standing expertise in ethical research practice.

Key considerations were:

- Participants should receive a clear and concise explanation about the project, including what participation would entail, how data would be used, and about privacy.

- Participants would be advised that they could, at any point, partially or fully drop out of the research if they became uncomfortable with any aspect of the project, and that they could tell the Atlas team not to use collected data after the fact.

- The anonymity of collected data. No personally identifiable information (name, address, clearly identifiable photos) would be released without the participant’s explicit authorization. In addition, because participants still might be identifiable to those in their immediate social circles, where appropriate, sensitive details would also be excluded.

- Participants would be offered copies of all data collected about them.

- Participants would be compensated for their participation.

Recruitment materials (a one-page description of the Atlas of Caregiving and a two-page outline of details about caregiver participation) addressed basic questions: What is the project?; Who can participate in the research?; What will I be asked to do?; What data will be collected?; and, How will data be used? Those who responded were interviewed to determine that they were eligible (that is, were actively involved in caregiving) and to ensure that they understood what participation would require from them.

At the start of the first interview participants were asked to sign a consent form. This two-page form, written in plain language, repeated the previously provided information about participation, privacy, and other key considerations. It also provided spaces for signatures of both the participant and researcher.

Participants were informed that a potential harm from participation was the possibility of feeling anxious or worried after seeing how much time, and physical and mental energy are being spent on caregiving. No one reported such problems, but in the event that participants did experience serious emotional issues they would have been referred to a local resource. Participants were also told that potential benefits would come from better understanding their own situation, which could possibly lead to finding more appropriate help or other ways to improve their caregiving situation. They were also informed that another potential benefit might come from the knowledge that this effort may help other families.

Participants were reminded that participation was voluntary and that they could stop at any time — either temporarily, by turning off or removing devices, or permanently. The participants were also told that when the devices were picked up, they could tell the researcher if there was any time period for which the data should not be reviewed: for example, to protect a family member’s privacy during intimate care.

Participants were informed that their data will be used to create diagrams to illustrate their care situations, and that these diagrams, along with a text description, will be published on the project’s
website and in reports. The consent form says explicitly: “Such published data will not include your name or other identifying information.”

In terms of privacy protection, the consent form states that personally identifiable information will be known only within the research team. Any use of personally identifiable information will require explicit permission. The researchers advised that they will take “reasonable and currently available efforts to keep your data secure on our computers. However, there is no way to guarantee that your data will be perfectly safe.”

Participants received $200 for their participation. In cases where two or three family members participated —meaning they participated in interviews, maintained a log, and wore sensors — each received $200.

While writing and publishing the case studies, several steps were taken to maintain privacy:

- All names were replaced by random pseudonyms. Though the pseudonyms match the person’s gender, no effort was made to use “ethnically appropriate” pseudonyms.

- Addresses are left out completely, with only a simple indication of neighborhood. So, “urban area” might stand for a city such as Oakland, “suburb” for a town like Dublin, and “semi-rural” for locations further out in California’s farming areas.

- No photos were used in which participants’ faces or homes were clearly identifiable.

- Honoring all requests to exclude certain information.

In addition, the team recognized that despite these efforts to maintain privacy, people close to each family might nevertheless be able to recognize them from the case study due to the uniqueness of their story. Therefore, the team made judgment calls to exclude possibly sensitive information.

Through the course of conducting the research, we came to realize that participants’ main privacy concerns had less to do with what strangers might learn about them through their participation in the project, and more to do with what people who knew them personally would learn. Indeed, one reason we chose to interview members of a single household as a group (caregiver(s) and care recipient(s) together), and not individually, is that this ensured that participants would only share information with us that they were comfortable with their partner knowing. Both partners are likely to read their own case studies, and we did not wish for there to be any surprises with respect to what the other person had said.
Case Studies

Each case study provides a description of the family, along with diagrams of their care network and of the data collected via logs and sensors. Each study highlights what researchers learned from the interviews and data. In addition, participants’ own perspectives and learning about the experience of participating is included.

Some case studies are far more detailed than others. This partly reflects the amount of data collected from that household, and partly conscious decisions by the research team to select certain situations to highlight project findings.

It should be noted that the case studies reflect the researchers’ view on what the data and observations told us. One cannot assume that these fully match participants’ own views. In addition, information captured in two interviews about a given family’s history and context, and other people involved in caregiving (as reflected in the care map), is likely incomplete and not fully accurate. Finally, some details are omitted or changed to be sensitive to participant privacy. Despite these caveats, we believe these case studies provide a good overall picture of each family’s experience and caregiving situation during the time of the study.

Detailed case studies of the 14 participating families can be found in the Appendix. There are 14 case studies for the 14 participating families listed in Table 1. The case studies can also be found on the Atlas of Caregiving website (http://www.atlasofcaregiving.com/studies). The web presentation makes it easy to zoom in on the diagrams, allowing a closer look at data and details.

Here, we highlight portions of Fay’s case study to provide an example of the format and information contained in each case study.

Example: Fay’s Household

Josephine, now in her 70s, raised her only child Fay (30s) as a single parent in Southern California. A little over two years ago, Josephine was hit by a car. Eventually she moved to the Bay Area to live with Fay. Her memory and decision-making skills have deteriorated so severely that Fay now makes all decisions, and provides her with constant caregiving support. In addition, Josephine is not as mobile as she once was. She has developed arthritis and suffers gastrointestinal issues. Fay and Josephine have always had a close relationship, but these recent events have significantly impacted their mother-daughter relationship. Fay was pursuing her PhD in public health, but has had to put her studies on hold due to the demands of caring for Josephine. As she faces potentially increasing expenses for Josephine’s care, having no income compounds Fay’s worry.
Care Network
Fay is Josephine’s sole regular caregiver. There are no other siblings or close relatives to rely on. In order to not have to leave Josephine alone at home for extended periods, Fay tries to limit herself to nearby trips that do not take her away for more than an hour or two.

Josephine has a close family friend who lives two hours away and visits at least once a month. Fay trusts this friend and also receives emotional support from her. Fay has tried to hire a caregiver for her mother, but Josephine objects to the idea. Her memory problems keep her from remembering when or why she needs help.

Zoom-able diagrams can be found at [http://atlasofcaregiving.com/studies](http://atlasofcaregiving.com/studies)
Activities
According to Fay, care was “easier than normal” during the study. Even so, data shows the difficulty she has balancing academic studies (she strives to stay connected with her academic colleagues) with her mother’s needs.

Josephine’s symptoms were milder than usual. Still, Fay spent six hours caregiving. She intermittently read and conducted research between caregiving tasks, creating disruptive switching patterns. Fragmentation of work time is a new normal.

On the day of study, Fay listed several meetings among the activities she logged. Logging made Fay feel guilty about the time she was spending on her studies or speaking with colleagues. But, it also provided her with a written account showing how much she devotes to the caregiving of her mother.

24-hour Log, 36-hour Log, and Activities diagrams.

Zoom-able diagrams can be found at http://atlasofcaregiving.com/studies

Atlas of Caregiving Pilot / Study Report
Photo Log
Fay wore the Narrative Clip for much of the study period, though she removed it during a meeting with her friend. She also removed it at home for private activities and sometimes forgot to put it back on right away. The Clip data provided researchers visual reference points for Fay’s 73 logged activity entries.

Reviewing the images sparked additional memories about the day, and also made Fay aware of how even everyday activities, like grocery shopping, include caregiving.
Body Sensors
Fay wore the Empatica E4 the entire study period, except when taking a shower. Her self-reported moments of stress correlated with the Empatica data. Some of the stressful moments did not involve caregiving. Others, such as when Fay and Josephine were talking about living accommodations, were directly related.
Environment Sensors
One Netatmo device was placed in the living room and another in the bathroom. The noise level in the living room correlates with activities recorded in Fay’s log, including the TV being on and construction noise (which was especially distressing at 4:00 pm on the first day).
Motion Sensors
There were seven SmartThings motion detectors placed throughout the house. Fay spent a lot of time in her bedroom, presumably at her desk studying. Josephine spent a lot of time in the living room.
Data Summary
This diagram shows all the time-based data collected for Fay’s household.

Zoom-able diagrams can be found at http://atlasofcaregiving.com/studies
Findings

Broad Findings about Family Caregiving

We deliberately designed this pilot to be an assessment of the viability of a multi-modal research approach, so that a wide range of stakeholders could consider the advantages and disadvantages of taking this sort of research further. Our findings, therefore, are really more of an indication of the kinds of things one might find using this method. They are deliberately not a full analysis.

What counts as a “full analysis” depends on what discipline a researcher is in, and we want to make it clear that there are many directions that researchers can take. Our research direction is shaped by the mission we have framed above. A psychology researcher would likely take analysis in a different direction, and anthropologists or engineers would also find entirely new directions for such research. Organizations that advocate for caregivers also have their own research needs. In addition, deeper analysis of what we have presented here, in dialogue with current scholarship on the topic, could also prove fruitful.

When discussing broad findings, the Atlas study’s small sample size should be kept in mind. Only 14 families are studied, and each of them for only 24-30 hours. While qualitative research traditions do have ways of making somewhat broader claims on the basis of a small sample, it nevertheless would be inappropriate to make universal claims about caregivers based on this pilot given that there are millions of families in which caregiving takes place in the US. If anything, our extremely limited study reflects the likely diversity of caregiving experiences.

Despite these caveats, even our limited study yielded early indications of the kinds of things that could be demonstrated through more research. Several of our team members have extensive prior knowledge about family caregiving, having made contributions to related research streams, worked with family caregivers, or both. Combining these experiences with the project’s findings, we feel confident making the statements below.

Caregivers are not fully aware of the extent of their caregiving activities

Caregivers often underestimate how much time they spend on caregiving, partly due to a lack of awareness and partly due to limits to the amount of time and effort they have to spend on accurately tracking activities.

Many participants were surprised to see how much they entered in their logs. For example, Ana thought she would spend about two hours caring for herself, and discovered she had spent six. This knowledge can simultaneously be affirming (illustrating that their exhaustion was well-earned) and discouraging (providing a clear sense of how hard things really were). For others, expectations of how much time they spend on caregiving activities matched well with what was recorded in their logs. Even still, for some, seeing it in the form of the log was somewhat of a surprise. The log demonstrated the sheer volume of what caregivers do. It makes it impossible for activities that are otherwise “no big deal” to fade into the background of daily life. These activities matter—they fill the cognitive load required to get through the day, even if they fade from memory after the fact.

However, in all cases interviews revealed that not as much was captured as “caregiving” in logs as could arguably be included. For example, during Sally’s 27 hours of participation, her log shows only 8.3 hours of caregiving activities. But, having to constantly be “on call” makes it impossible for her to do much else, meaning that her caregiving obligations extend beyond the hours that she recorded. In Tammy and Rafael’s case, their children’s intense medical needs meant they went from crisis to crisis. They were acutely aware of supposedly “simple” housecleaning tasks that went undone because they were in no position to do them, and could not afford to hire help. They spoke of having reached a state of desperation concerning this problem, even though their day was filled with arguably much more dire problems like dealing with the surprise of enormous ambulance bills. The case demonstrates that matters that do not show up as “activities” per se...
can add to burden. For this reason, an activity log should not be used on its own as a way to straightforwardly measure caregiver burden.

Sometimes, awareness catalyzed by the log led to reflection about the types of activities that were going on, instead of their sheer volume. Odette was surprised to note how often she had helped Marco to use the bathroom. She wondered whether the frequency of his trips was a symptom of boredom, and if he might take fewer bathroom breaks if he had more engaging activities. In this case, the log’s contribution was to create awareness about a possible problem. Odette’s hypothesis could then be tested, potentially generating new knowledge that could lead to improvements in Marco’s care situation.

The takeaway is that caregivers are so busy, day in and day out, that they may not be fully aware of all that they are doing. This may result in a lack of appreciation of the full range of their own needs and of challenges.

More people are almost always involved, sometimes a lot of people

Caregiving environments are rarely limited to a simple dyad of caregiver and care-recipient. In all the participating families, additional people were included in care maps.

Even Nate and Patty, who largely relied on each other for care, had additional people who played an important role. Fay is pretty much on her own from a day-to-day perspective, but she still gets emotional strength from knowing that there are other people who care, and may be able to help in emergencies.

In other cases, many people are represented in care maps. This not only includes many caregivers, but also multiple care recipients. While having others to help with caregiving is generally a good thing, it also adds to the primary caregiver’s burden: more people to coordinate and communicate with; more perspectives to juggle; more egos, emotions and disagreements to manage.

Similarly, our work provides some evidence to challenge the assumption that medical need is limited to the “patient” role. Caregivers themselves can also have quite serious medical needs, as is the case in Nate and Hanna’s households. Patients, it turns out, can also be caregivers.

Finding respite is difficult: Juggling multiple tasks and requiring contextual knowledge

Caregiving involves juggling multiple tasks and issues simultaneously: some planned, others spontaneous. In addition, it often requires special attunement to situations that would not draw attention from uninitiated observers. For example, while interviewing Nadine, we barely noticed background noise of cereal being poured. To Nadine, who cares for a son with Type 1 diabetes, the sound potentially signaled trouble. She quickly checked her son’s blood glucose level to verify that it was okay for him to eat it. Caregiving and the rest of life cannot easily be separated. One result is that days and nights are often fragmented, adding to stress and exhaustion, and hurting work productivity and sleep.

Detailed contextual knowledge is often required to carry out many caregiving tasks, whether mundane or complex, such that the caregiver’s and care recipient’s quality-of-life as well as the health-related benefits are balanced as well as possible. All of this makes it really difficult for someone else to step in and help. In some families we saw that getting two hours of respite from care may require four hours of preparation. It is no wonder that many caregivers find themselves unable to hand-off responsibilities (even assuming they could find willing takers).

In some cases, the level of complexity of care is unbelievable. Tammy and her husband have two young children with complex conditions. For each child, they have a thick binder of instructions and manuals, and a collection of training videos that can be used by anyone who comes to help care for their children. But, how could anyone quickly get up-to-speed on so much information, and do so in a way that gives the parents confidence that their children will be safe?

An important implication is that truly assisting caregivers is a non-trivial challenge. We saw that additional caregivers, including respite care, can be a big help, but only if done right. The effort required to acquire the assistance and the effort that must be put into preparing for the assistance must not be
more than the respite gained. There is a great benefit to long-term relationships in caregiving, whether with paid or family caregivers.

**Caregiving involves constant, sometimes dramatic, change**

Even within the study’s small sample size, we were exposed to dramatic changes. For many participants, their caregiving was relatively light during the period of their participation. But, the weeks or months before, or even the days after, were sometimes much more burdensome. Some of our participants had to deal with emergencies during the time of their participation. Chantal noted in her log that it was her “worst day ever”: in caregiving, things are constantly in flux.

This reality implies that the “best” assistance and solutions for caregivers will also vary from time to time. Sudden situational changes need to be met by equally rapid changes in the kinds of assistance provided or solutions used.

**Defining the caregiving experience by disease / condition / age is myopic**

One often hears statements about “caregivers of people with [disease or condition X]” or “caregiving for the elderly”. Our research suggests that the diversity in the caregiving experience is so great that siloing in this way is not very helpful. The caregiving experience can be just as strongly influenced by many other factors: whether you are on your own or have a lot of help; whether you are living in a city or in distant suburbs; etc. For any given family, at any given time, the appropriate group of “people like me” is defined by many factors.

In our study, we deliberately sampled for a diversity of conditions and ages. We do not have 14 families with, say, dementia, which would have enabled us to capture a broader diversity of dementia experiences. However, we argue that the tendency to group caregiving by disease is questionable for a few reasons. First, we found similarities across households dealing with different kinds of diseases that lead us to believe that the burdens are not likely to be a function of the nature of disease alone. Though very different in terms of age, health issues, finances and social circumstances, both Ida (who cares for Ian), and Patty (who cares for Nate), are struggling with similar challenges stemming from their husbands’ miraculous escape from death — the increased uncertainty of their day-to-day and long-term futures, and sudden decreases in caregiving assistance. Similarly, both Sally and Teddy, otherwise different in many ways, are constantly on edge and on alert due to their sons’ emotional and behavioral issues.

Second, within each household, participants noted that there were such dramatic changes over the course of months or years in what constitutes burden, and how much burden there is, that we cannot see a way in which a disease-based clustering would adequately capture something meaningful about stress.

Third, we found many different approaches to caregiving—from a largely administrative approach in the case of Fernando, to the hands-on approach of Gabrielle. Both these cases were dealing with similar illnesses, but their approaches were clearly much more inflected by a mix of class, personal inclination, and household dynamics than the nature of medical need. Finally, it was evident that while caregivers often had tremendous medical knowledge and sometimes performed what appeared to us to be full nursing tasks, much of caregiving was entirely non-medical. For example, for some caregivers, a large problem was dealing with administrative burdens brought on by paperwork from use of healthcare systems.

Understanding these factors and tailoring assistance appropriately is critical for properly supporting families. Solutions targeting family caregivers of “people with condition X” are unlikely to be universally useful for that population. On a positive note, solutions for “situation Y” may be of benefit across a wide range of diseases and conditions.

**Caregivers often too overwhelmed to avail themselves of potential assistance**

Interviewing caregivers provided a sense of what it is like to truly be maximally taxed. This was made evident not just in the stress levels recorded, but also in the constraints caregivers experienced in participating in our project. At best, participants maintained a kind of constant in-flow state, meeting a maximum amount of possible to-dos. At worst,
participants were in crisis and had no time for personal grooming, let alone broad reflection. In neither of these contexts is there much room for anything that is not an immediate concern. Most of the people we spoke with who had made use of assistance only did so when they had come to a point where they were at their wit’s end, and could no longer carry on without it. This was largely true even of more financially secure participants. The only person who made use of paid help from the beginning was Odette, who had seen the difference it makes, both through her experience with her own parents decline and her experience with a medical system in another country that provides much more help to caregivers than US-based counterparts. There were others in our study who knew they needed paid help but have difficulty accessing it for economic reasons.

We suspect that there are two factors at work that are leading to this situation of not seeking assistance before getting totally overwhelmed. The first is the sheer workload that caregivers are carrying, which makes even contemplating doing the work to access assistance daunting. The second is that each person’s situation was so changeable that it is not always clear what appropriate assistance would be.

Many participants did use online caregiver forums as a source of support, which is unsurprising given that online interactions can be worked in easily around other kinds of activities (and also unsurprising given that our call for participation had circulated online). Our participants also did not seem inclined to seek political solutions to the problem of access to support. This could have been the result of the caregiver burden interfering in the ability to conduct civic activities, or an indication of how American culture encourages people to see their own struggles only as individual problems (For a deeper analysis, see Caring For Our Own: Why There is No Political Demand for New American Social Welfare Rights, by Sandra Levitsky, Oxford University Press, 2014.)

Caregiver stress involves more than just stress events

The physiological monitors we used were capable of detecting fight-or-flight responses associated with emotional stress. However, in all case studies the important takeaway about stress did not necessarily have to do with precise moments of crisis, but rather the cumulative exhaustion that comes with caregiving. We saw examples of how exhaustion accumulates. For some, it is the on edge feeling of not knowing when the next crisis will hit. For others, it builds around the sheer amount of invisible labor or constantly having to “keep an ear out,” both of which prevents true relaxation and recuperation from ever taking place. For others still, the inability to sleep continuously because of caregiving duties that arise in the night is a major contributor to exhaustion.

We saw that moments of emotional response that sensors detect are in fact small portions of much larger, more complex patterns built up over time. They are not a straightforward indication that a particular activity (listed in a log or reported in an interview) was necessarily the source of stress per se. For example, Chantal reported that she had the “worst night ever” not just because her mother needed help with brushing her teeth for the first time, but rather because of what that meant for the future. Similarly, Nadine reported a high stress moment while at a meeting, and the various methods we used helped her identify just how many other factors had gone into making it a stressful moment. These factors had to do, in part, with social expectations placed on her. That source cannot directly be electronically sensed. Although we do not have expertise in the psychology of stress, our initial discussions with experts in the area suggest that psychology has come to recognize that stress response in real life is far more complex than the simpler stimuli and responses isolated in controlled lab experiments. Future work in this area could build on the methods we have used here to potentially better understand how the social and biological components of stress relate.

Where we do have expertise as researchers is in the social science of time use. Anthropology and sociology teaches us that how people frame their use of time, and whether those framings match cultural expectations, matters for how people experience time. In this study, we saw many different ways that people framed their use of time. For some, maintaining a distinction between “time for me” and other kinds of time made all the difference in getting through the situation. Those who were very
clear about the necessity of “me time” often sought the kind of help that would facilitate it. Others were unable to maintain that distinction, or did not particularly value it. Some participants held beliefs about productivity that are more commonly seen in the workplace, and brought them into the caregiving situation. As a result, they valued some activities as “productive” and categorized others as less so. This sometimes led to distress when one’s own caregiving or self-care needs prevented them from doing other things. Still other participants had come to see their situation as normal. They seemed not to feel particularly busy, even with a workload we researchers found extraordinary. These participants had surprisingly low levels of self-reported stress.

Our suggestion that cultural beliefs play a role is in no way a suggestion that stress is somehow “all in their minds”; or that participants’ burdens could somehow be lightened with a shift in perception or simple awareness. Hardly. Even those participants who self-reported low levels of stress while doing extraordinary amounts of work on very little sleep did not have strong ability to cope with the unexpected. We are suggesting, however, that cultural attitudes sometimes contribute to profound distress about leaving paid labor, undervaluing or misrecognizing the full extent of caregiving work, or the occasional sense of guilt or shame about sorely-needed leisure. It can also contribute to situations where people do not necessarily think to seek help before they reach moments of complete exasperation. All of this plays a very real role in stress.

While we invite other researchers and caregivers to come up with their own view of how to define the “caregiver burden,” our current evidence suggests that the notion must not only take into account the kinds of events that can trigger a sensor reading. It must also capture the fuller bundle of events that precipitated the reading, the social factors that create those events, and the cultural beliefs and framings that the people involved use to understand what is happening.

Value of Methods and Tools Confirmed

A fundamental question posed by the Atlas of Caregiving Pilot project was whether or not this new approach to studying family caregiving—using more or less “off the shelf” tools and methods, without specialist computer science or programming knowledge for analysis—would produce new insights. Would we learn something different than had already been produced through traditional means such as surveys, focus groups, and interviews, and would such new learning be valuable?

The simple answer is, yes! The knowledge we gained would not have been possible using traditional research means. While individual tools (e.g., interviews, the Empatica E4) were more or less valuable in themselves, it was the overall multimethod combination of tools that was critical. The whole was definitely more than the sum of the parts. Equally important is the finding that the participants themselves benefited from a new look into their own lives, as discussed further in the next section.

Process Needs Improvement

The learning produced by this new approach, however, was more labor-intensive than we expected. Gathering, processing, analyzing and visualizing the data required far more hours than the researchers had estimated. Commercially available data processing tools, and even in-house tools developed by academic and corporate researchers specifically for working with sensor-generated data, though helpful for creating the diagrams found in this report, proved to be more limited than hoped. Future research would benefit from custom application development to make the process less laborious and more fruitful. For this approach to be used more broadly, to study more families or for longer time spans, research teams should include such software developers as core members.

Below we discuss what we learned about the different tools we used. More details about the tools themselves can be found in the Appendix: Research Methodology section.
Interviews: Critical

The interviews, speaking directly with the participants, were invaluable. Participants’ perspectives were critical to assessing the log and sensor data. They are the experts in their own lives, and were key partners in helping the researchers make sense of the collected data.

Ethnography is a technique that has been around for over a century, and it was designed for research in social contexts where time pressures are far less intense. Interviewing has always been a part of that tradition, but in this context, our awareness of participants’ time pressures, coupled with the need to take interview time to introduce them to the gadgets they would be using, made interviewing challenging.

The first interview was scheduled for 90 minutes, and the second for 60 minutes. Knowing how busy our participants were, we made sure to stop on time. To make the most of this precious time, planning ahead for the interviews and being fully present during the interviews was even more crucial than in other interview situations. In retrospect, the second interview did not provide enough time for as close an examination of the data as we would have liked. It was a particularly tricky interview to do. On the one hand, the interviewer needs to provide some context to the sensor data so the interviewees know how to interpret it. On the other, interviewees also have to have ample breathing room to reflect on that data in their own way, unencumbered by what the interviewers believe it says.

Logs: Valuable to both researchers and participants

The self-reported logs were also very valuable. This was despite practical challenges that led to logs being incomplete and not perfectly accurate. Maintaining a log was hard work for the participants. Remembering to write things down and taking the time to write could be logistically and emotionally challenging. As a consequence, logs were often incomplete and inaccurate. The quality of the logs varied significantly across the participants, and even across each participant’s log (the start of 24-30 hour period tended to be of higher quality than the end).

Participants were asked to write in their logs as things happened, in order to keep logs current and protect against forgetting an activity occurred. However, given the busy nature of their days, and occasionally due to health factors, participants often could not do that. Instead they often came back to the log from time to time, and recorded activities, times and perceptions of stress as well as they could remember. Participants also found it much easier to make log entries of clear actions (e.g., making dinner) or events (e.g., grocery shopping) than to note times of mental effort (e.g., worrying, being on alert, monitoring). We suspect these activities take place during other activities, and as such are more difficult to assign a clear start time and duration.

The amount of logging varied significantly, from less than 20 entries to nearly 80 entries. In some cases this is due to people doing fewer discrete activities than others. In others, it is a reflection of how much detail people choose to log. For example, one more detailed participant had separate entries about the various stages of a meal, noting three entries: one for offering to make breakfast, a second for cooking, and a third for when they called someone to the table and sat to eat. We had encouraged participants to provide as much detail as they cared to, and we invariably found that when people provided such detail, it helped us better understand the nuances of their life.

Even with these limitations, the logs were perhaps the only way we were able to understand the activities that participants were doing. The 24-hour Log and 36-hour Log diagrams in the case studies make it very clear how busy participants were, the fragmentation of their days, and how much time goes into caregiving. The wide range of types of caregiving activities and levels of self-reported stress also show how diverse the caregiving experience can be. In addition, the logs successfully captured how participants thought about and defined those activities. If we had given them a closed multiple choice list to choose from, we would not have learned about the specifics of why certain types of activities matter for their particular situation, nor would we have been able to leverage the Narrative Clip data nearly as effectively given that the activity descriptions would have been stripped of contextual clues.
Sensor data proved useful for improving the logs, correcting times and adding missed items. However the reverse is not true—a log could not be inferred or reconstructed from sensor data alone (unless done by the participant themselves, using the data to recall events).

In the four families in which two participants kept logs, having a second point of view added significantly to our understanding of that family’s caregiving situation. The participants also benefited from the opportunity to learn about the other’s perspective.

The portion of the log asking the participant to record their perceptions of stress was also a key element in this project. High-stress events were discussed during the second interview, and these discussions often led to deeper insights into what was actually stressful. Often the stress was due less to a particular activity or event, than to emotional or mental stress from thoughts that were occurring at the time. For example, many participants reported stress about how unstable the present was and how uncertain the future, or feelings of frustration and lack of control. Comparing the self-reported stress to sensor measurements (particularly the calculation of Phasic EDA from the Empatica E4 device) exposed the potential of such sensors, as well as their current limitations (see Empatica E4 section, below).

The log included places to note “Level of Participation” and “Level of Cooperation.” These entries were not as immediately useful. No patterns were apparent from a visual analysis of them, but it is possible that deeper statistical analysis of these ratings, when compared to self-reported stress levels, could reveal interesting patterns.

Participants often felt they learned something from logging. They developed a deeper awareness of what they do, how much they do, how much time things take, how frequently certain things happen, and how fragmented their days were. They were often surprised by what they saw they had recorded. Sometimes this led to greater self-respect from an ability to better appreciate that their exhaustion was in fact the result of lots of hard work. At other times, it led to ideas for possible changes.

Sometimes the ‘hyperawareness’ that came from logging was more challenging, causing the person to worry more about how precarious their situation was, or to feel more guilty about even the brief time spent on small personal pleasures (like spending time having a coffee with a friend).

Keeping a log in order to track caregiving and other activities is very useful for understanding family caregiving, both for researchers and for caregivers themselves. It is also crucial for comprehending the significance of electronically generated data. Logging over time, rather than just for one day as in this study, could also prove to be valuable by showing how things change. With that said, logging is hard work, especially in the middle of busy and stressful caregiving days, and so it cannot be done indefinitely. A good balance may be to keep a detailed log for one day each month.

