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Quality of Life Technologies in Supporting Family Caregivers

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## 13.1 Introduction

The population is aging at an unprecedented rate in both developed and developing countries. By 2030 there will be about 72 million people over the age of 65 in the United States who will represent about 20% of the population. Also, the older population itself is aging; in the coming decades there will be a large number of people aged 85 and older who represent the oldest old (Figure 13.1). According to U.S. projections, the number of people in this age group could increase to 19 million by 2050 and will represent 35% of the older population by 2040 (Federal Agency Forum on Aging Related Statistics, 2010). The number of centenarians is also growing.

The growth in the number of older people, especially the old–old, has important implications for society and the health-care system. The likelihood of developing a chronic disease or disability and the need for support and health-care services generally increases with age. For example, within the United States, about 80% of older adults have a chronic condition such as heart disease, diabetes, or arthritis, and about 50% have at least two conditions (Center for Disease Control and Prevention, 2010) and large numbers of older people have functional limitations that interfere with the performance of daily living tasks. Further, about 5 million Americans aged 65 and older have Alzheimer's disease (AD) and this number will increase in the coming years especially with the growth in the "oldest old" (Alzheimer's Association, 2010). The majority of older adults (~96%) live in community settings with a spouse, alone, or with other family members (Administration

Millions
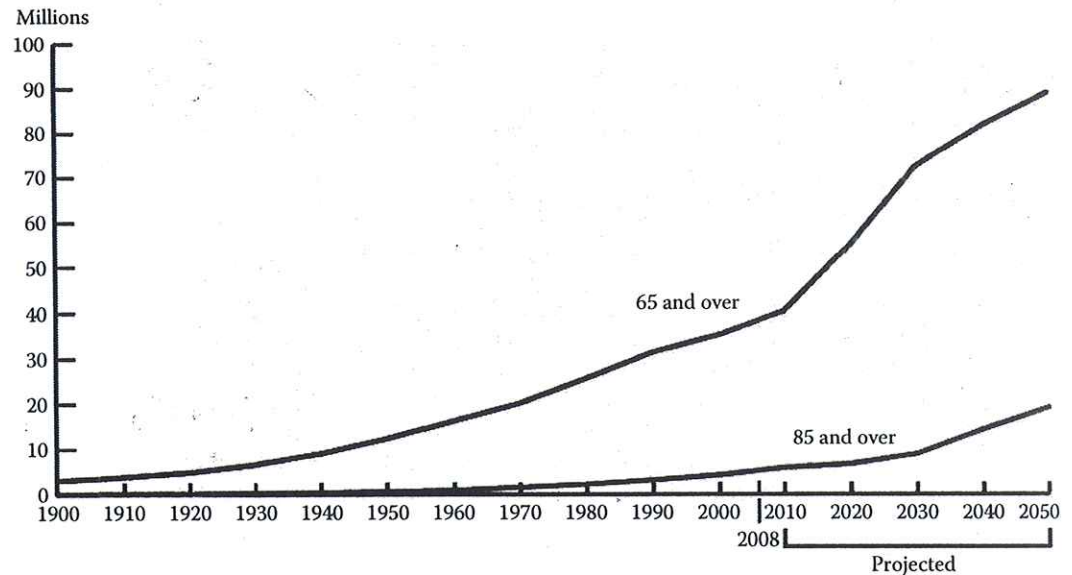
FIGURE 13.1
Population age 65 and over and age 85 and over; selected years 1900–2008 and projected 2010–2050. (From Federal Interagency Forumon Aging-Related Statistics, 2010.)

on Aging, 2011). A great number of these older people rely on family members or friends to provide needed care or some type of support to maintain their ability to live in the community. Although the estimates vary regarding the prevalence of caregiving, currently about 29% of the U.S. adult population is providing care to someone who is ill or disabled and most of these caregivers are providing care to someone over the age of 50 (Family Caregiver Alliance, 2011). Today with increased trends toward the delivery of health care in the home, outside of traditional clinical settings, patients and caregivers are being expected to assume an increasing role in the management of their own health and perform a range of health-care tasks (Figure 13.2).

