

Reducing the distance in distance-caregiving by technology innovation

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Abstract: Family caregivers are responsible for the home care of over 34 million older adults in the United States. For many, the elder family member lives more than an hour's distance away. Distance caregiving is a growing alternative to more familiar models where: 1) the elder and the family caregiver(s) may reside in the same household; or 2) the family caregiver may live nearby but not in the same household as the elder. The distance caregiving model involves elders and their family caregivers who live at some distance, defined as more than a 60-minute commute, from one another. Evidence suggests that distance caregiving is a distinct phenomenon, differs substantially from on-site family caregiving, and requires additional assistance to support the physical, social, and contextual dimensions of the caregiving process. Technology-based assists could virtually connect the caregiver and elder and provide strong support that addresses the elder's physical, social, cognitive, and/or sensory impairments. Therefore, in today's era of high technology, it is surprising that so few affordable innovations are being marketed for distance caregiving. This article addresses distance caregiving, proposes the use of technology innovation to support caregiving, and suggests a research agenda to better inform policy decisions related to the unique needs of this situation.

Keywords: caregiving, family, distance, technology, elders

Benefits and costs of family caregiving

People in the United States are living longer, and the oldest elderly are the most rapidly growing group. Dependence on others increases with age due to the rise in chronic debilitating conditions. As the population of elders grows, costs associated with care escalate. Family members become involved in the care of elders at a cost exceeding \$7 billion annually with over \$30 billion absorbed by businesses in lost productivity and absenteeism of family caregivers (Langa et al 2001; Koppel 2002). The financial value of time devoted to informal caregiving is an estimated US\$305 billion (Arno 2006).

Remaining at home is a preference for most older persons and 95% receive some level of caregiving from family and friends (Stone 2000; NINR 2001; AC 2002). Nearly all reports of benefits and problems associated with family caregiving of elders in their own homes come from those giving care on-site. The presence of family caregiving for elders improves quality of life, supports functional independence, delays functional decline and institutionalization (Dunkle and Kart 1997; Kelley et al 1999), and saves healthcare dollars. Research evidence suggests quality caregiving is possible as long as caregivers have ample resources (Greenberger and Litwin 2003). However, caregiving becomes heavier over time, making caregiver burden, stress, strain, and depression common (Kuhlman et al 1991; Schulz et al 1995; Schulz and Beach 1999). Caregivers report the reason they are caring for their family member or friend is because the care recipient does not require professional help (43%), could not afford help (40%), or does not want strangers in the home (37%) (HJKFF 2002).

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Caregiving from a distance: a growing demographic

The numbers of families caregiving from a distance and the numbers of elders who remain at home and require care are increasing (Zedlewski and McBride 1992; Brookmeyer et al 1998). Approximately five to seven million Americans are long-distance caregivers for elders, and this number is expected to double in the next 15 years. Geographic factors and population migration make caregiving for elders more difficult because family members do not live nearby. Factors that influence the trend for geographic distance to separate families reflect today's mobile society (see Table 1). Between one-fourth and one-third of distance family caregiving includes coordination of care provision, maintenance of elder independence, and socialization for the elder (Wagner 1997; NAC 2004). Distance caregiving varies by length of distance between the elder and the caregiver, the family relationship (Mercier et al 1989), and the elder's living arrangements.

Distance caregivers live, on average, 450 miles from elders and travel 7 hours to reach them. Between 25% and 40% of distance caregivers are the elders' primary caregiver (HJKFF 2002; NAC 2004). Distance caregivers report an average of 22 hours per month providing care. One third of distance caregivers visit the elder at least once a week, with an additional 17% reporting visits a few times a month (NAC 2004).

The majority of distance caregivers are women (76%) and the elder most often lives alone (35%) or with a spouse (24%) in his or her own home. Forty-six percent of distance caregivers arrange for needed services and 49% monitor the services being provided. Approximately 75% assist with Instrumental Activities of Daily Living (IADLs); 40% also report assisting with Activities of Daily Living (ADLs) such as bathing, dressing, and feeding. Most report that they receive support from siblings or other relatives (86%) (NAC 2004).