The log we used could be improved. This is true regarding both the content (what is recorded, how the questions are phrased) and the medium. For example, we learned, by how our participants filled in the “for whom [is the activity done]” section that many activities are not done for a particular person but for “the house.” Regarding the medium, we used hard-copy paper logs in this study, but a smartphone app, recorded audio-notes or other means could provide other useful channels through which to record activities. It is possible that these technologies could make logging easier and more accurate.

Empatica E4: Biometric data useful, and likely to become even more so

The E4 data was difficult to interpret, but still surprisingly useful. Unlike similar consumer-oriented products, Empatica does not provide any software that automatically processes the data into readily understandable figures and charts. For example, the accelerometer data is not translated into “steps” or “distance traveled,” and the multiple sensors (acceleration, heart rate, and skin conductivity) are not translated into different “stages of sleep” or a “sleep score.” Designed for researchers, Empatica expects those who use its devices to do such analysis themselves. Translating the raw data into familiar terms (e.g., distance, steps) is an emerging art, and in any case was beyond the original scope and budget of this project.
Even with the difficulty we had processing the biometric data, a simple visual analysis of plots of data mapped against what we learned from other sources (e.g., log, interview, Narrative Clip) was valuable. One could clearly see times when participants were more active, emotionally aroused, or sleeping well or poorly. The accelerometer data showed when people were active or not, and clearly captured when participants were sitting and working at desks or sleeping (including their tossing and turning). One participant (Ana) had a log entry saying “jog/walk,” and this pattern was very obvious in the data. Another (Ida) mentioned a restless night and difficulty falling asleep, which too showed up in data readings. A husband and wife’s (Hanna and Gaston) contrasting sleep patterns— Hanna sleeps well while Gaston sleeps poorly — were also evident in the data. Altogether, E4 data confirmed and provided more detail about the participants’ activities.

Similarly, the phasic EDA data provided insights into participants’ emotional arousal. Significant phasic EDA activity correlated well with self-reported periods and moments of stress. Looking across the participants, those who described themselves as more calm generally had lower phasic EDA measures than others. On occasion, seeing spikes in the phasic EDA signal prompted the researchers to ask participants about those moments, and these conversations led to insights beyond what had been captured initially in the logs.

Many academic and private sector teams have been using the E4 for judging emotional states. However, that research has generally been in much more controlled circumstances, in both place (e.g., in a lab) and context (e.g., only while doing one specific activity). The Atlas team consulted with several experts. We learned that gathering data in real life, in a wide variety of uncontrolled circumstances, and then interpreting that data to judge emotional states or stress is beyond the level of current scientific knowledge. Thus, our hope of getting a clearer picture of participants’ emotional stress from the sensor data, was not realized. However, what this project has done — collecting E4 data along with self-reported logs and other sensor data — may prove useful in advancing the field.

Narrative Clip: Images helpful to both researcher and participant, but need context

The images from the Narrative Clip were highly valuable in helping the participants to recall specific moments. During the second interviews, when asked about events noted in the log, participants’ recollections were often significantly richer when they looked at an image taken at that time. The families with multiple clip-wearing participants often found it interesting to see images from other cameras because it allowed them to see their world from another perspective. The images were also somewhat helpful in making corrections to the log (start or stop times of various events), or adding details (though only visually obvious details such as being in or out of a car).

However, the Narrative images would have been nearly useless to the researchers without the interviews and log. Most of the images were meaningless to anyone other than the wearer. Many of the images were blurry, indistinct, or just non-informative (such as images of walls or ceilings). Even clear images could hold little meaning, as they were often of mundane scenes. Indeed, we saw very little action in terms of images that conveyed specific caregiving activities, like giving medicines or doing laundry. Some of this might be overcome.

The field of wearable sensors is advancing rapidly. The variety of biometrics that can be sensed is expanding, the quality of the sensed data is increasing, and analytical tools to draw insights from this data are also improving. It is important to note, however, that researchers without a computer science background are unlikely to be able to create sleep state algorithms or write code that can translate data into more common indicators like “steps taken.” While raw, granular data is extremely important in many cases, the choice to work with it comes at the expense of being able to access more conceptually intuitive processed versions of the data. As more researchers outside of computer science seek to use wearables as part of their studies, publicly accessible algorithms for common data processing tasks will become more important. Even with these current limitations, the rapid improvements we are seeing in this field give us confidence that such biometric sensors will become more useful for studying family caregiving with time.
if pictures were taken at smaller time intervals (e.g., every few seconds), or if images were taken from a device incorporated into glasses, which would better indicate where a person's attention is directed. Speculatively, we wonder if a point of view camera stationed on a caregiver's hands might have been more telling.

Processing and viewing the images, especially against contemporaneous data from other sources like the log or E4 was laborious. Automation would be useful for pulling out visually distinct, unambiguous images, and for visually aligning the images to the log or other data. However, a fully automated process is unlikely, as some activities were interpretable either only because the researcher had an understanding of the physical space and people involved, or because the images were discussed in the interview. One area in which new tools could significantly speed up analysis would be developing a software application that extracts photos, reads their time codes, and aligns keyframes with log entry text and other sensor information. Unfortunately, developing such an application was never in the scope of this project. Automated photo analysis might also be aided by the fast emerging field of machine learning.

Initially, when the team tested the Clip prior to deploying it with actual participants, we became concerned about its value for research. There was so much that was not captured. Images taken at an office meeting or dinner table might only show two or three people even though many more were there. Images taken while driving mainly showed the steering wheel. Those taken while working showed only part of a computer screen. Slowly, we realized that these constraints were not important for our purposes. Looking at the images made us remember who else was at dinner, that we were driving to the store, or that we working on a certain project.

Indeed, the images jogged participants' memories. It helped them to recall events they hadn't thought to tell us about, and to discuss in more depth the events they did recall by adding more details or descriptions of the emotional valence of the activity logged. For example, photographs helped Fay explain how she felt while grocery shopping with her mother, and Nadine describe waiting with her son for a carpool ride to show up. Even with slightly blurry images, participants could easily say where they were when the image was taken. Knowing that he was wearing the Clip, one participant decided not to record anything in his log in real time. He later created a retrospective log based on the recorded images. The Clip was most valuable to the project for its ability to jog people's memories.

The researchers were also able to use Clip images to make corrections and additions to participants' caregiving logs. There were often time discrepancies that we could correct. For instance, that an event happened at 10:17 am rather than at 10:45 am, or that driving lasted 22 minutes rather than 15 minutes. This might not matter in studies that are concerned only with the sequence of events, or how much overall time was spent on what activity, but in our case we wanted to create a data set from which researchers could make correlations with sensor data.

In addition, careful examination allowed us to make note of micro-events, such as a brief trip to the kitchen, or a moment spent emailing or texting on a smartphone. In a few instances, especially with participants whose logs were less thorough, major un-logged events were seen in the images, enabling us to probe on these events during the second interview.

In five families there were multiple participants each wearing the Clip. This led to an unexpected finding — many of the participants found it interesting to see their own world from another's perspective. They could see how they looked to their family members (serious as they organized medications, or possibly impatient as they waited). They could also see how their home looked from the other person's perspective (because they spent more time in different locations or rooms). In Tammy's household, one Clip was placed on a dresser in their daughter Wanda's room. The parents got new insights into Wanda's wakefulness and the bustle of caregiving activity around her bed.

There were some challenges working with the Clip. The device's battery life was supposed to be more than adequate for the 24-30 hours of families'
participation. In our experience, however, the Clip often stopped recording some hours before the participation period was over. Also, an image every 30 seconds results in nearly 2000 images for a day (discounting time sleeping). So, manually looking through thousands of images for each participant to identify interesting moments for discussion and to correct the log was time consuming and tedious. Finally, in Omar’s family, the presence of the Clips worn by Omar and Cindy may have had a negative influence on their son Bob’s behavior, as he acted out for the camera’s attention.

**Netatmo Weather Station: Limited value, but identified possibilities**

The data from the Netatmo Weather Station proved to be of little value in this particular study. On a few occasions this data was able to corroborate events captured by other means, or was used to raise questions to ask during the interviews.

In some cases, the sound level measure proved useful in corroborating or raising questions about participants’ log entries. When Fay reported there was a loud bang due to construction, there was indeed a spike in the sound level. Gabrielle reported going to sleep at 12:30 am, but the noise level remained high until 1:30 am — she explained that she had fallen asleep while watching TV, and had later woken up and turned it off. A close examination of the humidity level in the outdoor sensor (usually placed in the bathroom) showed brief spikes, indicating hand washing, or longer spikes, indicating baths. The baths corresponded to participants’ log entries, though events of hand washing were rarely recorded in the logs. The CO2 plot was most interesting in the case of Fay. Rapid CO2 drops clearly indicated that windows had been opened.

Overall, little of significance was learned from this data for our particular purposes. However, there is potential value in a richer analysis of sound: recording sound and comparing sound characteristics (e.g., volume) to the family’s emotional and physical wellbeing. It may also be possible to identify certain events (such as a fall) from sound analysis, providing greater clarity to the caregiving experience.

**SmartThings Motion Sensors: More sophisticated system required**

Data gathered using the low-cost, low-hassle SmartThings system proved not to be useful in this study. It was difficult to map motion detector data onto the stories that caregivers were telling. The data was also fairly coarse and unreliable. To capture data that would be useful for better understanding of family caregiving will require the use of more sophisticated systems.

From a visual inspection of the Motion diagrams, one can get an overall sense of which rooms are more used than others, and how usage changes over time. However, the validity of this motion detection is difficult to gauge. For example, the Motion diagram for Nate’s household shows a lot of movement in the bathroom throughout the night. However, we know from the Empatica E4 data that Nate and Patty were in bed. So, what was the detector sensing? And therefore, how reliable is the rest of the data?

**The Value of Self-tracking to Caregivers**

One of the most important findings of the study was that caregivers directly benefited from participation. Most found value from the effort of self-observation and what they learned from it. The finding was a pleasant surprise as this was not one of the goals of the study; in fact, we had been concerned about the burden we were imposing on caregivers.

**Participation Burden**

Participation imposed several demands on caregivers. The two interviews took up 2.5 hours. Maintaining a log also took time, and created many small interruptions throughout the day. Wearing the Narrative Clip made some feel self-conscious and required a degree of alertness (to take it off for inappropriate situations, and then to remember to put it back on). Most participants found the Empatica E4 easy to wear, but for two it was physically uncomfortable.

Participation also made emotional demands. For example, Fay described herself as being “hyper-aware” of all she was doing and critical of herself for time spent on non-caring activities. Ida spoke
of a restless sleep driven by the fact that her mind was filled, more than usual, with the challenges and uncertainties of her situation.

The burden was mitigated somewhat by the fact that this was only a 24-hour study. Participants thought of it as a one-off exercise, which may have enhanced their view that it was a valuable exercise.

**Value, and Satisfaction, in Self-Learning**

As described in the earlier section on findings about family caregiving, caregivers are so busy doing what needs to be done, day in and day out, that they are not fully aware of all that they do. Many participants found it interesting to learn just how much they did, and to discover things they were unaware of. Sometimes this knowledge was self-affirming, providing confirmation of how hard they were working.

There was also a lot of interest in better understanding who does what within a household. When two people keep logs and wear Narrative Clip cameras, this becomes apparent. Sometimes this resulted in positive appreciation of all that the other person was doing. Seeing the same world through another’s eyes also engendered empathy. Other times, the clarity was less pleasant, especially, for example, if it made it more obvious that one person was carrying more of the caregiving burden, or doing more difficult or unpleasant tasks. Sometimes the interest in the other person’s camera data came purely out of curiosity—what does it visually look like to see the same day from a different point of view? Couples were also curious about each other’s own conditions, particularly seeing data of how poorly one slept compared to the other, or how one person’s situation and actions impacted the other.

In some instances, participants took the opportunity to rethink some aspects of their situation. One participant, for example, hired paid help upon seeing how little sleep she was getting. In general, this person was of course already aware that she did not get good sleep, but seeing a concrete visual representation of this fact was enough to cause her to pause and reassess. Similarly, another participant saw that she does much more waiting outside the bathroom for her husband than she realized, and started to think about whether his trips to the bathroom were about boredom, not biological necessity.

Participants also became more aware of the potential for technology to ease their lives. We encountered instances where families were already using some kinds of technologies to monitor their situations. For example, Hanna’s home has multiple streaming video cameras so that Hanna and Gaston can notice and respond quickly to Harvey’s epilepsy episodes. Seeing the Empatica E4 data and Narrative Clip images catalyzed conversation about such technologies providing rapid alerts or real-time analysis for sleep, seizures, and emotional outbursts.

Participants were relatively less interested in what the data showed about their own stress levels and when high-stress moments occurred. No one expressed surprise at how stressed the sensor showed them to be. Nor did they show the same level of interest in stress levels recorded in the log. It seemed to hold little value to the participants other than seeing one’s day framed in a new way. It is possible that participants’ lack of interest in stress levels was influenced by our own admission that we were trying to learn whether our ways of measuring stress were accurate. This may have led participants to be more skeptical of the stress data.

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Care Maps

The care map concept was initially developed by one of the Atlas team’s researchers, Rajiv Mehta, as part of an earlier study in 2012. For the current project, by diagramming the people involved in a particular care situation, the care map was intended to be a tool to help the research team to better understand each participant’s care network. The research team drew care maps for each participating family based on information collected in interviews. The participants themselves did not participate in the map drawing process, nor did they have a chance to see and respond to their care map.

There has been far more interest in care maps than the research team had originally envisioned for the project.

In June 2015, the Atlas project was publicized at the Quantified Self Conference in San Francisco. For a conference session on Self-tracking and Family Caregiving, we created a four-page handout explaining how a family caregiver could use two of the methods used in our research: the log and the care map. The audience’s openness to—and enthusiasm for—the ideas gave an early indication of interest in such self-awareness tools.

Later, during the actual Atlas study, as the team created care maps of participating families we realized that these diagrams were indeed quite powerful. As such, we decided to make it easy for anyone to do. We developed a method to draw care maps using just pencil and paper, rather than the sophisticated computer tools used to make the care maps presented in the project’s Case Studies. In December 2015 we published a blog post showing and explaining how to draw and learn from care maps: http://atlasofcaregiving.com/put-your-family-caregiving-on-the-map/.

Many people responded positively to the post, noting that they felt that the care map could be powerful for both self-understanding, and for identifying and advocating for better support. They also raised the idea that live, in-person workshops could be used to teach the concept.

Santa Barbara Care Map Workshops

The website blog post led directly to the first workshops to test the concept in groups. In late February 2016, the Santa Barbara Foundation organized a series of five care map workshops, three for family caregivers and two for social workers. These were held at a variety of locations across Santa Barbara County — Santa Barbara, Montecito, Lompoc and Santa Maria — covering much of the county’s diversity. A total of 80 people participated, with the smallest workshop having 12 participants and the largest 20. Participants learned about the Atlas of Caregiving project and the background of the care map concept and were led step-by-step through the process of drawing their own care map. They then shared their drawing, as well as their reflections on their drawing, in small groups. Finally, they participated in a full-group discussion about acting on what they had learned, and on whether or not the care map concept was worthwhile. The main workshop facilitator was Atlas of Caregiving principal investigator Rajiv Mehta, but several others led the small group discussions, including representatives from the Santa Barbara Foundation and the Coast Caregiver Resource Center.

The workshops were a great success. Despite the awkwardness of discussing personal issues with strangers, everyone participated. Even those who were initially shy or reticent joined in the conversations. Reflections were sometimes sad, as the loneliness and hardship of some situations was brought to light. Even then, some found some solace in discovering that they weren’t alone, that others faced similarly challenging circumstances. Others became more aware of the support they already enjoyed or had the potential to call upon, or gained ideas from hearing about other people’s circumstances. Most participants actively told us how glad they were that they came, and encouraged us to bring the concept to many more people.

Several family caregivers spoke about wanting to share their care map with other family members, especially as a way to start important discussions. Many of the social workers spoke about wanting to incorporate care maps into their own work, and
wondered how to make these a fundamental tool for their organizations. One social worker sent this via email: “Thank you so much for coordinating the care mapping session! I found it to be such an informative, helpful tool! We have started using it already with our resident case management teams and I will soon be rolling out the concept to my sales teams as well.”

There were also unexpected benefits. The Santa Barbara facilitators learned a lot about their own communities and the great diversity of the needs of local family caregivers. The workshops also raised the visibility of the organizations that helped organize or host the workshops, and of their efforts to help family caregivers.

Now, several organizations across the country are interested in holding similar workshops in their communities. There is also interest in investigating how other project methods, like logs and sensors, could be brought directly to family and professional caregivers.

We believe this is an example of the fundamental value of the Atlas of Caregiving project: that exploring novel methods to understand family caregiving will lead to both valuable new information and to new ideas for supporting family caregivers.
Implications of Project findings

In this section of the report, we highlight potential implications of the project findings for a variety of groups and institutions involved with family caregiving.

We again add the caveat that the project only studied fourteen families, each for roughly a day, while there are in fact tens of millions of American adults involved in caregiving. However, combining the findings with the teams’ extensive experience with family caregiving, we feel comfortable making the statements embedded within this section.

Below we comment on implications for these groups:

- Family caregivers
- Product developers and entrepreneurs
- Healthcare and social service organizations
- Employers
- Domestic care workers
- Researchers
- Foundations and philanthropists

Implications for Family Caregivers

The project’s findings about family caregiving had one major, direct implication for family caregivers.

It is possible for family caregivers to use the project’s tools and methods to better understand themselves, leading to several potential benefits.

One of the most significant findings of the project was that the participants themselves learned something. They were able to better understand their own activities and situation. The log, images from the Narrative Clip, data from the Empatica E4, the care map, questions asked during the interviews, and the person’s self-reflection during their participation all contributed to this.

In addition to the tools used for the study (e.g., the log, Clip), some of the participants also shared with us their own self-tracking efforts, including journals and spreadsheets, and how they benefit from them.

Sometimes deeper understanding led to greater self-appreciation, and perhaps more self-confidence. Sometimes it led to more questions, raising the possibility of hypotheses, experiments, and learning. Better understanding also raises the possibility of more control of the situation, and of better self-advocacy.

The implication of this is that those trying to support family caregivers should help caregivers conduct, learn from and act upon self-reflection. They might develop tools and/or educational materials to help with such efforts.

Implications for Product Developers and Entrepreneurs

The project’s findings about family caregiving have implications for those who develop or sell products and services for family caregivers.

Focus groups and surveys are inadequate for discovering needs

Caregivers lack full awareness of their own needs. This means that traditional, simple market-research techniques that are commonly used to identify user needs and define product features, such as surveys and focus groups, are likely to be inadequate. Big data approaches, without any attempt to understand the context in which data is generated, are equally likely to be inadequate. Products developed based on a superficial understanding of caregiver’s needs and circumstances are then unlikely to be adopted and used. Hence those developing products, whether these are apps and gadgets or human services, will need to look much more closely at user needs, and question traditional methods. To develop successful products, product developers will need to rely on their own observational skills.
Generating enthusiasm, even for great products, will require careful preparation
A further challenge is that caregivers who are unaware of their needs are unlikely to respond to marketing aimed at an un-realized problem. A brilliant solution, based on a deep understanding of caregivers’ actual needs, could still fail in the marketplace if caregivers are unable to hear the message. Developers of groundbreaking products will need to educate caregivers as well as those whose advice they rely on (e.g., social communities, caregiver support organizations, and healthcare systems).

The conundrum of focused vs. comprehensive products
The caregivers in our study all had many interrelated aspects of caregiving to attend to and very fragmented days. This complexity poses a conundrum for product developers.

Developing a focused solution, even to an important problem, may not be useful. For example, a product for assisting adherence to a specific medication, or even for all of a person’s prescription medications, may not be helpful if it causes the caregiver too much trouble to handle medications one way and all other tasks another way. A tailored but inflexible process to obtain a service may be impossible to use in practice. If a product makes overall caregiving more difficult, the benefits for improving a specific task may not be enough.

On the other hand, trying to solve the whole problem is a fool’s errand. One has to pick a small problem to start with, accept that the product is likely to fail initially, and plan on learning and evolving the product rapidly. In time, expanding its scope of reach may be possible.

One potential design approach is to emphasize ease-of-use, minimizing the cognitive burden that comes from using multiple products. An important aspect of such design is to not expect continuous usage. Instead, one should expect that the user may, at any time, stop using the tool, and then later come back to it—perhaps days, or months, later.

It is better to judge product value on usefulness not usage
Given that caregivers’ situations and needs change, sometimes quickly and dramatically, no solution is likely to be useful every single day, never mind forever. Those developing or recommending caregiver products need to keep this in mind. Judging a product based on the duration or regularity of use may be misleading. Rather, one should judge based on how well a product addresses a need when the need arises. Like a Band-Aid for a cut, or a cane when recovering from a twisted ankle, a temporary solution can still be a great solution, even if it is used rarely.

Opportunities for “non-medical” products
Another important product implication of the complexity of care management is that much of the activity is not directly medical. For product vendors, this may represent an opportunity in that their “non-caregiving” products may be of great interest to caregivers. For example, communication, coordination, transportation, and sleep are all general consumer challenges, but they are often especially challenging in caregiving contexts. Vendors of such products may benefit from directly targeting caregiving in some of their marketing materials. Caregiving is another “market segment” to pursue.

Human (not automated) coaching and support are likely to be critical
The case studies make clear how difficult caregiving can be, even on light days. Caregivers can feel overwhelmed, their mental bandwidth taxed. Therefore, they have neither the time nor the inclination to carefully research, evaluate, purchase, learn, and debug potentially useful caregiving products and services. Often even the fear that some new product will take time to learn and use (whether or not it is actually easy) can deter usage. To overcome this, product vendors may need to provide coaching and support as a fundamental part of the product. Caregivers need confidence that someone will be right there with them to make things easy, and assurance that a product will not make life even more complicated than it already is. Just the knowledge that help is readily available may be enough to allow the caregiver to try something new.
Implications for Health and Social Service Organizations

The project’s findings have significant implications for professionals and institutions providing medical care, and departments or organizations that work directly with family caregivers.

Assist caregivers in developing self-knowledge
Caregiver support organizations often view educating caregivers to be a key part of their mission. Much of such education is bringing expert knowledge to caregivers. This could be expanded to include educating caregivers on how to become better experts on their own lives.

Many of the participants found value in participating. They learned about aspects of their caregiving situation from questions that we asked about their care network, logging, and the data and images that sensors captured. Such self-knowledge could lead to better understanding of their own situation, ideas for self-experimentation, increased self-efficacy, and better advocacy.

Given this finding, caregiver support organizations should consider how they can help family caregivers conduct and benefit from such self-observation.

How can they empower family caregivers by helping them learn about their own lives? As one example, in early 2016 the Santa Barbara Foundation held a series of free care map workshops for family caregivers and social workers (see Care Maps section).

Understanding each family caregiver’s day-to-day reality is critical
Family caregiving involves a constantly changing and often complex choreography of activities, medical and non-medical. Families cannot avoid this juggling act. Any requests made of family caregivers for the care of patients must fit into this reality. Otherwise these requests (or demands) may be impossible to follow through on, leading to poor outcomes.

The case studies also show that family contexts can vary significantly, even when dealing with the same conditions (e.g., Alzheimer’s or Aspergers). Professional providers must tailor treatments to specific contexts of each patient, and each family.

Understanding care networks is critical
Understanding the care network of each patient can be very important.

Discussions about family caregivers in professional health settings often focus on the primary caregiver, blinding providers to other key people. The primary family caregiver may have to communicate, coordinate and even negotiate with many other people. Imposing burdens on that caregiver, without taking into account the implications for network dynamics, may make a difficult situation that much more difficult.

In addition, treating someone as the “primary” family caregiver may miss the reality that action, knowledge and authority may reside amongst multiple people in the care network, varying by topic and context. Multiple family members may benefit from education and training for at-home medical tasks. A professional provider may learn far more about one topic from one family member than another. And, a family’s primary decision maker is not always obvious. For example, in the Fernando household, Laura is the primary decision maker for her parents, who live far away. She researches and decides on treatments and providers for them. If a professional provider did not carefully ask questions, the provider might mistakenly identify or assume that Laura’s siblings, who live much nearer to their parents, are primary decision makers.

Professional providers must understand the social contexts within which their patients are cared for.

Triple Aim success depends on richer understanding of family caregiving
In the influential paper “The Triple Aim: Care, Health and Cost” (Health Affairs, May 2008, vol. 27 no. 3, 759-769), authors Donald Berwick et. al. argue that for chronic conditions healthcare must simultaneously focus on “improving the experience of care, improving the health of populations, and reducing per capita costs of health care.”

As the importance of family caregivers to improving outcomes and reducing costs is increasingly recognized, healthcare professionals and institutions must work to deeply understand family caregiving, and its impact on formal healthcare. In order to achieve the
Supporting caregivers is an investment in preventative health

With rising healthcare prices and increasing efforts to shift healthcare activities to the home, caregivers have taken on increasingly complex medical tasks. Yet this study made clear that in the context of a home, medical and non-medical tasks are intertwined. The ability for caregivers to provide medical support is in direct proportion to the size of the burden they must also take on with respect to day-to-day living.

The medical/non-medical distinction makes even less sense when we consider caregiver administrative burdens that are directly created by healthcare institutions themselves. Caregivers navigate complex bureaucratic systems, sometimes must fight spurious bills, and can need to assemble medical biographies because healthcare providers cannot be trusted to do it. Medical institutions benefit economically in the short term from shifting these burdens onto caregivers. In the long term, however, shifting unnecessary burdens onto people who are already overwhelmed is likely to backfire as a strategy. It increases long term costs through two channels. First, by reducing the amount of care that caregivers can provide, care recipients end up requiring more professional medical care. In addition, the added stress and physical toll on caregivers’ bodies can theoretically land them within the medical system as well.

Implications for Employers

Balancing work responsibilities and caregiving is a daily burden that already affects millions of Americans, limiting their productivity, health, and career trajectories. For employers, this impact — set to increase dramatically as the baby boomer generation reaches retirement age — makes supporting caregivers an increasingly critical strategic priority. The burden of caregiving undercuts the productivity of affected employees, who may be forced to miss time, perform caregiving tasks at work, and even retire early; all of which drain the talent and resources of American businesses.

Fortunately, leading companies have recognized that supporting caregivers is a business imperative, and are developing responses. In some cases, employers have acted as a central hub for resources and programs that measure employee caregivers’ activities. Some also promote flexible work arrangements, tele-commuting, and caregiving-focused communication campaigns. These policies are designed to support caregivers, while also generating a return on investment for employers.

The project’s findings about family caregiving imply that much more can and should be done by employers.

Even “light” caregiving days can significantly impact productivity

When employers think about the impact of their employees’ caregiving activities on productivity and performance, they are likely to think about crises, times when there is a dramatic worsening of the care recipient’s situation. In these cases, employees may be forced to spend significant time and energy on caregiving.

However, the case studies make it clear that even light caregiving can create fragmented, stressful days. Many things, large and small, must be managed. Some cannot easily be scheduled.

Hanna’s log contains several back and forth entries that show her intermittently working on an article in between the day’s caregiving and other tasks. At the end of the day, a log entry reads: “continue to work on article. Finished. Sent to be published. Irony alert: [the title is] ‘Successful time management—Practical tips for the caregiver’.” Time fragmentation makes it hard to concentrate, and hurts productivity.

Day-to-day schedule flexibility is required to mesh with caregiving realities

For the study participants, it was near impossible to compartmentalize the day into separate times for work and caregiving. Caregiving needs also varied constantly, sometimes dramatically. To cope with
this, employed caregivers need significant flexibility in their schedules. Even time-off schemes and flexible work schedules, if they require significant advance notice, are inadequate to meet the needs of caregivers.

In addition, jobs that impose schedules on workers could make caregiving very difficult. The trend of increasing flexibilization of labor, meaning employees must be increasingly flexible in when and how employers can demand they work, is very much at odds with the increasing prevalence of—and demands on—employee caregivers.

**Caregiving is a human issue, not an “elder-care” issue**

In the 14 families who participated in this project, the caregivers ranged in age from 30 to 73, and the care recipients ranged in age from 3 to 101. Employer programs and policies should be designed to support the human activity of caregiving, and not be based on a restricted demographic mindset, such as 45-64 year olds caring for people 80 and older. There are many employees who are like Sally, who cares for an adult son. Others are like Nate and Patty, a young couple who cares for each other. Still others reflect situations like Tammy, Omar, and Teddy’s, each of whom cares for young children.

**There are several things employers can do to support caregiving employees**

Helping employees be more aware of their own needs and of resources available to them, creating an environment where employee caregivers are able to be open about their situations, and helping to catalyze and support innovations in caregiving solutions are all things employers could do as part of a comprehensive support program for employee caregivers.

