The Use of Information Technology to Improve Quality of Care for Persons with Alzheimer's Disease

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The use of Information Technology to Improve Quality of Care for Persons with Alzheimer's Disease

By

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ABSTRACT

The average age is increasing due to which the number of persons with Alzheimer's disease is likely to increase in the next few decades. Information Technology can be used as cognitive prosthetic for those who are suffering from Alzheimer's disease. This paper discusses Alzheimer's disease and how Information Technology can be used to improve the quality of care for persons with Alzheimer's disease.
INTRODUCTION

Along with an increase in average life expectancy in the United States, the number of elders is increasing. Due to the increase, approximately 14 million people may suffer from Alzheimer’s disease (AD) in the next few decades (Guttman Et al. 1999). As a result a majority of the people living in the United States will know someone affected by the disease over the course of their lifetime.

In many situations, information technology (IT) is designed to perform complex cognitive tasks such as decision support. In addition, IT has been used for entertainment purposes. As a result IT can be used for people with cognitive disabilities as cognitive prosthetics as well as for enhancing quality of life.

IT can be used to help those who are suffering from AD and their caregivers. A variety of software can be used as cognitive prosthetics to help those suffering from AD. In this paper I will review the available literature regarding the use of technology to improve the quality of care for individuals with AD.
AD is a form of dementia. So in order to understand AD, one needs to understand dementia.

**Dementia:**

Dementia is derived from the Latin word “demens” that means, “being out of one’s mind” or insanity (Beach, 1987). Dementia is usually defined as a decline in one’s cognitive abilities, which will inhibit or reduce the activities of daily living (ADL). Memory is one of the most common cognitive functions that decline in dementia (Braunweld Et al., 2002). Also, it is important to keep in mind that dementia by itself is not a specific disease. The word dementia usually refers to a collection of symptoms that could be caused by many different disorders (NINDS). These symptoms include but are not limited to a decline in language skills, judgment, calculation, and visuospatial ability. In addition to a noticeable change in personality that could be caused by depression, hallucination, withdrawal, agitation, and insomnia (Braunweld et al., 2002).

Memory loss is one of the symptoms of dementia; memory loss in itself doesn’t imply that a person has dementia. Due to this reason, physicians usually diagnose dementia when more than one cognitive ability is impaired or declining, such as executive skills (judgment or abstract thinking) and visuospatial ability (NINDS).

Dementias can be classified into four different categories. These categories are

1. Primary Dementia
2. Secondary Dementia
3. Cortical Dementia.
4. Sub cortical Dementia.

(NINDS)

For a more detailed discussion on the types of dementia see Table 1.
Alzheimer’s Disease

Alois Alzheimer described AD in 1907. At that time, the average life expectancy was 45 years. Currently 50% of Americans are expected to live past 75 and 25% are expected to live to 85 years of age. The average life expectancy is 77.3 years (Graff-Radford, 2000). According to National Institute of Health, one in five people over the age of 65 are diagnosed with AD. The rate increases to almost 50% in people aged 85 or greater. As a result almost 360,000 people are diagnosed with AD each year and almost 50,000 people are reported to die from it each year (NINDS).

AD is usually defined as a degenerative, dementing illness (Guttman et al. 1999). AD is usually characterized by the formation of tangled bundles of fibrous protein (NNDS). The cause of AD is usually considered unknown. However, four genes have been identified as a potential reason for causing AD. Those genes are located on chromosomes 21, 19, 14, and 1 (Braunweld Et al. 2002). APOE 4 and APOCI A on chromosome 19 are considered risk factors for late stage AD (Poduslo & Yin, 2001).

Alzheimer’s usually affects different parts of brain in different people. As such, different people react to AD differently. However, the following seven stages are common among most of the Alzheimer’s patients.

Stage I: There are no symptoms.
Stage II: In this stage a person experiences a very mild cognitive decline. Memory problems are not yet evident during medical examination.
Stage III: Most people lose the ability to plan and organize during this stage. They could also become unaware of the time and place. Identifying people and remembering names also becomes difficult.
Stage IV: This is the stage when a person begins to lose long-term memory. The patient may also appear withdrawn from social situations. During this stage the patient usually loses the ability to manage finances and to perform mental arithmetic.
Stage V: During this stage major memory gaps in patients’ memory emerge. Patients usually forget their address and appear confused about the season and date. The patients need help in choosing clothing.
Stage VI: In this stage the patients can’t remember their personal history. They forget
the names of their caregivers however; they can distinguish between familiar and unfamiliar faces. Incontinence becomes a problem during this stage and the patient also needs help with dressing. Patients also tend to wander and become lost during this stage.

