FEASIBILITY OF MACHINE-BASED PROMPTING FOR PEOPLE WITH ALZHEIMER’S DISEASE

By

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To my mom and dad and to Mark.
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Alzheimer’s disease (AD) is the leading cause of dementia in persons over 65 in the United States (National Institute on Aging, 2004). As AD progresses, a person’s independent function may be affected. Cognitive impairments affect daily functional abilities of more than 10 percent of people over age 65, making caregiving challenging (Georges, Jansen, Jackson, Meyrieux, Sadowska, & Selmes, 2008; Hebert, Scherr, Bienias, Bennett, & Evans, 2003). Assistive devices have the potential to provide assistance with these activities to help the person with AD live more independently and reduce caregiver burden.

This study was completed in two steps. Step One was included to make sure that participants with AD would be able to operate the device. This step of the study included five participants and took place at an adult day program. Participants completed five separate trials with an electronic memory aid (EMA) completing the tasks of making a seasonal decoration, taking a drink of water, or making a list from an advertisement. Their responses were recorded to determine their success in responding to the prompts. Caregivers reported the behavioral symptoms of the person with Alzheimer’s using the Kingston Standard Behavioural Assessment (KSBA). Field notes and data taken from a modified Philadelphia Geriatric Center Affect Rating Scale (PGARS) were also recorded.
The goal of Step Two was to test this device over a four to six week period utilizing a single subject design. Three participants and their caregivers took part in this step of the study and were seen in their own homes. A specific activity of daily living (ADL) or instrumental activity of daily living (IADL) task was chosen by the principle investigator and the participant’s caregiver. The participants’ responses to prompts were recorded under two conditions: 1) in-person prompting and 2) machine-based prompting utilizing the EMA. The caregivers completed the Revised Memory and Behavior Problems Checklist (RMBPC) on the days the sessions took place.

In this study, participants with moderate cognitive impairment were able to consistently respond to machine-based prompting from the EMA. However, they frequently required reassurance that they were completing tasks correctly or needed additional in-person prompts for safety or to complete some step of the tasks thoroughly. Participants with severe cognitive impairment were either unable to respond to the EMA or needed a maximum number of additional in-person prompts or physical assistance to complete the tasks prompted by the EMA. Overall, prompting from the device used in this study was not successful in helping participants complete activities independently. However, valuable information regarding prompting needs of people with Alzheimer’s disease was collected and can be used in the development of more sophisticated prompting devices for this population.
CHAPTER 1
INTRODUCTION

Alzheimer’s disease (AD) is the leading cause of dementia in persons over 65, and those with the greatest chance of developing AD, people over age 85, are currently the fastest growing segment of the United States population (National Institute on Aging, 2004). Cognitive skills affected by AD include orientation, insight, attention, memory, abstract thinking, calculating, problem solving, and organization (Abreau & Toglia, 1987). A person experiencing impaired cognitive function may display confusion, disorientation, limited attention, memory impairment and decreased ability for learning (Alzheimer’s Association, 2007; Poole, Dunn, Schell, & Barnhart, 1991). Language disorders, apraxia, visuoconstructive difficulty and difficulty with abstract thinking are other common symptoms of AD (Pynoos & Ohta, 1991). As AD progresses, a person’s independent function may be affected. Cognitive impairments affect daily functional abilities of more than 10 percent of people over age 65 (Hebert, Scherr, Bienias, Bennett, & Evans, 2003). A recent informal caregiver survey of those who care for people with dementia reported that 68% of caregivers cite decreased independence with activities of daily living as the most problematic symptom they face (Georges, Jansen, Jackson, Meyrieux, Sadowska, & Selmes, 2008). A person with AD will decline in ability to meet safety, self-care, household, leisure, social interaction and vocational needs (Abraham, 2006). Eventually, the person will lose the ability to perform basic activities of daily living (Pynoos & Ohta, 1991).

The context in which an activity occurs also plays a role in successful initiation and completion of tasks. Therefore, exploring external prompting as a compensatory strategy for decreased cognitive abilities is valuable. Machine-based prompting devices, when correctly matched to the person with AD, their caregiver, and their home environment have the potential to increase independence with daily tasks and therefore decrease caregiver burden.
Theoretical Model: The International Classification of Functioning, Disability, and Health

The framework of the International Classification of Functioning and Disability (ICF) provides a structure for rehabilitation research to discuss the use of machine-based prompting strategies to promote health and independence for people with AD (Linveh, 1995; American Occupational Therapy Foundation Research Advisory Council, 2000). There are two main concepts to the ICF model. The first concept relates to Functioning and Disability: the second concept covers Contextual Factors. Each concept contains two components (World Health Organization (WHO), 2001). These concepts and components help frame the full range of rehabilitation from the cellular level to the environmental and societal level.

Cognitive Impairment and the ICF

Cognitive disorders, especially AD, are complex, and a holistic mindset is required to examine a person’s life, including the aspects emphasized by the ICF: body, activity, participation and environment. The ICF is particularly useful in examining these areas because it highlights rehabilitation potential in each area. The ICF not only addresses cognitive skills that may be affected by AD, but also the functional ramifications of AD, and impact of one’s environment. The ICF model provides a means to systematically address the complexity of AD regarding external machine-based prompting.

With a diagnosis of AD, a person’s cognitive status and resultant functioning can fluctuate not only from day to day, but can also be affected by time of day and the person’s surroundings (Mesulam, 2000). To properly assess function and provide appropriate interventions, the specific, subtle changes in the person’s life need to be identified as well as the overall impact of the disease on the person’s activity and participation. This allows the clinician or researcher to appropriately categorize the person’s current functional state within the environment and assess
appropriate options to increase his or her independence with daily tasks (Zwecker, Levenkrohn, Fleisig, Zeilig, Ohry, & Adunsky, 2002; Murray & Lopez, 2000; Helander, 1992).

Taking all aspects of a person with AD and the surrounding environment and placing these aspects systematically in a framework such as the ICF, can help delineate the areas in this person’s life where prompting can promote health and independence for people with AD. This will be done by first discussing Part One of the ICF and its components followed by Part Two and its components.

**Part 1: Functioning and Disability**

A body component and an activity and participation component are the two aspects of Functioning and Disability. In the ICF, the term functioning incorporates body functions, body structures, activities, and participation. The term disability describes deficits or impairments, activity limitations and restrictions to participation (De Kleijn-de Vrankrijker, 2003).