As discussed in the Preface, there are a myriad of existing and emerging quality-of-life technologies (QoLT) that are designed to maintain or enhance the physical, social, cognitive, and emotional functioning of populations such as older adults or those with disabilities or chronic conditions. Examples of these technologies include monitoring devices to help with the management of chronic illness; assistive technologies that compensate for sensory, physical, and cognitive impairments; rehabilitation technologies for physical and cognitive functioning; and technologies that support resource sharing, knowledge/learning, and social connectivity. Generally, these technologies offer great potential in terms of enhancing of the ability of older adults and those with disabilities to live in the community and receive the health care and support they need. These technologies may also be of great benefit to family caregivers. For example, computer and communication technologies may help caregivers overcome logistic barriers and have access to needed programs and services. Internet technologies can also be used to facilitate communication with family and other caregivers and health-care providers. Technology can also be used to enhance access to health-related information or information about available community resources. Monitoring technologies may also allow caregivers to maintain a check on the status or activities of their loved one while they are at work or at a distant location. In this chapter, we discuss the potential role of QoLT in providing support for caregivers and
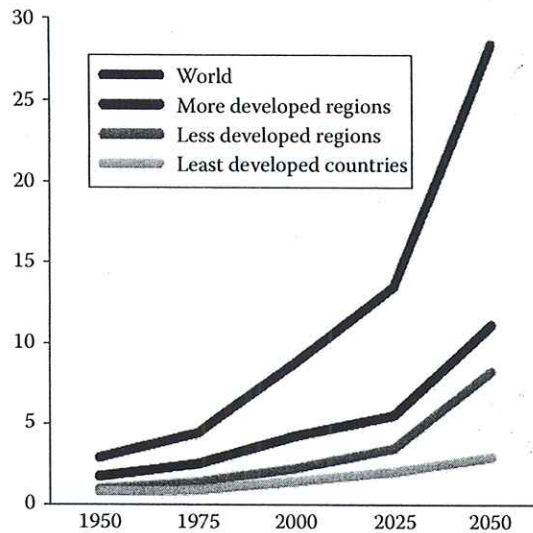
FIGURE 13.2

Parent support ratio: world and development regions, 1950–2050. (From United Nations, World population aging 1950–2050, available online http://www.un.org/esa/population/publications/worldageing19502050/, 2001. With permission.)

care recipients. We also discuss factors that affect the adoption and successful use of these technologies. Finally, we provide some suggestions for needed research in this area.

To provide a context for this discussion we begin by presenting some basic information on family caregivers. We are adopting the definition of caregiving provided by Schulz and Martire (2004, p. 240), that caregiving involves "the provision of extraordinary care, exceeding the bounds of what is normative or usual in family relationships. Caregiving typically involves a significant expenditure of time, energy, and money over potentially long periods of time; it involves tasks that may be unpleasant and uncomfortable and are psychologically stressful and physically exhausting." We recognize that there are distinct groups of caregivers such as children with chronic illness and disability who are typically cared for by young adult parents; adult children suffering from conditions such as mental illness, intellectual or physical challenges who are cared for by middle-aged parents; and older individuals who are cared for by their spouses or their middle-aged children or some other relative or friend. Because the nature of caregiving differs substantially for children versus adults, the focus of our discussion will largely be on caregivers of older adults (Schulz and Tompkins, 2010). However, much of the discussion can generalize to other caregiver populations.

13.2 Overview of Family Caregiving

13.2.1 Basic Demographics

Family caregivers have become an important extension of the health-care system and, in fact, are the largest source of long-term care in the United States. In 2011, the value of family caregiver services was $450 billion per year (Family Caregiver Alliance, 2011).

The prevalence of family members serving in a caregiving role is high and projected to increase in the future with the aging of the population, the projected shortage in geriatric health-care workers, and increased cost of formal long-term care. Veterans returning from wars such as Iraq and Afghanistan who have multiple injuries such as traumatic brain injuries and limb amputations or posttraumatic stress disorder (PTSD) will also require care and support from family members for extended periods of time.

In terms of demographics, the majority of caregivers (~66%) are females who are caring for a spouse, parent, or some other relative, and many are providing care for more than one person such as a parent and a child or two parents simultaneously. While people across the life span serve as caregivers, the current average age of caregivers is about 50 years. Most caregivers who are middle-aged are caring for parents while caregivers who are older are more likely to be caring for a spouse. Importantly many caregivers who are caring for someone aged 65+ are likely to be older themselves and many of these caregivers have health problems. For example, a typical scenario might be an older woman who had arthritis and mobility and some visual problems caring for her husband who has dementia. It has also been recognized that some informal caregivers are children. A recent survey estimated that as many as 1.4 million children in the United States between the ages of 8 and 18 provide care for an older adult (Levine et al., 2005).