**Stage VII:** During this stage the patients lose the ability to speak and respond to the environment. The patients usually need help with eating. Slowly the person loses the ability to walk, sit, smile, and other controls. During the very last part of this stage swallowing becomes impaired (Alzheimer’s Association, 2004).

**Alzheimer’s Disease Symptoms**

Forgetfulness is the most common and well-known symptom for AD. Other symptoms include loss of cognitive abilities, judgment, thinking and disorientation to place and time (Guttman Et. al, 1999). According to Bell and Troxel these symptoms could cause Alzheimer’s patients to suffer from the following (for additional information see Table 2).

1. Identification Loss.
2. Isolation and Loneliness
3. Depression
4. Confusion
5. Anxiety
6. Fear
7. Frustration
8. Paranoia
9. Self-Directed anger
10. Embarrassment

For different people the above symptoms may have different effects. For instance, for a 70-year-old man, not being able to drive may cause depression. On the other hand, not being able to remember a grandson’s name may cause embarrassment. Interestingly, depression, fear and worrying only make the disease worse and cause a quick decline in the mental abilities of the patient.
Alzheimer’s Treatment

Currently medicines that are available for AD slow down its progression or help control the symptoms such as anxiety or sleeplessness. However, there is no available cure for AD. For many people medicines such as tacrine, donepezil, rivastigmine, nemenda and galantamine may reduce the symptoms or keep them from becoming worse (NINDS). A clinical trial have shown that the combination of donepezil and nemenda produce better cognition results than donepezil alone (NINDS). Anti-inflammatory drugs, and antioxidants may also been shown to reduce the onset of AD (Guttman Et. al, 1999).

Caregiver’s Role

Caregivers play an important part in the life of a person with AD. Care giving for an Alzheimer’s patient can range anywhere from issuing reminders to following up on patient’s everyday chores (for instance, paying bills or grocery shopping). During the late stages the care giving may also involve taking care of basic necessities, such as feeding.

Caregivers are typically subjected to watching their loved one slowly die and at times can exhibit anger, anxiety or hallucinations. In many instances, AD patients blame their caregiver for not paying enough attention or for trying to hurt them (Mace & Robins, 2001). Caregivers also reduce their social activities in order to provide care and may incur financial burdens. As a result, many caregivers suffer from depression and other psychological illnesses. This affects their household routines, relationships and physical health (Glueckauf & Loomis, 2002).

According to a study by the Alzheimer’s Association, almost 50 percent of caregivers agreed that care giving is causing problems in their immediate families. Caregivers also admitted not having enough time for themselves, and as a result frequently suffer from depression. Typically, caregivers’ depression worsens as the AD patient’s disease progresses. Many caregivers provide care for an average of four years and 34% believed that they would not be able to do it longer. Their care giving also affected their careers. Twenty percent of caregivers stopped working due to care giving responsibilities and those who are still working missed an average of 17 days of work per year. Consequently, a majority of them have either reduced income or are denied promotion at work (Alzheimer’s Association, 2004).
Most of the caregivers of AD patients are between the ages of 45-60. For many people it is the time when they are in the prime of their careers. Leaving jobs at such time can affect the caregivers’ retirement plan. Sixty four percent of caregivers are worried about having enough money when they grow older (Alzheimer’s Association, 2004).

During their late stages of disease progression, people with AD usually look for explanations for their conditions. Mostly it becomes a caregiver’s duty to provide the person with explanations. Most of the time Alzheimer’s patients forget about the explanations that they receive and ask for them again. This can cause irritation in the caregiver. Eventually, a caregiver’s irritability may cause a “malignant social behavior” response toward the care receiver, which leads to further neurological impairment of the person with AD and lead to the person’s quicker downfall (Kitwood, 1996). Nonetheless, caregiver cannot be considered solely responsible for their behavior given the common depression (due to financial and/or emotional problems) they experience. As such, caregivers’ overall wellness should be considered as part of AD patients’ wellness because of the integral role they play.