Distance caregivers report financial burden associated with the actual cost of travel to and from the elder, pay for care in the home, and lost wages. Caregivers lose 15 million days of work each year to perform care and may rearrange their work schedules, take unpaid leaves, and consider chang-

ing employers to adapt to caregiving activities. The more distance between the caregiver and elder, the more often caregivers actually missed whole days of work to provide care. Distance caregivers incur losses due to diminished career development, salary, and retirement income. Studies suggest that compared with men, women travel further and more often, take more time from paid work, and provide more direct care (Joseph and Hallman 1998; NAC 2004). Even if distance caregivers classify their activities as caregiving, they may be reluctant to acknowledge the role, particularly to employers, who may see these activities as interfering with work productivity.

Responsibilities and recommendations for distance caregiving

Caregiving processes and actions vary by the degree to which geographic proximity, technology, and caregiver support influence the process (Silverstein and Litwak 1993). Distance caregiving includes additional responsibilities and roles beyond those of on-site care (Schoonover et al 1988; Baldock 2000; NINR 2001; Collins et al 2003).

Families become innovative in carrying out distance caregiving. A case study of one African-American family engaged in distance caregiving of an elder with dementia describes unique challenges associated with 1) understanding the disease process, 2) maintaining emotional support among siblings, 3) securing formal respite care, and 4) learning to deal with the day-to-day struggles. Solutions included siblings returning home on a rotating basis to care for their mother during her decline, others calling to check on their mother during their workdays, and the enormous task of learning how to care for an elder with dementia (Collins et al 2003).

Caregivers may unrealistically assess their ability to provide the needed care. As the elder's needs intensify, the distance caregiving strategies that once worked may become strained. Family members often lack the caregiver education, training, skills, and support services to provide distance caregiving for elders as frailty increases. Caregivers have

Table 1 Factors influencing geographic distance between elders and family members

Relative ease of travel facilitates family visits from distant sites
Elders retire to locations remote from their original family residence and support systems
For social and/or economic reasons, elders choose to remain in their home rather than following other family members to new locations
Adult children move from location of original family residence for educational and/or work requirements or opportunities
Adult children form relationships with significant others and relocate to form new family constellation

reported unintentional competition between generations for the energy and time of the caregiver, limited availability and use of community support, and challenges to create an adequately supportive and familiar social environment for elders (Jones and Brennan 2002). This may be particularly challenging in distance caregiving.

Technology as an untapped primary support for distance caregiving

When the physical location of the caregiver and elder are at a geographic distance, additional assists are required to support the physical, social, and contextual dimensions of the caregiving process. Numerous technological assists, including enabling, automation, and tele-health technologies, have potential for providing this type of caregiver support (Hudson 2004). Technology-based interventions that include computer and communication technology offer potentially strong support in the areas of prevention and detection, managing everyday life, social connectedness, and identity affirmation (McClendon et al 1998; Mynatt et al 2001; Intel Corporation 2003; Morris and Lundell 2003). Therefore, in today's era of high technology, it is surprising that so few affordable innovations are being marketed for distance caregiving. One explanation for this gap in application may be the lack of understanding about the relationship between technology and caregiving activities (Silverstein and Litwak 1993; Morris and Lundell 2003). Technology-based interventions could virtually connect the caregiver and elder and provide strong support for distance caregiving that addresses the elder's physical, social, cognitive, and/or sensory impairments (Mynatt et al 2001; ETAC 2004; Intel Corporation 2004).