Employers can assist caregivers in developing self-knowledge, by providing appropriate tools and educational materials (e.g., literature or workshops). Many of the study participants found value in participating, from learning about themselves through the questions that we asked about their care network, through the log that they kept, and through the data and images the sensors captured. Such self-knowledge could lead to better understanding of their own situation, ideas for self-experimentation, increased self-efficacy, and better advocacy. As an example, employers could organize care map workshops like those held by the Santa Barbara Foundation (see Care Map section). The more knowledgeable and more organized employee caregivers are, the more likely they will be able to integrate work, care and life successfully.

Employers can work with, and support, local and national caregiver support organizations to ensure that their employees are able to take advantage of all the resources that are available to them.

Employers can also foster an environment where caregivers do not feel that they have to hide this aspect of their lives. This may require educating everyone (especially non-caregiving employees) on the prevalence, importance and challenges of caregiving. Employer leadership can lead the way by being open about their own caregiving situations. Employers can encourage and support affinity groups where employee caregivers can meet and share insights. Participants may find emotional support in knowing that they are not alone, and may learn from each other.

Especially with an open environment, employers could help catalyze the development and uptake of technologies that support caregivers by participating in caregiving research and technology pilots. Employers could both help to provide technology to employees and measure the return on investment, either of which could trigger the widespread adoption of technology solutions for caregivers.

**Implications for Domestic Care Workers**

A few domestic care workers do appear in the Case Studies, but their presence is accidental and in the background. And yet, the project’s findings about family caregiving may have potentially significant implications for domestic health workers.

**Domestic care workers may be able to enhance their status and compensation by gathering hard data of their activities**

Family caregivers participating in the study were not fully aware of the extent of their caregiving activities. We have noted how family caregivers might benefit from better self-knowledge that can improve...
their own caregiving activities and situation, and allow them to better advocate for themselves.

As far as we know, no similar study of the activities and consequences of domestic care workers has been done. But, it seems possible that domestic health workers are similarly under-aware of their own activities.

The work of domestic health workers is underappreciated, a consequence of which is low status and low pay. If detailed data were captured about what domestic care workers do, using similar methods as this project, we could have a much richer picture of their work: How much they do; How complex the work is; The consequences of great vs poor training, and of long term relationships vs constantly changing workers.

Solid data and clear graphics could be very useful tools to help domestic care workers to advocate for better pay, status and treatment.

**Domestic care workers may be able to improve their profession by studying their own activities**

Domestic care workers would like to be treated as professionals, and many do in fact take their profession very seriously. As with any other profession, they could advance their field by measuring what they do and the impact they have, allowing them to strive for continuous improvement through experimentation and observation. Leaders of the domestic care worker field could champion similar research.

**Implications for Researchers**

**Directions for Further Analysis**

We deliberately limited ourselves to a kind of “first pass” synthesis of research findings, in order to make clear that many different kinds of research questions and intellectual leanings could be accommodated within this approach. Here, we further discuss what some of these directions might be, alongside some of the challenges likely to face researchers of all different stripes.

As a set of examples of the kinds of research that could be pursued using this method alongside various analytical approaches, consider the following research questions:

- For engineers: Which parsing methods for heart rate or EDA best match ground truth as determined by logs and interviews? What kinds of human-computer interactions would best support reduction in caregiver stress?

- For psychologists: How does self-perceived stress match up with bodily states? Can we use the contextual data in interviews and logs to better understand the mechanisms behind caregiver stress?

- For medical sociologists and public health researchers: What policies or economic arrangements most contribute to the caregiver burden? How do medical and other institutions intersect with daily life? What interventions might be piloted?

- For anthropologists and other ethnographically-minded scholars: How might we think about stress as both embodied and at the same time social and cultural? How do invisible forms of care work, like affective labor, interact with more visible forms of work?

The range of possible research questions highlights a broader concern. Solutions in this field very much depend on how one frames the question. Psychologists and engineers, for example, are far more likely to point towards individually-oriented interventions (e.g., mindfulness practices, medications, designing devices and apps), whereas public health researchers might be more apt to point to institution-based mechanisms. Medical sociologists and anthropologists are more apt to point to structural and cultural causes that no single institution can fix, but that must be addressed in broader political terms. While the socio-cultural view tends to overlook the individual changes that might indeed help particular situations, in the long term, foregrounding individual solutions at the expense of deeper social change is unlikely to be effective. We researchers might be concerned with different
aspects of the problem, but when it comes to building the evidence base for solutions, we cannot let these differences hinder the full scope of change that is likely necessary.

One further complication is that our study is premised on the idea that technologies from the commercial sector have something to offer. The technology industry, however, tends to see only individual, consumer-based solutions, because that is how it largely understands markets and designs products. Researchers who are in a better position to take a broader view are important voices in the ongoing push-and-pull about how technologies are designed, and the possible social effects of devices built for, or used in, this area. For this reason, we encourage researchers to not only engage in policy debates about caregiving, but also to participate in debates over the role of consumer goods and the technical trajectory of those goods.

Indeed, another reason researchers might concern themselves with issues of technology design has to do with the technical conditions in which researchers work. Many qualitative researchers have adverse reactions to the notion of using electronic data because of its longstanding association with traditions that seek to abstract away individual context, and undervalue that which cannot be quantified. We hope to have shown that it is possible to use sensor data in a different way. However, so many of the visualization tools available today are indeed tied to research traditions that seek to abstract and generalize. As such, they support certain kinds of analyses and visualizations at the expense of others; correlation, machine learning inference, and graph analysis are all far better developed as part of the data wrangling toolset that researchers have available to them. However, digital humanities and visual anthropology are also scholarly traditions that could be mobilized to develop alternative ways to visualize datasets like this. What forms of visualization would respect, or point towards, that which cannot be directly translated into data form? This methodological question is a humanist’s question as much as the substantive research questions at hand.

Assessing Stress and Burden

Those who introduce new programs, systems, and tools to support family caregivers will need ways to evaluate whether these actually improve the overall situation, and if they introduce new problems. We hope this study helps researchers think about what appropriate measurement might involve. For example, a program designed to reduce the administrative burden placed upon caregivers might use intermittent logging, in combination with other kinds of automated data, to assess whether the administrative burden is indeed reduced. A different kind a program might want to create more precise definition of what being “overstretched” or “coping” looks like, in order to design programs that help people before they get to a state of being thoroughly overstretched. Programs or digital tools that emphasize coping strategies, on the other hand, might look more to the physiological indicators of stress, and either long-term changes in those indicators, or changes in responses to particular activities.

Here we would encourage researchers to distinguish between something that could be called “burden”—the amount of work a caregiver must deal with in terms of activities, emotional support provided, and other opportunities abandoned—and “stress”—a kind of human experience that manifests in the body and in the mind. While the two are related, they are not necessarily a direct function of one another. This study showed that very high burdens can be managed successfully with very little stress as long as no further crises hit. On the other hand, seemingly “unstressful” situations can be experienced as “on-edge moments” because people are anticipating the next crisis. This is still an important form of stress, but it is not necessarily a function of workload, nor is it a form of stress that can be assessed using sensors alone. Therefore, any experiment, pilot, or intervention should identify clearly which aspects of burden or stress it seeks to address, and how to measure those aspects. Projects should resist the temptation to produce an overall “stress score” that attempts to index all conceivable factors, as this is likely to dilute the elements of interest, and make assumptions

1. Here we thank the participants and organizers of the Digital Humanities Data Visualization Workshop at Georgia Tech (March 2016) for sensitizing us to this issue.
that might not be applicable given the context-dependent nature of caregiving. With further work, measurements could be developed and tested that might apply to many types of interventions, but the radical heterogeneity we saw gives us reason to urge caution.

Engineers and some public health researchers might also ask if machine learning could be applied to learn individuals’ stress triggers, and perhaps make predictive inferences that could ground the timing of interventions. Whether this is feasible is one issue that is worthy of exploration. We found that there are hints that this is a possibility. But, the depth of what we might think of as a “trigger” or “stress incident” might prove too much for machines. There are myriad contributors to stress, and multiple valences of stress that machines can only partially detect. On the other hand, sophisticated pattern recognition techniques might help in limited ways, without necessarily attempting to calculate an overall stress score or assessment.

Technologically we are some way off from making meaningful inferences, but now is the time to have a robust debate about the ethical issues of doing so. Privacy become an even more complex issue to tackle when synthesizing multiple data sources into an inference about stress. The power to predict is not a power to be taken lightly. Predictions have a way of becoming self-fulfilling prophecies, and framing someone’s day-to-day affairs as always on the verge of a stress crisis may prove harmful in and of itself. Using data and inferences about activity and stress can do significant damage by making yet another metric in which people are deemed failures. A device telling caregivers that their data suggest they should be “making time for exercise”, or some such advice, is only going to add to the burden, not relieve the stress. Then again, one theme that came out clearly in the study was that figuring out what kind of help is necessary is a very real problem for caregivers. If there are patterns to be mined, and those patterns can in fact help people work out what is necessary to improve the situation, then ways of using these patterns to support people, rather than hinder them, need to be found. The debate about wise use of pattern recognition and machine learning tools needs to happen well before the tools are built, not after.

Data Aggregation and Questions of Ethics
Projects like the Atlas of Caregiving create pools of data. Many kinds of people stand to benefit from access to such pools. For example, while our own work dove relatively deeply into individual cases, one could easily imagine research approaches that asked more questions across all of the cases. It is not just researchers who might have analytically-minded questions. Those who advocate for caregivers, including some caregivers themselves, might have perfectly legitimate reasons to want access to a pool of data of this kind. Indeed, they are likely to be in positions to ask more sensible questions about the data than professional researchers.

In the future, we believe that it could be in the public interest, and in the interest of caregivers, for other researchers to have more granular access to anonymized forms of the data we collected. However, this raises thorny ethical issues that are emerging for many public health researchers. These issues revolve around how to ensure the participants have meaningful control over where their data goes, and how to ensure that any use of the data does indeed benefit those who created it. Some participants might be fine with all sorts of researchers benefiting from it, while others might wish for only non-commercial research projects to benefit. Some might be comfortable with all of their data being used, while others might wish to exclude certain data types, like photographs or interview transcripts. The notion of “data donation” is clearly not enough, because it is not obvious that all research ultimately leads to public benefit. “Data donation” also assumes a kind of passive role for research participants, where they leave it to professional researchers to decide what the important questions are. This seems inappropriate for caregivers, as our participants were very active analysts of their own data and have a strong stake in the kinds of questions that are asked and conclusions that are drawn from the wider dataset.

Clearly, for projects of this type, equitable and participatory models of data access need to be established, alongside techniques for preserving privacy. Indeed, there are currently some examples to draw from. Community-Based Participatory Research (CBPR) is a longstanding research tradition.
that has wrestled with these issues from the perspective of grassroots organizing. Some projects, such as Open Paths (https://openpaths.cc/) are not grassroots research projects, but have worked out how to enable their participants to opt-in to various research projects on a case-by-case basis, thus resolving important permissions issues. Until the Atlas project has the appropriate systems in place, we will not offer open access to data beyond the graphs presented here. In the future, we will consider doing so if we are able to provide meaningful control for our participants.

**Implications for Foundations and Philanthropists**

**It’s worth taking a risk**

Robert Wood Johnson Foundation (RWJF) supported this initial Pilot knowing that the project was exploring new methods to study family caregiving. As such, they were aware that the project could not guarantee clear outcomes and metrics. But trying something new opened the possibility for significant new discoveries. It was a risk well worth taking. Not only did the effort produce hoped-for new insights and powerful new visualizations, it validated a new research methodology. It also led to unexpected discoveries — we could not have predicted that care maps would have been received so strongly nor that uptake would occur so quickly. We would like to encourage philanthropic organizations to take more such risks.

**Significant funding required to develop necessary data about family caregiving**

RWJF funded the Pilot in the hope that, if successful, it would catalyze foundations, government grant making organizations and philanthropists to devote significant resources to furthering the effort. The pilot was successful. A lot was learned, though only from 14 families. Now we need continued funding to further the effort to build a broad and deep knowledgebase about family caregiving — an Atlas of Caregiving — that is useful and available to everyone supporting family caregivers.
Next Steps / Conclusions

The Atlas of Caregiving Pilot has shown that it is possible to look in detail at family caregiving. This new approach results in rich data and insights that are useful to both family caregivers and to those who strive to support them. And yet, we have only gotten a tiny glimpse of what needs to be known.

The project studied 14 families, for 24-30 hours each. To truly address the family caregiving crisis, we will need to learn from thousands, even millions, of families, and see how things change over time. Fortunately, the path forward is clearer.

We can make the hidden iceberg of family caregiving visible, and begin to understand the complex and varied situations that exist there, by devoting resources to a major effort to:

- Improve and expand research efforts — better technology, more participants, over a longer time period.

- Develop and deploy tools that empower family caregivers through self-learning.

- Bring actionable insights to entrepreneurs, healthcare institutions, social service organizations, employers, policy makers, and all others seeking to support family caregivers.

Improve and Expand Research Efforts

First, we must continue efforts: to develop ground-breaking tools and methods for studying family caregiving; to continue to learn what is worth doing and measuring; and scale the efforts step-by-step to ever larger groups of families. Our recommendations include:

- Improve upon the methods used in the pilot — more automation of basic data analysis and visualization, application of better sensors and analytical technologies, visualization improvements, and continued development of caregiving metrics.

- Study people over a period of time, to understand the nature and impact of change.

- Involve more families, and a greater diversity of caregiving contexts.

While the pilot involved 14 families over two days, a reasonable next step might be to study 30-50 families over three months. Over time this might grow to thousands of families tracked over several years. This might involve intermittent “check ins” over a long period of time, or perhaps some continuous sensing if it can be done unobtrusively. At some point, given the ever-increasing collection and digitization of data, it may become possible to replace or supplement a direct research approach with one leveraging existing data from millions of family caregivers.

Develop and Deploy Tools that Empower Family Caregivers Through Self-Learning

Second, we must further develop and widely deploy simple, powerful tools for family caregiver self-awareness and professional assessment, and ideally do this in a way that captures data for broad analysis. This includes:

- Continue the effort that has already begun with care maps. More can be done to improve on the paper-and-pencil concept and methods of teaching people how to draw and learn from care maps. In addition, an electronic version of the tool should be developed that makes possible additional benefits.

- Refine logs (through which many participants learned about themselves and their situation) into a simple tool for caregiver self-awareness. In addition, some of the participants had complementary logs or activity-audit techniques that are likely useful to many.

- Develop How-to guides to help caregivers repurpose their existing wearable technologies, or other home sensing products, for self-learning.

- Add additional tools, as they are identified by continuing research efforts.
Such efforts could lead family caregivers to gain a deeper understanding of their own situation, increasing self-efficacy as well as enabling better advocacy. Care professionals would also benefit from this information, given that it would allow them to better tailor processes and interventions to each family.

Our experience with the care map workshops in Santa Barbara also highlights the potential to form and/or deepen community bonds if such self-learning tools are taught and discussed in community settings, and if local institutions are engaged in that process.

Such caregiver self-awareness tools could be developed in ways that allow and enable the collection of individual data in electronic form. This would make it possible to provide personalized analysis beyond the level most individuals could achieve. In addition, individual data could be aggregated into population-level databases to be analyzed for larger trends. Such efforts would need to be sensitive to privacy and confidentiality issues.

**Bring Actionable Insights to Family Caregiving Supporters**

Finally, as the length of this report suggests, a lot was learned in the Pilot, both about the participating families as well as broader findings with implications for all types of organizations working to support family caregivers. Change will happen over time as people absorb this information and translate it to create change within their own efforts.

In the future, it may be possible to accelerate change by more deeply involving healthcare professionals, entrepreneurs, social service organizations, and other communities in the next stage of research and/or in deployment of caregiver self-learning tools. The reception to preliminary presentations of the Atlas study and findings has been very positive, and this augurs well for such future collaborations.

**Next Steps**

To execute these next steps will require funding support. Robert Wood Johnson Foundation supported this initial Pilot in the hope that, if successful, it would catalyze other funding institutions to add their capacity. We are hopeful that this will prove to be the case. Family caregivers, and society as a whole, are depending on it to mitigate the onrushing caregiving crisis.
Surveys

Caregivers interested in participating were first asked to complete an online Atlas of Caregiving Questionnaire. If selected, they were asked to complete an online Pre-Visit Survey. For both surveys, we used a web service, SurveyGizmo.com.

Atlas of Caregiving Questionnaire

This questionnaire was used to screen interested participants. The intent was to choose participants who spent at least two hours per day on caregiving activities, and who as a group represented a diverse set of ages, medical conditions, geographic locations (urban/rural), and ethnic and cultural backgrounds.

This brief survey asked for:

- Name, email, phone, address
- “Who are the main caregivers and care recipients, and who is caring for whom?”
- “What are the ages and sex of these caregivers and care recipients?”
- “What are the major health conditions of these caregivers and care recipients?”
- “How would you describe the ethnic/cultural background of your family?”
- “How much time do you spend on caregiving activities each day, in general?”
- “Which of the caregivers and care recipients you described above will participate in the research?”
- Preferred dates for participation

As it turned out, there were only three caregivers who filled out the questionnaire who did not participate: one because the care recipient changed his mind about participating, one because his care burden increased such that he felt he couldn’t take the time to participate, and one because of scheduling difficulties.

Pre-Visit Survey

This questionnaire was meant to help the researchers prepare for interviews by learning more about the various people and services involved in participant households. Participants were told to provide top-of-mind answers rather than worry about accuracy or completeness.

The survey asked for:

- “Who lives in your home, including pets?”
- “Who are the people (or pets) that you care for? Include those who need help because of physical or mental illnesses or disabilities. If you care for more than four people, choose those requiring most of your time.”
- For each of the four care recipients noted in the previous question: “Who else cares for this person? Include family and friends, but do not include paid health care workers at this stage.”
- “Who helps care for you, or provides practical and emotional support?”
- “Do you belong to any online forums, or in-person networks (such as support groups or religious organizations) that provide support or advice?”
- “Do you have any home health aides, nurses or other paid assistants who come in to the home?”
- “Do you use any kind of paid assistance, such as cleaning service, food delivery service, dog walkers, child care providers, etc.?”
- “What medical professionals (nurses, doctors, nutritionists, etc.) have you interacted with in the past three months?”

Appendix: Research methodology
• “Is there anybody else involved in your caregiving situation who we should know about?”

Processing the Surveys
We did no special processing of the survey results. Each response was simply read.

Interviews
Participants were interviewed twice. The first interview always occurred at the start of their data-collection period. At the end of this interview, they began to log their activities and the sensors began collecting data. The second interview occurred after the data-collection period, usually on the following day. In some cases the second interview was delayed by a few days.

The interviews were with the family caregiver(s), not with the care recipient(s). With some exceptions, care recipients were largely not in a position to participate in an interview, though we made every effort to introduce ourselves and to get to know them as their capacities would permit. In three cases, the care recipient sat with us but said little. In one case, both care recipients participated (Nate and Patty), as they were caring for each other. In two other cases, another family member joined the conversation.

The interviews, except one, were conducted in the participant homes. Interviews involved relatively open conversation guided by a series of topics (described below). These were ethnographic interviews, meaning that we deliberately let conversation flow in a mostly open manner in order to be able to understand how caregivers themselves framed their situation. There were no “off topic” discussions, as all pieces of the conversation helped us understand participants’ assumptions and perspectives. The first interview was scheduled for 90 minutes, the second for 60 minutes. The interviews were recorded (audio-only) using an iPhone.

Rajiv Mehta participated in all interviews. Dawn Nafus participated in four of the first interviews, and three of the second interviews. In Dawn’s place, her Intel colleague Katie Anthony participated in one first interview and one second interview.

First Interview
The first interview focused on the family context and health, and on the nature of the caregiving. At the start of the interview, we reviewed the overall project and the consent form with the participant. We asked caregivers about the following:

• how they got to their current circumstances
• their non-caregiving life — work, community, hobbies, etc.
• their own health
• important family and friends

We then asked for information about the care recipient:

• overview of their life and history of their health
• current health status
• current life and activities

Finally, we asked about the nature of day-to-day caregiving in that household:

• what is “normal” for them
• what is especially stressful or difficult
• what is positive
• what is involved in self-care activities (if any)
• what their caregiving expectations were for the upcoming days

At the end of the interview, we showed the participants how to use the log, the Empatica E4 biometric sensor, and the Narrative Clip camera, and placed the Netatmo and SmartThings environmental sensors around the home.

Second Interview
The second interview focused on the participation period, both on the experience of participating, as
well as on what actually happened and how it was captured in the data. During this interview we also asked about the care ecosystem.

We began by asking about the experience of participating: the ease or difficulty of maintaining the log and wearing the sensors; if the participant learned anything from the experience; and if anything was surprising. We then turned to the details of caregiving during the period: what happened; how similar or different was it than “normal”; what was most difficult or stressful; and what were positive experiences.

We then discussed the data collected, beginning with the log. We asked about entries that struck the researchers as interesting or requiring explanation, or entries with high self-reported stress scores. We asked about gaps in the data, to learn what was happening at the time. We showed participants the images taken by the Narrative Clip, particularly images taken around the times of log entries that came up in the discussion. We showed participants the biometric data collected by the Empatica E4, and discussed the similarities and differences between a participant’s self-reported stress and E4 data. Prompted by the E4 data, we also discussed their sleep. Finally, we looked at the Netatmo environmental data. We did not present or discuss the SmartThings motion detector data as it couldn’t be processed in time for the second interview.

The last topic discussed was the care ecosystem. We reviewed and expanded upon the information previously provided by the participant in the Pre-Visit Survey, framed by four questions: Who lives in your household?; Who do you care for?; Who else cares for these care recipients?; and Who cares for you or supports you in your caregiving efforts?

At the end of the interview, participants were given their compensation for participating (in cash).

Processing the Interviews
In addition to the audio recording, researchers took written notes during the interviews. We also took a few photos of the participants and their homes. The audio recordings were transcribed using an online service, Sribie.com. In line with longstanding ethnographic technique, we immersed ourselves in these materials. We used them to write case studies, which then informed the broader report.

Creating Care Maps
The Care Map diagrams in the case studies were created primarily from information gathered during the second interview. Later the information was organized into a set of tables for each participant, and used to make an initial, hand-drawn sketch of the care map. (Instructions for hand-drawing and interpreting care maps can be found at http://atlasofcaregiving.com/put-your-family-caregiving-on-the-map/). These were then further refined to create Care Map diagrams in the case studies.

Caregiving Activity Log
Participants were asked to use a log to keep track of all their activities, especially caregiving and self-care activities, and conversations. They were given a clipboard with 10 pages of a printed log to fill out. There was enough space for 80 entries; only one participant came close to running out of space.

During the first interview, researchers reviewed the log with the participants. Participants were also given printed instructions to refer to if necessary.
The log included several columns for each entry:

- **When**: The time of the activity/conversation
- **Duration**: How long they spent on the activity/conversation
- **Description**: For an activity, what was done; For a conversation, the topic
- **For/With**: For an activity, whom this was for (such as “me,” “mom,” etc.); For a conversation, who else was involved
- **Level of Assistance (only for caregiving activities)**: There were five checkboxes to note how much assistance was provided: None; Remind; Supervise; Help; Do all
- **Level of Cooperation (only for caregiving activities)**: There were three checkboxes to note the level of cooperation of the care recipient: Obstructive; Passive; Cooperative
- **Stress**: Participants were told to note their level of stress at the time of the activity, using a 0–5 scale, where 0=no stress and 5=very stressful

Participants were encouraged to provide as much detail as they could and to break up activities into smaller tasks if possible. They were not asked to log at a pre-defined rate (e.g., every 15 minutes). They were encouraged to think broadly as to what might constitute a “caregiving” activity, and were provided with a page-long list of example caregiving activities (similar to Table 2). Participants were also encouraged to note any non-caregiving activity (e.g., sleep, work, watching TV) that felt noteworthy or lasted more than 15 minutes. An example filled-in care log was also provided.

While participants were asked to keep the log current and to make entries as events occurred, in practice entries were often made some time after the event. One participant generated his log after the study period had ended, re-creating the events by looking at the images captured by his Narrative Clip.

**Processing the Logs**

The logs were processed in several steps, ending in the 24-hour Log, 36-hour Log, and Activities diagrams.

1. **Transcription** — With one exception, participants made entries on their paper logs by hand. One person asked for the Word document, and made entries by computer. The hand written logs were transcribed by the researchers into a spreadsheet. Participants’ self-reported stress scores were rounded to the nearest integer (0–5).

2. **Coding** — The log entries were coded using the scheme in Table 2.

This coding scheme worked well for the most part, though based on this experience more categories are needed.

3. **Adjustments** — The times of entries were corrected and additional entries were added based
## Coding Scheme For Log Entries

<table>
<thead>
<tr>
<th>1.0 Medical Activities (such as)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.1 Medications and supplements (including injections, IVs, oxygen, etc.)</td>
</tr>
<tr>
<td>1.2 Exercise, physical therapy</td>
</tr>
<tr>
<td>1.3 Equipment preparation and maintenance</td>
</tr>
<tr>
<td>1.4 Wound management</td>
</tr>
<tr>
<td>1.5 Tracking symptoms and body measurements (weight, temp, etc.)</td>
</tr>
<tr>
<td>1.6 Preparing special meals</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>2.0 Healthcare Management (such as)</th>
</tr>
</thead>
<tbody>
<tr>
<td>2.1 Arranging appointments</td>
</tr>
<tr>
<td>2.2 Communicating with health professionals</td>
</tr>
<tr>
<td>2.3 Visits with health professionals</td>
</tr>
<tr>
<td>2.4 Buying prescriptions and supplies</td>
</tr>
<tr>
<td>2.5 Insurance and payments</td>
</tr>
<tr>
<td>2.6 Researching conditions and treatments</td>
</tr>
<tr>
<td>2.7 Researching healthcare costs</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>3.0 Care Communication &amp; Coordination (such as)</th>
</tr>
</thead>
<tbody>
<tr>
<td>3.1 Keeping family and friends informed</td>
</tr>
<tr>
<td>3.2 Managing family and paid caregivers</td>
</tr>
<tr>
<td>3.3 Managing community services (paratransit, meals on wheels, etc.)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>4.0 “ADLs” Help with Personal Activities (such as)</th>
</tr>
</thead>
<tbody>
<tr>
<td>4.1 Bathing and toileting (including assistance with incontinence)</td>
</tr>
<tr>
<td>4.2 Dressing and grooming</td>
</tr>
<tr>
<td>4.3 Feeding</td>
</tr>
<tr>
<td>4.4 Getting in/out of bed, chair, etc.</td>
</tr>
<tr>
<td>4.5 Moving around the home</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>5.0 “IADLs” Household Assistance (such as)</th>
</tr>
</thead>
<tbody>
<tr>
<td>5.1 Cleaning</td>
</tr>
<tr>
<td>5.2 Cooking</td>
</tr>
<tr>
<td>5.3 Laundry</td>
</tr>
<tr>
<td>5.4 Shopping</td>
</tr>
<tr>
<td>5.5 Getting/Moving/Using things</td>
</tr>
<tr>
<td>5.6 Managing bills and savings</td>
</tr>
<tr>
<td>5.7 Transportation to/from home</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>6.0 Social Support (such as)</th>
</tr>
</thead>
<tbody>
<tr>
<td>6.1 Companionship</td>
</tr>
<tr>
<td>6.2 Emotional support</td>
</tr>
<tr>
<td>6.3 Plan and support participation in social activities</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>7.0 Be Available (such as)</th>
</tr>
</thead>
<tbody>
<tr>
<td>7.1 Be constantly “on alert” for any needs</td>
</tr>
<tr>
<td>7.2 Be “on-call” for problems</td>
</tr>
</tbody>
</table>

Table 2: Coding scheme for log entries.
on a careful examination of images captured by the Narrative Clip. Some things were clear and therefore easy to correct or add, such as leaving or arriving at home or other places, or brief moments of texting or web surfing on a smart phone.

4. Further adjustments — In some cases, data captured by the Empatica E4 biometric sensor and the Netatmo environmental sensor were also useful for adjusting log entries. For example, long periods of sleeping, sitting, or driving were clear in the E4’s movement data. Dramatic changes in sound or CO2 levels were indicative of presence and activity. On occasion, information we learned in the interviews helped fill-in some gaps in the log.

