Technology and Service Usage Among Family Caregivers

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Abstract. Family caregivers often assist their care recipients with a wide variety of activities ranging from basic personal care to transportation, medication management, finances and more. Furthermore, many caregivers live apart from the loved ones that they provide care to, and have responsibilities outside of caregiving including work and family. Use of technologies and services designed to make life easier for the general population can also be leveraged to reduce the burden and stress related with caregiving. In this study, 30 family caregivers were surveyed in depth to learn about their experiences with various technologies and services. Questions covered caregivers' use of technologies and services, perceived usefulness and ease of use, reasons for use and non-use, and ideas for new and improved tools. Many caregivers were currently using a technology or service for caregiving, but most of the technologies and services presented in the questionnaire were only used by a limited number of participants. While usage was limited, those that currently used technologies and services generally found them helpful for making caregiving duties easier. Responses showed that technologies and services were not being widely used mainly due to limited awareness and availability, and less because of lack of interest.

Keywords: Technology adoption · Family caregiving · Home services

1 Introduction

It is estimated that almost four in ten American adults are providing care to someone [1]. The National Alliance for Caregiving & AARP Public Policy Institute [2] reported that a large majority (85%) of its estimated 43.5 million adult caregivers in the United States are providing care to a family member. These caregivers are mostly unpaid individuals assisting a spouse, parent(s), or other relative.

Family caregiving is an important and difficult job for many and encompasses tasks in domains including health care, transportation, preparing meals, eating, housework, home maintenance, coordinating services, personal hygiene, managing finances, and keeping company. The National Alliance for Caregiving & AARP Public Policy Institute [2] found that the majority of caregivers assist their care recipient with one or more basic Activities of Daily Living (ADLs) and help with 4.2 of 7 Instrumental Activities of Daily Living (IADLs) on average. ADLs are defined as fundamental

personal care tasks such as functional mobility, including walking, getting in and out of beds and chairs, getting dressed, toileting and dealing with incontinence or diapers, bathing or showering, feeding, and personal hygiene. IADLs include activities required for independent living in the community, such as transportation, grocery or other shopping, housework, preparing meals, managing finances, taking medications, and arranging outside services using different forms of communication. In addition to caregiving responsibilities, the majority of family caregivers are likely to be employed and/or have other family-related obligations. Six in ten caregivers are employed, the majority of whom work full-time [2]. Additionally, 46% of caregivers reported being a parent of one or more children under 18 years of age [1].

Due to demands from caregiving, work, family and other responsibilities, caregivers often find it difficult to manage their time, well-being and stress levels. As a result, caregivers often experience high physical, emotional and financial strain, poor health, and are in need of help with managing caregiving burdens. For instance, while only about 10% of the general population describes their health as fair or poor [3], 17% of caregivers reported their health as fair or poor [2]. Hoffman and Rodrigues [4] also stated that caregivers are more likely to experience social isolation, psychological distress, and depression, partly due to the intensity of caregiving and a lack of personal time.

Many technologies and services developed to make life easier for the general population also have potential to assist older adults, as well as individuals who are charged with providing care to them. For example, Fox et al. [1] found that caregivers are more likely, than non-caregivers, to look for health information using their cell phone, and that many caregivers use the internet to find online resources for caregiving and managing stress. In addition, a variety of technologies and services specifically designed for caregivers and care recipients have been found to be beneficial. In a review of existing telephone-based caregiver interventions, Glueckauf and Noël [5] found those interventions for education, behavioral modification, and exercise and nutrition counseling were effective in improving the emotional and physical well-being of caregivers. Tindall and Huebner [6] demonstrated the effectiveness of a videophone-based therapy program in reducing caregiving time and financial burden. Kinney et al. [7] studied family caregivers of dementia patients and found internet-based monitoring technology to be potentially beneficial. Mortensen et al. [8] found a significant decrease in caregiver burden with the use of assistive technology. Blusi et al. [9] found caregiver support services offered through information and communication technologies contributed to improving the quality of life of older caregivers caring for their spouses, and had a positive influence on family relationships and perceptions of independence, competence and social inclusion. Gaugler et al. [10] found that the use of adult day programs, which provide a variety of services ranging from health monitoring and medical care to socialization and transportation, was effective in reducing caregivers' emotional and psychological distress and decreasing the amount of time they assisted their care recipients with basic ADLs, behavioral problems and memory issues.