Body functions and structures. The World Health Organization (WHO) defines body functions as physiological functions of body systems (including psychological functions). Body structures are defined as structural or anatomical body parts. An impairment is a loss or abnormality in a body structure or physiological function (WHO, 2001). At first, body structures and functions would not appear to be key in exploring prompting interventions for people with AD; however, this section is essential to prompting because the delivery of prompts could change depending on the pathology of the cognitive impairment. Different types of dementia can manifest cognitive impairments differently depending on the bio-chemical or anatomical changes that take place, thereby affecting the type of prompting that may be necessary (Arthanat, Nochajski, & Stone, 2004). The root of the dementia will determine how fast someone declines. It could also influence where deficits have a tendency to occur. For example, someone with vascular dementia resulting from a cerebrovascular accident (CVA) may also have a visual
neglect that may need to be prompted as well for successful completion of a task. Each individual’s type of dementia will help determine what prompting is appropriate. Also, someone experiencing AD may have a generalized deterioration of the brain, while someone with vascular dementia may have particular areas involved, and someone with head trauma may have particular lesions involved.

The severity of the cognitive impairment must also be considered. The level of severity determines when it is appropriate to implement prompting into a routine as well as when to end prompting in a routine when it is no longer beneficial.

In the ICF, the body function of concern with AD is ‘mental function’. Mental function is comprised of attention, memory, and other higher functions (WHO, 2001; Arthanat, Nochajski, & Stone, 2004). Assessing cognitive function is even more important than possessing knowledge of body structures, because mental functioning determines how much of an impact the anatomical changes have on the rest of the model. Subtle changes in mental function can necessitate a change in the amount of prompting required. Understanding a person’s functioning in each of these domains is important to ensure appropriate levels of prompting (Cammermeyer & Prendergast, 1997). The nature, progression, and types of cognitive deficits with respect to specific neuro-psychological conditions have been investigated (Mesulam, 2000; Snyder & Nussbaum, 1998).

Several studies show that with degenerative conditions such as AD, there can be quick changes in cognitive capabilities. One study involving 110 Alzheimer’s patients over 12 months tracked the progression of their cognitive impairments (Burns, Jacoby, & Levy, 1991). Results demonstrated significant declines throughout the sample in varying domains such as memory, language, orientation, attention, and abstract thinking. All of these are vital domains to consider
when hypothesizing appropriate prompting interventions for daily activities. A person with AD
could experience deficits in all of these areas, at varying levels (mild to severe) and at different
rates.

**Activities and participation:** In the ICF, an ‘activity’ is the execution of a task or action
by an individual, and ‘participation’ is involvement in a life situation (WHO, 2001). The ICF
examines a person’s capacity or ability to execute a task or an action in a uniform or standard
environment, as well as a person’s performance, or what the person does in his or her current
environment (Perenboom & Chorus, 2003). Both capacity and performance are most likely
compromised in people with AD, making prompting an appropriate avenue to explore. A
person’s level of independence in activities of daily living (ADLs) and instrumental activities of
daily living (IADLs) is the main determinant for prompting intervention. For example, if
someone is comatose or requires frequent physical assistance to complete a task, machine-based
prompting would not be appropriate. If someone needed only verbal prompting to complete a
task, a machine could have the capability it to provide the prompting.

Cognitive impairments can severely limit a person’s ability to perform certain activities,
such as hygiene tasks, and could therefore inhibit his or her participation in some life domain
(for example, interpersonal relationships). Much research exists documenting these limitations in
activity and participation according to the definitions of the ICF (Pynoos & Ohta, 1991; Zarit,
Todd, & Zarit, 1986; Zarit & Zarit, 1982). Several studies link cognitive impairments to
functional limitations. Gauggel, Peleska, and Bode (2000) found that cognitive impairments in
patients who experienced a stroke contributed to 28.9 percent of activity restrictions. One study
demonstrated that Mini-Mental State Exam (MMSE) scores were a strong predictor of functional
outcomes in patients following a stroke (Ferda Murat, Razi, Galip, & Siranus, 2001). Another
study found similar results related to people with AD (Muo, Schindler, Vernero, Schindler, Ferraria, & Frisoni, 2005). Nygard, et al. (1998) found that factors affecting cognition were behind 24-26 percent of IADL difficulties in people with AD. In another study, 42 percent of participants with decreased cognitive scores had severe limitations in ADLs (Rao, Leo, Ellington, Nauertz, Bernardin, & Unverzagt, 1991).

These limitations raise many questions when it comes to implementing prompts for activities and participation. Can prompting during an activity lead to increased participation? What types of prompting can increase activities and participation? Prompting has the potential to increase activity for individuals who are very passive. Could keeping someone engaged through prompting increase their level of activities, participation, and quality of life? Could prompting help maximize independence with activities and decrease the burden of care, leading to increased participation in the person’s context?

The ICF has several domains listed under the component of activities and participation. Since prompting is very much involved with activities and participation, the most involved subcategories related to prompting will be discussed further. These subcategories include: learning and applying knowledge, general tasks and demands, communication, self-care, domestic life, interpersonal interactions and relationships, and social and civic life (Arthanat, Nochajski, & Stone, 2004). Learning and applying knowledge and general tasks and demands will be discussed together. Communication and social and civic life will also be discussed together. Self-care will be addressed separately, followed by the combination of domestic life and interpersonal interactions and relationships.

‘Learning and applying knowledge’ and ‘general tasks and demands’ are impacted for the person with AD for several reasons. A person experiencing impaired cognitive function may
display confusion, disorientation, limited attention, memory impairment and decreased ability for learning (Mesulam, 2000; Poole, Cunn, Schell, & Barnhart, 1991). The decline in these areas will most definitely affect independent performance of general tasks and demands. Prompting could provide a means of increasing independence and participation in the performance of these areas.

Communication and social and civic life are other areas in which prompting could be helpful because language disorders and difficulty with abstract thinking are common symptoms of AD (Pynoos & Ohta, 1991). Prompting could engage the person with communication difficulties in an activity or social participation in which he or she would otherwise not participate. One study found that training nursing assistants to interact with a person with dementia while cueing the person to their own memory book encouraged increased interaction and participation in conversations (Hoerster, Hickey & Bourgeois, 2001).