Creating the Diagrams
The spreadsheet of the log was then processed using a customized D3 charting program to create three separate diagrams, which were further processed in Adobe Illustrator. The 24-hour Log diagram shows activities from 9:00 am on the first day to 9:00 am on the second day in a radial format. The 36-hour Log diagram shows all the activities in a linear format, along with labels for selected activities. The Activities Log diagram shows a bar chart of the amount of time spent on major activity categories (caregiving, leisure, work, sleep and other), along with a breakdown of caregiving activities based on the coding scheme.

Empatica E4
The E4, made by Italian company Empatica, is a device worn like a wristwatch. It has multiple sensors to measure the wearer’s heart rate, movement, skin conductivity, and skin temperature. In concept, it is similar to consumer devices like the Fitbit, but designed for scientific research.

We hoped that these measures would provide some insight into the wearer’s physical activity and emotional stress, and how these fluctuated over the time of their participation. As it turned out, we were unable to use the measures for an unambiguous assessment of activity and stress, as the other methods we used demonstrated that stress was more complicated than what sensors are able to detect. However, even just a visual analysis of the E4 data proved to be valuable.

Participants began wearing the E4 towards the end of the first interview. Most wore the E4 continuously for their entire participation period, only removing it briefly when bathing. One participant removed the E4 more frequently and for longer periods because he found it itchy. Another removed it when sleeping.

The E4 has enough battery and memory to collect and store data for well over 30 hours. This met project needs, as we were concerned about the burden we would place on participants if we had to ask them to handle uploading data and charging the device.

E4 Sensors
Photoplethysmography (PPG)
Photoplethysmography detects slight changes in skin color as the blood at the wrist, flowing under the skin directly under the device, ebbs and flows. The device uses these color changes to calculate Blood Volume Pulse (BVP). The E4 provides BVP values at a rate of 64 samples per second. Empatica’s algorithms then translate BVP into a measure of heart rate. There is a plot of this Heart Rate in the case studies. Note that this way of measuring heart rate (at the wrist, using PPG) is most accurate when the person is at rest; when the person is active accuracy declines. For this study, the heart rate plot and movement data were the most useful for seeing how well participants slept.
Movement
The E4 has a 3-axis accelerometer that provides values at a rate of 32 samples per second. Using an Empatica-recommended algorithm, these data are then converted into an overall measure of movement. This movement value is plotted as Acceleration in the case studies.

Electrodermal Activity (EDA)
Also sometimes known as Galvanic Skin Response (GSR), the EDA sensor detects slight changes to the electrical conductivity of the skin beneath the device. Roughly speaking, it is detecting how sweaty the skin is. The E4 provides EDA values at a rate of four samples per second. EDA changes under different physical and environmental conditions. Exercise, high temperature rooms, even being under a blanket: all can affect EDA values. This is referred to as “tonic” or “slow” EDA activity. EDA can also pulse — rise and fall rapidly — due to emotional arousal (e.g., being surprised by a noise or momentarily stressed). This is referred to as “phasic” or “fast” EDA activity. Emotional arousal can be negative (e.g., a moment of frustration) or positive (e.g., a moment of elation). The plots of EDA in the case studies show both the measured EDA value (gray) and the calculated phasic value (blue).

Temperature
The E4 has an infrared sensor for measuring the temperature of the skin directly beneath the device. The device provides values at a rate of four samples per second. This skin temperature data was not used in the study, and so is not plotted in the case studies.

Processing and Analyzing E4 Data
The E4 has two modes for outputting data. In one mode, the data is streamed to a smartphone. There, a smartphone app can show live graphs of heart rate, movement, and other readings. This mode was used in the project when first introducing the E4 to the participant, in order to help them to understand what the device was doing. After that demonstration, the E4 was placed into its second mode, in which data is stored in the device and later downloaded to a computer.

Later, the E4 was connected to a computer via a USB cable. Then a computer application, EmpaticaManager, was used to transfer the data from the E4, via the computer, to Empatica’s cloud server. There, Empatica processed the data. We then viewed the processed results on a web application, Empatica Connect, and also downloaded these results as a set of .csv files — EDA.csv, BVP.csv, etc.

These .csv files were then further processed using Python. This was for both additional calculations (an overall measure of movement from the three separate accelerometer measures), and to create a single file with all the metrics that could be imported into Tableau. The research team used both Empatica Connect and Tableau to examine the data visually.

In addition, as recommended by Empatica, the E4’s EDA data was processed by a software package Ledalab (a module for Matlab), using default settings, to separate it into the tonic and phasic components. These are two elements of stress that can be separated out algorithmically in EDA data. The separation enabled researchers to distinguish stress that is potentially driven by emotion from times when sweat is being produced by the body for other reasons.

Participants were told to not turn off the E4, even when they removed it from their wrist for activities such as bathing. Thus, the E4 continued to record measures during these periods. “Bad” data from these periods is included in the plots. Fortunately it was easy for the researchers to see these off-wrist periods in the data — the “skin temperature” value usually fell dramatically, and the “movement” value usually dropped to zero. Thus, it was easy to ignore these periods in our analysis.

The Case Studies include several plots of E4 data. Acceleration is calculated from the E4’s three accelerometers. Electrodermal Activity plots the EDA data. Processed Electrodermal Activity shows the phasic component of the EDA data. Heart Rate plots the heart rate data.
Some of the statements made in the Case Studies about the E4 data are the result of close analysis, “zooming in” to look at the data in detail (at the minute level, or even the second level) using Empatica Connect or Tableau software.

**Alternative Devices**
Several alternative devices were considered before the research team settled on the Empatica E4 for the purposes of this project (Fitbit, Spire, Basis, Neumitra, Ampstrip). Some were not selected simply because they were not available for purchase in time for the research. For the others, members of the extended research team wore different devices in order to assess their suitability for use in research. In the process, we discovered that there were several important technical considerations that other similar projects might want to take into account for their own studies. These considerations were:

- **Sensor quality:** How plausible are the readings given what we know about the context in which they were sensed? Spikes that could not be explained, or long periods without any reading would not enable successful research.

- **Data rate:** How many readings would the device make in the 24-hour period? Some forms of stress take place very briefly, and we wanted to build into the study the ability to capture these. We ultimately ended up focusing on the types of stress that happen over the course of a minute, or several minutes, but other researchers might be able to find something more subtle at the sub-minute level.

- **Data export:** Some of the devices designed for consumer use did not have data export available at all. Others either had data export available for some data streams but not others, or they reduced the amount of data available by averaging across a minute or day.

- **Battery/data storage:** We needed the device to be able to last the duration of the study period without intervention from the participants.

- **Wearability:** Some devices were more comfortable to wear than others. Other devices were sold as “gender neutral” but in reality were so large that they were only suitable for men’s wrists. As it was a brief study, we focused more on comfort and less on aesthetics. However, for a longer term project, asking caregivers to wear something every day that conflicts with their sense of gender identity would be a much more significant issue.

- **Parsers:** Some devices parse accelerometer data into an inference about steps taken and/or sleep states. The device we ultimately chose did not offer this. While acknowledging that there are legitimate concerns about how accurate steps and sleep state reading are, we also believe such reading would have significantly helped while discussing sensor reports during the interview process, as these are measures that ordinary people understand and are curious about. We were unable to find any publicly available algorithms to help us to translate data into steps or sleep states.

- **User Interface:** User interfaces that are legible and compelling could have significantly reduced the burden on researchers when it came to showing participants their own data.

**Narrative Clip**
The Clip is a small camera, usually worn clipped to a shirt, that automatically takes roughly two photos per minute, storing the images in its memory. Manufactured by the Swedish firm Narrative, it is intended for consumers to easily capture a record of their lives, a practice commonly known as “lifelogging.”

With a normal camera, the user chooses when to take a photograph, and what to take it of. The Clip just captures whatever is in front of it. The result is that most images are mundane, portraying things such as walls or ceilings. They can be blurry when the wearer is moving, too dark or light, or otherwise uninteresting from a traditional “snap shot” perspective. Occasionally, by chance, the Clip also captures clear, interesting images.
We hoped that these images would be helpful to the project in two ways. First, we felt that the images might help the participant to better recall the participation period during the second interview. The Clip in fact turned out to be very useful in this way. Second, we hoped that the images would enable us to make corrections to a participant’s caregiving log. Using the time stamps on pictures, we succeeded in adjusting the time and duration of self-reported activities. We also sometimes made additions that were altogether new, usually of brief activities the participant had omitted.

The Clip has no on/off button. If the camera sees any light, it takes pictures. Participants began wearing the Clip towards the end of the first interview.

There were significant portions of the participation period when no images were taken. Participants were told that they were free to remove the Clip whenever there were situations that they would prefer not to be photographed in. Participants often removed the Clip when they were in the bathroom, or when they helped care recipients with certain personal issues. Some participants continued to wear the Clip during meetings with friends or colleagues, while others removed it. After removing, sometimes it took a while before participants remembered to put it back on.

Participants were told that their personally identifiable data (e.g., names) and any images that revealed personally identifiable data would only be used or viewed by the research team, and otherwise be kept confidential.

**Processing and Analyzing Clip Data**

To view Clip images, the device is connected to a computer via a USB cable. Then, a computer application, Narrative Uploader, was used to transfer the images from the Clip, via the computer, to Narrative’s cloud server. Narrative’s system then processes the images: auto image rotation, cropping, exposure adjustment, and noise filtering. The system also organizes the images into “moments,” and selects some as key images.

The images can then be viewed on a Narrative smartphone app or on their website. One can view all of the images, or just the automatically selected key images.

Narrative provided the Atlas team with a specially written computer application that allowed us to download the images from Narrative’s server, and to give each image a file name with the date and time the image was taken (e.g. “2015-08-24T105310.jpg” means the image was taken on August 24, 2015 at 10:53:10 am). Narrative has since developed more extensive software to serve the needs of such research projects.

For consumer purposes, the Narrative smartphone app and website features are adequate. However, for this project, the research team generally worked directly with downloaded images rather than relying on an automated program to sort key moments. Similarly, during the second interview, when we showed participants their own images as part of the discussion, we showed the images from our laptops, rather than on the Narrative app or website. Given the filename convention, it was easy to find the images that corresponded to a log entry or event being discussed.

To produce the Photo Log diagram in each of the case studies, a small subset of images were chosen, and automatically cropped into square formats. Images showing clear faces were redacted.

**Alternative Devices**

The Narrative Clip was the only such device available for the project. A similar life-logging camera, Autographer, was examined, but we learned that it had been discontinued by its manufacturer.
Popular life-logging video cameras designed for sports capture higher-quality images and video. However, they are much larger and not suitable for wearing continuously during mundane activities. In addition, their battery life is shorter than the Clip. Similar industrial cameras, such as those sometimes worn by police, are also too large and have a short battery life.

**Netatmo Weather Station**

The Netatmo Weather Station consists of two, small, cylindrical modules. The larger, “indoor” module measures temperature, humidity, CO2 and sound levels. This module was usually placed in participants’ living rooms. The smaller, “outdoor” module measures only temperature and humidity, and was usually placed in participants’ bathrooms.

Netatmo was used with eight of the 14 participating families. The devices were plugged in and turned on near the end of the first interview.

Netatmo was included in the project out of curiosity, to discover whether or not environmental measures could be informative with respect to caregiving. The Netatmo data was not particularly informative in this study, though the experience leads to the conclusion that noise/sound data has the potential to be very useful.

**Processing and Analyzing Netatmo Data**

The indoor module was inside a researcher-provided basket, which also included a cellular WiFi hotspot. The indoor and outdoor modules streamed their data to the Netatmo cloud server via this hotspot. The data could be viewed, in real time, on Netatmo’s web and smartphone apps. This real-time view was only used when the equipment was first set up in a participant’s home, to make sure it was working properly.

In preparation for the second interview, the researchers looked at plots on the Netatmo web app, and captured and printed screenshots of the appropriate time periods. The plots were scanned visually for anything notable. We sometimes saw things that raised questions: spikes or dramatic changes in noise (the TV? an accident?), humidity (washing hands? a bath?), or CO2 (windows opened?). We discussed these plots with participants during the second interview.

To produce the Environment Sensors diagram included in the Case Studies, data was transferred from the Netatmo cloud server to the Sapient Datadeer app. From there, plots were created of CO2 and sound levels (from the indoor module) and humidity level (from the outdoor module).

Netatmo data was not collected from six of the participants. In two instances, there were unknown technical problems. In one case, the participant felt the Netatmo would be distracting to the care recipient, while another felt the care recipient would simply dislike its presence. In one case the participant expected to be away from home for much of the time. And for the very first participant, the research team was not yet ready to use Netatmo.

**Alternative Devices**

There were no alternative devices considered for “indoor weather” measures: temperature, humidity, and CO2. We investigated some other noise/sound sensors, designed for research, but none were readily available for our use.
**SmartThings Motion Sensors**

The SmartThings system includes a set of small modules that detect motion, and a “hub” that collects data from these modules. These modules were placed throughout a participant’s home. The system includes a key fob that communicates with the hub. If the hub cannot sense the fob, the person must be away from home.

SmartThings data was collected from seven of the 14 participating families. The modules were placed near the end of the first interview, and the hub was plugged in and turned on. At that time, the researchers made a quick sketch of the home layout, noting the living room, kitchen, bedrooms and other primary areas. They also noted the placement and direction of the motion sensor modules.

This system was included in the project out of curiosity, to discover whether or not basic motion detection, rather than a complex system that actually tracks the movement of individuals around a home, could be informative with respect to caregiving. As it turned out, the SmartThings data was not particularly informative in this study. It is possible that deeper analysis of the captured data, beyond what was done in the project, could be useful. And it is possible that a more sophisticated movement tracking system could be valuable.

SmartThings data was not collected from seven of the participants. In three instances there were unknown technical problems. In one case the participant felt the SmartThings modules would be distracting to the care recipient, while another felt the care recipient would simply dislike its presence. In one case the participant expected to be away from home for much of the time. And for the very first participant, the research team was not yet ready to use SmartThings.

**Processing and Analyzing SmartThings Data**

The SmartThings hub was inside a researcher-provided basket, which also included a cellular WiFi hotspot. The motion detector and presence modules send data to the hub, which then streams data to the SmartThings cloud server via the hotspot. The data could be viewed, in real time, on SmartThings’ smartphone app. This real-time view was only used when the equipment was first set-up in a participant’s home, to make sure it was working properly.

To produce the Motion diagram included in the Case Studies, data was transferred from the SmartThings cloud server to the Sapient Datadeer app. Plots were created showing moments of motion captured by each of the modules. Using information from the home layout sketch, the various modules were named (e.g., “living room”).

The home layout sketch was also used to create the Floorplan Diagrams included in the Case Studies.

The Motion diagram could not be produced in time for the second interview. Therefore the data captured by SmartThings was not discussed with participants.

With regards to analysis, the Motion diagrams were inspected visually. The researchers looked to see if anything stood out as unusual or unexpected, and if the data corresponded to our impression, from the logs and interviews, of participants’ movements.

**Alternative Devices**

Alternative systems were discussed, but were felt to be inappropriate for this project. The alternatives may have produced much more detailed and accurate data about family movements around the home. But, they would have required complex and semi-permanent installation (more work for the researchers and more hassle for the participants) and much more data analysis (beyond project scope and budget), and also would have raised more concerns about privacy.
Appendix: Case Studies

Study 1: Ana’s Household

Ana (50s) has had cystic fibrosis since birth. Ana devotes several hours a day to self-care and is currently the primary manager of her condition. She also cares for her teenage son Albert, who has depression.

Context
A retired medical professional and mother of two, Ana has called the Bay Area home for over 30 years.

She currently moves back and forth between two homes in the area. She lives with her current partner, Arienne, in one home. The other home is located much closer to her two boys, Albert and Alex. They also live with their other mother, Bonnie, with whom Ana splits custody. During time periods that Ana has custody of her sons, she stays with the boys in her second home.

Ana has had cystic fibrosis (CF) since birth. Throughout much of her life, symptoms were relatively mild compared to many others with this condition. She was able to have a long medical career before worsening conditions finally forced retirement. She continues to work as an independent coach and researcher. To manage her condition, she spends many hours each day in-home treatment. This primarily involves taking medications with a nebulizer, therapies that loosen the mucous that collects in her lungs, and staying as fit as possible. As is common with people with CF, she occasionally suffers from serious infections that require home IV treatments.

The Kind of Day it Was
Activity logging and recordings from sensors were gathered Tuesday through Wednesday. Ana noted that her stress levels during the period were remarkably low, though she did not indicate whether it was a particularly low stress day or simply a surprise that she had managed the day’s stress so well. She participated in several self-care activities and also took her son to an appointment.
Care Network

The care network diagram provides a synopsis of Ana’s household and the extended care network that surrounds it. On the diagram Ana and the boys’ each have two homes, illustrating that their support networks are embedded in multiple locations.

Ana’s cystic fibrosis requires her to perform a significant amount of daily self-care activities. While largely self-reliant, she does receive significant emotional support from family and friends. Arienne provides daily support by phone or in-person. Ana’s sons are also a significant source of comfort, especially when she is with them. Local friends and an out-of-state sister help occasionally.

Ana’s son Albert suffers from depression. Both of his mothers, Ana and Bonnie, constantly watch out for and help him. Albert sees a therapist weekly. Albert’s brother Alex provides emotional support and drives him to places as needed.

Ana and Arienne also care for four dogs. At the time of Ana’s participation, two of them had medical issues.

Zoom-able diagrams can be found at http://atlasofcaregiving.com/studies
Activities
Ana’s log entries began at 10:35 am on Tuesday, and ended at 3:45 pm on Wednesday. The 29 hours covered by the log included 4.9 hours of self-care activities, one hour of caregiving, four hours at leisure, about 2.7 hours of work, 6.8 hours on other activities, and 9 hours sleep. The table on the next page provides a breakdown of Ana’s primary care activities.

Ana was surprised to see that she spent five hours on self-care. “I assumed it was about an hour. But it’s really a lot longer than that,” she said. Seeing the length of time that she utilized the nebulizer made her wonder whether her equipment needed to be fixed.

In addition to medical activities, during the participation period Ana also spent one hour exercising, and an additional hour walking, and sometimes jogging, with her dogs. Exercise is a key part of her routine; it’s not only a tool to manage her health, but a passion. Ana even remains active in a professional capacity as an independent wellness and exercise coach.

Ana: 24-hour Log, 36-hour Log, and Activities diagrams.

Zoom-able diagrams can be found at http://atlasofcaregiving.com/studies
## Ana’s Main Care Activities

<table>
<thead>
<tr>
<th><strong>Medical activities</strong></th>
<th>Took pills</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Used VibraLung (a machine used to clear secretion and expand the lungs) and an electronic vest that loosens mucous from the lungs</td>
</tr>
<tr>
<td></td>
<td>Used nebulizer</td>
</tr>
<tr>
<td></td>
<td>Cleaned equipment</td>
</tr>
<tr>
<td></td>
<td>Treat sores</td>
</tr>
<tr>
<td><strong>Exercise (self-care)</strong></td>
<td>Lifted weights, and did calisthenics and yoga</td>
</tr>
<tr>
<td><strong>Caregiving</strong></td>
<td>Reminded Albert about a clinic appointment, and also took him to the appointment</td>
</tr>
</tbody>
</table>
**Photos**

Ana wore the Narrative Clip throughout her participation period. The photo stream was useful for making minor adjustments to the log (10 additional entries were added to a 61 entry log). The additional entries primarily captured computer activity and moments of driving that Ana had not noted.

Ana spent five hours on self-care during the study period, much of it while using a nebulizer. She often passes time by watching TV, web surfing, or looking at Facebook.

Zoom-able diagrams can be found at [http://atlasofcaregiving.com/studies](http://atlasofcaregiving.com/studies)
Body Sensors
Ana wore the Empatica E4 throughout her participation period, only removing it briefly for a shower.

The electrodermal activity (EDA) graph shows several periods of heightened emotional arousal. In Ana’s case, these peaks were associated with physical activity and social interaction rather than high stress. Ana noted that for the most part her stress levels had been “pretty dang low.” There was only one self-reported stress level of “3.” This occurred when she was doing a walk-jog with one of the dogs and nearly had an accident because the dog decided to chase a cat. The most significant EDA activity was around 4-5 pm on Tuesday, when Ana was watching a soccer game (USA vs Japan in the women’s world cup final). She was elated whenever the US team scored. Finally, there was significant electrodermal activity when Ana was tutoring her son in Spanish.

The acceleration graph during the walk-jog with the dog, between 12:00 noon and 1:00 pm on Wednesday, shows a clearly visible series of spikes. There were similar, but smaller peaks, for exercise periods on Tuesday. The acceleration data also shows sharp peaks when Ana wore her “vest” (a device which literally shakes the torso to loosen mucous in the lungs).
Environmental Sensors
No home sensors were used during this study.

Ana: Environmental and Motion Sensors diagrams.
Study 2: Chantal’s Household

Chantal (50s) plays a central role in her mother Debby’s (80s) caregiving and does a full range of caregiving tasks. The demands of caregiving have initiated several significant changes in Chantal’s life. She has moved homes and resigned from jobs in order to create the proximity and time necessary to provide care for Debby. She is currently unemployed.

In addition to Chantal, a paid home aide, Emily, provides significant assistance. Chantal’s brothers are also present and active in their mother’s care.

Context
Chantal lives with her husband Bill and a dog in a small house in a distant suburb of Silicon Valley. The house is part of a compound that has been in Chantal’s family for decades.

Her mother Debby, who is in her eighties, lives just across the driveway in a similarly small house. Debby has a long list of medical issues: hypertension, hyperlipidemia, CHF, atrial fibrillation, arrhythmia, allergic pneumonia, thyroid issues, renal insufficiency, sinus issues, reflux, dementia, asthma, severe osteoarthritis, and arthritis and stenosis in her back. In addition, Debby has had pelvic support surgery, and in the past suffered fractures in the hip and pelvis.

When Debby’s major health decline began in 2009, surgeries, rehab, and the need for home health services quickly narrowed Chantal’s world to just work and caregiving. At the time Chantal lived more than two hours away. Long drives every weekend to visit and care for Debby took their toll, and in early 2011 Chantal and Bill moved into the house next door to Debby. Part of the rationale was to protect her brothers’ health, as both have back problems and other health issues. Chantal continued to work at her job (a 2-hour commute), living with her other brother during the week, and at home next to her mother on the weekends.

As Debby’s health worsened, she needed growing assistance with basic home and personal activities. By late 2012, Chantal had to take a leave of absence from work, and eventually resigned. Resigning meant losing insurance coverage in addition to reliable income. Debby’s decline continued. She was diagnosed with several more conditions, and now required a wheelchair.

One year later, Chantal found a part-time professional job, with a 45-minute commute. In early 2014, Debby was admitted to at-home hospice. She was discharged from hospice six months later, but then readmitted in early 2015.

Throughout this time, Chantal had very little respite — working part time during the day, and devoting evenings, nights, and weekends to care for Debby. She gained 30 pounds and began to be worried about her own health. Exhausted by the last six years, in the summer of 2015 Chantal resigned from her part-time job, enabling her to carve out time to care for herself. Now, during the times that Emily, a home care aide, or her brothers are caring for Debby, Chantal rests and exercises by doing yoga, walking, or hiking. She can also more easily take care of home and shopping needs, and has a little time to share with her husband. The change has made a difference, she says.

The Kind of Day it Was
The study occurred on a typical weekday. Chantal confirmed that the amount and types of caregiving work she did were fairly usual, as was the amount of free time she had. The level of emotion that caregiving imparted was more uncharacteristic. Debby was particularly agitated on the day of the study. It also became clear that she could no longer brush her teeth for herself, which represented a worsening of the condition. In the log, Chantal labeled the night as the “worst ever with regards to confusion, agitation, and talking nonsense.”

Chantal’s concerns were centered on the worsening health deterioration of her mother, however these changes also signified that care needs were likely to, again, increase. Chantal’s stress was compounded when her husband returned home upset about his day at work shortly after Chantal had finished dealing with her own stressful realizations about her mother. The following morning, when Chantal attended a yoga class, was calmer.
**Care Network**

The care network diagram provides a synopsis of Chantal’s household and the extended care network that surrounds it.

Debby requires 24×7 care. This need is fulfilled through a core care network comprising Chantal, Emily (a home aide), and two of Chantal’s brothers. While each of the family members lives in separate homes, all of the homes are on the same street.

Emily has been employed by Chantal’s family as a home aide for a long-time and is highly trusted. Emily remarks that she has “seen it all before.” She provides practical support six days a week. She also provides emotional support to Chantal, in particular by helping to reassure her that what is going on with her mother is normal. As Debby requires 24-hour care, Emily and Chantal work in shifts. Emily does the care work in the day.

Chantal takes over from early evening to the following morning, six days a week. She would also be there whenever hospice nurses or other aides come. Chantal’s two nearby brothers cover the gaps. For 2-3 hours each day, when neither Chantal nor Emily can be there, one or the other provides Debby with company. The backup support is important; however, both brothers are over age 60 and each has back issues that limit the kinds of care they can provide for Debby. A third brother, who lives further away, helps by managing Debby’s financial issues.

The second tier of Debby’s caregiving network consists primarily of two hospice aides and a hospice nurse, who visit Debby weekly. In addition, a pain management doctor sees Debby monthly. Given Debby’s numerous illnesses, there are many other medical professionals in the background.

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**Chantal: Care Network diagram.**

Chantal and Bill have consistent sources of support, both within their home and outside of it. They support each other through this difficult time. The family’s dog plays an important role, staying with the person he senses needs him most. Family members are present and active in their life. Chantal and her aunt call each other weekly. Bill’s distant parents and brother are an important source of emotional support for him.

Outside of family, Bill relies on occasional conversations with his friends at work. Chantal has found some comfort and stress relief by attending caregiver information sessions organized by local agencies, and especially from an online caregivers community (caring.com). She remarked that caregiving has been isolating, and that these connections have been helpful to forming connections.
Activities

Chantal’s participation occurred from 11:00 am Monday morning to 11:45 am Tuesday, during which time she kept an activity log and wore sensors. A follow-up interview about the experience occurred on Wednesday afternoon. Emily, the home health aide, also kept a log during her 8:00 am to 4:00 pm shift on Monday.

During the 24 hours that Chantal logged, based on the interpretations of the log by the research team, she spent 6.5 hours on caregiving activities, 1.6 hours leisure (a yoga class), 4.3 hours on other activities, and got 6.1 hours sleep. It is important to note that although the “caregiving” activities in Chantal’s log only added up to 6.5 hours, her caregiving shift was an 11-hour stretch, from 6:20 pm Monday to 7:40 am Tuesday, during which time what she could do with her time was restricted.

The table on the next page provides a breakdown of Chantal’s primary care activities, showing that Chantal’s caregiving day required performing a variety of tasks to meet the medical, physical, and emotional needs of Debby and other family members. Maintenance of Debby’s medical records was a particularly prominent task on this day. Chantal has created a detailed accounts of Debby’s medical diagnoses and treatments in order to more easily communicate that complex history to doctors. Logging for the Atlas project inspired her to spend several hours revisiting and updating that history.

Emily’s log includes notes about preparing meals for—and feeding—Debby, general housekeeping, helping Debby with toileting (diapers) and clothes, providing medications, and keeping her company.

Zoom-able diagrams can be found at http://atlasofcaregiving.com/studies
<table>
<thead>
<tr>
<th><strong>Chantal’s Main Care Activities</strong></th>
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<tbody>
<tr>
<td><strong>Medical activities</strong></td>
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<tr>
<td><strong>Family communication</strong></td>
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<td></td>
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<tr>
<td><strong>Food</strong></td>
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<tr>
<td><strong>Medical History</strong></td>
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<tr>
<td><strong>Personal Care</strong></td>
</tr>
<tr>
<td><strong>Transferring</strong></td>
</tr>
<tr>
<td><strong>Household management for Debby</strong></td>
</tr>
<tr>
<td><strong>Observation</strong></td>
</tr>
<tr>
<td><strong>Listening</strong></td>
</tr>
</tbody>
</table>
Photos
Chantal wore the Narrative Clip throughout. Sensitive to her mother’s privacy, Chantal occasionally removed the Clip during sensitive caregiving activities. Tuesday morning, she took it off around 7:45 am and neglected to put it back on. The captured photos helped the researchers to refine, and in some cases correct, log entries. Twenty-one entries were added to the original 61 entries that Chantal logged. Many of these additions captured times when Chantal was text messaging, driving, and assembling her mother’s medical history. These activities represented the bulk of the afternoon, before Chantal began her scheduled caregiving duties.