Little is known, however, about how the family caregiver population is utilizing various technologies and services, what their perceptions are of different solutions available to them, and what their unmet needs are. Furthermore, studies have found that many existing technologies and services currently are not widely adopted and used by

caregivers. For example, Fox et al. [1] found that while medication management is a common task among caregivers, a very small percentage of caregivers use tools to help manage their care recipient's medications. Glueckauf and Noël [5] reported that while internet-based and mobile tools are increasingly available, telephone-based interventions remain a popular form of service delivery, especially in rural areas. Gaps often exist between caregiver needs and types of available services. Based on a study of services offered by the Area Agencies on Aging in California, Whittier et al. [11] found that existing services mostly offered institutional care, while other services needed by caregivers, such as transportation and financial assistance, were less available. Kinney et al. [7] also found gaps between the needs of family caregivers and the tools that they currently have available. In a survey of smartphone-based tools for behavior management, clinical treatments, symptom tracking and education, Luxton et al. [12] noted possible issues related to acceptance, security and privacy, and related policy that need to be addressed for widespread use. A review of networked technologies for caregiver decision support, communication and education by Powell et al. [13] demonstrated moderate benefits, but also found low usage rates. Brodaty et al. [14] identified that only a limited portion of the caregivers providing care to people with dementia utilize services available to them, and also reported on reasons for lack of use including reluctance on the part of the care recipient, lack of awareness and knowledge, and limited understanding of their own needs.

The objective of this study is to better understand family caregivers' use of technologies and services that can potentially improve their caregiving experiences as well as their quality of life. In this study, the types of technologies and services used by caregivers, the reasons and purposes for use, and level of satisfaction and perceived usefulness are described based on a survey of 30 family caregivers in the United States. Open responses on unmet needs and suggestions for improvement of existing tools, as well as ideas for future services, are presented in this paper.

2   Data Collection

2.1   The MIT AgeLab Caregiver Survey

A series of in-depth online diaries and questionnaires as well as phone interviews were completed as part of a larger study on understanding the caregiving experience. In this study conducted by the Massachusetts Institute of Technology AgeLab, 30 adult family caregivers in the United States were surveyed over a 3-month period. At the beginning of the study period, caregivers participated in a phone interview about their demographics, characteristics as a caregiver, characteristics of the family member for whom they provide care, and the overall caregiving situation. During the study, caregivers were asked about various aspects of their caregiving experiences, including how they assist their care recipients with different tasks, how they manage time and stress, how they seek help and support, how caregiving affects their work and family life, and how they use tools and resources to make their caregiving jobs easier.

In one questionnaire, caregivers were asked about their use of technologies. Specifically, caregivers answered questions about their overall technology experience,

knowledge of new technologies, use of various technologies for personal use and for caregiving, reasons for use and non-use, and level of satisfaction with technologies that they use for caregiving. In another questionnaire that focused on management of time and task priorities, caregivers were asked about their use of services that could help with their caregiving responsibilities. They reported on which services they used for caregiving, reasons for use and lack of use, frequency of usage, perceived usefulness, perceived importance and ease of use. In both questionnaires, caregivers were provided with spaces to describe their unmet needs, suggestions for improving existing technologies and services, and ideas for future systems. These questionnaires were completed online.

2.2   Data Profile

All of the caregivers who participated in the study were providing unpaid care to a family member and employed for pay in addition to their caregiving responsibilities at the time of study enrollment. The convenience sample had a median age of 53 and was mostly female (90%). The majority of the sample was employed full-time (87%), married or living with a partner (57%), and caring for a parent or parent-in-law (87%). Table 1 summarizes the characteristics of the participating caregivers, their care recipients, and the overall caregiving situation.