Caregivers are also ethnically diverse, and although in the United States the majority of caregivers are White (~72%), the number of minority caregivers is increasing rapidly (National Alliance for Caregiving/AARP, 2009). Understanding the ethnic/culture background of caregivers is important because the expectations, roles, and impact of caregiving vary as a function of caregivers' ethnic/culture background (e.g., Belle et al., 2006; Lee et al., 2010). Finally, with respect to employment, a large number of caregivers are currently working or have worked while serving as caregivers. Simultaneously working and being a caregiver results in added stress for caregivers and also has an impact on their job performance and is costly to business/industry. Many working caregivers report that they make workplace accommodations such as absenteeism, missed opportunities for promotion, and early retirement due to caregiving. Employed caregivers have higher rates of absenteeism than other workers and most report that caregiving responsibilities interfere with their work. These types of job accommodation are more likely for female caregivers. It is estimated that these accommodations cost U.S. employers between $17 and $33 billion per year in lost productivity. For the individual, caregiving costs include losses in wages, pensions, and social security and other benefits. QoLT may be especially beneficial for caregivers who must juggle work and caregiving responsibilities (Family Caregiver Alliance, 2011). In this regard, we are currently evaluating the benefits of a multicomponent psychosocial intervention for working caregivers. The intervention is modeled after the REACH II program (Belle et al., 2006) and is delivered via a website to facilitate the ability of caregivers to access the program. The website contains videos on caregiving skills, videos from "experts" on various topics relevant to caregivers, a resource guide, information and tips, and a recommended reading list (Figure 13.3).

Demographic characteristics of care recipients are also diverse. The average age of care recipients varies across the life span and includes children as well as adults; however, in terms of adults receiving care, it is about 77 years of age. Interestingly, the average age of care recipients has increased in the last few years because of an increase in the number of people in the older cohorts. A majority of care recipients are female, and about 50% of those needing care are widowed. About 60% of care recipients live in their home and about 24% live in their caregiver's household. Caregivers who are older are more likely to report living with their care recipient. In terms of geographic proximity, according to a recent
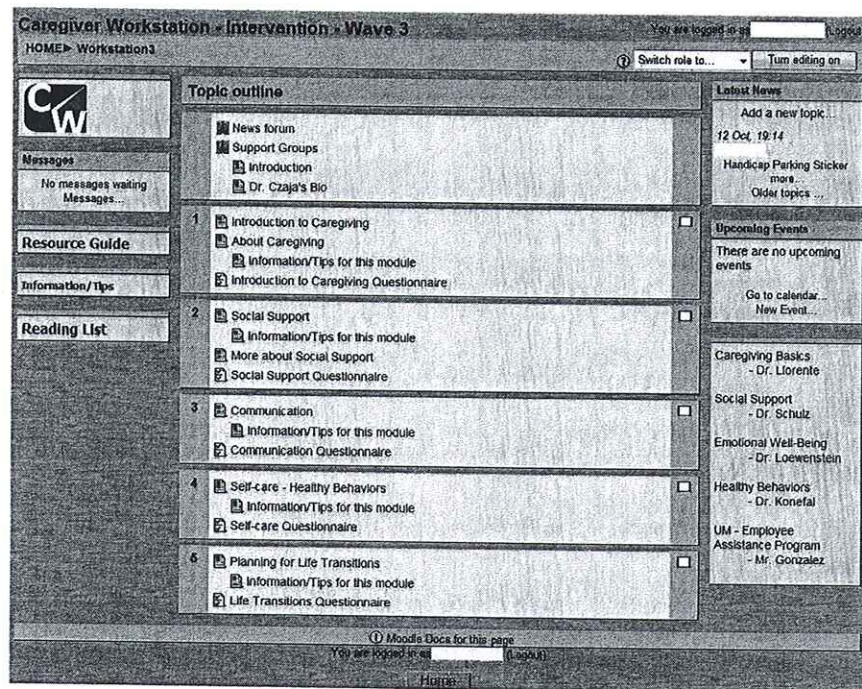
FIGURE 13.3
Working caregivers home page.

survey of those care recipients who live independent from their caregiver, 51% live less than 20 min away, 14% live 20 min to 1 h, 5% live 1–2 h, and 11% live more than 2 h away. Clearly, caregiver distance from the care recipient influences the demands and stress of caregiving. QoLT may be especially beneficial for caregivers who live far distances from their loved ones. The most common reasons for care recipient's need for care include aging, long-term physical conditions or chronic illnesses (e.g., Alzheimer's disease), and emotional or mental health problems (National Alliance for Caregiving and AAPR, 2009).

In summary, it is quite clear that people who receive and those who provide care are very diverse and possess variable skills, resources, knowledge, and experience. They also differ on a number of other characteristics such as age, cultural and ethnic backgrounds, education, health status, and living arrangements. Thus, when considering the design and implementation of QoLT for these user groups it is important to remember that, "one size does not necessarily fit all."