Negative emotional reactions can lead to a quicker decline of an Alzheimer’s patient. These feelings can be further reinforced by the negative behavior of caregivers. In Dementia Reconsidered Tom Kitwood described 17 “malignant” social behaviors toward an Alzheimer’s patient. Briefly, those behaviors are as follows (a more detailed description appears in Table-3);

1. Treachery
2. Disempowerment
3. Infantilization
4. Intimidation
5. Labeling
6. Stigmatization
7. Outpacing
8. Invalidation
9. Banishment
10. Objectification
11. Ignoring
12. Imposition
13. Withholding
According to the Alzheimer’s Association, many caregivers have expressed the need to share the care giving duties. Traditionally the options include home care (provided by a family member), a visiting nurse, adult day care (a protective setting for the patients during day time hours) and respite care (a service that provides temporary relief to caregivers).

With the advancement in IT another available option could be the use of technology to ease the caregivers’ burden. Before the concept of IT is further discussed, it is important to define this term for the purpose of this paper.
Figure 1 shows the life of a woman who was diagnosed with Alzheimer’s disease. It portrays the neurological impairment (NI) that was further influenced by the various malignant social behaviors of the caregivers.

Figure 1. Story of a woman who’s Neurological Impairment (NI) was increased by malignant behavior

Kitwood, Tom. *Dementia Reconsidered* p 54, 1996
The term “information technology” can have multiple definitions. For example, it could refer to computer related technologies or it can, more broadly, refer to any kind of communication technology. For the purpose of the current paper, information technology is defined as, “applied computer systems including hardware, software, telecommunications and Internet” that can be used to provide information to people with AD and their caregivers.

**Information Technology for Alzheimer’s Disease**

Much of the information technologies use to enhance care for those suffering from AD can be divided into three main categories. Those categories include (a) Information Technology for persons with AD (b) Information technology for the caregivers of AD and (c) Information technology for healthcare professionals.

**Information Technology for persons with Alzheimer’s disease:**

With respect to the different applications of information technology for patients with AD, classification by the three main stages of disease is possible.

a. Information Technology for the early stages. (Stages I-II)

b. Information Technology for the mild to moderate stages. (Stages III-IV)

c. Information Technology for the moderate to moderately severe stages. (Stages V-VI)

**Information Technology for the early stages.** The early stage of AD primarily consists of mood swings, lack in energy and memory problems. At this stage a person can live independently and usually only requires assistance in remembering certain tasks. Cognitive prosthetics are helpful in aiding a person to remember such tasks. There are many different kinds of devices available to act as cognitive prosthetic for the patient or to monitor patient’s movement and help the caregiver. According to a research done by Cole and Dehdashti (1998), a pager was used to help a person remember the tasks during the early stage of AD. The pager was able to record an 80
letter alphanumeric message and then display the message at scheduled time. Following the use of the pager, the person was able to perform independent tasks within a week. After using this pager for six months the functional memory of the person had improved.

**Information Technology for the mild to moderate stages.** The majority of people with Alzheimer’s disease usually fit into the category of mild to moderate disease progression because misdiagnoses are common at earlier stages. At this stage individuals typically need more active care giving. Depending upon different patients’ needs the care giving could range anywhere from making sure that the patient is drinking plenty of fluids to making sure that the person is not wandering on the streets. At this stage it is common for patients with AD to move-in with a caregiver. To do so usually requires the patient to relocate thus placing them in a less familiar environment. This could increase depression and the feelings of alienation, which in turn can cause a quicker decline in the patient’s health.

The use of technology for people with AD provides hope that they can live on their own for longer periods of time. For example, patient’s situation could be helped by the use of motes. A mote is a very small battery operated computer with radio networking. Motes are most effective when part of a larger network (Intel Mote). By employing the mote technology a network of small battery operated computers can be constructed at a person’s home. This network can consist of sensors that keep track of different activities for the patient and help the patient remember different tasks. For instance, if sensors in the kitchen cabinet do not detect any movement during a specified time period, the mote in the cabinet sends information to the main computer. The main computer then locates the person and reminds them to drink water by playing a commercial for water on TV or by using text commands on the computer. These motes can be effective in replacing caregiver’s duties related to watching over the patient. Other kinds of motes in a household include sensors that could be placed in chairs to “tell” the system if someone is sitting. An infrared badge, worn by the patient, that could be detected by a camera can help locate the individuals whereabouts (Dishman, 2004)).

Sensors like these are already used in some assisted living facility. For example, Elite-Care, an Oregon based facility, uses these sensors to monitor residents’ weights and movements. Computer screens in the rooms are used to aid residents in getting in touch with their caregiver. Sensors in the bed measure a resident’s weight and the amount of rest the resident gets by
detecting the amount of movement in the bed. Infrared badges are used to detect resident’s motion. These badges alert the system if a resident is leaving the facility, which prompts the other systems that take the appropriate action by either informing the caregiver or closing the gate. Different programmable lights cue a person to use the bathroom to prevent incontinence. Elite-Care has used a combination of sensors and software to create an assisted living facility for people with different degrees of AD. Once a person is categorized into a stage of AD badges are programmed to their individual needs. People with certain Infrared badges are not allowed to perform certain activities.