Table 1. Participant profile (N = 30)

Category	Characteristics	Descriptive statistics
Caregiver characteristics	Age	Median: 53, Range: 35–63
	Gender	Female: 27, Male: 3
	Employment	Employed full-time: 26, Part-time: 4
	Marital status	Married or living with partner: 17, Single: 13
	Household	Average size: 2.5 including the caregiver Living with child(ren): 6
Care recipient characteristics	Age	Median: 83, Range: 33–98
	Gender	Female: 19, Male: 11
	Relationship to caregiver	Parent or parent-in-law: 26, Grandparent: 1, Uncle/aunt: 1, Spouse: 1, Adult child: 1
	Living arrangements	Caregivers living with care recipient: 15, Living within walking distance: 4, Living at a short driving distance: 8, Living at a far distance: 3
	Conditions	Long-term physical condition: 23, Memory problem: 19, Emotional or mental issue: 15, Behavioral issue: 8, Short-term physical condition: 3, Developmental or intellectual issue: 2

(continued)

Table 1.   (*continued*)

| Category	Characteristics	Descriptive statistics
Caregiving situation	Caregiving load	Average: 30.8 hours per week providing direct care
	Duration of care	Less than 1 year: 2, 1 year or more but less than 5 years: 15, 5 years or more but less than 10 years: 11, 10 years or more: 2
	Caregiving tasks and responsibilities	Number of caregivers helping with… taking and managing medications: 30, transportation and getting to places: 27, grocery and other shopping: 27, arranging services and appointments: 26, seeking information and resources: 26, social activities and interactions: 23, preparing meals and eating: 23, housework and home management: 22, managing finances: 22, using technology: 18, personal hygiene and getting dressed: 16
	Effect on family life	Negative effect: 11, Positive effect: 7, Both negative and positive effects: 5, No effect: 5, Not sure or not applicable: 2
	Effect on work and career	Negative effect: 16, Positive effect: 3, Both negative and positive effects: 3, No effect: 7, Not sure or not applicable: 1
	Effect on caregiver's own health	Negative effect: 14, Positive effect: 3, No effect: 11, Not sure or don't know: 5
	Need for help	A total of 29 caregivers reporting need for help in… keeping care recipient safe at home: 19, managing their own emotional and physical stress: 18, making end-of-life decisions: 14, managing care recipient's toileting problems: 8, managing care recipient's challenging behaviors: 7, other: 20 (finding resources, coordinating between doctors, understanding insurance terms, finding assistive tools, finding available services, etc.)

As shown in Table 1, most of the caregivers in this study were experiencing some difficulties and negative effects of caregiving. Very few reported positive effects of caregiving. Many caregivers reported a severe burden associated with caregiving and difficulties balancing various responsibilities in life. For example, the majority of the sample said that they had gone to work late, left early or had to take time off during the work day (25 participants), been unable to do housework (22 participants), missed family events (21 participants), and gotten involved in arguments with family due to caregiving (20 participants). Many also reported that they had fallen behind in managing their own finances (13 participants), had to stay out of their home for several days or longer for caregiving duties (13 participants), cut their work hours or changed to part-time (9 participants), took a leave of absence from work (5 participants), or turned down a promotion (4 participants). In addition, while all 30 caregivers in the sample were helping their care recipients with medication management, 25 of them were also taking daily prescribed medications themselves. The sample characteristics suggest that caregivers can potentially benefit from use of technologies and services that can ease their burden by making caregiving tasks easier, less stressful and more efficient.

3 Results

3.1 Caregivers' Use of Technology

A series of questions was asked about caregivers' experiences with various technologies (e.g., mobile devices, monitoring systems, computers, entertainment technologies, smart home appliances and more). Questions were asked about caregiver's use of given technologies generally (i.e., personal use for purposes other than caregiving), as well as in relation to their caregiving responsibilities. Figure 1 shows a selection of technologies included in the questionnaire, along with a summary of responses.