13.2.2 Caregiving Activities

The amount of time caregivers spend on caregiver activities varies with the age of the caregiver and the needs of the care recipient. On average, caregivers spend about 20 h per week providing care, whereas older caregivers provide about 31 h of care per week and those who live with their care recipient about 40 h of care per week. Caregivers of people with AD or another type of dementia provide more hours of care, on average, than other types of caregivers. As expected, the number of hours of care increases as the progression of the disease worsens or if the care recipient has comorbidities (Alzheimer's Association, 2009). The duration of caregiving also varies but is about 5 years. Caregivers of AD patients tend

to spend longer in the caregiving role, on average 1–4 years. Also, as noted, caregivers of newly returning veterans will also likely be needed to provide care and support for extended periods of time.

Caregiving typically involves a significant expenditure of physical and emotional and economic resources and can involve unpleasant and uncomfortable tasks and interactions. Caregivers engage in a wide range of tasks and support a wide range of activities including monitoring the health and safety of the patient; assisting with complex medical tasks and treatments and medication adherence; management of physical and behavioral symptoms; assistance with bathing, dressing, and toileting, meal preparation, and eating; transfers; shopping, other errands, and transportation; and legal and financial issues. Caregivers frequently need to interact with complex medical technologies such as infusion pumps or feeding tubes when performing these tasks. Many caregivers also provide emotional and social support. They must also interact with health-care providers and other personnel from service agencies. In addition, they are often faced with complex care coordination activities and decisions about treatment and medical insurance options. Generally, caregivers of people with AD or dementia are more likely to provide assistance with basic ADLs and personal care tasks.

It is important to note that caregiving is not static and that the demands of caregiving may change over the course of a caregiver's career. For example, in the early stage of a patient's illness, a caregiver may need information about the disease and available resources, whereas in the later stages they may need assistance with the treatment of behavioral or emotional problems. Thus, designers of QoLT need to be aware of the trajectories and changing needs of caregiving when designing caregiver support systems.

13.2.3 Consequences of Caregiving

Although caregiving can be rewarding and many caregivers are proud of their role and glean positive benefits, caregiving clearly creates challenges. Many caregivers experience stress and burden, which affects their physical and mental health and ultimately their ability to provide care. The negative consequences of caregiving are well documented in the literature. Overall, caregiving has been shown to result in psychological distress, the adoption of poor health habits, and increased use of psychotropic medications; sleep disruption, psychiatric and physical illnesses, and mortality. Caregiving also often disrupts social and family relationships and employment activities (Pinquart and Sörensen, 2003a,b, 2007; Schulz et al., 1995; Vitaliano et al., 2003). Furthermore, many caregivers must adapt to a new familial role and in some cases are continually confronted with the loss of a loved one.

The extent to which a caregiver experiences negative outcomes is influenced by caregiver characteristics (e.g., gender, age), care recipient attributes (e.g., type and severity of illness), and social (e.g., available support) and environmental factors (e.g., neighborhood, housing type). For example, individuals with low socioeconomic status (SES) and with small support networks report lower levels of health than caregivers who are younger and have more economic and interpersonal resources. Family caregivers of people with AD and other dementias are more likely than other caregivers to report that their health is fair or poor (Schulz et al., 1995; Vitaliano et al., 2003) and that caregiving made their health worse (Alzheimer's Association and National Alliance for Caregiving, 2004; Bynum et al., 2004). They are also more likely to have high levels of stress hormones (Lutgendorf et al., 1999), reduced immune function (Kiecolt-Glaser et al., 1991, 1996; Lutgendorf et al., 1999), and cardiovascular disease (e.g., Vitaliano et al., 2002).

13.3 QoLT to Support Family Caregiving

13.3.1 Examples of Technology Support

The accumulating evidence on the personal, social, and health impacts of dementia caregiving has generated a broad range of intervention studies, including randomized trials aimed at decreasing the burden and stress of caregiving. Several studies have demonstrated small to moderate statistically significant effects in reducing caregiver burden, lowering depression, and delaying institutionalization (Brodaty et al., 2003; Schulz and Martire, 2004; Schulz et al., 2005) through either targeted interventions that treat a specific caregiver problem, such as depression, or broad-based multicomponent interventions that include counseling, case management, skills training, and social support. One potential reason for the limited success of these interventions is that many caregivers face difficulties in accessing available services. Barriers such as transportation problems, insufficient support from others, lack of knowledge about available services, and cultural beliefs often limit caregivers from participating in intervention programs. This is especially true for lower SES, minority caregivers. Given that the majority of caregivers provide care in the patient's home and the increased cost of care in clinical settings, there is a need for innovative strategies to provide needed support to both caregivers and care recipients. The need to develop innovative interventions for caregivers is also underscored by current demographic trends such as the increased number of women in the labor force and fewer children available to provide care.