Global positioning system (GPS) is another technology that may prove to be very helpful for the Alzheimer’s patients during the mild to moderate disease stages. During these stages individuals with AD are prone to forgetting their way home or wandering in the streets. GPS is a tracking device that can be used to identify the location of the patient. GPS uses orbiting satellites and the GPS units on the ground receive radio signals and find out the exact location of the signal. A patient can wear a GPS unit as a badge, watch, bracelet or pin and a caregiver can be notified when a care receiver wanders out of the designated area. Currently GPS devices used to locate Alzheimer’s patients are being used with personal locator devices (Parnes, 2003). Safe Return program, which was started a partnership between the U.S Department of Justice and the Alzheimer’s Association, could benefit from this type of GPS technology. In the Safe Return program, patients are required to wear a necklace or badge with their name and number engraved on it. If a person found wandering, this badge could be used to inform the patient’s caregiver about the patient’s position. A GPS unit could be placed on the badge and used to inform the caregiver about care receiver’s position.

Information technology for the moderate to moderately severe stages. At these stages, behavioral disturbances, and thus the need for more care, among AD patients typically increase. During the moderate to late stages of Alzheimer’s motes can be reprogrammed to inform caregiver of all the conditions of the care receiver. Sensors could be placed in the person’s bed to monitor weight loss. A combination of sensors placed in chairs and infrared tags detected by cameras could inform the caregiver if the AD patient has fallen down or is sitting in the chair (Dishman, 2004).
At this stage, patients benefit from having familiar activities and familiar pleasant memories stimulated. This is helpful because it provides a sense of familiar comfort for individuals with declining cognitive functions. Family members, who are frequently in the caregiving role, are uniquely positioned to stimulate memories and facilitate familiar activities. These memories can be in the form of either pictures or conversation. According to Kavé and Levy’s (2003) findings, persons with AD were able to match simple words with provided pictures. From this study one can conclude that one way of communicating with Alzheimer’s patients is by using pictures. The use of pictures can stimulate the mind of an Alzheimer’s patient even though he or she may not be able to explain the pictures because of the inability to articulate themselves in spoken language.

Similarly a study that was conducted in Scotland used computer software to decrease the communication barrier between Alzheimer patients and their caregivers. The software used in the study, called CIRCA (Computer Interactive Reminiscence and Conversation Aid), used audio, video and animation to stimulate verbal and non-verbal communication. CIRCA helped the communication by stimulating the long-term memory. For the majority of subjects, CIRCA acted like an electronic memory book. Many patients happily sang along with the songs, discuss their childhood memories that were brought back from seeing a picture. In this particular study, many caregivers didn’t know that much about the patient they were helping. CIRCA was also beneficial in strengthening the bond between caregiver and care receiver. Among the beneficial outcomes of this study was that many patients who reacted poorly to traditional reminiscence responded more positively to this intervention (Gowans Et. al, 2004).

The CIRCA project also showed that most caregivers don’t know many aspects of a care receiver’s past and hence are unable to help the care receiver recall them. Stimulating patient’s long-term memory can bring old ideas, reduce or eliminate loss of identification and make them feel better. By using CIRCA a patient can visit old neighborhood, old friends or places they grew up at. Software such as CIRCA can engage the care receiver in meaningful activities as well as reduce their dependence upon the caregiver. It can reduce the stress that a caregiver experiences and as a result can eliminate the chances of negative behavior toward the patient. Furthermore, the reduction or elimination of negative behaviors may reduce the rate of deterioration of patients’ mental abilities (Kitwood, 1996).
**Information Technology for the Caregivers**

IT can be used to help the caregivers with the responsibilities of monitoring the care receivers as well as informing the caregivers about AD and answering their questions. For example, a telephone-based intervention has been used to provide help and support to caregivers. The project is known as REACH (Resource for Enhancing Caregiver Health) used an interactive voice response (IVR) to provide support and answers to caregivers. The system provided four intervention options. Three of those were used to provide the caregiver with information. The fourth option provided the caregivers with a temporary break in care giving by diverting the patient. In this study, the majority of the caregivers were pleased with having a personalized telephone call that safely diverted the patients’ attention to allow for some free time (Mahoney Et al., 2001).