Debby’s complex medical history is laid out in reams of documents. Chantal spent 3.5 hours re-organizing this information in order to be able to accurately convey to doctors the quantity and types of Debby’s past care.
Body Sensors
Cantal wore the Empatica E4 during the entire duration of the study, removing it only when she took a shower and briefly when washing dishes. The acceleration and heart rate data clearly shows Chantal’s period of sleep (about 11:30 pm to 4:40 am) and, upon awakening, leisure time reading in bed (5:00 am to 6:30 am). Additional times of relatively low acceleration readings are reflected in times during which she was working at her computer (Monday, roughly 12:15 pm to 1:00 pm, and 3:00 pm to 5:00 pm), and at yoga (Tuesday roughly 9:45 am to 11 am).

In the log, Chantal noted several times that when she was helping Debby eat or bathe she felt high stress levels (4 or 5). On one occasion she recorded: “[I] helped feed mom. She told me to go away. She keeps falling asleep while eating.” On another occasion, when bathing Debby, she wrote: “[Debby] was being kind of mean, just wanted to go to sleep, wanted it to be done. It’s quite involved, feeling a bit resentful—I’m doing all this stuff and she doesn’t appreciate it, but you have to let stuff go—these are real emotions though.” There were several other caregiving moments when Chantal noted stress levels of 2 or 3.

Looking at the processed electrodermal activity (EDA) signal, we can see peaks on Monday evening that correspond to the period that Chantal was caring for Debby (roughly 6:00 pm to 10:00 pm). The tallest spikes are highly correlated with times when Chantal was trying to feed or bathe Debby. There is also high activity when Chantal was at her morning yoga class — this is common as yoga is both physically and emotionally stimulating.

Zoom-able diagrams can be found at http://atlasofcaregiving.com/studies
**Environmental Sensors**

As Chantal did not want to disturb her mother, she installed the SmartThings and Netatmo devices at various times and moved them on several occasions. The data, therefore, is unreliable for analysis.

**Data Already Present**

During the first interview, Chantal told us that she kept a written history of her mother’s major health events so that she could relay that information accurately to each new doctor who attempted to take her mother’s medical history. The history was contained in a simple document, a few pages long. However, during the second interview Chantal noted that she had assembled more of that history during the day of the study. Clip pictures revealed the complexity of that task. Chantal spent 3.5 hours synthesizing reams of documents—calendars, bills, handwritten notes, computer files, and documents and brochures from medical institutions.
Study 3: Fay’s Household

Only-child Fay (30s) cares for her mother Josephine (70s) who has Alzheimer’s. With no one to help her, she has put her PhD studies on hold to provide 24×7 care.

Context
Fay is a graduate student and an only-child. She was raised in Southern California by a single parent, her mother Josephine. She and her mother are very close.

Fay left for college and then worked on the East Coast for several years before returning to California to start a public health PhD program near San Francisco. A few months ago she took a leave from her studies to devote herself full-time to caring for Josephine.

Josephine, who is in her 70s, had been living by herself and doing well, until about two and a half years ago when she was hit by a car. She broke her leg and several other bones. Though she recovered, she is no longer as fast or mobile as she once was, and movement is more painful now. In addition, Josephine has developed arthritis and often has gastrointestinal issues.

Initially Fay hired an in-home caregiver to help Josephine (in Los Angeles). But soon after Josephine moved to the Bay Area to stay with Fay “for a while” to help her recover, which meant Fay’s housemate had to move out. Fay began to notice her mom’s memory was worsening, so Josephine has continued to stay with Fay.

Josephine requires near-constant oversight. Her memory and decision-making skills have deteriorated. The result, for Fay, has been an impactful change in her mother-daughter relationship. From small household decisions to large financial planning ones, Fay must constantly make decisions for both herself and her mother. In addition, as she faces potentially increasing expenses for Josephine’s care, having no income compounds Fay’s worry.

The Kind of Day it Was
Fay’s participation began with a first interview on a Monday morning, at which time activity logging and sensor recording began. The logs and sensors were collected Tuesday afternoon. A second interview took place on Wednesday afternoon.

From a care perspective, Fay described that Monday-Tuesday as “easier than normal.” However, the data gathered during the study reflects Fay’s difficult balancing act between keeping up with academic interests and colleagues and providing the intensive care that her mother needs.

Fay had expected the participation period to be difficult. She had several scheduled meetings; one would take her out of the home for an hour and another meant that she would have to leave Josephine alone at home for four hours—much longer than she normally dares. Given that Josephine’s dementia symptoms and gastrointestinal pains were milder than usual, fears about these periods did not manifest. Still, even with light care needs Fay spent six hours on caregiving activities. The time between when the logging stopped and the follow up interview took place was much harder. Fay had to take Josephine to the hospital for a GI test due to pains, and then to a yoga class (which Josephine left early because her back was hurting). Interviews with Fay indicate that the fragmentation witnessed during the study period is a new normal. She attends intermittently to PhD studies between caregiving tasks, creating disruptive switching patterns.

In addition, another consistent form of disruption in Fay and Josephine’s lives manifested during the study: construction noise. It is an ongoing problem with their apartment that agitates Josephine greatly, in turn distressing Fay. They are unable to get away from the noise easily, though on this occasion Fay decided that it was a good moment to take Josephine to the grocery store. That trip, however, had its own stressors (see Photos section), and during the car ride a difficult conversation about why Josephine could not return to living by herself in another city arose. Later in the day Josephine was suffering some GI distress, which was difficult for Fay because she wanted to help, but there were limits to what she could do and she also was trying to work on her studies at the same time.
**Care Network**

Fay is central to all of the regular care that Josephine receives, having no other siblings or close relations to rely on. This is nearly a 24×7 job. Fay is able to leave Josephine alone at home for an hour or two, but while away she finds it hard to relax, and so she tries to remain within 15-20 minutes of home.

Josephine has a close family friend who lives two hours away and comes at least once every other month to help. Fay trusts her to keep Josephine safe and gets emotional support from her, too. Fay also has two friends her own age and another family friend in Southern California. She also sees a therapist.

Fay has tried to hire a paid caregiver for Josephine so that she could resume her studies, but Josephine is not very receptive to that idea. Josephine’s memory problems keep her from remembering when or why she needs help.

There is also a small network of medical support. Four doctors—a primary care physician, psychiatrist, gastroenterologist, and urologist—see Josephine occasionally.

Zoom-able diagrams can be found at [http://atlasofcaregiving.com/studies](http://atlasofcaregiving.com/studies)
Activities
In her initial survey, Fay had checked the box for “5-10 hours” per day of caregiving. During her participation she spent about 6 hours on caregiving tasks, but they were interspersed with work and other activities, making for a fragmented day.

In general, Fay helps Josephine with all medical activities and visits. She also does all the driving, and manages all health, financial affairs, and home affairs. Only some of these things are represented in the table on the next page, which provides a breakdown of Fay’s primary care activities during the day of study.

Josephine contributes as she can (e.g., cleaning the dishes), but Fay has to be watchful. In addition, Fay must remain nearby whenever Josephine attends any out-of-home events (such as a yoga class) as Josephine sometimes becomes scared or worried, or feels too tired or too much pain to continue. It is okay for Josephine to be alone at home for short 1-2 hour periods, which allows Fay to meet with friends and colleagues, as she did on the day of study. Her friend has her own caregiving responsibilities, and Fay noted that it felt good to relax with someone who understands and sympathizes with her situation.

For Fay, the experience of logging activity created some dissonance. She noted that it made her “hyperaware” of how she spends time. In particular she noted how much time she devoted to work tasks— meeting colleagues, speaking to them on the phone, doing research and writing at her desk at home — and felt guilty about not spending this time providing company to her mother or doing “fun things” together. She felt especially guilty about “time-wasting” activities (e.g., Facebook). To a degree, however, the log can stand as an objective account of the amount and quality of time that Fay devotes to caregiving. For example, she patiently waited for long periods in the grocery store so that Josephine could participate in selecting household items.

Zoom-able diagrams can be found at http://atlasofcaregiving.com/studies
<table>
<thead>
<tr>
<th>Fay’s Main Care Activities</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Providing company</td>
<td>Shopped and ate together</td>
</tr>
<tr>
<td>Orchestrating the day for Josephine</td>
<td>Left notes for Josephine about where she is and checked-in with calls when gone</td>
</tr>
<tr>
<td></td>
<td>Where possible, left decision making and delegating decisions to Josephine</td>
</tr>
<tr>
<td>Emotional support</td>
<td>Held repeated conversations about things like Josephine’s current living conditions and why Josephine cannot return to living by herself</td>
</tr>
<tr>
<td></td>
<td>Repeated management of Josephine’s agitation, resulting from things like construction noise.</td>
</tr>
<tr>
<td>Legal/financial</td>
<td>Sought to speak with experts, and conducted web research</td>
</tr>
<tr>
<td>Medical support</td>
<td>Medications — pills, eye drops, creams, and injections</td>
</tr>
<tr>
<td></td>
<td>Helping with a cut — cleaning and applying a band-aid</td>
</tr>
<tr>
<td></td>
<td>Helping with GI issues — providing emotional support (sympathetically listening to mom’s complaints), pills, preparing probiotic drinks, food</td>
</tr>
<tr>
<td>Supporting Josephine’s activities</td>
<td>Finding activities (e.g. yoga classes) and encouraging Josephine to attend</td>
</tr>
<tr>
<td></td>
<td>Changing television channels, dealing with radio reception issues</td>
</tr>
</tbody>
</table>
Fay felt self-conscious about wearing the Narrative Clip, and chose not to wear it for meetings and for tea with her friend. She also removed it often at home, and then forgot to put it back on. Clip data was thus relatively incomplete; however, existing images still served as reference points that allowed for seven entries to be added to the original 73 that Fay logged.

In addition, when Fay reviewed Clip images, the process sparked new memories about the experience of grocery shopping, allowing for a full picture of how caregiving can exist even in quotidian activities. In particular, while viewing the picture at right, Fay recalled details about her grocery experience with Josephine. At the store, Fay explained that she had asked Josephine to select a breakfast cereal. She asked her to do this because she wanted to help Josephine retain her mental abilities as much as possible, but the choices were too much for her and so she asked her to select some bananas instead, where the choices were more limited.

The grocery store incident provides three insights. First, it revealed the extent to which Fay is responsible for making all family decisions. Second, it illustrates how Fay must constantly strategize about finding things that challenge Josephine but that she can also manage. Finally, it shows the benefit of using multiple mediums to capture the depth of the experience of caregiving. The log alone does not capture the complexity of the grocery store experience. The mnemonic experience of seeing the photo and time devoted to a follow-up interview were essential in order build a “three-dimensional” look at what was at first only a simple entry in the activity log.

A simple trip to the grocery store became a caregiving experience when Fay asked Josephine to select a cereal. The exercise was meant to keep Josephine’s decision-making sharp and mind active.

Fay: Photo Log diagram.

Zoom-able diagrams can be found at http://atlasofcaregiving.com/studies
Body Sensors

Fay wore the Empatica E4 during the duration of the study, only taking it off to shower. In her log, Fay noted several instances when she felt stressed. Some of these stressors were not caregiving-related, such as frustratingly loud construction noise and an alarm clock that startled her. Others were, such as a difficult conversation with Josephine about living circumstances.

At each of the self-reported stress incidents, there was significant electrodermal activity (EDA). The EDA analysis also detected a large spike at 6:45 am. Fay confirmed that she had been startled by her alarm clock, but did not include it in the log. The E4’s acceleration data show that Fay slept soundly from 1:30 am until she was woken by the alarm. In the acceleration data, there are also several periods of relative inactivity, where low values reflect periods during which Fay sat and worked at her desk.

Zoom-able diagrams can be found at http://atlasofcaregiving.com/studies
Environmental Sensors

Seven SmartThings motion detectors were placed throughout the house. The detectors are sensitive — one even picked up Fay’s shifting sleep positions. The density of blue columns in the row representing Fay’s bedroom show that she was there often during the day, presumably at her desk. Josephine, on the other hand, spent far more time in the living room than her bedroom. We can see that Josephine went to the bathroom around 4:45 am, which we conclude given that Fay logs this as a period during which she was asleep. The motion detectors fell silent during the time Fay and Josephine were out of the house.

One Netatmo device was placed in the living room and another in the bathroom. The noise level in the living room, as recorded by Netatmo, correlates with the activities recorded in Fay’s log. Noise levels were higher when the TV was on, and lower when it was off. A noticeable spike in the noise at 4 pm was a particularly distressing example of construction noise. Carbon dioxide (CO2) levels tend to decrease rapidly when windows are opened and rise slowly after windows are shut, which may explain the wavy appearance of the CO2 line on Monday afternoon. The humidity level in the bathroom shows a large spike (when Fay showered) and smaller spikes at other times (using the toilet or washing hands in the sink).
Study 4: Gabrielle’s Household

Gabrielle (60s) is the primary caregiver for her mother Karen (101), who has Alzheimer’s. Gabrielle also has health issues of her own. Recently, sleepless nights, brought on by Karen’s caregiving needs, have begun to take a toll.

Context

Gabrielle lives in an urban home in the San Francisco Bay Area. At age 101, Karen lives with her, as do a pet cockatiel and a dog.

Gabrielle has lived in the area all of her life. Though widowed now, she and her husband had two sons. Both are now married, and one son still lives nearby. After a long career in healthcare, Gabrielle briefly retired at age 60. But, finding herself quickly bored, she leapt back into the job market and landed a part-time job in retail. Today, Gabrielle is active and describes her health as fair; but she has to manage hypertension, diabetes, and sleep apnea.

Karen was diagnosed with Alzheimer’s in 2004. She was recovering from surgery at the time and physically seemed to be mending well. During her recuperation, however, Gabrielle noticed that her mother’s mood and alertness seemed worse. Continued observation eventually led to an Alzheimer’s diagnosis. Karen, who up until the diagnosis had lived on her own, moved in for a few years with Gabrielle’s sister. But then Gabrielle’s sister’s health also began a significant decline, and Karen moved into Gabrielle’s home.

Karen requires a complete regimen of 24×7 care, including help eating, toileting, grooming, and dressing. She depends on a wheelchair to be moved around. At home, Gabrielle has placed both of their beds and a TV in a small room just off the kitchen so that she can stay alert to Karen’s needs. With sleep apnea, Gabrielle should sleep with a Continuous Positive Airway Pressure (CPAP) machine to assist with breathing. But lately she has foregone the machine so that she can hear Karen and wake up if needed.

Gabrielle finds lack of sleep the most challenging part of the arrangement. It leads her to become impatient, and sometimes to lose her temper and yell. Exhausted, a few days after Gabrielle kept a log for the Atlas project she hired a homecare aide to watch over Karen four nights a week.

The Kind of Day it Was

In Gabrielle’s case, the Atlas participation period was a relatively light on caregiving activities. During the second interview, which occurred a week later, she was asked whether this low level of stress was usually the case. She replied:

If [the study] was last Monday the results would have been the total opposite. I was at my son’s house and things were starting to pile up. Karen was constantly calling me, and my dog wouldn’t eat or go out. It looked terrified. I had to go to work. …After Monday night I’d just had it. … I thought: ‘I think I’ll put her in a home.’ But then I decided I couldn’t do it. The next best thing was to hire someone to watch her. So far [the home aide] is working fine, but I might end up spending her money this way.
Care Network

Gabrielle shares her home with her mother Karen, a cockatiel and a dog. Gabrielle is responsible for providing the majority of the 24×7 care that Karen needs.

Anywhere from 3-5 days a week, Karen goes to a daycare facility. The facility affords Gabrielle space and time to work or take care of personal activities. At times, however, this link in the care network is tenuous. Gabrielle noted that getting Karen ready for day care is a daily challenge. Because Karen is often sick, Gabrielle regularly has to decide whether it is okay for her to go that day or not. If Karen needs to stay home, then Gabrielle has to rearrange her work responsibilities and other activities.

A week after the Atlas study was completed Gabrielle hired a homecare aide to watch over Karen four nights a week. Finally, Karen has a primary care physician and a neurologist.

Alongside these professionals, there are several family members who also care for Karen on occasion — Gabrielle’s brother and sister-in-law, daughter-in-law, and niece. Some come to Gabrielle’s home to help; for others, Gabrielle must take Karen to their home. Not all are comfortable helping Karen with her full-range of needs. On rare occasions, to be able to meet a friend for dinner, Gabrielle will hire a sitter to watch over Karen.

Gabrielle also conducts a significant amount of pet care. Her cockatiel has its own complex medical needs that stem from liver disease. The bird requires blood tests, and takes medication that is difficult to administer and that causes skin complications. Gabrielle must regularly clean the bird.

Self-care takes backseat among all this caregiving. Gabrielle mentioned only that she gets emotional support from speaking with a social worker on occasion.

Zoom-able diagrams can be found at http://atlasofcaregiving.com/studies
Activities
In the initial survey Gabrielle checked the box for “5-10 hours” of caregiving per day. On this day she logged 5.8 hours of caregiving, 5.5 hours of sleep (with a 15-minute interruption), 2.2 hours leisure activities, 4.2 hours on other types of activities (mainly errands), and 4.3 hours of work. The table on the next page provides a breakdown of Gabrielle’s primary care activities.

Gabrielle was asked if maintaining a log revealed anything surprising about her caregiving activities. She replied that most of what she does is routine, and that she felt that this routine was reflected on the log.

Zoom-able diagrams can be found at http://atlasofcaregiving.com/studies
<table>
<thead>
<tr>
<th>Gabrielle’s Main Care Activities</th>
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<tbody>
<tr>
<td><strong>Transferring</strong></td>
</tr>
<tr>
<td>Helping Karen get into the transport van to day care</td>
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<tr>
<td><strong>Interacting with medical professionals</strong></td>
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<tr>
<td>Following up with hospice nurse</td>
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<tr>
<td><strong>Cooking</strong></td>
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<tr>
<td>Preparing meals and snacks</td>
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<td></td>
</tr>
<tr>
<td>Feeds Karen and pets</td>
</tr>
<tr>
<td><strong>Medication</strong></td>
</tr>
<tr>
<td>Intermittently for pain</td>
</tr>
<tr>
<td><strong>Measuring</strong></td>
</tr>
<tr>
<td>Monitors blood pressure, temperature, oxygen saturation, etc.</td>
</tr>
<tr>
<td><strong>Grooming</strong></td>
</tr>
<tr>
<td>Dressing, helping with toothbrushing, toileting</td>
</tr>
</tbody>
</table>
Photos
Gabrielle wore the Narrative Clip, and the photos supported researchers’ ability to revise Gabrielle’s log. Fifteen entries were added to the original 23 that were recorded by Gabrielle. In one case, Gabrielle had underestimated the time spent meeting with a nurse by 45 minutes.

When we showed Gabrielle the photos, she remembered that she had made a trip to the mall and had stopped for lunch. This was not recorded in the activity log. While the errand itself provides little insight into caregiving, it does highlight how automated picture taking by the Narrative Clip can act as a reliable, supplementary source of data. Here, pictures fill in where memory or human error have left blanks and reduced accuracy of the activity logs. That trip did not help us understand particularly more about her caregiving situation, although the fact that she was able to take it at all suggests that she does indeed have the ability to get on with some aspects of her life despite caregiving, and is still able to drive despite the difficult sleep situation.
Body Sensors

Gabrielle wore the Empatica E4 throughout the time of her participation. A close look at acceleration data shows Gabrielle’s interrupted sleep pattern. She fell asleep in the recliner around midnight while watching TV. She got up around 1:30 am, turned off the TV, and moved to bed. She was up again around 3:30 am for 15 minutes to give Karen juice and medication for pain, and then twice more: briefly at 4:00 am and 4:30 am. She then slept soundly until 6:00 am.

The acceleration data also clearly shows other low-motion activities, including times when Gabrielle was driving (around 11:00 am and 1:00 pm on both days) and a nap (around 6:00 pm on the first day).

According to her log, nothing was particularly stressful during the period. This matches the fact that we see very little electrodermal activity. What little there is corresponds to the times she was helping Karen prepare to sleep (bathroom, medications), and getting Karen ready for daycare in the morning (bathroom, grooming, medications, dressing).
**Environmental Sensors**

Seven SmartThings motion detectors were placed around the main floor of the home. The two Netatmo sensors were placed next to Gabrielle’s bed (in the same room as the TV and Karen’s bed), and in the adjoining bathroom.

When home, most of the activity takes place near where the Netatmo sensor was located, near Karen’s bed. The sound level clearly shows the moment when the TV was turned off — at 1:30 am — and also when it was turned back on around 6:30 am. It is also easy to spot when Gabrielle was asleep or out of the house. Slow declines and low levels in the CO2 reading are another indicator of when the home was empty.

Zoom-able diagrams can be found at [http://atlasofcaregiving.com/studies](http://atlasofcaregiving.com/studies)
Study 5: Hanna’s Household

Hanna and husband Gaston care for her brother Harvey, who has several major health issues. Gaston also cares for his mother, while managing his own chronic pain and edema. Both Hanna and Gaston also work.

Context
Gaston, Hanna, her brother Harvey, three dogs, a cat, and a turtle share a suburban home in California’s Central Valley. All three are about age 50.

Hanna is an experienced office manager for a local professional firm. She is a long-time employee and has many responsibilities that she cannot delegate, but she is still able to get everything done around her caregiving responsibilities. Gaston works from home, mainly by phone, as a scheduler for a small business. Work issues are rarely urgent, and he too is able to fulfill work obligations in between his self-care and caregiving activities.

Hanna and Gaston have been married for about 20 years. They have three grown children; one daughter lives in the same neighborhood, a few homes away.

Prior to their meeting and marrying, Gaston was in a serious car accident that left him with a major back injury and a long recovery. He continues to have serious back and leg issues, with constant and sometimes severe pain. He has developed a regimen to combat the pain: frequent stretching, and application of heat and ice packs. Medications also reduce the pain, but Gaston minimizes their use because of significant side effects. The pain and discomfort make it impossible for him to sleep well. He knows that certain activities will lead to excessive pain, but sometimes does them anyway. “There are times I have to fight to not bust out crying. I know in the future I won’t be able to do things.”

Despite these challenges, Gaston joins Hanna in caring for Hanna’s brother Harvey. Harvey suffers from intractable epilepsy, Parkinsonism, Chronic Traumatic Encephalopathy, recurring pneumonia and sepsis, and difficulty swallowing. Harvey’s health problems began at an early age. He was diagnosed with epilepsy at age seven, and during his youth he had two brain surgeries. A near-drowning also once left him in a coma for several days.

With a pleasant demeanor and a positive outlook on life, Harvey conveyed an impression that everything was fine. About a decade ago, however, his family realized that physically and mentally things were not in fact “fine.” They moved him to a nursing facility where he stayed for a few years. Then, in 2013, Harvey moved in with Hanna and Gaston.

Harvey’s health—including his cognitive and motor skills—has declined dramatically in the past few years, but Hanna and Gaston are determined to care for him as long as they possibly can. As Hanna put it: “Long term, caring for Harvey, I have to consider what’s happening with Gaston. How much more care will Gaston need, and how can he participate in helping Harvey without damaging his own health?”

The Kind of Day it Was
The family’s participation occurred Labor Day Monday through Tuesday. It was a relatively smooth period from a caregiving perspective, as both Gaston and Harvey were in relatively stable health. No major incidents or seizures occurred. As Monday was a holiday, the activities on that day were more typical of a weekend.
Care Network

At the heart of their care network is the everyday support that Hanna and Gaston provide caring for, watching over, and otherwise interacting with Harvey. In addition, Harvey interacts with several other people within the care network. Most weekdays, for several hours, Harvey goes to a day care facility nearby. His church provides support by sending DVDs of sermons so he can “go to church” remotely. Hanna mentioned five doctors who occasionally care for Harvey. Finally, Hanna’s other brother provides financial support and guidance.

Gaston and Hanna mutually reinforce each other. In terms of housework, they each step in where the other cannot: either for physical reasons, time constraints, or because one is taking care of Harvey.

Gaston sees two doctors and a massage therapist. In addition, he interacts daily with a few online communities. Gaston’s care attachments also extend to his mother, who lives nearby. She has Chronic Obstructive Pulmonary Disease (COPD), suffered a stroke five years ago, and broke her leg last year. Gaston has concerns about her living independently. For now, however, he supports by calling daily, taking his mother to all doctor appointments, and helping with food and laundry when she is depressed. His brother and aunt assist in this care, but Gaston is the primary caregiver.

One of Hanna and Gaston’s three children lives a few minutes away, and is in daily contact with both parents. Outside of Gaston, Hannah primarily derives support from her daughter, who she regularly speaks with, and daily communication with a few online communities and a nearby friend.

Zoom-able diagrams can be found at http://atlasofcaregiving.com/studies
Activities
Hanna made frequent entries in a paper log that she kept nearby. Gaston preferred making notes on his smartphone, and later transcribing to a log on his computer.

What surprised me about the [Atlas] study this time was the concept of time. ... Many caregiving tasks don’t take longer than five or ten minutes so it may not seem like much to a non-caregiver. The killer is that these five or ten minute tasks are relentless!

In a similar logging exercise one year earlier Hanna and Gaston had been surprised by the amount of time they allocated to care activities and also by the large number of interruptions that occurred during a typical day. This time, logging re-confirmed their awareness of how much time is devoted to care, but it also deepened their ability to understand how much time individual tasks take.

This revelation occurred in part because of the logs’ ability to visualize the extent to which Hanna and Gaston multi-task to meet immediate demands that crop up during the day. Hanna, for instance might be doing laundry, helping Harvey, and working all in the span of twenty minutes, switching from one task to another before the first task is complete.

“You can get a lot done in five minutes,” says Hanna, “but it feels longer because there are so many tasks. Folding laundry feels like 20 minutes. In reality it’s five, but you keep going back to it.”

Interruption to overall flow is a common occurrence in their complex and fragmented lives. Classifying their activities is thus an imperfect exercise, as demonstrated by the many overlapping activities in the diagrams.

Despite the amount of caregiving work, lack of breaks, and constant fragmentations of tasks apparent in the diagrams, Gaston and Hanna have a stable routine and distribution of labor. Hanna can safely assume that Gaston has started to prepare a meal, for example, and can attend to Harvey’s other needs. However, a well-honed routine cannot spare someone from unpredictability and interruption (nor from the cognitive toll that repeated switching between tasks can impart). Hanna, for instance, sat down to write a 1,000-word article on seven different occasions. On the sixth occasion, she noted she had only written 106 words. When she finally was able to log that she had completed the article, she commented on the irony that the article was about successful time management while caregiving.

Hanna later wrote about the experience on her blog:

What surprised me about the [Atlas] study this time was the concept of time. ... Many caregiving tasks don’t take longer than five or ten minutes so it may not seem like much to a non-caregiver. The killer is that these five or ten minute tasks are relentless!

Two minutes to change the laundry and fold towels; Five minutes to tidy up the house; Ten minutes to get Harvey up for the day and give him meds; Five minutes to get Harvey to the bathroom; Ten minutes to get Harvey into the tub; Fifteen minutes to help Harvey dress; Thirty minutes to prepare medications for the week; Five minutes to restock Harvey’s supplies;

There are breaks between the tasks but there is always something to do! And the interruptions—oh boy! Caregivers know about interruptions.

During the interview, Hanna commented further on how surprised she was to learn about how little overall time certain tasks take. In particular, she talked about how perceptions of time can stretch and shrink. Ten seconds, she said, can seem like an eternity when Harvey is having a seizure. As observers, we suspect that the relentlessess she talks about in her blog can also be seen as a statement about the way that the sheer amount of work that caregiving involves can go underappreciated precisely because it is made up of “small” activities that are difficult to account for, but that quickly add up as a whole.
### Hanna’s Main Care Activities

**Caregiving for Harvey**
- Met with professional caregivers — booked appointments, prepared for and attended a meeting with the daycare facility
- Organized and provided medications, handled oxygen, checked vitals
- Assisted with toileting, bathing, grooming, clothes
- Prepared meals and assisted with eating
- Laundry — many loads throughout the day
- Monitored Harvey (often via video)
- Helped Harvey move around the home, and to/from car
- Waited — while Harvey works on eating, bathing, toileting, etc. by himself

### Gaston’s Main Care Activities

**Caregiving for Harvey**
- Repaired Harvey’s wheelchair
- Helped Harvey move around the home, and to/from the car
- Attended meetings with professional caregivers
- Shopped for Harvey
- Prepared meals and assist with eating
- Provided assistance with toileting, bathing, grooming, and clothes
- TV management
- Monitored Harvey (often via video)
- Laundry
- Waited — while Harvey works on eating, bathing, toileting, etc. by himself

**Self-care**
- Stretched repeatedly throughout the day and night in order to relieve tightness and help with pain
- Meditation
- Organizing and taking medications
Photos
Hanna, Gaston, and Harvey all wore the Narrative Clip. Based on the photos, 18 refinements were added to Hanna’s 69-entry log, and 14 were added to Gaston’s 66 entries. Gaston’s log required more adjustment to the time stamps; however, this was unsurprising given that he had noted that he felt his recorded times were imprecise.