As introduced earlier in this chapter, there are a variety of QoLT that offer this potential. Clearly, technology offers several advantages over more traditional intervention approaches such as increased ability to deliver and access information on demand, asynchronously, and over long distances; increased access to health professionals and social support; and enhanced opportunities to monitor the status and activities of care recipients and help address environmental safety concerns. Computers or mobile devices can also be an efficient means for delivering health risk assessments and health promotion material. Technology also affords the opportunity to present information in a wide variety of formats to suit the needs of the user population. For example, multimedia offers the potential of providing information in text with narration and animation. In this section, we provide examples of how QoLT can be used to support family caregivers. This is an emerging field in the caregiver literature, driven by the expanding power of computers, mobile devices such as Smartphones, and the Internet. Many caregivers are beginning to turn to technology for support in their caregiving role. In fact, a recent survey of 1000 family caregivers (National Association of Family Caregivers and United HealthCare, 2011) queried caregivers who already used the Internet or some other form of technology to support their caregiving about how various technologies might be helpful to them in terms of providing care. The findings indicated that of the technologies evaluated, the three that offered the greatest potential were: personal health record tracking, a caregiving coordination system, and a medication support system.

One basic way that technologies such as the Internet and mobile devices can aid caregivers is through the provision of information that enhances caregiver knowledge. A critical challenge facing many caregivers and requisite to providing quality care is having the necessary knowledge about the care recipient's illness or disability, how to provide care, and how to access and utilize available services. There are a vast number of websites available that can provide caregivers with information on illnesses/diseases, medications and treatments, health-care providers, and health resources. These applications

can also enhance direct access to experts and professional organizations, which can also facilitate decision making by the caregiver.

Recent findings from an interview study of approximately 1500 caregivers indicated that 53% use the Internet as a source of information about caregiving (National Alliance for Caregiving and AARP, 2009). Findings from the Pew Internet and American Life Study (Fox, 2011a) indicate that 26% of Internet users caring for a loved one have looked online for someone with similar health concerns. Another recent Pew study (Fox, 2011b) queried caregivers, who said they had found the Internet to be crucial or important during a loved one's recent health crisis, about the Internet's specific role during that crisis. The findings showed that the Internet helped the caregivers find advice or support from other people (36%), helped them find professional or expert services (34%), and helped them find information or compare options (26%). Many of these websites also offer caregivers an opportunity to join support groups (Figure 13.4). There are concerns of course about the quantity and quality of health information that is available on the Internet. Caregivers and patients are able to access information from credible sources (e.g., Family Caregiver Alliance, Medline Plus) and unreviewed sources of unknown quality. Inaccurate health information could result in inappropriate treatment or delays in seeking needed support from health-care professionals.

FIGURE 13.4
Family Caregiver Alliance home page.

The amount of information available can also be daunting for caregivers, especially those who have limited Internet experience, limited knowledge of credible sources of information, and low health literacy. Data from our group indicate (Czaja et al., 2008, 2010) that both caregivers and older adults trust health information on the Internet and, generally, find the Internet to be a valuable source of health information. However, data also indicated that health websites can be challenging to use (Czaja et al., 2008; Taha et al., 2009).

Networks can also link caregivers to other family members or long-distant caregivers to the person for whom they are providing care. The Internet is increasingly being used as a forum for individuals to exchange information about health difficulties, needs, and strategies for managing health challenges. Several studies have also shown that the computer networks (e.g., Bank et al., 2006; Czaja and Rubert, 2002; Gallienne et al., 1993) can increase social support for caregivers. Demiris et al. (2008) recently completed a small pilot study that evaluated the benefits and challenges of a videophone system designed to facilitate communication between long-distance family members and loved ones in long-term care facilities. Overall, the findings were promising and showed that although there were some technical challenges, the participants were enthusiastic about their ability to use the videophones and engage in videocalls and indicated that it enhanced their sense of closeness. These types of systems can also be used to connect family members with facility staff and the entire health-care team. Marziali and Donahue (2006) evaluated an Internet-based psychosocial intervention for family caregivers of older adults with neurodegenerative disease. The website included links to information, e-mail, and a video-conferencing link that enabled caregivers to participate in guided support groups. Although the sample size was small and there was a relatively high dropout rate among the participants in the control group, the results provided support for the efficacy of the technology-based intervention. Caregivers who received the intervention experienced a decline in stress and they also reported that their experience with online support groups paralleled experiences with face-to-face support group programs. Lewis et al. (2010) conducted a pilot evaluation of an Internet-based psycho-educational program designed to provide knowledge and support to caregivers of dementia patients. Caregivers in their study reported that the program was educational, convenient, and useful. They also reported feeling more confident in their caregiving skills and in their communication with other family members. However, the sample size was small (N = 47) and the participants had prior computer and Internet skills. Similarly Gallagher-Thompson et al. (2010) evaluated a cognitive behavior therapy (CBT) skill training program delivered on a DVD for Chinese American dementia caregivers. The CBT training was compared to a general educational DVD program on dementia. The results showed that it was feasible to use a DVD format to deliver the intervention and that the caregivers who received the CBT intervention reported higher positive affect and less stress in dealing with the patient's behavioral problems.