Along side the increase in AD patients, there has been an increase in the population’s use of computer technologies. As such, caregivers will be able to utilize the internet in their care giving responsibilities. According to the Pew Internet & American Life Project, 46% of Americans aged 59-68 year have Internet access. With the passage of time this number will increase. As a result the AD caregivers (that mostly range between 45-60) will more likely to be computer literate. This can be very beneficial as computers and Internet can be used to educate the caregivers regarding different activities for care receivers as well as providing support to the caregivers. IT can help the caregivers in many different ways.

**Web help for Caregivers.** In recent years many support groups have formed for caregivers. However limited available time due to care giving responsibilities diminish the opportunity among caregivers to spend time in support groups. Also, if the caregiver resides in a rural area the time spent on traveling to meet the group adds stress to the caregiver’s busy routine rather than reducing it.

It is necessary for the caregiver to receive the support they need in order to perform their job easily. The World Wide Web can easily solve that problem by providing knowledge and support to the caregivers. The challenge of accessing the validity of online information is partially eased by a valuable online service called AlzOnline.net.
AlzOnline was developed at the University of Florida in response to the need recognized by the Florida Department of Elder Affairs (DOEA) to provide Internet based educational services to the Florida’s caregiver of dementia. There are around 400,000 people in Florida that are affected by dementia (Glueckauf & Loomis, 2002). The website was built in order to provide education and support for dementia caregivers and provides classes and other information. The 300% increase in the use of website within one year showed that the information was needed and was accessed. AlzOnline is beneficial for the Alzheimer’s caregivers for two main reasons; it provides lectures and support as well as an online library.

One of the beneficial features of AlzOnline site is the fact sheets that are provided. Most of the fact sheets contain frequently ask questions regarding that specific area of problem. Currently there are four different kinds of classes that are being offered at AlzOnline to emphasize different aspects of care providing. The same information is available in Spanish, which increases the usability of the site.

*Information Technology for the Health Care providers*

Many people with AD also have other chronic illnesses such as diabetes and hypertension. Due to their cognitive disabilities many Alzheimer’s patients cannot monitor their own progress. In many cases it becomes the responsibility of caregivers and healthcare providers to constantly monitor the patient’s condition. Many times a patient’s condition worsens due to the lack of close monitoring of his or her health. For many caregivers it is not possible to constantly monitor the patient’s health because of lack of medical knowledge or equipment (Buckwalter Et. al, 2002).

An important part of care giving consists of taking the patient to the physician. This can add further stress to the caregiver. On many occasions persons with AD become stressed during a visit and as a result behave differently in front of the physician. This could affect the accuracy of physician’s judgment about the patient’s condition. A healthcare provider might have a better idea regarding a patient’s condition if they could monitor him or her in a natural setting. A telehealth system could be used in order for the healthcare provider to monitor the patients in their home setting. Likewise, driving long distance, a source of stress of rural caregivers, can be alleviated with telehealth technology (Buckwalter Et. al, 2002). Telehealth application can be
used to monitor patients at home and eliminate unnecessary travel. A number of telehealth applications have been used to monitor the elders.

For example, a telehealth project called Resource Link of Iowa (RLI) was conducted in that state to manage chronically ill people including persons with dementia. The project supported a two-way audio/video communication between the healthcare provider and the patient’s home. The unit at the home consisted of a monitor, a web camera and a remote control, similar to a television remote control. A healthcare provider can visit the patient by activating the base unit and the patient can respond by pressing the start button on the remote control. At the end of the visit the patient can press the end button and terminate the session. Due to the ease of use, cognitively impaired individuals were able to use the system. The project resulted in a 21% reduction of inpatient and outpatient visits and saved approximately $9,000 per patient (Buckwalter Et al., 2002).

A similar project was conducted in Fairfield County, Connecticut for the purpose of managing elders with the heart disease and diabetes. One person with end-stage AD and recurring problems of pneumonia and diabetes was also monitored under this project. Due to the constant monitoring, subtle changes were detected early and the person was put on antibiotic by the healthcare provider. This potentially saved another hospitalization due to pneumonia for this person (Walsh & Coleman, 2005).

In Australia a study was conducted to find the effectiveness of the Mini Mental State Examination (MMSE) (a test of cognition) and Geriatric Depression Scale (GDS) administered via video conferencing to AD patients. The results showed feasibility in conducting cognitive assessments via video conferencing. It also showed strong correlations between the face-to-face and video conferencing evaluations (Saligari Et. al., 2002).