The captured photos provide a window into the family’s everyday world, and also into their relationships and the moods with which they interact. Hanna, Gaston, and Harvey each found it interesting to see the world from the point of view of other family members. For instance, Hanna commented on how serious she looked in an image captured by Harvey’s camera as he sat across the table from her while she organized his medications. Another photo showed Gaston as he stood, perhaps impatiently, outside the bathroom door waiting for Harvey.

From Harvey’s camera we were able to construct a “log” of sorts that noted caregiving activities we could see happening from his visual point of view. Excluding sleep, we were only able to account for seven and a half hours of the study period. For much of that period we relied heavily on contextual information from Hanna and Gaston’s logs and photos.
Hanna: Photo Log diagram.

Gaston: Photo Log diagram.

Harvey: Photo Log diagram.
Body Sensors

Hanna, Gaston, and Harvey each wore an Empatica E4 sensor during the study. Gaston wore it throughout, from 11:00 am to 3:00 pm the next day. Hanna wore it from 11:00 am to 10:00 am the next morning, when she left for work. Harvey wore it from 12:30 pm on the first day, when he woke up, to 9:30 am the next morning when he left home for the daycare facility. All three wore it while sleeping and removed it for bathing.

The acceleration data shows that, overall, Hanna is more physically active than Gaston. Gaston, however, has periods of higher intensity activity than Hanna does. Harvey’s data corresponds to his more sedentary life.

Neither Hanna nor Gaston noted any especially stressful moments within their logs, recording a few 2s and 3s, but no 4s or 5s. Still, while the logs included many stress entries of 0, during the second interview they noted that in fact there is always some level of stress. Interestingly, the electrodermal activity (EDA) data tended to peak at times that correspond closely to log entries showing that one person was both helping Harvey, and also simultaneously performing household chores and/or work activities.

Hanna self-reported a “3” stress level while dealing with Harvey’s meds. Her EDA was higher here than with other 3s, but Hanna reports it was also warm in the room, which increases electrodermal activity. Still, the sensor spike prompted a conversation that helped illuminate exactly how stressful organizing medicines can be. “(It’s) because an error is really serious for him. I put a lot of pressure on myself to do it right. There are six different meds, and all of them have different schedules,” she said, while demonstrating an elaborate method for organizing the medications. Gaston’s EDA registered stress associated from a grass fire on the side of the highway when he was driving with Harvey to a meeting at the day care center.

The E4’s nighttime acceleration and heart rate readings were striking. Gaston sleeps poorly, often waking up due to pain. He regularly has to get up to stretch and relax. This night, around midnight, having gotten up to use the bathroom, he fell back asleep on the toilet. Then, after getting up to stretch around 4:00 am, he returned to bed to find that one of the dogs had taken over his pillow. He moved to sleep on the living room couch. During the period from 10:00 pm to 5:30 am, he only slept for around 3.5 hours and he got up at least five times. This is significantly less sleep than the 6.1 hours that he reported in his log. Viewing the nighttime data was troublesome to him, as it confirmed in stark clarity his concerns about sleep. By contrast, Hanna slept well. From 10:00 pm to 5:30 am, she slept for seven hours, with brief periods of wakefulness around 12:30 pm—when she found Gaston asleep on the toilet—and 5:00 am.
Hanna: Body Sensors diagrams

Gaston: Body Sensors diagrams

Harvey: Body Sensors diagrams

Zoom-able diagrams can be found at http://atlasofcaregiving.com/studies
Environmental Sensors
SmartThings and Netatmo sensors were placed around the home. No data was captured from these devices due to an unknown technical glitch.

Data Already Present
Hanna and Gaston use a video feed to monitor Harvey while they are in other parts of the house, but they have concerns about figuring out ways to use the video that do not violate Harvey’s privacy. They are also both enthusiastic Fitbit users. Gaston uses it as a small part of his self-care. His doctor has said he should be getting between 3000 and 5000 steps. He can often meet the lower bound of that recommendation, realizing 3,000-4,000 steps, but on many days even that much is impossible. Hanna and Gaston enjoy teasing each other about how many steps they get, and have a small competition with Gaston’s daughter. They did not draw a connection between the activity data and how it may relate to what they are doing with respect to caregiving, or stress.

Hanna and Gaston and Harvey: Environmental and Motion Sensors diagrams.
Study 6: Fernando’s Household

Fernando and his wife Laura (50s) are the primary caregivers for Fernando’s mother Maria (80s), who was diagnosed with Alzheimer’s disease last year. Together, Fernando and Laura have built a care network to support Maria.

Context
Both Fernando and Laura work in the technology sector in the Bay Area. They have one son, who is in college.

Fernando’s mother lives in the home next door to Fernando and Laura. She raised three children in the neighborhood that she has called home for all of her life, and had a successful career as an educator within the local school district.

In early 2014, Maria suffered a concussion and skull fracture in a traffic accident. Fernando and Laura provided significant assistance to her as she recuperated. But during her recovery they noticed that she often appeared forgetful and confused. It was a sharp turn from the Maria they knew as independent. Up until the crash she had retained her ability to manage all household and personal activities, and she traveled easily—both locally and by plane. Fernando and Laura’s location next door allowed them to track Maria’s behavior in detail for a month. Eventually she was diagnosed with Alzheimer’s.

The diagnosis, and Maria’s other medical issues—lymphoma (in remission), hepatitis B (under control), and high blood pressure—have placed Fernando and Laura in position as Maria’s primary caregivers. Together they provide support, and coordinate efforts of family and professionals.

The Kind of Day it Was
Fernando and Laura’s participation occurred at the end of the work week. They began logging activities and wearing physiological sensors on Friday morning.

Before beginning, Laura cautioned that much of the couple’s care for Maria involves setting up systems for coordinating care and ensuring that Maria has what she needs. “It may appear that we don’t do much,” Laura said. “We don’t do much hands-on caregiving [right now]…[Maria] doesn’t like it, and we have no bandwidth or patience for it. We put our energy into research, planning, and coordinating three paid caregivers and three family members.” Indeed, on this day caregiving was relatively light.
**Care Network**

Fernando and Laura are the primary caregivers for Maria. For a time, Laura bore much of the responsibility for Maria’s care. But, the role soon became too much. Three assistants were hired, and they now split shifts to provide about 40 hours of assistance each week.

Today, Fernando and Laura’s role is to primarily assist Maria with household and other daily tasks, and check in on her several times each day. However, having the assistants still requires a lot of daily communication and coordination. Laura is the first person that the assistants contact when they have questions or problems. Laura then contacts Fernando if needed. The couple sometimes devote significant amounts of time to coordination. When something goes wrong, and they have to attend personally, it can take hours to resolve the issue.

The three home care aides—one weekday mornings, one weekday afternoons, one Saturday—provide Maria with extensive care. They help her with home activities, and take her on outings (e.g., to the park or shopping) and to basic doctor visits. Maria has nine doctors. Fernando listed a primary care physician, two dentists, neurologist, neuropsychologist, oncologist, hepatologist, ophthalmologist, and gynecologist.

Maria’s other children provide additional support, though at first they struggled to accept Maria’s diagnosis. Now, on occasion, Fernando’s brother and sister-in-law help care for Maria and with her financial affairs. Fernando’s sister and niece sometimes provide social support.

Fernando and Laura’s care responsibilities also extend to other family members. Fernando helps his father, who lives two hours away in an assisted care facility. However, Fernando’s brother lives closer and takes a bigger role.

Laura is involved in the care of her own parents, who live far away. Her sister and brother live much closer and help often, but for several reasons Laura is the primary decision maker for her parents’ health and other needs. She is the oldest daughter and is expected to lead. In addition, Laura ends up being the family’s central node of communication because her parents speak English poorly and her siblings speak their native language poorly. Laura occasionally visits to provide direct support, but mostly helps with what are often daily research and decision-making tasks.

Infrequently, Fernando and Laura attend a caregiver support group and meet with a family therapist. Both of these help them cope with the challenges of caring for Maria. Otherwise, Fernando and Laura rely on each other for support. Fernando also cares for their dog, who has had major back surgery and is not as self-sufficient as he used to be. With Type 2 Diabetes, Laura must manage her own health issues alongside caregiving.
Activities
Fernando's log covered about 29 hours. This included 1.9 hours of caregiving, 4.6 hours of other activities, 4.9 hours of leisure, and 2 hours of work. The log did not specify when he slept, and he took off the wrist sensor too early for readings to provide insight. It should be noted that many hours are unaccounted for and Fernando's log entries for non-caregiving activities were sparse. It is thus difficult to be confident in the recorded time distributions. The table on the next page shows the primary caregiving activities that were recorded.

Laura intended to keep a log, but failed to do so aside from one entry denoting a discussion with one of the paid caregivers. Anecdotally, she told us that her day's caregiving revolved around planning and discussions for Maria's situation and needs.

Fernando: 24-hour Log, 36-hour Log, and Activities diagrams.

Zoom-able diagrams can be found at [http://atlasofcaregiving.com/studies](http://atlasofcaregiving.com/studies)
<table>
<thead>
<tr>
<th><strong>Fernando’s Main Care Activities</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Day-to-Day Caregiving</strong></td>
</tr>
<tr>
<td>Scheduled medical appointments</td>
</tr>
<tr>
<td>Checked-in on Maria (multiple times)</td>
</tr>
<tr>
<td><strong>Household tasks</strong></td>
</tr>
<tr>
<td>Dealt with heating and cooling problems linked to the air conditioner and fan</td>
</tr>
<tr>
<td>Cooked for Maria</td>
</tr>
<tr>
<td><strong>Communication</strong></td>
</tr>
<tr>
<td>Conversed with siblings about Maria’s current wellbeing and overall caregiving needs</td>
</tr>
<tr>
<td>Communicated with Maria’s paid caregivers</td>
</tr>
<tr>
<td>Held conversations with Laura about Maria’s need and scheduling issues</td>
</tr>
</tbody>
</table>
Photos
Fernando and Laura both wore the Narrative Clip. In this case, however, photos did not significantly contribute to a better understanding of caregiving. Fernando commented that if they did more direct caregiving there may have been more to triangulate between the photos and the log. This prompted a discussion about whether there would be value in asking the caregivers they hire to wear a Narrative Clip, even if temporarily. Doing so would allow for a glimpse of the world through the caregiver’s eyes, and lend insight into incidents that they sometimes report like Maria looking tired or ready to faint. However, Fernando felt that this might be problematic as an act of surveillance.
Body Sensors
Fernando wore the Empatica E4, except from 8:00 pm Friday night to 8:30 am Saturday morning.

On his log, Fernando recorded low stress levels (0s and 1s) for most of his entries. The highest stress moment (3) occurred around 3:00 pm when he was at a store trying without success to return a fan he had bought for his mother. A little later, at 3:46 pm he noted a stress level of 2 when discussing Maria’s needs with a paid caregiver. This period corresponds to the greatest activity seen in the electrodermal activity (EDA) signal from the E4.

The EDA data also shows a spike around 2:30 pm, which matches a log entry of a conversation with Laura about Maria’s care schedule. The self-reported stress level, however, was only 1.

Zoom-able diagrams can be found at http://atlasofcaregiving.com/studies
Environmental Sensors
The SmartThings motion sensors and Netatmo environmental sensors were not deployed as Fernando felt that Maria would find the devices disturbing.

Data Already Present
As part of Fernando and Laura’s care coordination work they have created multiple spreadsheets that document assigned tasks. These spreadsheets break out tasks on both a weekly and long-term basis.

On the spreadsheets, Fernando and Laura identified 41 separate types of caregiving support, each one with an individual assigned responsibility. Often, the assigned responsibility is to themselves, suggesting that they are not totally hands-off. They also have written a detailed history of Maria’s situation since her accident, and ask that care assistants fill in daily logs.

Of all the participants, Fernando and Laura seemed to get the fewest fresh insights from their participation in the Atlas project. One possible explanation may be that they are already highly cognizant of their caregiving due to their extensive efforts to track and organize their care activities.

Fernando and Laura: Environmental and Motion Sensors diagrams.
Study 7: Ida’s Household

Ida (70s) cares for her husband Ian (70s), who has Lewy Body Dementia and dysautonomia. Ian’s health worsened considerably in early 2015. Though he has since recovered enough that he is no longer receiving hospice care, Ida lives with much stress about a future in which such changes could be permanent.

Context

Ida and Ian moved to the San Francisco Bay Area two years ago after living for decades on the East Coast. Leaving behind a lifetime of friends and many other connections was a difficult decision, but ultimately they made the move based on Ian’s health and the desire to be closer to their children. Their daughter lives a few minutes away and one of their sons lives about an hour away. Two other sons live abroad.

Ian had a long law career and had remained active after retirement. Ida’s background is in health. She is a registered nurse, but is not currently practicing. She also had a holistic healing practice for many years. She has deep experience with health and wellness but during the study Ida commented that being the primary caregiver for someone is very different.

Ian was diagnosed with Lewy Body Dementia in 2010. He also has severe dysautonomia, meaning his blood pressure can vary dramatically from moment to moment. The condition puts him at high risk of falling, which causes great concern to Ida and other caregivers. Even so, Ian has made it clear that he prefers the risk of falling to having a caregiver follow him all day. After a discussion, his family relented and agreed to remove such care. Ida feels uncomfortable about the arrangement, but she also understands Ian’s desire for freedom.

Two months prior to the Atlas study Ian’s condition severely worsened. He was under 24×7 hospice care. After a long visit by his children and their families, his health improved dramatically. Ian and Ida participated in the study during this period of improved health.

The Kind of Day it Was

The last few months have been a roller coaster. Ian’s recovery has ushered in a period of relative calm, but Ida still has to cope with constant, gnawing uncertainty. During interviews, Ida spoke of being always vigilant: on alert because she does not know if—or when—a calm day will turn another direction.

The day of the Atlas study was relatively stress-free, but Ian’s dysautonomia still required Ida to make difficult decisions. For instance, during one part of the day Ian wanted to go for a walk. It was up to Ida to make the call. She took his blood pressure. Ian had been standing and the reading was 69 over 49. “I think: ‘He can’t do that; it’s too risky,’” she said. When she took it again after he had been sitting, the reading swung to 176 over 97. In a day full of similarly routine activities, the blood pressure readings seem to underscore—and symbolize—Ida’s apprehension over just how quickly things can change.
Ida and Ian live by themselves. Ida is Ian's primary caregiver.

They have a large supportive family. A daughter and son-in-law live nearby, and are pictured in the house next to Ida’s. A son lives about an hour away. Both provide important sources of help. Ida leans on both her daughter and son for emotional support, and her son also aids with major financial decisions. Two other sons, grandchildren, and several siblings live far away. Ian is especially close to his sister, who he speaks with by phone almost daily.

These distant family members are an important source of emotional support, but they are rarely able to help directly. Day-to-day care is Ida’s responsibility. When Ian’s health was much worse a couple of months prior to their participation, several home care aides, hospice nurses, and social workers were involved. They are featured on the care network map given their recent role in rehabilitating Ian’s health, but at the time of the Atlas study a trainer was one of only a few remaining sources of consistent professional care. The trainer helps Ian to exercise twice a week, a change that has significantly improved Ian’s life. A primary care physician and a neurologist are also a part of Ian’s care network.

Ida maintains her own wellness by participating in a local support group and maintaining contact with her east coast friends. She also cares for her son-in-law and granddaughter, drawing on her experience as a registered nurse and practitioner of health and wellness.
Activities

The 27 hours covered by Ida’s log include 2.8 hours caregiving, 6.8 hours of leisure, 9.8 hours sleep, and 6.5 hours of other activities. Of note, the self-reported sleep duration might better be classified as “time in bed” given that Ida spent much of the night half-awake, worrying about the family’s caregiving situation. In the initial survey, Ida had checked the box for “5-10 hours” per day of caregiving.

[Keeping track of activities in a log] was a simple thing to do, but it’s constantly in your consciousness, and the ramifications—thinking about the past and the future—are all right there.

As with many other Atlas participants, Ida noted that the log made her more conscious of the caregiving that she does. She joked: “Oh, I should give my kids a copy of that! They have no idea.” But, when offered a copy of the log it became apparent that she didn’t mean it literally. “There’s no way [anybody] can know what’s involved unless you really live it,” she said. The comment neatly captures a goal of the Atlas project: to use a variety of mapping techniques to create a more three-dimensional understanding of what caregivers do and how burdensome their activities are.

Interestingly, the activity log itself had an impact on the day, making it more stressful than it otherwise might have been. For Ida, participating in the project raised concerns about the future. “I had a really hard time sleeping that Monday night,” she said. “Keeping track of [activities in the log] was more difficult than I expected. It was a simple thing to do, but it’s constantly in your consciousness and the ramifications—thinking about the past and the future—are all right there. There was no way to escape thinking about…what things could look like soon and how I have no way to know.”

Zoom-able diagrams can be found at http://atlasofcaregiving.com/studies
<table>
<thead>
<tr>
<th>Ida’s Main Care Activities</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Oversight of Ian’s activities</strong></td>
</tr>
<tr>
<td>Checked that his phone is on</td>
</tr>
<tr>
<td>Re-vacuumed after he is done</td>
</tr>
<tr>
<td><strong>Helped Ian with daily activities</strong></td>
</tr>
<tr>
<td>Navigating email, getting bedroom ready for sleeping, etc.</td>
</tr>
<tr>
<td><strong>Communication</strong></td>
</tr>
<tr>
<td>With family, friends, caregivers about Ian’s condition</td>
</tr>
<tr>
<td><strong>Record keeping</strong></td>
</tr>
<tr>
<td>Updated records containing Ian’s health condition and activities</td>
</tr>
<tr>
<td><strong>Medical tasks</strong></td>
</tr>
<tr>
<td>Tracking symptoms and body measurements</td>
</tr>
</tbody>
</table>
Photos
Ida wore the Narrative Clip, in her case, the photos were not particularly helpful in providing a better understanding of her day. Twenty-four entries were added to the original 37 activities that Ida logged, but most of these were small refinements (e.g., adding moments that she checked email or poured herself a drink). During the follow-up interview, the photos did not spark notable memories for her in the same way that they did for many other study participants. The most notable discovery from the photos was that Ida conducts significant care coordination and scheduling work via a paper calendar (see Data Already Present section).
**Body Sensors**

Ida wore the Empatica E4 during most of the participation period, save for when it was removed for a water aerobics class. Overall, the electrodermal activity (EDA) chart shows little activity, matching Ida's self-report that it was a relatively uneventful, stress-free day.

Acceleration data is able to confirm Ida's reports of a restless night's sleep. Her log notes that she began reading in bed at 9:10 pm, went to sleep at 10:00 pm, and got up at 7:50 am. However, in the second interview she noted that she slept badly. Ida's movement goes down noticeably around 9:10. (There is an odd gap in the data from about 10:30 pm to 12:45 am—it appears as though Ida removed the E4, but in interviews she confirmed that she kept it on.) Thereafter, she shows consistent, small movements for several hours, before apparently sleeping more soundly from about 3:00 am onward.

Zoom-able diagrams can be found at [http://atlasofcaregiving.com/studies](http://atlasofcaregiving.com/studies)
**Environmental Sensors**

SmartThings and Netatmo sensors were placed around the home. One Netatmo sensor was placed next to the dining table and another in the bathroom used by Ian.

The sound level near the dining table is higher in the evening and corresponds to the TV being on, as reported in Ida’s log. There are spikes in the noise midday on both days, which could be conversations at the dining table or construction noise outside (the home next door was being remodeled). The carbon dioxide level spiked at 6:47 pm while dinner was being prepared. Little information can be gleaned from this data in regard to caregiving.

The motion detectors seem to suggest that there is significant daytime activity in Ida’s bedroom, Ian’s bedroom, and the office, but that did not seem to signify anything in particular about Ida’s caregiving.

**Data Already Present**

Ida keeps a diary of Ian’s medical conditions. She spent some time on it during the period of study, and noted that she had not made an entry in a month and a half. She explained that if she does not write information down it becomes very difficult for her to keep relevant medical information in her head for the time when it is needed. During an interview this comment led to a discussion about medical records, which should nominally supply this information. Ida replied: “My experience with medical records is that it’s so difficult to get them that if I don’t keep track of things myself, nobody is going to.”

As a former nurse, it’s a situation she finds particularly frustrating. She understands the value of medical records and the fact that providing them should not be an especially burdensome task for professional health providers. In this case, perceived road blocks within the medical system add to Ida’s caregiving workload.

Zoom-able diagrams can be found at [http://atlasofcaregiving.com/studies](http://atlasofcaregiving.com/studies)
Study 8: Nadine’s Household

Nadine (50s) lives with her husband Jerry and two teenage sons, Larry and Karl. Karl has Type 1 Diabetes. Nadine is his primary caregiver.

Context
Nadine and Jerry live with their sons Larry and Karl in an urban part of the San Francisco Bay Area. Jerry is an engineer in the technology industry. Nadine was a lawyer, but when Karl was diagnosed at age four with Type 1 Diabetes (T1D) she retired to care for the children.

Karl is now a teenager. With age, he has become more proficient at self-care. He is alert to blood sugar highs and lows, and knows how to check glucose levels. He also self-administers glucose pills when needed. Despite this, Nadine is still heavily involved and bears primary responsibility for his health.

The Kind of Day it Was
The Atlas study period coincided with several challenging care situations. High readings by Karl’s continuous glucose monitor set off alarms throughout the night. With each alarm, Nadine rose to assess the situation and treat Karl. This kind of nocturnal care activity is not uncommon for Nadine, but the frequency of the alarms was higher than usual and may have been due to the insulin pump’s infusion set getting infected.

Karl woke up exhausted and grumpy from the tumultuous night. His impaired state interfered with his normal morning routine and he did not fill his insulin pump properly. As he rode his bicycle to school, Nadine checked her mobile monitor and saw that his blood sugar was rising rapidly. Later that morning, she noticed that it was continuing to rise. Unable to leave a meeting, she tried to call and text him several times but got no response. She contacted Jerry and asked him to try to contact the school nurse. Eventually Karl texted from the nurse’s office with an explanation for his high blood sugar; he had not adjusted his insulin intake to compensate for juice that he drank. A dose of insulin brought his blood sugar back to normal.
Care Network

Nadine assists and monitors Karl throughout each day. Meeting this responsibility requires a state of constant vigilance, even when Karl is away from home. When Karl is at school or soccer practice, or out playing with friends, she regularly monitors his glucose level through her mobile phone and communicates with him as needed. Jerry provides additional support, especially when Nadine is not around, but he is less comfortable and not as confident with the caregiving responsibilities that Nadine manages.

Outside the home, Nadine has identified several people who could help Karl in an emergency. She trained two immediate neighbors in basic T1D management, as well a friend who lives a few minutes away.

Karl’s primary source of professional care is an endocrinologist located 45 minutes away. During the first year after Karl’s diagnosis a major nearby medical center provided a closer source of care, but ultimately the family was dissatisfied with the advice they were receiving. They switched to their current endocrinologist and have been happy despite the distance.

Nadine receives emotional support from several sources, including two nearby friends who she sees weekly. Nadine is involved with several local groups. She interacts daily with an online community of other mothers who care for children with T1D and is active in the local T1D community. While she receives support from the latter, she also puts a substantial amount of work into keeping the community going.
Activities
The 26 hours covered by Nadine's log included 7.3 hours of caregiving, 7.5 hours of sleep, and 11.2 hours of other activities. Nadine's caregiving activities during the study involved monitoring and managing Karl's blood glucose levels, managing supplies, and building the communities that support this work more broadly.

“[Seeing the activity log], now it feels a little more like: Yeah, I'm not just wasting my time... I've been doing things.”

As is commonly true of Nadine's daily caregiving, the majority of her activities were related to working out how Karl's food and insulin are likely to affect each other, and how much of each to take in at a given time. Nadine explained: “It's always a little bit of a balance trying not to take in too many carbs; it's very hard to cover [them] with insulin and to predict how they will be absorbed.” She also described that things are especially difficult when Karl is away from home and physically active for a few hours. In that case, she said that she reduces Karl's insulin, sets a temporary basal rate of 60 percent for two hours, and then “hope[s] for the best.” She added: “if things get too much out of whack I call the coach [while Karl is playing soccer].”

Nadine's ability to perform this kind of care derives from an experienced ability to stay attuned to all possible situations. During the interview portion of the Atlas study, for example, she heard her son in the next room pouring cereal into a bowl. In one fluid gesture she checked the glucose readings on her phone, decided it was okay, and returned to the conversation.

Zoom-able diagrams can be found at http://atlasofcaregiving.com/studies
<table>
<thead>
<tr>
<th>Nadine’s Main Care Activities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Monitoring &amp; managing Karl’s blood glucose (BG) levels</td>
</tr>
<tr>
<td>Texted/called Karl as needed</td>
</tr>
<tr>
<td>Responded to alarms from Dexcom (a BG monitoring device)</td>
</tr>
<tr>
<td>Tested BG levels</td>
</tr>
<tr>
<td>Tracked and analyzed food consumption</td>
</tr>
<tr>
<td>Managed insulin doses</td>
</tr>
<tr>
<td>Managed and performed maintenance on medical equipment (insulin pump and continuous glucose monitor)</td>
</tr>
<tr>
<td>Managing Karl’s supplies</td>
</tr>
<tr>
<td>Healthcare management</td>
</tr>
<tr>
<td>Research</td>
</tr>
<tr>
<td>Type 1 Diabetes community involvement</td>
</tr>
</tbody>
</table>

When Nadine discussed the experience of logging caregiving activities, she drew an interesting comparison between her former work as a lawyer and the work she does now as a caregiver. She noted that as an attorney when she logged billable hours they usually reflected large chunks of time for one activity or case, and that she was generally in one location. As a caregiver, however, her log reflected that she is often dashing between different types of work and that she frequently encounters interruptions (e.g., by the alarms on Karl’s blood glucose monitor).

The activity log also confirmed to Nadine the true extent to which she fills her day with caregiving activities. Seeing the day’s activities laid out, she said “Now it feels a little more like: ‘Yeah, I’m not just wasting my time; I’ve been doing things’.” Nadine’s comment seems to suggest that the log contributed to helping her to value the daily work that she does.
Photos
Nadine wore the Narrative clip throughout the period of study, save for during a meeting and at night.

In total, 40 mostly minor refinements and new entries were added to Nadine’s original 71-entry log as a result of evidence captured in photos from the Clip. They revealed additional activities that Nadine did not log—emailing, text messaging, driving, reading, eating, and food preparation—and also assisted in honing in on the exact time that activities occurred. Finally, they showed that she uses her bike as a primary mode of transportation.

In our interview, Nadine mentioned that the picture at right shows the home where she had the first of several morning meetings. When the time stamp for the picture (8:23 am) was combined with reports from the activity log and body sensors, researchers began to piece together exactly what catalyzed mounting “stress” for Nadine on Friday morning.

The story of this discovery is reported in the Body Sensors section, but it is important to note here the way that the Narrative Clip combines with other reporting mechanisms in the Atlas study to tell a story. The image contributes to analysis only because Nadine herself participated in that analysis. She understands the significance of this building; if researchers were to examine it without knowing the context, they might easily mistake it for a random moment in her bike ride. Instead, viewing the photo triggered memories of additional things that were occurring at the time, which led to discussion about what her high stress levels were about.

This photo helped Nadine delve into the reasons she felt stressed at this moment.

Nadine: Photo Log diagram.

Zoom-able diagrams can be found at http://atlasofcaregiving.com/studies
Body Sensors

Nadine wore the Empatica E4 throughout the time of her participation. She only removed the E4 when she took a shower. Although Nadine described the study period as involving a difficult night and second day, the only events in her log for which she ascribed a stress level of 3 or 4 were on Friday morning. Electrodermal activity (EDA) data shows a small period of emotional arousal around 7:00 am, and another smaller period just after 8:00 am.

Nadine at first noted that her stress spiked in a school meeting because her son’s insulin levels were rising and she was unable to contact him. “I felt so bad because I was constantly texting and there was a counselor sitting with a direct view of me... [I felt like saying to her]: ‘I’m sorry; I know you don’t know why I’m texting, but I have to text now’.”