In an early study (Eisdorfer et al., 2003) we found that a computer-telephone information system (CTIS) designed for family caregivers of patients with AD was effective in reducing depression among a sample of White and Cuban American caregivers. The system was designed to enhance a family therapy intervention and facilitate the caregivers' access to formal and informal support services and information databases such as the Alzheimer's Association Resource Guide. In a follow-up study with a community agency (Finkel et al., 2007), where we used the CTIS system almost exclusively to deliver the intervention, we found that caregivers who used the system with high levels of depressive symptoms at baseline exhibited statistically significant decreases in depression at follow-up and those with high levels of support showed relatively greater capacity to maintain

that support. Caregivers also reported increased confidence in their skills as caregivers and their ability to deal with difficult caregiving challenges.

More recently, we completed a study (Czaja et al., 2011) that evaluated the efficacy and feasibility of a videophone-based psychosocial intervention aimed at reducing stress and burden and enhancing the quality of life of minority family caregivers of patients with dementia. The intervention was modeled after the REACH II caregiver intervention (Belle et al., 2006) and compared to an information-only control and wellness contact control conditions. The videophone was installed in the homes of minority caregivers (Haitian, Hispanic, African, American) of dementia patients and included text and voice information features (e.g., a resource guide and information/tips) and allowed for face-to face communication between the caregivers and their interventionist and facilitated support groups (Figure 13.5). The videophone was preprogrammed so that the information was available in the preferred language of the caregivers—Creole, Spanish, and English (Figure 13.6). Preliminary data from the study are encouraging and suggest that the intervention was helpful in terms of alleviating caregiver distress. The majority of caregivers indicated that the videophone was understandable and easy to use. The caregivers in our sample were generally of lower SES and had limited experience with technology prior to this study. We also learned some valuable lessons about technology implementation. For example, none of our caregivers had Internet connections prior to the study (a requirement for the technology), and the interactions between the clinical and the technical team were sometimes challenging.

Technologies that monitor behavior and communicate with professionals and family members offer great promise for enabling older adults to age in place, and provide support for family caregivers especially those who are working or long distance. Such systems could, for example, know how well a person slept the previous night, identify potential health problems before they become serious or catastrophic, know whether they are able to carry out daily routines, and assure a daughter who lives in a distant city that they are doing well today. Various monitoring systems for older adults and their caregivers are
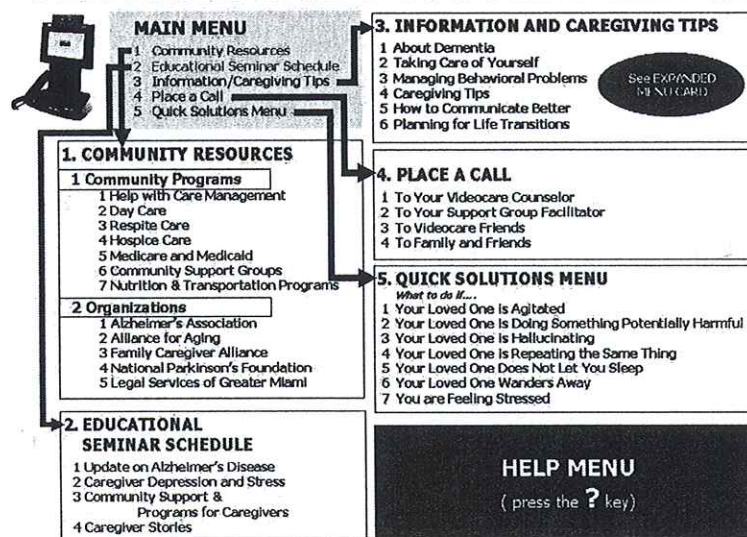

FIGURE 13.5
(See color insert.) VideoCare caregiver program: phone menus.