A similar kind of study was conducted in Hong Kong, China regarding providing cognitive intervention (CI) via video conferencing. In that study, a Cantonese version of the MMSE, Cantonese version of Rivermead Behavioral Memory Test (C-RBMT) and Hierarchic Dementia Scale (HDS) were given to the participants. The participants were divided into two groups, face-to-face and videoconference. Twelve CI sessions were conducted over six weeks. At the end of six weeks both face-to-face and videoconferencing groups significantly improved in the areas of attention, memory and language (p<. 001). Over 90% of the people in
videoconferencing group were satisfied with the audio, visual quality and the outcome (Poon Et. al., 2005).

The above studies show that telehealth could be used to deliver services to Alzheimer’s patients and their caregivers. The patients could be monitored more effectively using telemedicine. Telehealth can save the patients from the burdens of waiting to see a physician. This can save money and other health care resources. It can also save caregivers time and stress associated with their responsibilities. With the increase in the number of elders, the number of persons with AD is likely to increase. The number of physicians treating the elders may not increase proportionally to the number of elders. Therefore, telehealth is a promising set of technologies that will facilitate a more efficient use of physician services than is possible in a traditional clinical setting.

There are many examples in which IT has been used to take care of persons suffering from different illnesses. The same kind of technology that is used in helping those people can be used to help persons with AD. Those technologies range from software to telemedicine applications.

_The use of Information Technology in other cognitive and mental diseases_

IT has been used to help people with other cognitive disabilities and mental diseases, such as anorexia, epilepsy and stroke. Dehdeshti and Cole (1998) conducted research in which different kinds of cognitive prosthetics were used for people with cognitive disabilities. The software used for two of those people is could be used for Alzheimer’s patients. The first case was of a 50-year-old lady who was involved in an automobile accident in which she suffered from short-term memory loss, inability to process information on the left side of the visual field and apraxia, which interfered with the fine motor skills in her left hand. She wanted to write checks without the assistance of a caregiver. In this case software was used as a prosthetic in order to help her write the checks and pay her bills. She was able to learn the software in 3 half-hour sessions and as a result didn’t require a caregiver to help her in the bill paying activities. It remains to be seen whether a similar kind of software could be written for an early to mild stage Alzheimer’s patient that can help him or her manager their accounts and increase their confidence level.
In another case, a 34-year-old woman suffered from a series of strokes. These strokes significantly affected her cognitive functions. She had impaired ability to process and retrieve information, memory, and language. As well as impaired visual and verbal memory for new information. Text-writing software was created for her in order to help her express herself in writing. The initial design had just the commands of print, save, retrieve and exit. Slowly more functions were added as the person’s cognitive abilities improved (Dehdeshti & Cole, 1998). A same kind of text writing software could be written for people with mild to severe AD.

Telehealth can be used in psychiatric services, especially for those who do not have an easy access to urban clinics/hospitals. In eastern Ontario, telehealth was used to provide psychiatric services to an anorexic patient whose family was residing in a small under-served northern Ontario city. Family therapy was important for this patient because her family’s situation had played a role in her Anorexia Nervosa. She was admitted in the Children’s Hospital of Eastern Ontario. Due to far distances, her family could not be there for family therapy sessions. As a result the therapy was conducted using telehealth. At the end of the eighth session, the patient had felt closer to her family and had gained significant weight. The patient’s family was very satisfied with the services and the therapy had a very positive affect on the patient as well as improved her relationship with her family (Goldfield & Boachie, 2003).

A study conducted by University of Texas Medical Branch (UTMB) and Epilepsy Foundation of South East Texas compared care provided to Epilepsy patients in a traditional clinical setting and those using telehealth. Usually, care for Epilepsy patients were provided at Galveston, however, a remote clinic with telehealth capabilities was setup in Beaumont (about 110 miles away). A nurse was present at the telehealth clinic to enable the care provider at the Galveston to perform examinations on the patient. Both clinics were effective in managing the patients and there were no significant differences in all outcomes studied between the telehealth Beaumont clinic and the face-to-face Galveston facility. The biggest advantage of Beaumont facility was that the patients didn’t need to travel to Galveston (Rasmusson & Hartshorn, 2005).
CHAPTER 3
DISCUSSION

IT has been used in different forms to provide services to many chronically ill patients. It has been used in the form of software as well as in telemedicine. IT can play a very important role in the life of a person with AD. During the early and mild stages of dementia a person with AD can live independently by using different forms of IT. The use of IT for a person with AD can extend the time of their independent living. The use of IT can also increase the confidence level in a person with AD that can slow the progression of the disease. Furthermore, during later stages of AD, IT can be used to reduce stress on caregivers.