A total of 25 caregivers reported currently using some form of technology to assist with their caregiving responsibilities. As shown in Fig. 1, the most commonly used form of technology for caregiving was smartphones (currently used for caregiving by 20 participants), followed by laptop computers (13 participants), wireless home internet networks (12 participants), and televisions (11 participants). While the majority of caregivers were providing care to a parent with memory issues and/or long-term physical conditions, few reported currently using an emergency call system (6 participants) or GPS trackers (2 participants). When asked about the effect of using technologies for caregiving on a scale from 1 (not at all easier) to 5 (very much easier), the 25 caregivers currently using technologies said that technology has made caregiving somewhat easier for them (average score: 3.44). Also, on a scale from 1 (not a strain at all) to 5 (very much a strain), caregivers said that technology use is not too much of a strain for them physically (average score: 1.32), financially (2.16), or emotionally (1.64).
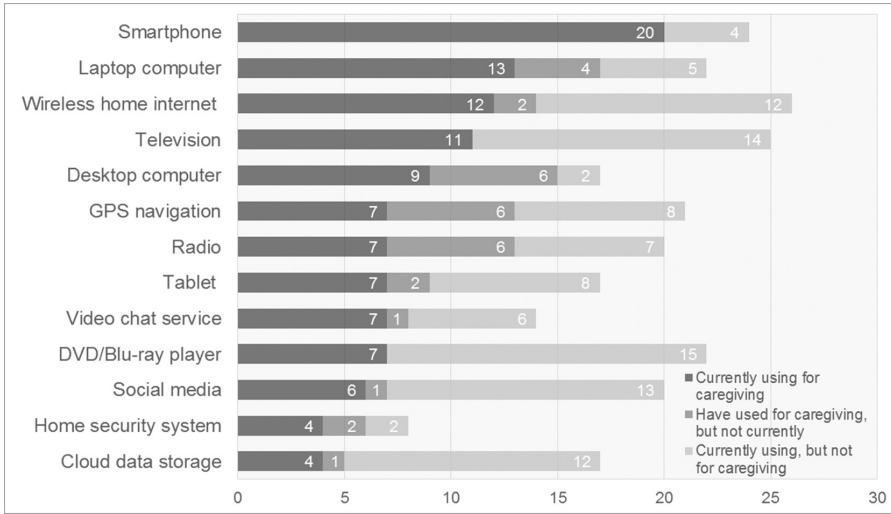
**Fig. 1.** Caregivers' use of various technologies (N = 30)

When caregivers indicated current use of a technology, they received additional questions on reasons for using that technology. Caregivers' responses to these questions – reasons for use in terms of task domains and anticipated benefits – are summarized across technologies in Fig. 2. As shown in Fig. 2, technologies currently used by caregivers were mostly used to assist with health care and management (47.0% of chosen technologies), followed by information search (42.4%), social interactions and communication (36.4%), intellectual stimulation (31.8%), shopping and retail (30.3%), entertainment (24.2%) and personal care (24.2%). Responses indicated that caregivers were mostly using technologies to save time (54.5% of chosen technologies). Many caregivers also used technologies to ease their emotional burden (36.4%), but less to ease their physical (16.7%) or financial (4.5%) burden.