A person with AD will progressively decline in ability to meet safety and self-care needs (Zarit, Todd, & Zarit, 1986). Eventually, the person will lose the ability to perform basic activities of daily living (Pynoos & Ohta, 1991). While there is no cure for AD or many other forms of dementia, investigators are testing types of prompting and prompting devices to determine if these approaches can promote independence and health. Examples of promoting health include preventing dehydration and correcting poor hygiene habits. Generally thirst sensation declines in old age. Someone with full cognitive capacities can be aware of this and take the steps needed to ensure he or she stays hydrated. However, a person with a cognitive impairment may not be able to do this without prompting. The same can be said of hygiene. Someone with cognitive deficits may only brush the front of their teeth because that is all they can see. Alternatively, the person with AD could also perseverate on brushing one particular area
or continue brushing until prompted to stop. Issues such as decreased hydration and hygiene can
decrease physical health and thereby be detrimental to body structures and functions as well as to
comfort and quality of life. Prompting has the potential to help promote health and increase
independence of people with AD in these self-care areas.

As AD progresses, a person’s independent function within the home and in his or her
relationships may be affected. A person with AD will decline in ability to meet household,
leisure, social interaction and vocational needs (Zarit, Todd, & Zarit, 1986). The person with AD
may also exhibit more problematic behaviors such as wandering that could lead to falls or other
injuries (Rowe & Fehrenbach, 2004). A recent survey of informal caregivers of people with
dementia (un-paid caregivers) reported that ADL declines and behavior issues ranked as the most
problematic symptoms displayed by the person with dementia (Georges, Jansen, Jackson,
Meyrieux, Sadowska, & Selmes, 2008). Caregiver burden due to these deficits increases and
therefore impacts interpersonal relationships. Reducing the burden of care by reducing direct
care time could improve caregiver health. The use of machine based prompting devices could
lessen the burden experienced by caregivers of patients with AD (Lo Presti, Mihailidis, &

Part 2: Contextual Factors

Contextual factors are divided into environmental factors and personal factors that
constitute the complete context of a person’s life. The context of a person’s life is made up of
facilitators and barriers. Facilitators are factors in the environment that improve or reduce
disability, while barriers limit functioning and create disability (WHO, 2001).

Environmental factors: The impact of environmental factors can be felt in all areas of a
person’s functioning. Disability is not merely a result of a health condition. A person’s
environmental factors may also contribute to his or her disability, including a person’s actual
physical environment, the attitudes of society and the services available, and legislation (Dahl, 2002). Environmental factors are made up of the physical, social and attitudinal environment in which people live and conduct their lives (Dahl, 2002).

The domains listed within the environmental factors section include: products and technology, natural environment and human made changes to the environment, support and relationships, attitudes and services, and systems and policies (WHO, 2001). Providing prompts to aid in daily activities for people with AD fits under all domains in this area.

“Products and technology” includes any type of assistive device used as a prompting device or to help simplify a task. Two low tech examples of products and technology include calendars and a color coded reminding system (Nochajski, Tomita, & Mann, 1996). Higher-tech examples of products and technology in this area include machine-based prompting devices or context-aware home monitoring systems. The effectiveness of many of these products is reported in the literature (Labelle & Mihailidis, 2006; Nochajski, Tomita, & Mann, 1996).

“Natural environment and human made changes to the environment” could consist of minimizing clutter to increase safety or providing a lighted path to the toilet. Compensation for cognitive impairments through the implementation of home modifications, such as a lighting cue to a towel or to the toilet, could be categorized under the domain of natural environment and human made changes to the environment. This would be a higher tech, but similar system to that of using picture cues, color-coding, minimizing clutter and installing safety alarms.

Support and relationships in this scenario primarily affect the caregiver, which could eventually affect the care recipient with AD. If a prompting device eases the burden of care, the caregiver may feel more supported and consequently, be better able to provide support.
Attitudes of people using assistive technology are important for device acceptance. The person with AD and the caregiver must accept prompting devices if they are to be useful. This area is discussed further in the “personal factors” section.

Finally “systems and policies” must also be included in this equation because they relate to payment for these technologies and availability of related services. If prompting strategies are found to be effective, potential for third party funding could be possible. This could delay nursing home placement, and decrease financial burden.

By adapting the environment through prompting, changes in the functional status of the person with AD could increase his or her participation in society and ease caregiver burden. This can lead to improved quality of life for all involved since caregivers who are less stressed have the potential to provide better care (Vellone, Piras, Talucci, & Cohen, 2008).

**Personal factors:** Personal factors relate to the individual (age, gender, social status) and are not classified in the ICF (Perenboom & Chorus, 2003). However, personal factors are important when considering any type of intervention. Personal factors of both the caregiver and the care recipient include education, previous exposure to technology, and lifestyle (smoking, eating and drinking habits). Factors like temperament, self efficacy and coping style are also important. Work related personal factors like motivation/ drive, past experiences and willingness to participate in activities are also personal factors (Heerkens, Engels, Kuipers, Van der Gulden, & Oostendorp, 2004).

To ensure successful use of a machine based prompting device, or any assistive device there must be a good fit or “match” between the person and the technology (Shererer, 2001). A “match” can help prevent abandonment. Therefore user input (that of the person with AD and the
caregiver) must be taken into account when developing or prescribing a device (Sixsmith & Sixsmith, 2000).

Summary

The application of prompting strategies for people with AD is relatable to most aspects of the ICF model. The development and progression of AD affect not only the person with AD, but also the caregiver. The goal of machine-based prompting is to increase independent function of the person with AD while decreasing caregiver burden. By increasing independent function of the person with AD, there is potential to increase societal participation for both the caregiver and the person with AD.
CHAPTER 2
LITERATURE REVIEW

Introduction

This literature review addresses prompting for people with AD. First, cognitive components relative to prompting and daily functioning are discussed, followed by caregiving issues. The review then explores current assistive technologies for prompting (external prompting devices) and considerations for successful use. Lastly, variables that limit prompting effectiveness are discussed.

Cognitive Components Relative to Prompting and Daily Functioning

Cognitive decline, specifically in the area of executive function can significantly impact a person’s daily functioning and social roles. Executive function is required for task planning, performing a task, and satisfactory task completion (Insel, Morrow, Brewer, & Figueredo, 2006). If actions are repetitive (such as routine –type IADL tasks), the ability to complete an intended task may be more difficult (Einstein, McDaniel, Smith, & Shaw, 1998). Researchers have found associations between performance on cognitive tests (including tests of executive function) and IADL performance (Cahn-Weiner, Boyle, & Malloy, 2000; Grigsby, Kaye, Baxter, Shetterly, & Hamman, 1998). Specific components of executive function related to prompting and daily activities will be discussed in more detail. They include: 1) prospective memory, 2) working memory, and 3) initiation.