Based the research presented here, two challenges limit the adoption of IT among those with AD. The first problem is that there are limited IT companies inclined toward developing technology for Alzheimer’s patients in the marketplace. Currently, Intel Corporation is the only company that is working in order to provide technology for people with AD. There could be many factors contributing to the lack of IT companies’ involvement. A major factor is likely the investment risk. It is difficult for companies to invest in an area where they are not certain about the returns. More studies needed to be done regarding the usefulness of technology for the Alzheimer’s patients to provide evidence that the technology is beneficial both clinically and financially for the IT industry.

Secondly, there is not enough research available regarding the use of technology for people with AD. Most of the research that is being done in the area of AD is geared toward the medication or the caregivers. There are scattered projects all over the world such as the telehealth project in Canada and in China and CIRCA in Scotland. What we know is that various software applications can be developed to sustain the activities of daily living for AD patients. In some telehealth projects, Alzheimer’s patients were excluded because they couldn’t learn the technology. With the population aging, IT should be made easier to help those with different forms of dementia and Alzheimer’s disease.

Thus far, the available research does not make a clear distinction between dementia and AD. As a result, most of the literature that I have used to develop this thesis used the word dementia and AD interchangeably. Due to the varied definitions of dementia it is very difficult
to say if the researchers meant AD or some other form of dementia. AD is a primary progressive cortical dementia. If the dementia that the studies have mentioned is not similar to AD then the studies are not beneficial for the AD patients. Due to the limited number of studies, generalizability to AD patients from those with dementia should be cautioned. It is common among Alzheimer’s patients to hallucinate and only one study mentions the hallucinations due to the computers among the Alzheimer’s patients. Also, studies have mentioned the savings but not the cost of intervention. Without knowing the cost of intervention it is difficult to judge the financial benefits of the research.

The biggest concern regarding most of the literature is that it could have been conducted on a group of patients suffering from different kinds of dementia and due to the “Alzheimerization of Dementia” (declaring different kinds of dementia as AD) it was reported that the patients suffered from AD (Kitwood, 1996). However, in the literature where a clear distinction was made between AD and dementia it was very hopeful to see that IT can be used to improve the condition of the people suffering from AD. More research needs to be done in order to find out more about the use of technology for those who are suffering from AD.

To improve the condition of the people with AD, IT can play a very important role. On one hand, IT can provide a caregiver with information and support. On the other hand it can engage the care receiver in many different activities to reduce the caregiver’s stress. A combination of telemedicine, telecommunication projects and technologies for daily living can help us with the aging of our elders the medical conditions they will face.
CONCLUSION

There is no cure for AD. However, a combination of medication, IT and a positive approach to the person can help a person with AD live a better life. Due to the stresses related to care giving it is natural for a caregiver to experience stress. The use of technology has the potential to help the care receiver to be more independent and reduce stress on the caregiver. This could also result in an increased level of confidence in the care receiver and reduce financial burden for the caregivers.
Table 1. Different types of dementia.

<table>
<thead>
<tr>
<th>Types of Dementia</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Primary Dementia</td>
<td>Dementia that caused by a disease in the brain.</td>
</tr>
<tr>
<td>Secondary Dementia</td>
<td>Dementia that is caused by injury or disease outside the brain that affected the brain.</td>
</tr>
<tr>
<td>Cortical Dementia</td>
<td>Dementia that leads to problems in thinking, memory and social skills.</td>
</tr>
<tr>
<td>Sub cortical Dementia</td>
<td>Dementia that results in a decline in memory as well as changes in emotions.</td>
</tr>
<tr>
<td>Progressive Dementia</td>
<td>Dementia that leads to problems in other cognitive functions.</td>
</tr>
</tbody>
</table>
Table 2. Discussion of the consequence of forgetting in an Alzheimer’s patient.