As shown in Fig. 1, several caregivers reported that they had used some technologies for caregiving before, but that they stopped using them. For example, some said that they used digital cameras (7 participants), desktop computers (6 participants), GPS navigation systems (6 participants), radios (6 participants) and basic mobile phones (6 participants) for caregiving at one point, but not currently. Furthermore, while use of various technologies in caregiving was limited, caregivers were utilizing them in other situations and for personal use outside of caregiving. For example, smartphones, laptop computers, wireless home internet networks, televisions, GPS navigation systems, DVD or Blu-Ray players, social media, USB flash drives and radios were used for purposes other than caregiving by at least 20 participants. When asked why they had not used or have stopped using these technologies for caregiving, caregivers reported the primary reason as that they had never thought of using them for caregiving (34.7% of technologies not currently used for caregiving). Other reasons reported were that caregivers found the selected technologies costly (9.5%), that they did not find them useful (9.5%), and that they found them difficult to learn or use (3.2%).
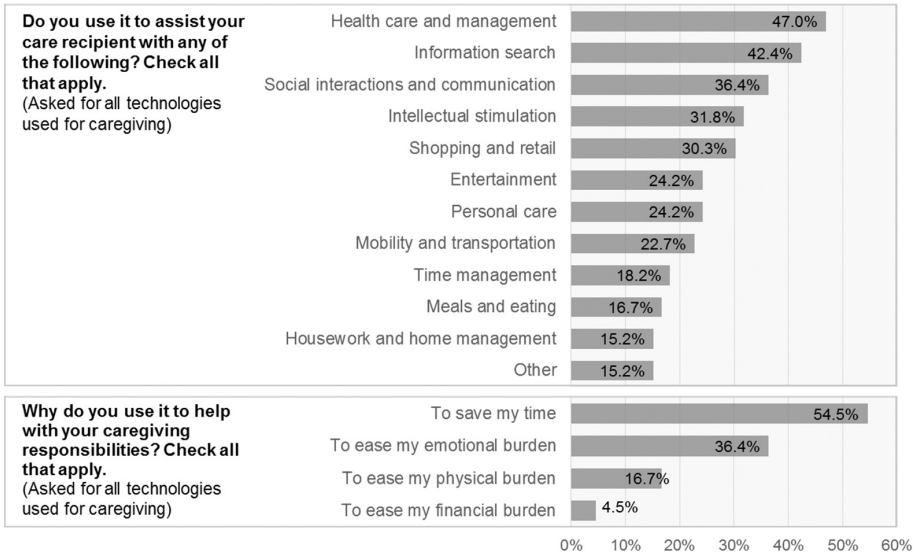
Fig. 2. Reasons for caregivers' use of technologies (aggregated across all technologies used)

The study also identified characteristics that caregivers look for when they decide to get and/or use new technologies for caregiving, and compared the results against technologies for personal use. Caregivers were presented with a list of criteria adapted from a multidimensional set of technology adoption factors defined in [15] and were asked to choose all factors that applied in their decisions. Results are summarized in Fig. 3.
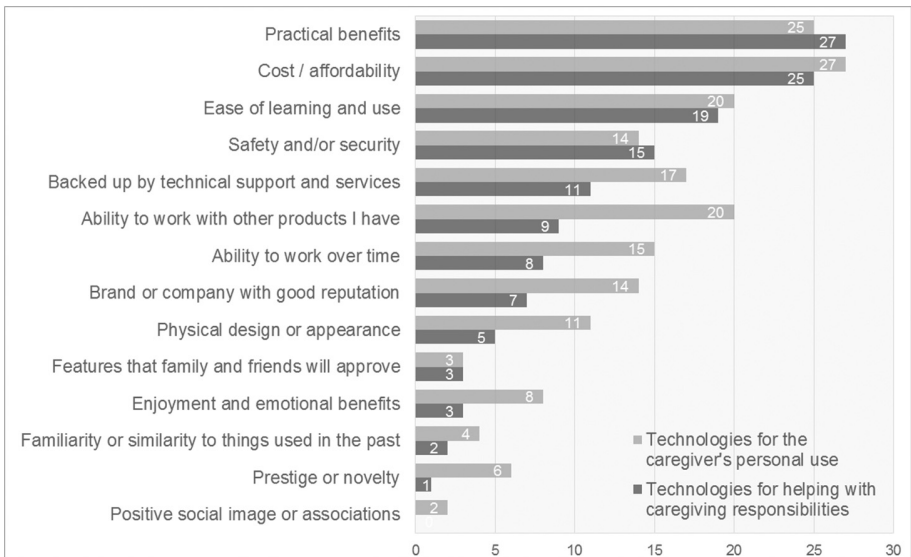
Fig. 3. Criteria for getting and using new technologies (N = 30)

As shown in Fig. 3, practical benefits and cost or affordability were the most important criteria for adopting both technologies for personal use and for caregiving. Ease of learning and use was also considered to be important in both cases. While technical support and ability to work with other products were considered important when getting technologies for personal use by the majority of participants, however, a smaller number of participants considered these key criteria when getting technologies for caregiving use. In general, while a variety of different factors were considered around technologies for personal use, caregivers' decisions for getting and using technologies for caregiving seemed focused on a smaller number of criteria.