Later in the interview, Nadine and researchers looked at the EDA data together. Zooming into the morning revealed that her period of elevated EDA actually corresponded precisely with the time when she was about to enter the building for her meeting (see Photos section). Seeing that the EDA spike had actually started a little earlier than the meeting prompted an additional reflection on the source of the stress. Nadine commented that it likely derived from a fleeting thought she had about having to manage another meeting immediately following the one that she was entering.

This finding suggests that it might be useful to think of stress in Nadine’s case as a multi-layered phenomenon. She first experienced the stress of a potential medical emergency. Layered on top was another source of stress: her inability to contact the people who could resolve the problem, coupled with the social anxiety of appearing to behave inappropriately while trying to do so. Her last set of comments suggest that perhaps this would have been more manageable if she had not also been experiencing the strain of having to manage back to back meetings.

During the rest of the study period the EDA signal remained relatively low. According to the data Nadine stayed calm despite her activities and concerns. A few small spikes in the EDA may correspond to brief, difficult moments: 3:30 pm on the first day when she had a conversation with one of her sons, 4:45 pm as she rushed out to pick up her children, and 11:30 am on the second day when she arrived at a meeting feeling guilty that she had missed the previous meeting.

Nadine said that she went to bed at about 10:30 pm and awoke at 6:15 am, but she also added that she did not sleep well as a result of having to get up many times to care for Karl. The E4’s acceleration data matches Nadine’s perception of a busy and restless night. The data shows that she was up at least six times (12:15 am, 1:15 am, 2:30 am, 3:10 am, 3:30 am and 5:30 am), and that she tossed and turned throughout the night. There were five stretches, each about 30 minutes, when she slept soundly.

She gets up frequently to monitor Karl’s glucose level because she is not fully confident in the continuous glucose monitor’s alarms.

Zoom-able diagrams can be found at http://atlasofcaregiving.com/studies
Environmental Sensors
SmartThings motion sensors and Netatmo atmosphere sensors were deployed; however, an unknown technical error prevented the collection of reliable data.

Data Already Present
Nadine uses a mobile phone application that receives blood glucose levels from the continuous glucose monitor that Karl wears. She primarily relies on the application for real-time monitoring, but it also tracks and catalogs readings to generate reports on blood glucose levels over time. These data exist, but were not reviewed for the present study.
Study 9: Odette’s Household

Odette (70s) and her husband Marco (70s) share their home with several other people: their son, son-in-law, and five tenants. Marco has Parkinson’s disease and Type 1 Diabetes. Odette is his primary caregiver, but several others are also involved.

Context
Odette and Marco live in a large urban home with many other people. They rent rooms to five tenants, and their son and son-in-law live on the top floor.

Odette organizes and provides 24×7 care for Marco. Marco has had insulin dependent Type 1 diabetes for over 35 years, and he was diagnosed with Parkinsonism and Lewy Body Dementia five years ago. “Marco has some neuropathy from the diabetes, and nerve damage from spinal stenosis,” explains Odette. “He can do very little for himself due to mobility and strength issues, and mild cognitive impairment from the Parkinson’s disease.” The dementia sometimes causes Marco to get confused, and to see scary hallucinations.

Marco and Odette have both lived in the area for nearly 50 years. He transplanted from the East Coast; she came from Southern California. They married 45 years ago and have two children. Odette had a long career in architecture and property management in the government sector. Marco had a long career in education and teaching, before becoming a clergyman. His clergy work took them to Europe for a few years, but they eventually returned to the Bay Area due to his failing health.

The transition home has not been easy. They discovered that the caregiving support that they received from government, friends, and neighbors in Europe was much greater than what they find in California. In addition, it has been hard to re-build a community. This is true in part because of Marco’s health, but also because their experience abroad reshaped their expectations about community involvement in care.

Odette’s parents were both in their 90s when they died about ten years ago. Up to the time of their death, her parents insisted on living on their own and resisted accepting outside help. This was hard on Odette and her siblings. This experience, alongside the impact of seeing a more European approach to caregiving, has influenced Odette’s caregiving philosophy. She seeks to make the most of assistance from paid and unpaid caregivers. Doing so requires a concerted effort to maintain finances so that they can afford to pay for assistance. Filling their large house with paying tenants is part of this effort.

The Kind of Day it Was
Odette spent much of the day at home and did not mention that caregiving or other activities were out of the ordinary. The day was not overly stressful, but neither was it stress-free.
**Care Network**

Odette is Marco’s primary caregiver, but several others are also involved.

A home care aide helps Marco get ready every weekday morning for an hour. She wakes him, and helps him with toileting, dressing, grooming, and breakfast. One of the tenants, a friend, cares for Marco for a few hours about four days a week. His help is mostly confined to the morning and early afternoon. He helps with medications, activities, and lunch. Twice a week, for two hours in the afternoon, another home care aide helps Marco with bathing. This aide also prepares dinner. A massage therapist treats Marco at home once a week.

“I knew when coming home [from living in Europe] that I would want to hire help…it just makes such a difference.”

Odette finds comfort in knowing that her son and son-in-law live in the same home, and that they are there to help whenever needed. Their daughter lives nearby and visits weekly. She and Marco often read together or go for outings.

About every other day one of Odette’s friends visits. Usually they just sit and talk, but sometimes they go for a walk or run errands. Another friend lives far away. Odette’s communication with her has grown infrequent, but Odette supported the friend through her own caregiving situation in the past so the friend understands Odette’s situation. Odette also receives support from her church and from several caregiver support groups.

Zoom-able diagrams can be found at [http://atlasofcaregiving.com/studies](http://atlasofcaregiving.com/studies)
Activities
Odette’s log entries begin at 1:00 pm on Monday, and end at 3:11 pm on Tuesday.

The list of activities in the table on the next page does not capture Odette’s high level of awareness of what Marco is doing. She watches closely, even when he is only engaged in small or very basic activities. For instance, during the interview researchers observed that Odette was repeatedly conscious of Marco’s movements to put his glass of water on the table, knowing that his motor skills are impaired by Parkinson’s.

Logging helped Odette to observe that Marco seemed not to ask to go to the toilet as frequently when he was engaged with activities. This made her wonder if being bored made him go to the toilet more often, and whether she might need to find more things to help him to stay busy.

Odette perceives herself as a “less regulated person.” The log helped her to understand the sheer variety of tasks that she attends to.
### Odette’s Main Care Activities

<table>
<thead>
<tr>
<th>Category</th>
<th>Activity Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Basic activities</strong></td>
<td>Retrieved water, reading materials, and glasses.</td>
</tr>
<tr>
<td></td>
<td>Turned on lights, TV, music, etc.</td>
</tr>
<tr>
<td></td>
<td>Assisted Marco with toileting on multiple occasions</td>
</tr>
<tr>
<td><strong>Medical activities</strong></td>
<td>Checked blood glucose level and administered insulin</td>
</tr>
<tr>
<td></td>
<td>Managed and provided medications (e.g., cut pills, restocking)</td>
</tr>
<tr>
<td><strong>Healthcare management</strong></td>
<td>Deal with insurance and appointments</td>
</tr>
<tr>
<td></td>
<td>Managed home health aides</td>
</tr>
<tr>
<td><strong>Mobility</strong></td>
<td>Helped Marco in and out of his wheelchair and bed, and assisted him with moving</td>
</tr>
<tr>
<td></td>
<td>between rooms or up/down stairs</td>
</tr>
<tr>
<td></td>
<td>Drove Marco to appointments</td>
</tr>
<tr>
<td><strong>Emotional support</strong></td>
<td>Gave support, especially after Marco remembered a hallucination</td>
</tr>
</tbody>
</table>
Photos
Odette made 45 entries in her log. 21 more were added based on evidence from photos taken by the Narrative Clip she wore. In the second interview, Odette told researchers that many of the pictures were likely to be of her on the phone checking email and texts. This was indeed true, but not more so than other Atlas participants.

Photos show that baking cookies involved a large portion of the evening. Odette made a batch to thank her friend for giving Marco a massage, and pictures reveal that it is an activity that she went back and forth to throughout the evening. Some pictures would not have been interpretable without the log. In one instance a photo showed someone else's shoe with no other context. By checking the photo's time stamp against the log, researchers were able to determine that this was around the time that Odette's friend visited. The definitive time-stamp allowed them to slightly adjust Odette's hand-recorded time of the visit.

Baking cookies was a major activity for Odette that evening.

Zoom-able diagrams can be found at http://atlasofcaregiving.com/studies
Body Sensors
Odette wore the Empatica E4 from 1:00 pm on Monday to 3:00 pm on Tuesday. She only took it off once, on Tuesday morning when she bathed.

Odette did not record any entries denoting high stress (4 or 5) events in her log. However a few moderate stress (2 or 3) events did occur. One was during a moment that Marco became emotional after recalling a past hallucination. Odette also recorded moderate stress when Marco’s blood sugar was low and once when she helped him with toileting. The electrodermal activity (EDA) signal does not capture these moments.

The EDA analysis does show that the period when Odette was the most emotionally aroused was late Monday evening around 11:00 pm. The elevated EDA activity may result from a burned batch of cookies. Its persistence into the early morning correlates with Odette saying that she had a difficult time falling asleep.

The study itself may have had some impact on her difficulty sleeping. She said that wearing the E4 made her wonder: “What is it recording?” Acceleration and heart rate data from the E4 shows that she slept most soundly from 12:30-2:00 am. There were several periods of tossing and turning during the rest of the night, and she had to get up to help Marco to the toilet at 6:45 am.

Odette and Marco went to see a movie on Tuesday morning, and this period shows up as a time of low acceleration in the E4 data.

Zoom-able diagrams can be found at http://atlasofcaregiving.com/studies
Environmental Sensors
Due to the large size of the house, and so many people using the common rooms (entry area, kitchen, stairs, downstairs bathroom, etc.), SmartThings motion detectors were not deployed throughout the home. Instead, they were placed in the rooms where Marco and Odette spend most of their time: the downstairs living-dining room, and bedroom and bathroom upstairs. Netatmo sensors were placed in the living-dining room and bathroom.

Sound levels rise and fall in the dining room on Monday evening, roughly corresponding to conversations in Odette’s log. The sound-level rise on Tuesday morning likely reflects the household waking up as well as increasing traffic on the busy street they live on. CO2 levels may be representative of the whole home, rather than just the living room, given that the floor plan is relatively open. The bathroom humidity sensor clearly shows when Odette showered at 8:30 am on Tuesday.

Other Data Present
Odette keeps a journal. She records how she is feeling about every five days, and also what activities she and Marco have been involved in. It serves as a cathartic exercise. It allows Odette to get emotions out and onto the page, and also to reflect on how actions and activities affect her emotions. She observed that she normally does not record hour-by-hour events and emotions in her journal, unless there is a crisis.

Zoom-able diagrams can be found at [http://atlasofcaregiving.com/studies](http://atlasofcaregiving.com/studies)
Study 10: Nate’s Household

Nate and Patty, both in their 30s, care for each other. Patty has multiple sclerosis and Nate has glioblastoma, a terminal condition.

Context
Nate and his wife Patty live in an urban apartment in the San Francisco Bay Area. They met in college and have been together for over a dozen years.

Both Nate and Patty have significant health issues. Patty was diagnosed with multiple sclerosis (MS) soon after graduating college. Patty lived and worked internationally prior to her diagnosis, complicating the diagnosis process. Her early experience with doctors was not positive. She feels that it took them a long time to settle on a diagnosis, and then that they treated her merely as an interesting test subject (due to being diagnosed with MS at such a young age). “I really lost my faith in the medical system because I didn’t feel like my doctors had my best interest at heart,” she said. For many years after she stayed away from doctors.

About six years ago, after a serious incident of vertigo, Nate persuaded Patty to see a doctor again. This time she liked the medical team and her experience was better. Still, she felt that they had little to offer other than steroids, which she is allergic to, and encouraging her to rest. A year ago, the couple had to move for work. Patty finds it too difficult to visit her previous doctors and has not found new ones.

Patty has worked for a science organization throughout this time. She is passionate about her work, but its demands—lots of travel, sometimes to remote locations, and challenging negotiations—are particularly difficult for someone with MS. The last two years have been very challenging, a “dark period” in Patty’s words. “I just feel like I’ve run out of the ability to be flexible,” she says.

For Patty’s employer, being flexible is very important. The ability to take a meeting in the middle of the night or fly to a foreign country on a moment’s notice is highly valued. Conversely, needing flexibility from an employer violates work norms to an extent. Sociologists coin this the “flexibilization of labor,” referring to the wide trend of employees being expected to be more accommodating and more available than employers. This trend may have an even greater effect on caregivers and those with health conditions.

Nate faces critical medical issues. In 2014, he was diagnosed with glioblastoma (a stage 4 brain cancer), that is expected to be terminal. Life changed dramatically, and Nate needed a lot of support. The couple activated a large support network of family and local friends. Nate had brain surgery and then extensive physical therapy rehab.

The surgery went well and the original tumor is gone, but Nate’s cancer is expected to come back at some point. This has left Nate and Patty in a difficult situation. Nate is not well enough to work and, in part due to the added stress, Patty’s MS has gotten significantly worse since Nate’s sickness. Finances are strained and their support network has dried up. “People are eager to participate and support in the short-term, but in the long-term it’s draining;” explains Nate. “The problem with being terminal [is that] everybody expects you to [die] in the first year.”

The Kind of Day it Was
Nate and Patty’s logs give the impression that the study period’s caregiving and self-care burdens were light. However, it was apparent during interviews that both are physically and mentally exhausted. They struggled to get through the study day. Patty explained that she had been “really tired and unhappy that week.” Nate added: “Yeah, it’s a really difficult time. But there’s no good time.”

Patty’s day began with a medical appointment in the morning. She returned home afterward and began working from her computer. She attempted to push through, but ended up having to stop working in the middle of the day when she felt that she could not carry on. Nate also had a difficult morning. He was responsible for handling a financial matter that required a difficult phone call during which he felt badly treated. In turn, he may not have reacted in an optimal manner. Finances have become a point of contention in the relationship. They both spent the late afternoon and evening recovering.
Care Network
Nate and Patty share a home. Occasionally they host Airbnb guests.

When Nate’s health was much worse and it was expected that he had little time left, friends and neighbors pitched in to help. His health has improved a little, and in the past year that help has dried up. Now, Nate and Patty find that they are largely dependent on each other for their care.

Patty and Nate mentioned various health professionals during the interview, but they did not mention them specifically during the portion of the interview devoted to mapping their care network. These professionals are therefore not included on the care map.

Patty’s mother lives several hours away and helps on occasion with advice and support. Likewise, Patty cares for her mother. Patty also gets emotional support from weekly conversations with a friend.

Zoom-able diagrams can be found at http://atlasofcaregiving.com/studies
Activities
Nate and Patty participated in the study Wednesday–Thursday. The first interview took place on Wednesday evening. Logs and sensors were picked up on Thursday night. A second interview had been scheduled for Saturday, but Patty had a last-minute opportunity to take a needed relaxation break in the mountains. As a result, the second interview took place more than a week later on the following Sunday morning.

“People are eager to participate and support in the short-term, but in the long-term it’s draining.”

Nate logged 3.2 hours of caregiving, 2.1 hours of self-care, 4.5 hours of leisure, 7.75 hours of sleep, and 3.1 hours on other activities. Patty logged 1.25 hours of caregiving, 1.9 hours of self-care, 1.85 hours of work, 9.3 hours of sleep, and three hours on other activities.

For the most part, Nate and Patty are currently self-sufficient with respect to the day-to-day tasks of managing their conditions. They take their own pills and make their own doctor’s appointments. They largely share in tasks like cooking, cleaning, managing finances, and providing emotional support for one another. Patty is more likely to remind Nate of things than the other way around.

Nate and Patty did not provide significant detail in their respective logs. Logging can be particularly problematic when fatigue is a major problem, as is the case with Patty. Indeed, she described the activity as an “extra thing to do.” Even still, both Nate and Patty found some value in it, noting that it opened up a conversation about who did what for whom. “It was funny sometimes. We’d go to do an activity and kid each other: ‘oh, you think you’re taking care of me? I’m taking care of you!’ It opened up a dialogue. So that was good.”

Nate remarked that it made him think about everyday minutia in their relationship, and how they approach this minutia differently. He was also surprised to learn how much marijuana he smoked, noting that he is aware that he smokes often but that it is different to see it written in a log. This is not something he felt needed changing—being clear about why marijuana plays a role in his life—but the study was an occasion to contemplate the totality of its role in his life.
Zoom-able diagrams can be found at http://atlasofcaregiving.com/studies
### Nate's Main Care Activities

<table>
<thead>
<tr>
<th>Self-care</th>
<th>Took medication—pills and marijuana</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Scheduled doctor appointments</td>
</tr>
<tr>
<td></td>
<td>Prepared meals and ate</td>
</tr>
<tr>
<td>Caregiving</td>
<td>Provided emotional support to Patty by encouraging her decision to stop work for the day</td>
</tr>
<tr>
<td></td>
<td>Conducted financial planning the family</td>
</tr>
<tr>
<td></td>
<td>Shopped for household items</td>
</tr>
</tbody>
</table>

### Patty's Main Care Activities

<table>
<thead>
<tr>
<th>Self-care</th>
<th>Took medication—pills and marijuana</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Prepared meals and ate</td>
</tr>
<tr>
<td></td>
<td>Visited a therapist</td>
</tr>
<tr>
<td>Caregiving</td>
<td>Provided emotional support, calming Nate's anxieties</td>
</tr>
<tr>
<td></td>
<td>Conducted financial planning for the family</td>
</tr>
</tbody>
</table>
Photos
Nate and Patty’s photos were useful for supplementing their logs. Researchers added 23 entries to the original 14 that Patty logged. As one example, she forgot to enter her trip to the therapist in the morning, as well as a phone meeting that she took immediately afterwards in a quiet area of the medical center. Researchers would not have been able to infer these events from photos alone. Patty provided the necessary context. Seventeen entries, mostly constituting leisure, were added to Nate’s original 23. Again, leisure is somewhat deceptive given that his health issues require low levels of activity.

A series of similar images allowed us to understand that Patty was in one place, and the cord running through gave us a clue that she was on the phone, but where she was and what she was actually doing was not clear from the photo alone.

Zoom-able diagrams can be found at http://atlasofcaregiving.com/studies
Body Sensors
Nate and Patty both wore the Empatica E4 throughout their Atlas participation. Nate removed the devices three times for showers.

The E4 acceleration data show that Nate slept from about 11:00 pm to 7:00 am. He slept soundly for most of the night, though was increasing restless after 4:30 am. Patty appears to have fallen asleep a little earlier, and she got out of bed later. Her sleep was more restless than Nate’s. They both reported that, in general, they are good sleepers. Patty appears more sedentary than Nate for the rest of the time that is studied. This is likely due to the fact that her MS flared up, and that she was tired and in discomfort.

In many instances, the electrodermal activity (EDA) signal does not provide a good match with Nate and Patty’s self-reported stress levels. There is no EDA spike during Nate’s difficult phone call, and Patty’s steady running out of steam while attempting to work remotely in the morning was not fully captured. Others, however, do match well. Patty’s most significant EDA readings begin around 1:30 pm on Friday and last until 3:30 pm. In her log she reported a stress level of 5 and noted that her MS symptoms—fatigue, numbness, and vision trouble—were acting up. In addition, consistent with Patty’s frustration about not being able to be a flexible employee, this period coincides with the time at which she decided she could not carry on working (2:30 pm).
Environmental Sensors

SmartThings motion detectors were placed throughout Nate and Patty's apartment. The main Netatmo sensor was placed in the living room, and the secondary sensor in their bathroom.

The Netatmo bathroom humidity sensor clearly shows three peaks during times that Nate showered. These times correspond exactly to when the Empatica E4 was taken off. The CO2 level seems high given that Nate and Patty had windows open that should have been bringing in fresh air. It is possible, however, that these elevated readings are due to outside traffic. Patty expressed concerns about pollution from traffic in the first interview.

Zoom-able diagrams can be found at http://atlasofcaregiving.com/studies
Study 11: Sally’s Household

Sally (50s) cares for her son Pablo (20s), who has behavioral and emotional difficulties stemming from XYY Chromosome Disorder.

Context

Sally lives with her son Pablo in a rented home in a small town in California’s Central Valley. Pablo requires continuous monitoring due to many health conditions: XYY Chromosome Disorder, Hydrocephalus, mild mental retardation, anxiety, and behavioral and motor skill delays. He also has impulse disorder, is overweight, and is emotionally disturbed. Sally has sleep apnea, which adds to her fatigue.

Sally used to work as a lawyer in a major city, and once had well-developed interests in music and non-profit causes. She has not worked for many years due to her care responsibilities, and misses the professional and intellectual interests that were once a part of her life. Currently, as time allows, she runs a small business making and selling candies.

Sally has three children. Her oldest daughter, along with her husband and two children, lives about 30 minutes away. A younger daughter is in college. Pablo is the youngest child. Sally’s husband left the family soon after Pablo’s birth, unable to deal with Pablo’s condition.

Pablo was born three months early and was very underweight. He developed slowly, and did not sit up until he was two and a half years old. At age three he had major brain surgery. He has continued to develop more slowly than usual; now, in his early 20s, he behaves like a 16-year-old. People with XYY Chromosome Disorder are known to have severe emotional and behavioral challenges. They’re antsy, impulsive, have poor control, can be set off by little things, violent to themselves and others, and sometimes suicidal. In addition, they have poor motor control and grow very large (Pablo is 6’4” and 320 lbs.).

Caring for Pablo has gotten more difficult as he has gotten older. Medical problems were once the main issue; now Pablo’s growing behavioral problems create the biggest challenge. “He talks back,” Sally said. “He wants to do what he wants without understanding consequences. What can I do with this grown man? There’s no easy answer to the question. So many social services want him to be independent, but if he crosses the street … he doesn’t have that [built-in] safeguard telling him to look.”

The Kind of Day it Was

Sally described the day of the Atlas study as relatively calm, but noted that if the study extended over five days “it would be all over the place.” Indeed, the following day she did have problematic interactions with various medical and social services personnel after Pablo suffered a rough fall while breakdancing.
Care Network

Pablo is dependent on Sally’s care, and Sally must remain watchful and alert to Pablo’s needs. His impaired motor skills make him vulnerable to physical harm. As an example, Sally remarked that if he is around the stove he will burn himself.

Pablo recently began attending a day care program for a few hours about three days each week. The church-run center is willing to put him with teens, rather than young adults. This provides Sally with some much-needed respite, but she is always on-edge waiting for the “other shoe to fall.” Even when he is at daycare, Sally remains alert for calls or texts from Pablo or the daycare staff — there were several such communications during her Atlas participation. On occasion, Pablo’s older sister will keep him company, also giving Sally a break.

Pablo sees a therapist weekly, and a primary care physician and a neurologist infrequently.

Sally receives emotional support from a friend who she sees weekly. She attends a caregiver support group on occasion and also meets with a therapist weekly. Her daughter has her own family to care for, but is available to help when needed.

Zoom-able diagrams can be found at http://atlasofcaregiving.com/studies
Activities
During the first interview, Sally described what caring for Pablo is like. Day-to-day, she is unable to plan for activities in advance because she is watching out for Pablo. She remains on standby constantly to deal with small or large crises, and frets often in such situations about the possibility of what could happen. Noticeably absent in this “on-call” state are things like paid work and socializing, which are common tradeoffs people make when trying to remain available to other’s needs.

Sally wakes Pablo every morning, and assists him with shaving and showering. She helps him plan for the day. While doing so, Sally has to judge his mood. Does he appear psychotic or calm? Is he motivated or not? In assessing these things and others she decides whether it is okay to let him go to daycare.

Sally stays alert to Pablo’s mood. He doesn’t talk much, and has an odd sense of humor, so she relies on observation to know how he is doing. Sally works hard to maintain a calm environment, especially by keeping her own emotions (or at least the outward show of emotions) in check. She is “always on.” Finally, on top of all this, caregiving also involves a lot of laundry. Pablo often dirties his clothes and underwear. Together the totality of these tasks is both physically and emotionally exhausting.

Despite her clear explanation of how all-encompassing her caregiving is, Sally was still surprised by how much her log showed that she did during the day of study. It helped her to better understand her fatigue. During the interview she explained, “It's non-stop. It's a constant movement of me for someone else. I don’t think about me until the end of the day. [On the day of the study] that’s when I realized I hadn’t had breakfast.

“I saw that I’m on call, constantly,” she added. “It can be a lonely feeling. I don’t get to socialize anymore, but I don’t have the energy for that [anyway].”

Zoom-able diagrams can be found at http://atlasofcaregiving.com/studies
<table>
<thead>
<tr>
<th>Sally’s Main Care Activities</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Emotional management</strong></td>
</tr>
<tr>
<td>Listened to, helped, and comforted Pablo (including encouraging him to take a walk and helping him to calm down)</td>
</tr>
<tr>
<td>Rewarded Pablo for good behavior</td>
</tr>
<tr>
<td><strong>Household tasks</strong></td>
</tr>
<tr>
<td>Did several laundry loads</td>
</tr>
<tr>
<td>Prepared meals for Pablo, and watched to make sure he ate safely</td>
</tr>
<tr>
<td>Ran errands, and drove Pablo to activities and day care</td>
</tr>
<tr>
<td><strong>Monitoring</strong></td>
</tr>
<tr>
<td>Regularly checked on—and stayed alert to—Pablo’s state (both while he was home and away) and remained prepared to drop everything if need be</td>
</tr>
<tr>
<td>Texted with Pablo while he was away, providing advice and emotional support</td>
</tr>
<tr>
<td><strong>Medical and personal assistance</strong></td>
</tr>
<tr>
<td>Helped Pablo with medications and to apply lotions</td>
</tr>
<tr>
<td>Encouraged and assisted him with bathing, grooming, dressing, and getting ready for bed</td>
</tr>
</tbody>
</table>
Photos
For the purposes of analysis, the photos largely corroborated Sally’s extensive log (82 total entries). Photos only assisted in creating seven additions, which are mostly small errands that Sally neglected to mention.

Sally and Pablo drive to get ice cream to reward Pablo for good behavior. Atlas participants often do not log activities like car trips, but they are visually distinct enough that researchers can reliably include them in participants’ processed logs to give a richer overall picture of how time is spent.

Zoom-able diagrams can be found at http://atlasofcaregiving.com/studies
**Body Sensors**
Sally wore the E4 for most of the participation period, though she took it off while washing on Monday evening and forgot to put it back on until two hours later. She also took it off while showering on Tuesday.

The acceleration data confirm Sally’s log entry that she slept uninterrupted for eight hours from 10:00 pm to 6:00 am.

Sally’s log did not include any high-stress events, but a few entries expressed that she experienced medium stress levels (2 or 3). In agreement, the E4 electrodermal activity data shows little. The few, small peaks that exist correspond to physical household activities like washing or vacuuming. Neither the log nor the E4 captured the low-level, ongoing, grinding stress that Sally experiences.

Zoom-able diagrams can be found at [http://atlasofcaregiving.com/studies](http://atlasofcaregiving.com/studies)
Environmental Sensors
Though the SmartThings motion detectors and Netatmo environmental sensors were deployed around Sally’s home, no data was captured due to technical problems.

Sally: Environmental and Motion Sensors diagrams.
Study 12: Tammy’s Household

Tammy (40s) and her husband Rafael (50s) care for their pre-teen children, Wanda and Sam.

Wanda has severe epilepsy and cerebral palsy. She is effectively quadriplegic and requires 24×7 care. Sam has severe autism and also requires a lot of care.

Context
Tammy and Rafael live with their two children in a home in one of the distant suburbs of Silicon Valley. They have been married for 15 years. They are both originally from the Midwest, but have lived in California for the past 10 years. Tammy was a schoolteacher. She was about to return from maternity leave after Sam’s birth when Wanda had a serious seizure that signaled a health turn for the worse. Since then Tammy has been at home caring for the children. Rafael is currently unemployed.

Wanda has severe epilepsy (Lennox-Gastaut Syndrome) and cerebral palsy. Her development was slow as a baby and toddler, and she didn’t walk until she was 18 months old. At age three she had a seizure, and numerous other seizures followed. In an effort to help, doctors tried many different combinations of medicines—at one point as many as five major medications simultaneously (with serious side-effects)—but nothing seemed to help. Today the family finds that the best way to keep Wanda’s seizures under control, meaning at most 3-4 per day, is with a ketogenic diet (high-fat). Wanda lost the ability to chew and swallow at age five, and now has a gastronomy tube. She cannot speak or communicate in any other ways; no one can really say what she thinks or feels. She has nearly total paralysis in both arms and legs, and needs complete care.