<table>
<thead>
<tr>
<th>Reaction</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Identification Loss</td>
<td>For most people their relationships, work and interests define them. Due to AD people have to give up their work, or activities. They also forget their relationships. All of these could cause a person to feel an identity loss.</td>
</tr>
<tr>
<td>Isolation and Loneliness</td>
<td>After being diagnosed with Alzheimer’s disease many people have to move to stay with a caregiver. Many times it means leaving one’s friends behind as well as adjusting to a new environment. This can cause the feeling of loneliness.</td>
</tr>
<tr>
<td>Depression</td>
<td>One of the major consequences of Alzheimer’s disease is the loss of memory. This loss of memory can bring the feelings of hopelessness and helplessness, which in turn can cause depression.</td>
</tr>
<tr>
<td>Confusion</td>
<td>Many times forgetfulness brings confusion. A person who is diagnosed with Alzheimer’s disease forgets many things. As a result most of the people with this disease suffer from constant confusion.</td>
</tr>
<tr>
<td>Anxiety</td>
<td>People with Alzheimer’s disease usually suffer from anxiety. In the beginning stages of Alzheimer’s this anxiety could be due to worrying about the future. In the late stages of Alzheimer’s a patient usually suffers from hallucinations that can also cause anxiety. A lady I once worked with was very worried about the dog that wouldn’t stop following her. This was the cause of constant anxiety for her.</td>
</tr>
</tbody>
</table>
## Table 2. Continued

<table>
<thead>
<tr>
<th>Reaction</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fear</td>
<td>People with Alzheimer’s disease are usually fearful about the future. A person with Alzheimer’s disease once told me that the disease had cause her to fear the future and wonder about what is going to happen next.</td>
</tr>
<tr>
<td>Frustration</td>
<td>Forgetfulness can cause frustration in anyone. Alzheimer’s patients forget many things from the name of their grandson to their favorite dish. This forgetfulness can cause frustration in them.</td>
</tr>
<tr>
<td>Paranoia</td>
<td>Paranoia in an Alzheimer’s patient is usually caused by their mistrust for others. People with Alzheimer’s usually look for explanations about what is happening to them. When they don’t find those explanations they usually imagine them. They could imagine anything from someone trying to hurt them to the world is coming to an end. This imagination can cause paranoia.</td>
</tr>
<tr>
<td>Self-Directed Anger</td>
<td>A person with Alzheimer’s disease usually suffers from anger because of their disease. During the early stages this anger could be about the future or the process. During the late stages it could be about the caregiver or forgetting.</td>
</tr>
<tr>
<td>Embarrassment</td>
<td>Embarrassment also comes from forgetting everyday tasks. It could be caused by not knowing how to dress, or calling the grandson by a pet’s name.</td>
</tr>
</tbody>
</table>
Table 3. “Malignant” behaviors toward persons with dementia.

<table>
<thead>
<tr>
<th>Behavior</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Treachery</td>
<td>To manipulate or deceive the person to comply with the caregiver</td>
</tr>
<tr>
<td>Disempowerment</td>
<td>Denying the person to use their powers or to perform tasks.</td>
</tr>
<tr>
<td>Infantalization</td>
<td>Treating them like a young child.</td>
</tr>
<tr>
<td>Intimidation</td>
<td>Inducing fear in the care receiver.</td>
</tr>
<tr>
<td>Labeling</td>
<td>Calling the person names or degrade them by calling them demented or crazy.</td>
</tr>
<tr>
<td>Stigmatization</td>
<td>Treating the care receiver as an outcast or as an object.</td>
</tr>
<tr>
<td>Outpacing</td>
<td>To inform them in a way that they can’t keep up with it.</td>
</tr>
<tr>
<td>Invalidation</td>
<td>To reject the person’s experiences or ideas.</td>
</tr>
<tr>
<td>Banishment</td>
<td>Excluding them from decision-making or everyday life.</td>
</tr>
<tr>
<td>Objectification</td>
<td>Consider the person an object.</td>
</tr>
<tr>
<td>Ignoring</td>
<td>Not acknowledging the person’s presence.</td>
</tr>
<tr>
<td>Imposition</td>
<td>Denying the person their choice and forcing them to do against their will.</td>
</tr>
<tr>
<td>Withholding</td>
<td>To not attend to the care receiver’s needs.</td>
</tr>
<tr>
<td>Accusation</td>
<td>Blaming them for their actions due to their disability.</td>
</tr>
<tr>
<td>Disruption</td>
<td>Intruding in their thought process or actions.</td>
</tr>
<tr>
<td>Mockery</td>
<td>Making fun of their disability, actions or mistakes.</td>
</tr>
<tr>
<td>Disparagement</td>
<td>Damaging the care receiver’s self esteem.</td>
</tr>
</tbody>
</table>


Aisha Waheed is majoring in Information Studies. She received her Bachelors degree in Information Studies from Florida State University. She is very interested in improving the Quality of healthcare by using Information Technology. Aisha is very interested in Alzheimer’s disease and in improving the life of people who are affected by Alzheimer’s disease with the use of technology.