Caregivers also reported difficulties and challenges that they faced in using technologies to assist their caregiving responsibilities. Caregivers emphasized the need for better education and training, and the need for improved ease of use. For example, one participant said that it is "hard to teach the care recipient how to use technology", and others said that it is "hard (for the caregiver) to learn to use at the beginning" and that "the care recipient can't understand how to use them". In addition, they explained how the use technologies for caregiving can be made easier for them. Again, caregivers indicated the need for "professional instructions" and "education on how to use the tools to make caregiving easier", as well as the importance of "simplicity".

3.2   Caregivers' Use of Services

Caregivers also provided insight on their use of and perceptions about a variety of available services (e.g., delivery services, housekeeping, retail services, healthcare services and more). First, questions asked about caregivers' current and past use of various services with regard to their caregiving responsibilities. Figure 4 summarizes the results with the full list of services included in the questionnaire.
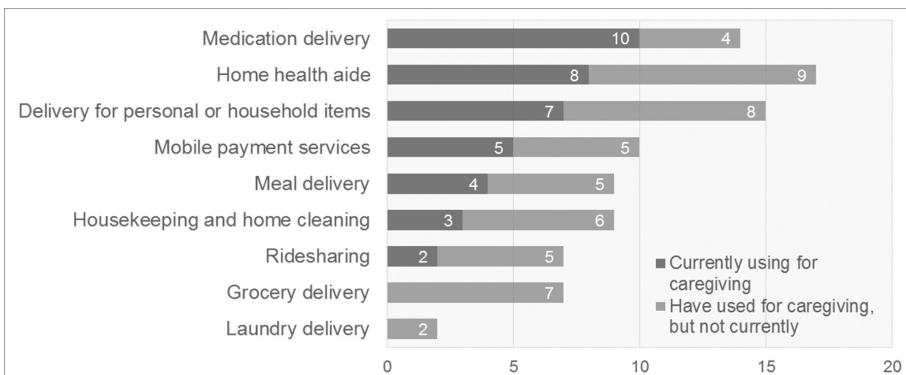

Fig. 4. Caregivers' use of various services (N = 30)

A total of 19 caregivers reported currently using at least one of the services presented in the questionnaire to assist with their caregiving duties. As shown in Fig. 4, services for medication delivery were most common (10 participants), followed by the use of home health aides (8 participants), delivery for personal or household items (7 participants) and use of mobile payment services (5 participants). It is evident, however, that even the most common services were only used by a minority of caregivers.

When asked about reasons for using services to help with their caregiving responsibilities, caregivers reported that 68.4% of selected services were currently used to save time. Another main reason for use of services was to ease caregivers' emotional burden (36.8% of chosen services). Services were less used to ease physical burden (21.1%) or financial burden (13.2%).

Questions on perceived importance, usefulness and ease of use explored how caregivers felt about the services that they were currently using. While only a limited number of participants were using given services, current users found these services to be important, useful and easy to use. On a scale from 1 (not important at all) to 5 (very important), the overall average perceived importance score was 4.31, and ranged from 3.71 for delivery for personal products or household items to 4.75 for home health aides. Perceived usefulness, on a scale from 1 (not useful at all) to 5 (very useful), was also very high with an overall average of 4.49 and ranged from 4.00 for ridesharing to 5.00 for home health aides. Caregivers also rated the services they currently use as very easy to use, with an overall average score of 4.69 on a scale from 1 (very difficult) to 5 (very easy). Average scores for ease of use ranged from 4.00 for ridesharing to 5.00 for mobile payment services.