Sam is a “very loud, excited, happy” child who also has autism. Caring for Sam is an endless endeavor to try to keep him safe. His judgment is poor and he is too trusting. In addition, he needs help with basic activities. For example, he can dress himself, but he often puts the clothes on backwards. He also needs help eating, and requires numerous vitamins and supplements (many delivered via syringe). Due to all the attention Wanda requires, the parents worry that Sam does not get nearly enough.

Tammy and Rafael constantly worry about bad things that could happen to Wanda and Sam—at school, on the school bus, and with other caregivers. They also worry about how much worse things could get as the children get older.

The Kind of Day it Was
Participation in the Atlas study occurred on a weekday. Both children were in school for part of the day, but Wanda came home early due to health issues, and later had to be rushed to the hospital. She came home later that evening. The second interview occurred over the weekend, a time period that is typically intense for Tammy and Rafael given that both children are home. Indeed, prior to the second interview Tammy was somewhat embarrassed that she had not had the time to even shower.
Care Network
Caregiving is a 24×7 part of Tammy and Rafael’s lives. Documentation and logging factor heavily as tasks that make up that care. They administer many different treatments to their children each day, and also manage, operate, clean, and otherwise maintain an assortment of medical equipment.

Wanda has several nurses who care for her. She attends special education in a public school for about five hours each school day, and the district hired a licensed vocational nurse to provide care for her there. Another nurse visits the home weekly, and a third nurse comes occasionally to provide additional respite. Nineteen other medical professionals care for Wanda: a pulmonologist, geneticist, GI doctor, dentist, pediatrician, eye doctor, allergist, pain doctor, podiatrist, physical medicine doctor, orthotist, orthopedic surgeon, occupational therapist, physical therapist, acupuncturist, endocrinologist, palliative physician, and two neurologists. Some of these professionals practice nearby, while others are up to an hour away. Wanda goes to a hospital that is about one hour away about once or twice a week. At the time of the family’s participation she had spent over 60 days in a hospital this year.

Sam attends a different school that is dedicated to children with autism. There, staff watch over him. Four medical professionals care for Sam, including two pediatricians, an eye doctor, and a dentist.

Tammy and Rafael are each other’s most important caregivers.

Tammy also receives emotional support during weekly visits to a therapist, and through weekly conversations with a sister and friend who live far away.

Zoom-able diagrams can be found at http://atlasofcaregiving.com/studies
Activities

Both Tammy and Rafael kept activity logs during the study period. The 29 hours covered by Tammy’s log include 10 hours of caregiving, 1.5 hours of other types of activities, and 6.8 hours of sleep. The 29 hours covered by Rafael’s log include 11 hours of caregiving, 7.8 hours of work (searching for a job), 0.9 hours of other activities, and 5.5 hours of sleep. The upcoming table breaks down each of their primary caregiving activities during the study period.

Tammy and Rafael already log care information as a regular habit. They track seizures, urine & bowel movements, medications, treatments, and other relevant information. They were thus familiar with the concept behind the Atlas log. In practice, however, given everything they were already doing, maintaining an accurate log was difficult. Tammy’s log contained little detail and some entries didn’t include the time of the activity. Rafael’s log was more thorough, but it often included large bunches of activities as a single entry. These logging “deficiencies” reflect the reality that, when their children are at home, their life is a non-stop stream of activities.
Applied a series of breathing treatments to Wanda.

Day 1
- Called insurance company
- Dentist visit
- Seizure—Wanda
- Took Wanda to the ER
- Scheduling a hospital visit

Day 2
- Got debrief from nurse—Wanda not doing well today
- Started breathing treatments
- Focusing on Sam while cleaning and doing laundry
- Give Wanda medications and start her feeding
- Preparing special meals

Tammy: Activities diagram.
Rafael: Activities diagram.

Tammy: 24-hour Log diagram.
Rafael: 24-hour Log diagram.

Tammy: 36-hour Log diagram.
Rafael: 36-hour Log diagram.

Tammy: Activities diagram.
Rafael: Activities diagram.

Zoom-able diagrams can be found at [http://atlasofcaregiving.com/studies](http://atlasofcaregiving.com/studies)
<table>
<thead>
<tr>
<th>Tammy's Main Care Activities</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Healthcare management</td>
<td>Spoke with the insurance company</td>
</tr>
<tr>
<td></td>
<td>Managed supplies</td>
</tr>
<tr>
<td></td>
<td>Paid bills</td>
</tr>
<tr>
<td></td>
<td>Conducted research</td>
</tr>
<tr>
<td>Coordination and communications</td>
<td>Communicated with transportation company, Rafael, doctors, teachers, and hospital administrators</td>
</tr>
<tr>
<td>Home medical treatments</td>
<td>Dealt with seizures, and nausea and vomiting</td>
</tr>
<tr>
<td></td>
<td>Applied breathing treatments and gave medications</td>
</tr>
<tr>
<td></td>
<td>Applied catheter, feeding pump, and vest</td>
</tr>
<tr>
<td>Assisting with personal activities</td>
<td>Changed diapers</td>
</tr>
<tr>
<td></td>
<td>Helping with bathing, clothing, and grooming</td>
</tr>
<tr>
<td>Mobility</td>
<td>Transported children to and from medical visits (dentist, ER)</td>
</tr>
<tr>
<td></td>
<td>Drove kids to and from school</td>
</tr>
<tr>
<td></td>
<td>Moved Wanda on/off wheelchair, and on/off wheelchair transport van</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Rafael's Main Care Activities</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Healthcare management</td>
<td>Managed inventory and restocking of medical supplies</td>
</tr>
<tr>
<td></td>
<td>Paid bill</td>
</tr>
<tr>
<td>Coordination and communications</td>
<td>Coordinated with nurses</td>
</tr>
<tr>
<td></td>
<td>Supported Tammy</td>
</tr>
<tr>
<td>Home medical treatments</td>
<td>Dealt with seizures</td>
</tr>
<tr>
<td></td>
<td>Applied breathing treatments</td>
</tr>
<tr>
<td></td>
<td>Managed medical equipment, and application of a feeding pump, vest, nebulizer, and oxygen</td>
</tr>
<tr>
<td>Assisting with personal activities</td>
<td>Helped with cooking, feeding, bathing, diaper changes, and clothing</td>
</tr>
<tr>
<td>Emotional support</td>
<td>Comforted Sam, and Tammy</td>
</tr>
<tr>
<td></td>
<td>Watched over Sam</td>
</tr>
</tbody>
</table>
The pictures showed Rafael spending a good deal of time working online, a few hours at a time fit in around his children’s caregiving needs.

**Photos**

Both Tammy and Rafael wore the Narrative Clip. An additional Narrative Clip was placed on a cabinet overlooking Wanda’s bed.

Rafael did not wear the Clip on Thursday from 10:00 pm to 7:30 am. Tammy took off her Clip several times: during a nap on Thursday, from 5:30 pm to 8:00 Thursday evening when she was in the ER, 10:00 pm to midnight, and when she slept from 2:00 am to 5:30 am. The Clip ran out of power a little after 10:00 am on Friday morning.

As with Hanna’s household, Tammy and Rafael were interested in the photos for what they say about other people’s perspectives. They were particularly intrigued to view photos taken by a Narrative Clip aimed at Wanda’s bed, and were surprised to see that during the night there were many times when Wanda was awake, eyes wide open and looking different directions. They also saw that at one point she had slid down the bed, and that they should therefore find a better way to keep her elevated. Indeed, by the end of viewing the photos they saw so much utility in the Narrative Clip that they began discussing using it as a part of their caregiving.

Between the photos in taken in Wanda’s room, and both Tammy and Rafael’s photos, researchers were able to triangulate to fill in many of the more substantial gaps in the activity logs. For example, Rafael reported that Tammy was upset while on the phone, but Tammy herself did not record this. Using a photo and accompanying time stamp, researchers inserted that phone call into Tammy’s log.

The camera placed in Wanda’s room took pictures at one-minute intervals, allowing researchers to estimate the total amount of time that Tammy and Rafael spent with her in that room. If caregiving involved brief in-and-out trips that were shorter than the camera’s sampling interval, then estimates would be off. However, assuming this is not the case, photos indicate that they each spent around two hours in the room with Wanda. Overall, the log reports show that Rafael spent 11 hours caregiving and Tammy spent 10. The difference suggests that the majority of caregiving work is not stereotypical images that come to mind involving caregivers literally being at the bedside of the cared for.

The pictures showed Rafael spending a good deal of time working online, a few hours at a time fit in around his children’s caregiving needs.
Tammy: Photo Log diagram.

Rafael: Photo Log diagram.

Zoom-able diagrams can be found at http://atlasofcaregiving.com/studies
**Body Sensors**

Both Tammy and Rafael wore the Empatica E4. Although Rafael told us he only took the E4 off for a shower on Friday, a period of odd data from 12:00–2:00 pm on Thursday suggests it may have been off.

Rafael’s E4 acceleration data show that his overall sleep period was from 10:30 pm to 7:00 am. However, he was up caring for Wanda (mainly) and Sam (a little) at 4:00 am, and then again from 5:30–6:00 am. His sleep was often restless. This is not surprising as Wanda had several seizures that night. The acceleration data also visualizes a busy morning getting Wanda and Sam ready for school (7:00-8:15 am), and then relative quiet in the period immediately following when he sat and worked at his computer at home. The electrodermal activity (EDA) data spiked the previous evening when he was cleaning things in the kitchen.

Wanda came home from school Thursday afternoon around 2:30 pm, and Rafael’s EDA data shows high activity around this period. He was dealing with several stressors at the time. Both children had difficult days at school, including Wanda having seizures, and Rafael had been administering non-stop medical treatment after their return home. Then, he opened the mail and discovered an unexpected bill for several thousand dollars. There are more EDA peaks later in the evening after Tammy comes home from an ER visit with Wanda, and as he deals with pre-bed medical caregiving activities. In the early morning there are also peaks that presumably correspond to seizures that Wanda had at that time. The EDA peaks correlate fairly well with the log entries of Rafael’s self-reported stress.

Tammy wore the E4 throughout the period of study, except for a brief period around 11:00 am Friday morning.

Tammy’s E4 acceleration data shows that she took a nap on Thursday morning from 10:45 am to 12:30 pm. At night, she slept from 10:15 pm to midnight. She was awake for several hours reading and doing Internet research before sleeping again from 3:00 am to 6:30 am. The latter part of that sleep was restless, presumably due to her hearing Wanda’s seizures.

Tammy’s EDA data did not pick up all of the times where her self-reported stress was high. The EDA data has peaks when she was at the ER (7:00 pm Thursday), during times she was caring for Wanda (Friday morning), and when she was trying to schedule a hospital stay for Wanda (11:30 am Friday). The scheduling attempt was especially stressful for Tammy; she told us she felt overwhelmed and was close to crying. There are many instances that Tammy categorized as high-stress in her log—some of which are corroborated by Rafael—that are not reflected in the EDA data. Overall, the EDA sensor picked up little data during much of the study period; it is possible that the E4 was worn too loosely.

Even when there is good data, reports do not show the true extent to which Tammy and Rafael deal with constant, grinding stress. The graph shows ebbs and flows of stress, but there are few opportunities to escape from stress altogether. Wanda and Sam’s care needs are nearly constant, and Tammy and Rafael’s financial situation is dire. They work hard, try to keep a positive attitude, and state that they will keep going until they simply cannot; but there is no hiding how exhausted and overwhelmed they are.
Tammy: Body Sensors diagrams.  
Rafael: Body Sensors diagrams.
Environmental Sensors
SmartThings motion detectors were placed throughout the home. The main Netatmo sensor was placed in Wanda’s bedroom and the secondary sensor was placed in the kitchen.

The most interesting aspect of the Netatmo data is the sound level in Wanda’s room. It clearly shows when she was present or away, and when there was significant activity in her room. The sound level is low until she comes home from school at about 2:30 pm on Thursday, and it goes down again when she is gone on a trip to the ER from 5:00–7:30 pm. Additional periods of high sound correspond to her parents’ efforts to respond to seizures at 3:00 pm and 8:00 pm on Thursday, and again Friday morning from 6:00–8:00 am.

Data Already Present
As mentioned, maintaining logs, checklists, and written schedules plays a very large role in Tammy and Rafael’s burden of caregiving. For privacy reasons specifics from these documents cannot be shared, but the extent of coverage speaks to the complexity of the caregiving burden.

A thick binder contains detailed instructions for Wanda’s equipment and other care items. It also holds an eight-page care plan, a log of urine & bowel movements, and a detailed two-page care schedule. The schedule contains care activity instructions down to the half-hour in some cases. These documents help Tammy and Rafael to manage and track Wanda’s health needs, and to communicate them to doctors and other caregivers. In addition, a checklist also exists to ensure that other people who provide care are up to speed; caregivers have to be trained to operate 26 devices that are necessary to maintain Wanda’s health.

Though Sam has less extensive needs, a six-page care plan plays a central role in his care as well.

Zoom-able diagrams can be found at http://atlasofcaregiving.com/studies
Study 13: Teddy’s Household

Teddy (40s) and his wife are the primary caregivers for their two young sons, Van and Walter. Van has Aspergers (ADHD type) as well as encopresis, and Walter has cyclical vomiting syndrome.

Context
Teddy and Valerie met in graduate school and have been married for over a decade. Valerie is an educator and Teddy is a lawyer. They have two young sons, Van and Walter.

Teddy and Valerie were living on the East Coast when Van was diagnosed with Aspergers. In the time after his diagnosis Van had several different applied behavioral analysis (ABA) therapists, a pattern that is not uncommon due to high turnover in the ABA field. Some were good. Others were not.

Eventually the family found an excellent ABA who worked long-term with Van. Neither Teddy nor Valerie had known anything about Autism or Aspergers before Van’s diagnosis, and the therapist helped them enormously by setting an example through which they could learn best-practice caring behaviors. But then, about a year ago, the family moved to the Bay Area. They are slowly finding appropriate professional providers, but they have yet to find an ABA therapist and have noticed that their caregiving skills have suffered as a result.

Van requires constant oversight and constant reminders. Valerie explains: “He’s either not focused at all, or is hyper focused on something that’s not compliance related [such as reading a book].” Van is very intelligent, but can be argumentative, perseverating, and defiant at times. He finds transitions from one activity or location to another very difficult. Van also has encopresis. This gastrointestinal issue leads to emergency searches for restrooms and occasionally soiled clothes, especially when combined with Aspergers tendency to hyper focus Van on something else.

Walter has cyclical vomiting syndrome, a condition where one begins vomiting and cannot stop. Walter has to be rushed to the hospital during episodes brought on by the syndrome. In the past six months, Walter has been admitted to the hospital three times. The most recent incident occurred one week prior to the family’s participation in the Atlas project. These incidents are made more complicated because of Van; he copes poorly with emergency situations and is not empathetic.

The Kind of Day it Was
The period of study was somewhat unusual in that the family was attending Van’s live action role-playing (LARP) event on both days. LARP involves participants dressing up and fulfilling character roles in a live-action game. Outside of the event, the Atlas study was relatively normal for the family in that it involved little down time. As Teddy remarked, “the biggest stress is that we never get a break.”

Teddy’s log showed only a little over an hour of relaxation time, helping to visualize just how challenging and emotionally draining it can be to care for Van. It also contained several examples of challenges the family faces while providing care for him. These included difficulty preparing Van for a transition between activities, getting him to have lunch when he was engrossed with something else, and an emergency bathroom situation. “There are a lot of emergency bathroom situations we have to deal with,” said Teddy.

The family was together on Saturday, but Valerie and Walter were off on their own for much of Sunday.
**Care Network**

Teddy and Valerie are the primary caregivers for their sons. Van requires constant supervision, or at least a watchful eye. Walter’s condition is not as constant. He does not require the same level of vigilance as Van, but his symptoms are serious when they occur.

Three medical professionals currently see Van: an occupational therapist, a psychiatrist, and a pediatrician. Teddy and Valerie also hope to find an ABA therapist and a speech therapist for Van. A pediatrician also cares for Walter.

Though Valerie’s parents live a few hours away, on occasion they help care for Van and Walter and also provide household assistance. In addition, they support Valerie’s efforts to manage and coordinate healthcare. Teddy’s father lives farther away, but also helps as needed.

Zoom-able diagrams can be found at [http://atlasofcaregiving.com/studies](http://atlasofcaregiving.com/studies)
**Activities**

Only Teddy kept a log, but Valerie made several entries on his behalf. Teddy’s log covered about 30 hours, from 9:00 am on Saturday until 3:30 pm on Sunday. This included 10.2 hours caregiving, 1.4 hours of leisure, and 8.4 hours sleep.

“I often do think I’m doing everything, and it is often completely unreasonable when I’m thinking that.” Valerie added, “Yeah, I often think the same thing too.”

Teddy and Valerie originally estimated that they spend 2-5 hours on caregiving a day. Teddy’s log shows that he did just over 10 hours of caregiving that day. Some of this difference is likely accounted for by the fact that Van was attending a special event for two days, which meant Teddy was too.

Teddy told us that he found it hard to log everything as well as he would like. Intense events that lasted 5-10 minutes got included in the log as entries that cover a longer period of time. In addition, at times the emotional element of what was happening made logging more difficult. It was unrealistic, for instance, to make a log entry during intense or acute events. At other times he felt he was just too busy to take time to log. Log entries during these situations were often made well after the time of those activities.

Teddy: 24-hour Log, 36-hour Log, and Activities diagrams

Zoom-able diagrams can be found at [http://atlasofcaregiving.com/studies](http://atlasofcaregiving.com/studies)
Teddy’s Main Care Activities

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mobility</td>
<td>Drove Van to an activity especially designed for children with Aspergers</td>
</tr>
<tr>
<td></td>
<td>Helped Van transition between activities</td>
</tr>
<tr>
<td>Oversight</td>
<td>Monitored and paid attention to Van’s activities, behaviors, and emotions</td>
</tr>
<tr>
<td></td>
<td>Regularly prompted and reminded Van to do basic activities (e.g. eating, preparing for bed, bathing, putting on clothes, toileting)</td>
</tr>
<tr>
<td>Cleaning</td>
<td>Cleaned up Walter’s vomit</td>
</tr>
<tr>
<td>Emotional / social assistance</td>
<td>Helped Van become comfortable with other people, new activities, and changes in plans</td>
</tr>
<tr>
<td>Research</td>
<td>Discussed treatment options with other parents</td>
</tr>
</tbody>
</table>

To help, during times that Teddy was busy or distracted Valerie logged some entries for him. While doing so, she looked over the entries that Teddy had made and found herself disagreeing with his assessment of how much of the caregiving load he had borne for certain activities. For one activity, under Level of Assistance Teddy wrote “Do all” to denote that he undertook 100% of the work. But, Valerie felt that she was not being recognized for her contribution to that activity. During the second interview, this led to some reflection. “I often do think I’m doing everything, and it is often completely unreasonable when I’m thinking that,” said Teddy. Valerie responded, “Yeah, I often think the same, too.”

In general, Valerie found the logging exercise worthwhile: “I thought it was a really useful exercise to write everything down, because … It makes you aware of how much time you’re spending doing various kinds of things.”
Photos
The images from Teddy’s Narrative Clip allowed the researchers to refine the accuracy of Teddy’s original 28-entry log, and to add a few minor details to his account of Saturday. In total 8 entries were added. The Narrative Clip did not capture data on Sunday; it is unclear why this occurred.

Teddy loads a small bag into the car after the LARP event. Van has major difficulties transitioning between activities, and it took Teddy and Valerie a full hour to get both kids into the car at the end of the LARP event.

Zoom-able diagrams can be found at http://atlasofcaringiving.com/studies
Body Sensors
Teddy wore the Empatica E4 but found it itchy and took it off for long periods—roughly from 6:00–7:30 pm Saturday, 8:15 pm Saturday to 4:30 am Sunday, and 6:00–9:00 am Sunday. In addition, his quality of sleep cannot be judged because he did not wear the E4 while sleeping.

The electrodermal activity (EDA) readout shows almost no variation. It’s possible that what the sensor recorded is in fact accurate, as the couple noted that Teddy is generally calm and unflustered. However, in 10 of 28 entries in the log he rated his stress level as 3 or 4. The EDA sensor largely did not pick up on these and it also notably missed his highest self-rated stress event (getting the kids into the car after the LARP event). There was, however, a clear spike in the EDA data around 6:00 pm on Saturday. Teddy explains, “I was upset at [Valerie] for a second and then I got over it.” He had just learned that she had lost an item he had bought for her earlier that day.

TEDDY: Body Sensors diagrams.

Zoom-able diagrams can be found at http://atlasofcaregiving.com/studies
Environmental Sensors
The SmartThings motion sensors and Netatmo environmental sensors were not deployed, both because the family planned to spend so much time outside the home during the time of their participation and because they may have been distracting to Van.
Study 14: Omar’s Household

Omar (40s) and his separated wife Cindy (40s) share a home with their young son Bob, who has Aspergers.

Context
Omar, Cindy, and Bob live in a semi-rural area about two hours from San Francisco. Bob, not yet 10, has atypical autism (PDD-NOS) and oppositional defiant disorder (ODD). Omar and Cindy are effectively separated, though they still live in the same home due to their financial circumstances. They consider themselves “co-parents”.

Omar and Cindy moved to California from the East Coast in the early 1990s. Omar worked in the technology industry for a time, and expects he will eventually return. For now, however, he stays at home to home-school Bob. Cindy works part-time at a restaurant.

Bob is home-schooled because his parents are dissatisfied with options that the local school district is offering. Bob is very bright. He needs to be in classes with other advanced children, but without an aide to help Bob manage behavior he is too disruptive. The school district only offers aides in a special-education classroom. That class is populated with children who are far behind in learning.

On weekdays, Omar and Cindy try to mimic a normal school schedule at home. This is a challenge, as Bob wants full control over his learning. There is constant disruption, and endless negotiation.

The Kind of Day it Was
The Tuesday-Wednesday of Omar and Cindy’s participation was a fairly normal weekday. Omar spent much of the day home-schooling Bob, which required his full attention. Omar’s wearing of the Narrative Clip may have contributed to Bob being more difficult to manage than usual. Occasionally Cindy took over schooling responsibilities. Cindy went out for a support group meeting, as well as a behavioral-parenting training class. Throughout the period Omar and Cindy also spent time, together and alone, on negotiating a parenting agreement.
Care Network
Omar and Cindy constantly supervise Bob and spend many hours each day caring for him. This responsibility is not divided evenly. Omar is the primary caregiver, and devotes at least twice as much time as Cindy.

Bob goes to a drop-off daycare center weekly, which allows his parents some respite. On rare occasions, a babysitter also allows some reprieve.

Omar and Cindy used to have weekly meetings with a co-parenting therapist and a parent coach, but at the time of their Atlas participation these had stopped. Cindy finds daily emotional support from one particular online community. She also participates in three other online communities, as well as a local support group. Omar receives emotional support from weekly meetings with his church pastor and participation in a local support group.

Zoom-able diagrams can be found at http://atlasofcaregiving.com/studies
Activities
Cindy made log entries during the time of her participation, but Omar did not. He felt that constant supervision of Bob interfered with his ability to keep a log during the day. But, he later recreated a log from viewing images from the Narrative Clip he wore. Omar was the only participant in the Atlas study who did this.

Cindy’s log entries run from 11:15 am on Tuesday to 2:45 pm on Wednesday. Within those 27 hours Cindy logged 7.7 hours of caregiving and 5.6 hours on other activities. Because of issues with the Empatica E4 and the absence of a sleep entry in the log, we do not know anything about how long or well she slept.

Omar’s log entries run from 11:12 am on Tuesday to 10:40 am on Wednesday (when the Narrative Clip ran out of battery). He logged 3 hours of caregiving, 11.6 hours on other activities, and 6 hours of sleep. Researchers were skeptical of this self-report because of the unusual way he logged (using the Narrative Clip) and because as with other participants, we coded any activity done for the household as “other.” But, in Omar’s case, much of what falls in this category derives from time spent working on a strategy for parenting, the need for which could arguably be traced back to Bob’s care needs. Thus, the line between Omar’s caregiving and “other” activities is somewhat hazy.
Zoom-able diagrams can be found at [http://atlasofcaregiving.com/studies](http://atlasofcaregiving.com/studies)
<table>
<thead>
<tr>
<th>Omar’s Main Care Activities</th>
<th>Cindy’s Main Care Activities</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Monitoring and enforcement</strong></td>
<td>Regularly monitored to make sure that Bob adhered to rules</td>
</tr>
<tr>
<td></td>
<td>Spent time explaining proper behavior to Bob</td>
</tr>
<tr>
<td></td>
<td>Disciplined, using inducements and punishments to elicit proper behavior</td>
</tr>
<tr>
<td><strong>Communication</strong></td>
<td>Conversed and negotiated with Cindy about parenting Bob</td>
</tr>
<tr>
<td><strong>Home schooling</strong></td>
<td>Ran a home-school session for Bob</td>
</tr>
<tr>
<td><strong>Parental training and practice, and self-care</strong></td>
<td>Attended a behavioral-parent training class, and a support group meeting</td>
</tr>
<tr>
<td></td>
<td>Conversed and negotiated with Omar about parenting Bob</td>
</tr>
</tbody>
</table>

Like other Atlas participants, Cindy noted that the log made her more aware of the activities she performs. She was particularly attentive to how recording stress levels led her to reflect on stress. “When the number was high on the scale,” she said, “it would remind me that…I need to do something to bring my mood down.” Cindy has developed extensive knowledge about psychological issues while caregiving for Bob; it is possible that her knowledge influenced which aspect of the logging activity caught her attention.

Having a separate log for each caregiver allowed researchers to compare listed activities and the tone in which they were written. Omar and Cindy’s situation is unique; they have ended a romantic relationship, but remain together for the purposes of caregiving. Despite the fact that entries are short and simple, several contain elements of emotion and differing perspectives on what needs doing.
Photos
Both Cindy and Omar’s Narrative Clip batteries ran out before the end of the study, and as a result there are small gaps in the photographic data. The batteries in Omar’s unit lasted until 10:40 am Wednesday. Cindy’s lasted until 3:00 pm Wednesday.

Cindy’s photos did not provide substantial new caregiving evidence to help supplement her log, but it is notable that Omar was able to put together a 35-entry log solely by viewing images from the Narrative Clip. Omar’s efforts almost exactly matched how one Atlas researcher would have performed the same task. In the end, she was able to add only a single one-minute emailing task to what Omar put together. It is less clear whether a richer log was generated this way, but it is nevertheless notable that some signal of the day was feasible.

The presence of the camera may have affected Bob. Omar stated that it became a kind of audience for him, and that he began acting up in its presence. In addition, it was also another object to grab and pull in order to elicit a reaction from Omar. In the photos, Bob is almost constantly in Omar’s field of view, which may indicate that his log significantly underestimates the amount of time he spent caregiving.

The request to wear the camera prompted Cindy to make some decisions about other people’s privacy. “I was gonna be around other people and I didn’t want to have them question me about what the device was. I almost felt like I needed their permission to video.” She distinguished between filming strangers and acquaintances. “I would have been more comfortable wearing it in the grocery store than I was at my meeting: because [there] I have people that I know and I don’t wanna record them. I would be more willing to wear it in places where I don’t know people and I probably won’t see them again in my life.”

Zoom-able diagrams can be found at http://atlasofcaregiving.com/studies
Body Sensors

Both Omar and Cindy wore the Empatica E4. Cindy’s E4 stopped recording after less than two hours. The most likely explanation is that the researchers did not properly charge the batteries. Omar’s unit behaved strangely. It showed zero electrodermal activity for a long period, followed by a massive jump. It is possible that the unit was worn too loosely on his wrist to generate meaningful data. Omar’s accelerometer data indicates that he slept from 1:20-7:20 am, and that he took the device off once for a shower.

In his log, Omar generally reported low stress levels (0–1). On a few occasions these elevated to moderate stress (2–3) due to Bob’s misbehavior or the difficulty of discussing custody issues with Cindy. Cindy’s log included several high (4-5) and medium (2-3) stress moments for the same reasons. In this case, the self-report data and information from interviews are the only indications we have about stress levels. Nevertheless, Cindy expressed curiosity about the Empatica, and voiced how it might one day be used to inform people that their stress levels are rising and that it is time to take a break.
Environmental Sensors

The Netatmo environment sensors and SmartThings motion detectors were not deployed. Omar felt that Bob would be distracted by them and possibly might break them.

Omar and Cindy: Environmental and Motion Sensors diagrams.