Prospective memory involves remembering to initiate previously planned actions, including daily functional tasks. The importance of the task can impact prospective memory performance. In one study, two experiments were performed (Kliegel, Marin, McDaniel, & Einstein, 2004). The first involved a computerized word rating and digit detection task that relied on more automatic processes. Performance on the prospective memory task was not affected.
Experiment two involved a more demanding word ranking and digit detection task. The more demanding task demonstrated that importance had a positive effect on performance. The main finding was the discovery that prospective memory could possibly be improved given importance instructions prior to the task. Because the sample consisted entirely of undergraduate students, its generalizability to older adults is limited. However, it does suggest how certain factors, such as importance of task, may influence prospective memory performance.

Maylor, Darby, and Scala (2000) performed two experiments to see if a long-term intention-superiority effect (reporting more to-be-performed tasks than performed tasks) was present in older adults and people with dementia. The first experiment compared middle-aged adults and older adults in their written recollection of what they did the last few days (performed tasks) and what they intended to do over the next few days (to-be-performed tasks). There was a significant intention-inferiority effect for the older adults, but not for the middle-aged group. The second experiment followed the same protocol except that recollection was done verbally, and young adults, older adults, and people with dementia were compared. Young adults displayed an intention-superiority effect, but this did not occur for the older adults or the people with dementia. The authors suggest that the lack of intention-superiority effect in the older adults and people with dementia may be part of prospective memory decline for people who are normally aging as well as for people with dementia.

Several studies have investigated prospective memory tasks in non-laboratory settings (i.e. in people’s own homes or other familiar environments). These studies found increased performance of older adults in prospective memory tasks, demonstrating the significance of a person’s context when performing prospective memory tasks (Rendel & Craik, 2000; Rendel &
Thomson, 1999). This study also suggests that familiar environments themselves can provide external prompting for daily tasks.

A recent study investigated the association between cognitive processes and medication adherence among community-dwelling older adults (Insel, Morrow, Brewer, & Figueredo, 2006). Participants completed a battery of cognitive assessments including measures of executive function, working memory, cued recall, and recognition memory. The composite of executive function and working memory tasks was the only significant predictor of medication adherence over an eight week period, highlighting these aspects of cognition in their role with daily activities.

Therefore, working memory also contributes to everyday task completion. Throughout the day, distractions and preparation activities to complete a task can delay the time between the intention to do a task and actually completing a task. In a task like meal preparation, a person must first recognize that the response to hunger is to obtain and prepare food. In that process a person must decide what they are going to eat, gather the required food and preparation items, look at instructions, etc., therefore delaying the time between initiation of obtaining or preparing food and actually performing the eating task.

Several investigators have studied interruptions or delays in everyday tasks and have simulated similar circumstances in their laboratories comparing younger and older adults (McDaniel, Einstein, Stout, & Morgan, 2003; Einstein, McDaniel, Manzi, Cochran, & Baker, 2000). While memory loss between intention over 5-30 second delays was marked for all participants in these studies, it was especially prominent for older adults. Considering that performance can be affected like this in a laboratory setting, it is likely that performance would be affected in real-world scenarios that often have multiple distractions in addition to delays.
This is especially significant considering that older adults are more susceptible to distraction and have difficulty multi-tasking (Kray & Lindenberger, 2000; Hasher, Zacks, & May, 1999; Salthouse, Fristoe, McGuthry, & Hambrick, 1998).

Initiation is comprised of both working memory capabilities and executive functioning. A large component of the initiation process also relies on prospective memory function, which declines as people age as well. Decreased ability to initiate and complete activities will occur as AD progresses. Decreased initiation largely affects completion of ADLs and IADLs. The caregiver burden due to decreased initiation and completion of these tasks by the person with AD is significant and often leads to nursing home placement (Rowe & Fehrenbach, 2004).

Cognitive functioning for daily activities also seems to be influenced by importance of the task, the context in which the task takes place, and role changes in the caregiving relationship. In one study five groups of people (n=862) answered a 16-item questionnaire regarding the frequency of prospective memory and retrospective memory failures (Smith, Sala, Logie, & Maylor, 2000). The highest frequency of memory failures as a whole was found in people with AD and the lowest for their carers (carers rated the person with AD). The investigators hypothesized that the carers were comparing themselves with the people with AD in their care. Another key finding especially where AD care is concerned was that carers reported higher rates of frustration with prospective memory failures, which suggests that external prompting devices could possibly aid in relieving caregiver burden. These memory failures could include something relatively complex like remembering a medication regimen or something as basic as washing hands properly. While these cognitive changes demonstrate how prompting has the potential to help people with cognitive impairment, they may also help caregivers.
Caregiving Issues

The majority of people with dementia are cared for in the home by family and friends or “informal” caregivers with estimated costs of informal caregiving ranging from approximately 13,000 to 58,000 dollars per person with dementia (Moore, Zhu, & Clipp, 2001). Families pay almost all “formal” or “paid” care out of pocket (Fox, Kohatsu, Max, & Arnsberger, 2001).

Poor health of family caregivers and lack of knowledge or information regarding the disease process is common (Paton, Johnson, Katona, & Livingston, 2004). Caring for a person with dementia is more stressful than caring for a person without dementia, due to the nature of dementia itself. Caregivers have difficulty in coping with the unpredictable behaviors common in people with dementia (Levesque, Ducharme, & Lachance, 1999). Elders in a caregiving role experience more fatigue, have less energy, and experience more sleep difficulty than elders who are not in caregiver roles (Tell & Press, 1999). Reducing the burden of care by reducing direct care time through the use of external prompting devices could lessen the burden experienced by caregivers of patients with dementia.

As a person with AD ages he or she requires increasing amounts of supervision due to decreased safety and judgment, as well as increased behavior issues such as rummaging or wandering. The increasing demands on caregivers, both formal and informal, to provide care and maintain safety for the care recipient can be significant. Vascular and non-AD types of dementia tend to become more stable over time compared to dementia caused by AD, however, caregiver burden can still be significant (Alisky, 2006).