A possible solution to acceptable application of technology into the homes of elders is through ubiquitous computing. This approach integrates computer technology into the environment, rather than having computers that are distinct objects. Ubiquitous computing and embedded technology are emerging as assists in the home environments. Weiser (1996), who coined the term, reflected, "Ubiquitous computing names the third wave in computing, just now beginning. First there were mainframes, each shared by lots of people. Now we are in the personal computing era, person and machine staring uneasily at each other across the desktop. Next comes ubiquitous computing, or the age of calm technology, when technology recedes into the background of our lives." For those with cognitive decline, Morris and Lundell (2003) identify four principles to guide the use of calm technology solutions including assessing while helping, adapting

assistance to variability in cognitive abilities, catalyzing instead of replacing social interactions, and leveraging familiar interfaces. These needs are embodied in the technology-based solutions that are being proposed for the caregiver/elder dyad. Technologies for adaptive aging include: wireless broadband; biosensors and bodily diagnostics; activity sensors and behavioral diagnostics; information fusion; personal health informatics; ambient displays and actuator networks; agents, assistants, coaches, and companions; adaptive, distributed interfaces; and remote community and collaboration (Dishman et al 2004) (See Table 2).

Two-way video connections adapted for the elder's level of physical and cognitive ability can engage the elder in social and cognitive stimulation. Intelligent assistive technology such as activity cueing, autominders, televideo monitoring or a ComputerLinks network could assist in remote wellness checking, providing information and decision-support, and address distance caregiving needs to assess changes in health or functional status (Brennan et al 1995; Czaja et al 2001; Czaja and Rubert 2002; Morris and Lundell 2003; ETAC 2004). Telecommunication innovations could bridge some of the socialization and communication gaps imposed by distance and assist the caregiver in assessing and enhancing the elder's functional status. The use of family portraits, ambient displays, and customized two-way video and computers offer methods to connect and represent a way of feeling presence across distance (Mynatt et al 2001; Mankoff et al 2003; Morris and Lundell, 2003; Dishman et al 2004).

Using technology to communicate and interact with elders offers avenues for novel approaches to care and opens new areas of exploration. The challenge to using advanced technology-based interventions is to match these technological capabilities to actual caregiving needs, understand how people prefer to interact with technology, and learn how it fits into caregivers' and elders' lives without introducing new burdens associated with technology use (Czaja et al 2001; Morris and Lundell 2003; Dishman et al 2004).

Needed research and policy initiatives

Because the exact nature of distance caregiving remains virtually unexplored, there is a need for funding initiatives to determine its problems, cost-benefits, and impact on caregivers. Despite the growing body of literature addressing technology-based initiatives, the exact nature of how technology can assist distance caregiving is unexplored, yet essential for planning interventions. Research initiatives to address distance caregiving could assist in developing

Table 2 Selected core technologies and their capabilities

Core technology	Capabilities
Technology	Values to aging in place
Wireless broadband	Anywhere in the home, any device connectivity Rich and multiple streams of health information delivery
Biosensors and bodily diagnostics	Real-time, routine chemical analysis Targeted drug delivery and effects analysis
Activity sensors and behavioral diagnostics	Location, object, and person tracking around the home Regular activity and activities of daily living measurement and assessment
Information fusion and inference engines	Personal baselines and alerts to meaningful deviations Reliable data even from temperamental technologies
Personal health informatics	Central repository for personal and professional health information Tools for easy visualization of long-term trends
Ambient displays and actuator networks	Lightweight ways to notice “okayness” of loved ones Smart home controls of all devices and appliances
Agents, assistants, coaches, companions	Reminding and coaching of activities of daily living that are declining Companionship for intellectual stimulus and support
Adaptive, distributed interfaces	Any device interactivity—do not have to use a personal computer to compute Interface experience personalized for familiarity and function
Remote community and collaboration	Multiple modes and media for communicating across distance Ways of representing and feeling “presence” at lonely times

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healthcare policies to address this need in the community-based eldercare system.

Clearly, there is a paucity of research literature related to distance caregiving. Although demographic assessments provide a snapshot of the distance caregiver, the foundational research to inform our understanding of the growing phenomenon of distance caregiving is lacking. Few tested interventions are available to assist caregivers and interventions that may offer potentially strong support for distance caregiving have not been adequately explored and customized. Therefore, the empirical evidence and experience of distance caregivers suggest the following list of research imperatives.