While 11 caregivers said that they were not currently using any of the given services for caregiving, many said that they had used or tried using some of the given services for caregiving before but had stopped doing so, as shown in Fig. 4. For example, while no participant reported current use of grocery delivery services, 7 participants said that they had used these types of services before. While 8 participants said that they currently used home health aides, a larger portion of the sample (9 participants) said that they had stopped using them. When asked why they had stopped using or had not tried these services, the main reason was that they replaced the services with something else (15.7% of selected services), and that they found the services too expensive to use (11.8%). Other reasons included that the services were or became unavailable to them (9.8%), that they did not enjoy using the services (7.8%) and that the services did not fit into the caregivers' lifestyles (5.9%).

Caregivers were encouraged to provide any ideas or suggestions to improve existing services. Responses addressed the need for better and easier ways of scheduling services and being reminded on time. These suggestions included receiving "email reminders", getting "notifications on time", and making "online scheduling" available. Caregivers also discussed their unmet needs for better tools to manage time and resources, with options such as "a user-friendly scheduling application", "something that would combine work, home and caregiving information together securely to keep track of everything in one place", "a digital day planner", "a database of local agencies combined with shopping and errand services that link automatically to your calendar", and "alerts and timers to move along faster".

4 Discussion and Conclusion

The family caregiving experience entails a broad spectrum of tasks, needs and pain points. Technologies and services available to the general public have the potential to ease the challenges that family caregivers manage (e.g., balancing between caregiving tasks and responsibilities outside of caregiving, managing stress and well-being). In order to better understand the current state of technology and service usage among caregivers, this study looked at responses from 30 unpaid family caregivers to questions on use of technologies and services, perceptions of importance and usefulness, reasons for use, criteria for adoption, and unmet needs.

While the majority of participants reported using at least one technology for caregiving, smartphones were the only technology that most of the caregivers in this study were currently using. While many of the technologies in the questionnaire were widely used by caregivers for personal use outside of their caregiving responsibilities, they were only used by a limited number of caregivers to assist with caregiving duties. Similarly, when asked about the use of services to help with caregiving responsibilities, it was found that the services presented in the questionnaire were used only by a small number of participants. Furthermore, several caregivers had used some of the technologies and services asked about in the questionnaire at some point in the past, but had stopped using them.

Even though technologies and services were used by only a fraction of caregivers surveyed, those who used them were generally satisfied with them, as indicated by high ratings for perceived importance, usefulness and ease of use for services, and by self-reported scores indicating that the use of technologies have made caregiving easier. Additionally, reasons for stopping use of or not having tried these technologies and services were connected more to limited awareness and accessibility, including cost and expense, rather than to a lack of interest or minimal perceived usefulness. For example, during interviews and in response to open-ended questions, many caregivers expressed interest in exploring and experimenting with new technologies and services that would potentially help them manage their time, save money and access information, as well as ease the physical, financial and emotional burdens associated with caregiving. Also, several caregivers showed interest in using a caregiving robot, even though the technology is new, potentially expensive, and unfamiliar to them. Many caregivers also discussed the need for better instructions, education programs and professional support for using technology and service solutions generally.

Future research can explore ways to improve access to various technologies and services so that caregivers can more easily access the tools they may need to ease their burden. Better coaching and education may be necessary to enable caregivers to learn about ways that they can use existing and new technologies and services to assist with their caregiving responsibilities, as well as to save time and balance caregiving with work and family life. There are also avenues of research open around caregiving in the workplace, as many participants expressed concerns related to the cost of getting and using technologies and services, and workplace benefits and insurance subsidization are possible means to support and ease the demands on working caregivers.

Addressing these awareness and accessibility barriers may encourage caregivers to adopt more caregiving technologies and adapt more general technologies for caregiving purposes. Increased technology use may provide support to the 43.5 million American unpaid family caregivers and help them manage their physical, financial, and emotional caregiving burden, improving their well-being and quality of life.

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