Caregivers may also contribute to the loss of functional performance when they “do for” the person rather than allowing the person to do a task independently (Vogelpohl, Beck, Heacock, & Mercer, 1996). This is a major issue in long-term care facilities, where caregiving is often focused on efficiency rather than on maintaining the cognitively impaired older adult’s
remaining abilities (Jirovec, 1991). It can be an issue in the home environment as well. Rogers et al. (1999) demonstrated that an intervention using prompts by the caregivers increased independence in self-dressing as well as increased active participation in ADL’s in nursing home residents with functional disabilities due to cognitive impairment. This study also found that there were more appropriate requests for help when independence was encouraged. Another study demonstrated that supportive interventions by nursing assistants to a group of nursing home residents with cognitive impairments increased dressing independence of the residents who could do more for themselves when they were given supportive care rather than given total care (Beck, Heacock, Mercer, Walls, & Vogelpohl, 1997). A similar study taught certified nursing assistants (CNA) to utilize a graduated prompting procedure to increase dressing independence for three residents in a seven-bed dementia care unit. Through a repeated measures experimental design, this program demonstrated increased dressing independence and increased range of motion in the residents with dementia (Engelman, Mathews, & Altus, 2002). A technique known as the system of least prompts (SLP) has been found to be effective in teaching skills to people with developmental disabilities (Winborn, Wacker, Richman, Asmus, & Geier, 2002). This approach has also been shown to successfully coach people with dementia through daily tasks (Labelle & Mihailidis, 2006).

The impact of the stage of dementia on the time required for bathing-related care in a nursing home including time to get to the bath, dressing, and undressing was studied by Kobayashi and Yamamoto (2004). They focused on the interaction between the caregiver/ care recipient dyad and the stage of dementia according to a functional assessment staging of AD instrument called FAST (Reisberg, Ferris, Deleon, & Crook, 1982; Reisberg, 1986). All participants were at different stages of dementia and did not have any other serious medical
conditions. Their specific stages with ‘n’ sizes were as follows: 1) N= 2, Stage 5- requires assistance selecting attire, may require coaxing to bathe properly, 2) N= 2, Stage 7b- intelligible vocabulary lost, 3)N=2, Stage 7c- ambulatory ability lost, chair-bound 4) N=2, Stage 7e- ability to smile lost, bed bound. The average time required was calculated for the three tasks previously described and collected written information about the context of the bathing task taking into account social environment, physical environment, and medical treatment. Guiding to the bathroom for bathing took the largest amount of additional time, much more than additional time required for undressing or dressing. The investigators concluded that stage of dementia only affected the time it took to guide the person to the bathing room, not dressing or undressing. Residents in stage 5 of FAST can walk and dress themselves, but refuse to bathe frequently which increases the amount of time it takes to complete the task of guiding the resident to the bathing room. Extra time with dressing tasks was attributed to caregiver error in this study and did not correlate with the resident’s level of dementia. The authors also note that appropriate use of prompts by the caregiver was associated with efficiency of task completion.

While a machine-based prompt may not be appropriate due to safety issues involved with bathing, an interesting consideration here is that problems were attributed to caregiver error or change in routine. A machine-based prompting system could have the potential to overcome these issues.

Making appropriate judgments and decisions about safe and dangerous situations is difficult for people with AD. Therefore, the care provider must create a simple, safe and familiar environment for the person with a cognitive impairment (Reimer, Slaughter, Donaldson, Currie, & Eliasziw, 2004). Suggestions and guidelines for environmental interventions in the homes of persons with cognitive impairments are common in the literature (Corcoran & Gitlin, 1991;
Olsen, Ehrenkrantz, & Hutchings, 1993; Pynoos & Ohta, 1991). Further, Gitlin and colleagues (2001) have found that certain modifications of the home can decrease spousal caregiver upset and frustration, increase caregiving self-efficacy in handling behavior issues and decrease difficult behaviors of the person with dementia. This is another area where the environment has the potential to serve as an external prompt to increase function and safety.

**Assistive Technology for those with Cognitive Impairments (External Prompting Devices)**

Environmentally oriented or “external” prompting systems can be a useful compensatory mechanism for people with AD. External prompting systems to aid prospective memory tasks can take many forms. The most basic aids include but are not limited to pictures, alarm clocks, buzzers, and calendars. However, in some cases, especially for those with AD, declines in cognition, especially lack of memory needed to remember to listen to a device, may prevent a person from using something this basic (Evans, Emslie, & Wilson, 1998). Other drawbacks exist with external prompting. LoPresti, Mihailidis & Kirsch (2004) reported on the state of the art of assistive technology for cognitive rehabilitation. Many assistive devices for cognitive impairments require the user to provide some feedback, such as pushing a button after the prompted task has been completed. Someone with a cognitive impairment may be unable to remember which step they have just taken. Context-aware external cuing systems or “smart devices” could remediate these problems.

More automated prompting systems (like wireless monitoring and messaging systems) may be appropriate for people with prospective memory impairments. With external prompting devices (also known as cognitive orthoses), especially for those with AD, the focus is on providing compensatory strategies rather than remediation.

A number of studies report interventions based on external prompting. In two studies, Kim and colleagues (Kimj, Burke, Dowds, & George, 1999; Kim, Lamb, & Wilson, 1995) reported
that an individual with memory and executive functioning deficits could improve recall of appointments and medication schedules when using either microcomputer or “palmtop computers” capable of generating audible and visible reminders. Hersh and Treadgold (1994) have shown that a specialized paging system can be used to facilitate prospective performance of functional tasks. Broek, Downes, Johnson, Dayus & Hilton (2000) use a “Voice Organizer” to facilitate performance of prospective tasks for a small sample of individuals with severe memory impairments.

Assessment of portable wireless devices has been reported by Wilson and her colleagues (Wilson, Emslie, Quirk, & Evans, 1999; Evans, Emslie, & Wilson, 1998; Wilson, Evans, Emslie, & Malinek, 1997). These studies have demonstrated that an alphanumeric paging system can facilitate performance of functional activities for adults having a variety of acquired neurological impairments. While AD does not necessarily belong to this category, some of these technologies may also be appropriate for this population.

DeVaul (2000) developed a context-aware memory aid called Memory Glass which provides reminders using a minimum of the wearer’s attention. The system detects people, locations or places and displays an image on one small part of the visual field of one eye.

Ramakrishnan & Pollack (2000) are developing a mobile robot to monitor cognitively impaired elders in their performance of daily activities. The robot learns which activities need to be monitored and when reminders need to be issued.

Friedman (1993) developed a wearable computer to be used as an external prompting device for memory and attention. The system uses radio and ultrasonic waves to determine a person’s location, and then provides voice prompts as needed. Cavalier and Ferreti (1993) further
evaluated the efficacy of this system and found that its use reduced dependency on external supervision for prompting.