Agitation

- Try to assess what is causing your loved one to be agitated.
- Remain calm and redirect them by asking them what they need.
- Try and eliminate the source of the agitation.
- Avoid screaming or confrontation.
- Switch to a new activity.
- Offer something of comfort and speak ina calming voice.
- Walk away and give yourself some space.

VideoCare

(a)

Agitación

- Trate de evaluar que es lo que esta potencialmente causando que su ser querido se ponga agitado.
- Manténgase calmdo y redirija su atención por medio de preguntarle que es lo que quisiera hacer.
- Trare de eliminar la fuente de agitación.
- Evite gritar, confrontarle, o escalar en la agitación.
- Ofrézcale algo que le dé consuelo y hable con una voz calmda.
- Finalmente, aléjese, y dése su propio espacio.

VideoCare

(b)

Ajitasyon

- Eseye jwèn kisa ki lakòz moun ou renmen'an ajite konsa.
- Rete kalm epi mande yo kisa yo bezwen.
- Eseye eliminen sous[kòz] ajitasyon'an.
- Evite rele sou moun nan oswa konfwontasyon avèk li.
- Eseye dirije atansyon li sou yon nouvo aktivite.
- Ofri'l yon bagay ka rekonfote'l avèk pale ak yon vwa ki kalm.
- Bay moun nan yon ti distans pa rete trò prè li.

VideoCare

(c)

FIGURE 13.6
Selected information from VideoCare caregiver program in (a) English, (b) Spanish, and (c) Creole.

already on the market, and many more are being developed. These include systems such as fall detection and prevention systems, wearable activity monitors, non-wearable embedded sensor activity monitors, medication compliance systems, and safety monitors such as smoke and temperature monitors. A more recent development is the design and implementation of smart home applications. These involve integrated networks of sensors—which may include a combination of safety, health and wellness, and social connectedness technologies—installed into homes or apartments to simultaneously and continuously monitor environmental conditions, daily activity patterns, vital signs, sleep patterns, etc. over the long-term. The goal is to capture physical and cognitive behavioral patterns and develop algorithms to detect deviations from normal patterns in the hopes of early detection of health problems and prevention of health declines (see Chapter 12 and Czaja, Beach, Charness, and Schulz [in press] for a more complete discussion of monitoring technologies). Health and wellness monitoring may benefit family caregivers by enabling them to be more informed about their loved one's health, improved health-related communication, opportunities for prevention and early detection and intervention, and reduced burdens and strains of care. However, issues related to data integration, privacy, and user interface design may outweigh some of the potential benefits of these technologies.

Overall, the findings from our research and that of other investigators indicate that it is feasible to use technology to deliver intervention programs and support to family caregivers. However, as discussed in the next section, there are a number of factors that influence the success of these applications. These factors include issues pertaining to training needs and technical support, reliability, access to technology, the adaptability of technology to individual needs, the extent to which a technology undermines individual autonomy, control, and dignity, and privacy issues as well as possible legal or liability issues raised by some technological applications.

13.4 Factors Influencing Technology Adoption

The previous section provided examples of various technologies and their potential benefits for family caregivers and care recipients. In order for the benefits of these technologies to be realized by caregivers, patients, and health-care providers, it is important that the technology is useful and useable by these populations and that systems are reliable and responsive. If a system is unavailable, it cannot be used, and if it is unreliable, users will become frustrated and avoid using the technology regardless of potential benefits. All technology involves potential barriers to acceptance that must be overcome to facilitate widespread acceptance, adoption, and continued use. These include a broad range of user characteristics (socio-demographics, health status, social support, experience with and attitudes toward technology) and resources (sensory, cognitive, psychomotor); system characteristics (user interface, instructional support, aesthetics, engagement, functionality); and the fit between the user and the system (see Chapters 2 and 11). An issue particularly important for caregivers and older care recipients is access to technology. Although the rate of technology adoption is increasing across age groups, existing data indicate that there are still age-related gaps in usage. For example, in the United States in 2010, about 42% of people age 65+ were Internet users as compared to 78% of people age 50–64 and 87% of those 30–49 years old (U.S. Census Bureau, 2011). Older adults using computers and the Internet tend to be better educated and White, and have greater social resources and fewer functional impairments than non-adopters. Home broadband adoption is also lower among older people. In 2010, only 31% of people aged 65+ had broadband access at home, which limits the scope and potential of the online experience and the ability to use many health applications (Smith, 2010). Also, although caregivers use technology such as the Internet to support caregiving activities, the rate of using this technology among caregivers is still relatively low (Czaja et al., 2010; National Alliance for Caregiving and AARP, 2009).