The theoretical foundations that support the study of distance caregiving including linkages with coping-stress, filial family relationship theory, and/or role theory should be further developed and address the following questions. Should the work being done with support-seeking versus emotion-focused coping be expanded (Gottlieb and Wolfe 2002)? Is a task-specific paradigm of social support structures (Silverstein and Litwak 1993) more likely to capture the unique dimensions of caregiving from a distance?

Descriptions of activities involved in performing distance caregiving are lacking. The scope and complexity of the role must be better understood. Tests of application of a skills-based model of caregiving to study the actual performance of distance caregiving are required. For example, Schumacher and colleagues (1998) identified five concepts related to effective onsite caregiving: caregiving mastery, self-efficacy, competence, preparedness, and quality. Additional work identified nine core caregiving processes: monitoring, interpreting, making decisions, taking action, making adjustments, assessing resources, providing hands-on care, working with the elder, and negotiating the health care system (Schumacher et al 2000). The skills-based processes of on-site family caregiving proposed by Schumacher and colleagues may provide the beginning structure of distance caregiving. Subsequent studies could define the levels of expertise and success measures in distance caregiving and profiles of excellence for distance caregiving.

The processes by which families choose to provide care to elders from a distance must be identified to inform current and future intervention research. Factors that promote

or hinder distance family caregiving must be better understood. These include generic caregiver knowledge, skills, and support and caregiver needs on sorting through options and decision-making (NINR 2001).

In on-site caregiving, the filial responsibility is usually shared and is influenced by family structure, the elder's health status and needs, and the availability of adult children (Stoller et al 1992). What are the effects of family type, availability of siblings, gender, cultural and ethnic differences, and the nature of the caregiver/elder relationship beyond the typical dyad in distance caregiving (Pinquart and Sorensen 2005)?

The trajectory of care and changes in roles and distance care tasks may change over time. Studies are needed to determine whether caregiver support is required on an intermittent or continuous basis to determine levels of intensity of distance caregiving for elders with cognitive impairment, physical limitations, or both. Patterns of caregiving attrition over time and its relationship to the elder's placement in a facility must be addressed.

What interventions might assist with the process of balancing caregiving engagement in and detachment from caregiving from a distance (Carmack 1997)? How do distance caregivers balance engagement and detachment? Are distance caregivers better able to balance engagement and detachment based on their physical location from the elder? Which distance caregivers are at greater risk for difficulties in response to caregiving and role strain?

The role of community resources in distance caregiving is unexplored. Specifically, studies are needed to determine the impact of poverty, rural location, and ethnic and cultural disparities on distance caregivers who attempt to access and coordinate health services from afar.

The exact nature of how technology can assist distance caregiving for families caring for elders is unexplored yet essential for planning interventions. Studies are needed that prioritize and match caregiver actions and needs best addressed by technology. Application, feasibility testing, and customization of technology-based interventions to assist with elder care in the home environment are warranted (NCA and PCT 1997; Magnusson et al 2002; Charness and Schaie 2003; Dishman et al 2004; ETAC 2004). The usefulness of technologies in special populations, eg, those with cognitive decline or physical impairment, to identify the most helpful solutions to inform development of the underlying technology must be pursued simultaneously with the best methods of training caregivers for technology-based interventions.

Conclusions: Building the evidence base for appropriate distance care

Family members provide a significant portion of the long term care for elders in the United States. Family caregiving is a multidimensional construct including cognitive, psychomotor, and affective dimensions that involve complex reasoning and behavioral processes (Schumacher et al 2000; Farran et al 2004). Providing family caregiving from a distance involves physiological, social, contextual, and geographical dimensions that have not been adequately explored.

Many people find themselves in the position of distance caregiving for economic, employment, or personal reasons. The exact nature of caregiving at a distance for frail elders remains poorly described, yet the need for caregiver relief is apparent (Morris and Lundell 2003). There is a vital need for research to inform our understanding of the concept and process of distance caregiving and the role of current and emerging interventions to address distance caregiver and elder needs. A much closer integration between theory-based research and policy is required to achieve workable caregiving solutions for caregivers and elders separated by geographic distance.

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