One study demonstrated that people with AD can be taught to use a simple computer program. They learned to do a simple task using a touch screen on a computer. The investigators reported that subject acceptance of the training was positive, motivation was high, and the trained skills transferred into everyday activity (Hofmann, Hoch, Kuhler, & Muller-Spahn, 1995).

The Ubicomp laboratory at National Taiwan University currently has several context aware prompting projects in development. While these products are primarily aimed at children, they may be applicable to adults with AD as well. One of these is the ChroMirror which is a digital mirror imaging system that helps people pick out appropriate clothing (as far as color combinations are concerned) (Cheng, Chung, Yu, Ouhyoung, Chu, & Chuang, 2008). Another item potentially useful to people with dementia is the Playful Toothbrush (Chang, Lo, Huang, Hsu, Chu, Want, Chi & Hsieh, 2008). This toothbrush is designed to teach children the correct technique when brushing their teeth to ensure proper hygiene. A vision-based brushing tracker comprised of a web camera with a brush extension coded with LED marker patterns and a game presented on an LCD screen in front of the child provides real-time input to the game that shows the child where they need to brush.

Certain ADL and IADL tasks may require a person to process rather complex information. For tasks such as running errands or preparing a meal, several steps are involved. In these instances information processing demands are high. One goal of external prompting aids is to break these activities down into basic sequential steps in order for the person to carry out a task successfully. In one instance a computerized system was developed to assist with the task of
hand washing for elderly persons with moderate and severe dementia (Mihailidis, Barbenel, & Fernie, 2004; Mihailidis, Fernie, & Cleghorn, 2000). The system used artificial intelligence (AI) and consisted of a nine step verbal prompting device equipped with transducers to monitor step completion. It did not require user input or intervention for effective operation which is important when working with clients with dementia. The study showed that the device was effective in assisting the majority of the participants. There was an improvement in the number of tasks completed without a caregiver. Use of a computerized device reduced the amount of time a caregiver needed to spend with the participant when completing ADLs.

Labelle and Mihailidis (Labelle & Mihailidis, 2006) recently discussed further testing with this handwashing device to determine if audio or audiovisual cueing was more effective in guiding a person with moderate to severe cognitive impairment through a handwashing task. Their system incorporated the system of least prompts approach and “wizard of oz” technology (Doyle, Wolery, Ault, & Gast, 1988). Descriptive group statistics demonstrated minimal difference between the use of audiovisual or audio-alone prompts in handwashing performance. In this single-subject design, caregiver interactions decreased in both prompting scenarios when the subject moved from baseline to intervention phases, with the audiovisual prompting showing statistically fewer interactions.

A study at the University of Florida utilized simulated machine-based prompting by having investigators observe participants with Alzheimer’s while they completed three types of self-care tasks: 1) drinking water, 2) brushing teeth, and 3) upper body dressing (Mann, Witte, Belchior, & Dasler, in press). Participants were observed by investigators in another room via a web camera and were provided an appropriate prompt either with the investigator’s voice, a simulated male voice, a simulated female voice, or through a video display depending on the stage of the study.
The participants’ prompting needs were highly individual, but given appropriate machine delivered messages, they were able to successfully complete the task. Some participants were able to perform the task only using the starting task prompt, while others required further prompting.

Considerations for Successful Use

To ensure successful use of an external prompting device, or any assistive device, there must be a good fit or “match” between the person and the technology (Shererer, 2002; Shererer, 2001). A person’s view of his or her needs and physical characteristics as well as the characteristics of the environment in which he or she will be performing the task needs to be assessed to decrease the likelihood of device abandonment. The attitudes a person attributes to a device must also be considered. If a person associates a device to stigma or a diminished self-concept, abandonment is likely (Louise-Bender Pape, Kim, & Weiner, 2002; Shone, Ryan, Rigby, & Jutai, 2002). Sixsmith and Sixsmith (2000) also discuss this paradigm shift from a technology driven approach to a needs-led approach when instituting telecare and intelligent home monitoring systems. Therefore user input (that of the person with AD and the caregiver) must be taken into account when prescribing a device. Sixsmith also discusses the need to have a more specific approach when prescribing technologies for people with dementia (Sixsmith, 2006).

O’Connel, Mateer, & Kerns (2003) provide an overview of the process involved with selecting an external prompting device for someone who experiences difficulty with initiation. Some of the devices have demonstrated effectiveness specifically with people who have prospective memory deficits. They begin by discussing initiation, followed by rehabilitation strategies used when working with someone with initiation problems. Then they discuss considerations when prescribing an external prompting device, training the person or caregiver
on the use of the device, and how to program the device. The authors conclude by discussing the importance of measuring the efficiency of an external prompting system and whether or not it is actually helping the client or not. Most resources cited in this text seem to focus on clients with traumatic brain injury or stroke, but the same principles could possibly be applied to someone with AD.

The Veterans Health Administration also discussed these concepts in the implementation of telemedicine to support Veteran healthcare (Ryan, Kobb, & Hilsen, 2003). In initial interviews, the interviewers noted that education, impaired vision, manual dexterity, willingness to use technology, and compliance with the medical regimen all could potentially affect the Veteran’s participation in the program. An algorithm was developed on the preceding information to be used as an AT selection guide for the client. The emphasis of the algorithm was that it be used based on the patient’s clinical need and ability, not the type or brand of technology. As the clients’ needs change, the algorithm can be used as a decision tree to guide AT selection alternatives. Patient satisfaction and compliance were extremely high (94% and 93%, respectively). Patients also reported that the technology was easy to understand, to use, and was reliable. This study reiterates the idea that consumers must be involved with device development and that technologies must be reliable and easy to use for successful use among caregivers and care receivers.

A current problem with utilization of context aware devices at the moment is that many are still in development and cost is high which does not make them readily available for a home situation. Even some of the more basic systems that are currently available and relatively cheap have not been tested in in-home situation with people with AD.
Components not Amenable to Prompting

This literature review has emphasized the ways in which prompting can aid in assisting people with dementia or AD through daily tasks as well as aid caregivers in coping with the daily demands of caring for a person with dementia or AD. However, prompting strategies will most likely not be able to aid all of these dyads either initially or indefinitely. One must take into consideration that some forms of dementia, especially AD, are progressive in nature and that at some point machine-based prompting may not help coach someone through a task. More importantly, machine-based prompting alone may not be able to ensure the safety of a person with AD.