A number of studies have examined factors influencing technology adoption among older adults and caregiver populations. For example, Mahoney (2010) recently completed a meta-synthesis of adoption of four technology systems that provided support to family caregivers. The results indicated that factors critical to technology adoption included the targeted end users' perceived value of usage, training sufficiency, reliability and stability of the systems, and concerns about having too many technologies. We (Czaja et al., 2006) have shown that technology self-efficacy and anxiety about use are also important predictors of technology adoption. Chiu and Eysenbach (2011) examined factors influencing caregiver's use of a Web-based intervention. The intervention was designed for caregivers of dementia patients and included information on the disease and caregiving strategies, community resources, and a personalized e-mail support system. They found that the three main factors that influenced use of the intervention were as follows: (1) caregiver needs that are influenced by personal capacity, social support available, and caregiving beliefs; (2) technology factors such as accessibility barriers and perceived effort in using the technology; and (3) style of the technology such as degree of interactivity. Importantly, they found that the new caregivers needed a different type of support than experienced caregivers.

With respect to monitoring technologies, concerns about uptake were related type of information being recorded, how it is recorded, and with whom it is shared. A recent national web-based survey of 1518 disabled and nondisabled baby boomers (age 45–64) and older adults (65+) found significant variations in attitudes toward adoption (Beach et al., 2009, 2010) as a function of the type of information being recorded (e.g., vital signs, moving about the home, driving behavior, taking medications, toileting), methods of recording (video with

sound, video without sound, sensors only), and the target recipient of the information (self, family, doctor, researchers, insurance companies, government). The results showed that potential users were less accepting of the use of video cameras, either with or without sound, than of sensors; less accepting of sharing information about driving or toileting behavior when compared to other types of behavior; and less willing to share information with insurance companies and the government when compared to other groups such as family members or physicians. The other major finding of the study was that both baby boomers and older adults reporting higher levels of disability were more accepting of having information recorded and shared than those with lower levels of disability or no disability.

Other important issues related to the acceptance and use of technology are perceived need and perceived usefulness of the technology. Caregivers and older adults are much more willing to be monitored if they perceive it as providing clear benefits. System design features such as the complexity of the technology and difficulty in learning how to use it and remembering how to use it and maintain it are also critical factors with respect to adoption. Generally, adoption is enhanced if the system is relatively easy to use, has an intuitive interface, and requires minimal training of end users and other stakeholders. The issue of interoperability is also becoming increasingly important with the expanding power of networks and smart applications. Of course, another crucial system "demand" is the cost of the system. The results from the survey conducted by the National Association of Family Caregivers and United Healthcare (2011) indicated that the most prevalent potential barriers to use of technology among caregivers included perceived expense, the belief that technologies do not address caregiver needs, and fears that the care recipient would resist acceptance of new technologies.

13.5 Conclusions

While information technologies hold the promise of improving the quality of life for caregivers and care recipients, there are a number of issues that must be addressed before the full benefits of these technologies can be realized for these populations. Existing barriers to widespread adoption for current cohorts of caregivers and care recipients include large and diverse user groups with varying needs and abilities; caregivers' lack of knowledge about the potential benefits of technology; low technology self-efficacy and anxiety about using technology among caregivers and care recipients; cost and accessibility; training opportunities; and system design characteristics. For example, much more research is needed regarding the relative advantages of more advanced technologies such as multimedia and smart mobile devices when compared to simpler technologies. What is the optimal combination of low- and high-tech strategies that best serve a particular caregiver group?

Monitoring devices are likely to play a central role in caregiver technology applications, and we are beginning to learn about end-user preferences with respect to people's willingness to be monitored, but we know relatively little about caregivers' preferences for how data should be presented to them and how they should be designed to promote effective caregiving. Inherent in this question are many others concerning effective interface designs for both caregivers and care recipients as well as questions about access and training requirements. Developing systems that integrate caregivers with patients and their health-care providers into an effective communication network should be given high

priority. Ideally, such a system would enable the exchange of all types of information, including monitoring of vital signs, behavior, and functioning of the patient, along with verbal and visual communication. It is also essential to investigate sources of potential harm inherent in some technologies such as privacy intrusions, false perceptions about the capabilities and safety of technology systems, the proliferation of too much and inappropriate information and miscommunication among caregivers, patients, and healthcare providers.

Finally, the widespread adoption of technologies to support caregiving will depend on powerful demonstrations that these technologies are not only effective but are cost-effective; that is, they improve the quality of life of caregivers and their care recipients at a lower cost when compared to alternative strategies.

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