Many prompting technologies are designed for people with developmental disabilities or traumatic brain injuries, rather than people with AD. While these technologies are interesting and useful to explore for people with AD, they may not necessarily be designed to adjust for the progressive nature of AD which not only will change a person’s functioning over time, but could affect a person’s function throughout the day.

Prompting may not be feasible for other reasons, including the presence of co-morbidities. Many people with AD also have other disabilities that need to be addressed like hearing or visual impairments. Personal factors must also be taken into account. People with AD and their caregivers will all bring their own attitudes and contexts to the situation that may affect their view of machine-based prompting. Stigma could be associated with these devices. Caregivers may not want their home environment changed to accommodate a prompting system. Some may even be wary of the technology because of past experience or inexperience with technology. Others may find it too impersonal.

Until prompting technologies become more reliable and integrated into everyday life of the general population there may be some hesitancy in using them. However, while prompting
may not be helpful for some, the potential for these devices in increasing independence for both
the caregiver and the person with AD is clear.

**Study Purpose**

The purpose of this study is to 1) investigate whether or not people with dementia are
able to operate a non-context aware machine-based prompting device, 2) determine if people
with dementia will be able to understand and follow prompts issued by a machine-based
prompting device, and 3) explore the use of a machine-based prompting device in an in-home
situation.
CHAPTER 3
MATERIALS AND METHODS

Introduction

This study was completed in two steps. Step One was included to make sure that participants with AD would be able to operate and understand the device used in Step Two. This device was called an electronic memory aid (EMA) and is described below. The goal of Step Two was to test this device over a four to six week period utilizing a single subject design. Step One of the study took place at a facility with an adult day program. Step Two of the study explored the use of the EMA in the participants’ homes at their caregiver’s invitation.

The EMA

An EMA is a device which allows vocal recording of specific appointments or tasks and can then be pre-programmed. The EMA in this study consisted of two small electronic devices that when placed together as described below measured about 3 ½ by 2 inches. The first device, a Voice Cue©, was a pocket-sized voice recorder with an alarm playback feature. The Voice Cue© could not be used alone since it was only capable of providing a total of five prompts that could only be delivered at five minute intervals, so a second device was used with it. The second device, an Olympus Digital Voice Recorder© (DVR), was attached to the Voice Cue© with Velcro© tape to make the two devices appear more like one device to decrease participant confusion. The DVR was placed on top of the Voice Cue© so the participants could press the “start” button on the DVR. The DVR was modified by placing a green foam sticker on its “start” button making it easier to locate. The Voice Cue© was then set to provide the initial auditory prompt which indicated that the participant should “push the green button” on the second device. A picture of the EMA is provided in Figure 3-1.
The initial prompt and the steps of the task were recorded using the PI’s voice with one exception in Step Two where a male voice was needed because of a participant’s hearing impairment. Modifications could be made easily to the EMA. The level of sound for the DVR varied depending on the needs of the participant and could be easily adjusted. Adjustments in sound could also be made to the Voice Cue©, but only three volume options were available: low, medium, and high.

Once activated, the DVR played the series of prompts for the activities described in the treatment protocol. For Step One these activities included making a seasonal decoration, taking a sip from a glass of water, or finding items in a one-page advertisement and making a list, depending on the cognitive level of the participant. These activities are described in more detail in the study procedures and in Appendices A-C. In Step Two each activity set is described in detail for each participant and in the corresponding appendices.

Specific Aims and Hypotheses

Step One

Aim 1: To determine if people with AD will be able to follow the instructions provided by the EMA.

Hypothesis 1: The participants with AD will be able to follow the instructions provided by the EMA.

Aim 2: To determine if the EMA helps people with AD complete a specific leisure or IADL task.

Hypothesis 2: Following training on use of the EMA, people with AD will successfully complete a specific, simple leisure task.

Step Two

Aim 1: To observe if someone with AD can use the EMA in his or her home environment.

Hypothesis 1: The person will be able to use the EMA in his or her own home.
Aim 2: To test whether or not an EMA can be helpful for a variety of daily tasks.

Hypothesis 2: The EMA will be able to be utilized for a variety of daily tasks.

Steps One and Two

Research Question 1: What are the limitations with the EMA pertaining to elder/caregiver needs?

Research Question 2: What are participant/caregiver attitudes toward prompting technology both prior to participation in the study and after participation in the study?

Participants

Recruitment

Purposeful sampling was used for both steps of the study. All participants in Step One attended a local adult day program and were recruited through a caregiver support group and by a letter sent by the facility which explained the study. To be eligible to attend this facility, the client had to: 1) be a resident of the county (even before the person was put on the waiting list), 2) have a primary or secondary diagnosis of dementia, 3) be able to eat and toilet independently, and 4) be able to participate in the program activities.

For Step 2, participants were identified and recruited through the adult day program and through other community presentations, distributed flyers, and referrals from other health care providers and investigators.

Inclusion/Exclusion Criteria for Participants

To be included in this study, participants had to:

- be over age 50
- have an established diagnosis of AD by a physician
- score less than 23 on the Mini Mental State Exam (MMSE) (administered by the principal investigator (PI))
- have difficulty completing at least one ADL or IADL activity without prompting
- be available for multiple sessions
If participating in Step 2 participants also had to be willing to have treatment sessions video recorded.

**Inclusion/Exclusion Criteria for Caregivers**

To be included in this study the caregiver had to be:

- the primary caregiver for person with AD who fit the criteria above
- the legal representative for the participant with AD
- able to read and write English fluently
- available to complete certain measures and interviews in the study protocol

If the caregiver was participating in Step Two of the study, he or she also had to:

- reside with person with AD who fits the criteria above
- be willing to have treatment sessions video recorded

**Informed Consent**

The PI reviewed the informed consent forms with all participants and their caregivers in person prior to their participation. The participant with AD signed his or her own consent form with the caregiver validating the consent by providing a co-signature. In one instance the caregiver signed for the participant as well because she was unable to write. Each caregiver also signed a separate consent for his or her participation in other aspects of the study. The participants and their caregivers were then given the opportunity to review the informed consent on their own and ask questions. Consent took place in the subject and caregiver’s home at the caregiver’s invitation or at the adult day program center, depending on the step of the study for which they were consenting.

**Participants in Step One**

**Participant 101 (P101)**

Participant 101 was an 89-year-old, Caucasian female. She was widowed and lived with her daughter. According to her caregiver her AD was in a moderate stage and her major impairments
involved short term memory loss and difficulty sequencing tasks. She also had difficulty hearing and wore a hearing aid. Her MMSE score was 14, indicating a moderate cognitive impairment.

**Participant 102 (P102)**

This participant was a 76-year-old Hispanic male who lived with his wife. He had a ninth grade education, but served in the air force and owned his own business for several years. According to caregiver reports, he had significant short term and long term memory impairments and significant impairment with sequencing activities. He required total assistance with all IADLs and needed prompts for some ADLs, but could complete toileting independently. He also had partial hearing loss. He scored a two on the MMSE, indicating a severe cognitive impairment. However, this score may not have been valid since he seemed to be reverting back to Spanish.

**Participant 103 (P103)**

Participant 103 was an 83-year-old Caucasian male. He was married and lived with his wife. He completed a doctorate and served in the air force. He scored a seven on the MMSE, indicating a severe cognitive impairment.

**Participant 104 (P104)**

Participant 104 was a Caucasian female over age eighty-nine, widowed and lived with her daughter. She completed some college, but did not graduate. She was diagnosed with AD seven years ago and her caregiver reported that her hearing and vision with glasses were “adequate”. She used a walker to ambulate. She scored a 16 on the MMSE, indicating a moderate cognitive impairment.

**Participant 105 (P105)**

Participant 105 was an 83-year-old Caucasian female. She was divorced and lived with her son and daughter-in-law (primary caregiver) in a suite attached to their garage. Her highest level
of completed education was high school. She had macular degeneration, but was able to read large print and read frequently. She walked with a walker. According to her caregiver she was unable to use the phone or cook for herself. She completed ADLs on her own, but needed frequent reminders to shower since she did not like this activity. She scored a 19 on the MMSE, indicating a moderate cognitive impairment.

Participants Withdrawn from Step One

Participant 102 and P103 were withdrawn from the study by the PI after their second and first sessions, respectively, as a result of their severe cognitive impairments which interfered with their ability to interact with the device.

Procedures for Step One

Intake Assessment

Prior to beginning the sessions the PI collected demographic information for the participants from the participants’ caregivers and administered the MMSE to each potential participant (Folstein, Folstein, & McHugh, 1975). This instrument measured the participant’s level of cognition within five domains: orientation, recall, registration, attention and calculation, and language (Harvan & Cotter, 2006). Although severity of a person’s cognitive decline cannot be measured definitively by the MMSE, it is generally agreed that a person with a score less than a ten is considered severely impaired (Cummings, 2005).

At this stage of the study, the relationship of the MMSE to successful use of the prompting device was being explored to help determine a score range for the MMSE which reflected the relationship between cognitive impairment and successful use of the device.

Caregiver Ratings of Behaviors

Before the intervention, the caregiver completed the Kingston Standardized Behavioural Assessment (KSBA) for each participant. The KSBA is a 65-question assessment that provides
an indication of the number of behavioral symptoms a person with dementia displayed within the last month. For each question, the caregiver had to check “yes” or “no” for whether the participant exhibited that behavior. If the person used to exhibit the behavior, such as “showing poor judgment when driving,” but is now supervised when doing it or kept away from it, the informant had to check “yes” and assume that the person would still exhibit that behavior if he or she were to do the activity today. If the person exhibited the behavior a few months ago but it had since disappeared, the informant was to answer “no” (Hopkins, Kilik, Day, Bradford, & Rows, 2006).

For the purpose of this study, only the behavior profile of the KSBA was interpreted and computed. The KSBA provided background information regarding the person’s behavior at home and/or at the day care facility and on where the participant was experiencing limitations that might be addressed with prompting (Hopkins, Kilik, Day, Bradford, & Rows, 2006). The KSBA also identified behavioral issues that might impact success in use of the prompting device. The assessment is divided into 12 major sub-categories: 1) Daily Activities, 2) Attention/Concentration/Memory, 3) Emotional Behaviour, 4) Aggressive Behavior, 5) Misperceptions/Misidentifications, 6) Paranoid Behavior, 7) Judgment/Insight, 8) Perseveration, 9) Motor Restlessness, 10) Sleep/Activity/Sundowning, 11) Motor/Spatial Problems, and 12) Language difficulties. The KSBA sections used in this study are included in Appendix D.

**Trained Observer Ratings**

The Philadelphia Geriatric Center Affect Rating Scale (PGARS) was used to measure affect during the sessions (Lawton et al., 1996). This scale addressed six affective states: Pleasure, Anger, Anxiety/Fear, Sadness, Interest and Contentment with specific signs for the raters to circle relating to those six states. Raters could list other signs they observed that related to the six affective states. The PGARS can be found in Appendix E.
Observation Checklist

This checklist was created by the PI and listed each specific prompt that was delivered during each session. Under each prompt were three options that could be checked: 1) response, 2) correct response, and 3) no response. There was also space for additional comments such as observations that did not pertain to the PGARS. A “response” is defined here as when the participant acknowledges a prompt in some way either by looking at the person or device, talking to the person or device by making a comment or asking for a clarification regarding the prompt, or by performing an action as a result of the prompt. A “correct response” is defined as the participant responding exactly how the prompt asked him or her to respond. “No response” is when there is no visible or audible acknowledgement that a prompt was delivered. Examples of these checklists are included in Appendices A-D.

Treatment Protocol

The PI administered the MMSE to five possible participants (Folstein, Folstein, & McHugh, 1975). All five participants given the MMSE met the study criteria. The participants’ caregivers all completed the KSBA to provide information regarding the participants’ behaviors and provided demographic information for the participant.

In this step of the study, the person with AD was prompted to complete one of the following activities depending on their cognitive level: 1) making a seasonal decoration, 2) taking a drink of water, or 3) making a list from a one-page advertisement. Initially all participants started their prompting sessions with the ‘seasonal decoration’ activity, but the activity was changed to something simpler (taking a drink of water) or more difficult (list) based on their task performance and level of engagement as noted on the PGARS and in observer comments. For P102 and P103, the “seasonal decoration” activity was too complex, so the
activity was changed to taking a drink of water. P105 found the decoration activity too easy and “silly” so her activity was changed to making the list.

Materials for the decoration included a blank piece of cardstock, one or two large foam stickers (depending on the participant doing the activity), and a marker. Following the initial prompt to “push the green button” the participant was prompted to place the stickers on the cardstock in specific places and then write his or her name on the back of the cardstock. The observation checklist for this activity is found in Appendix A.

The only object for the “drink of water” activity was a glass half filled with water. Taking a drink of water was a two-prompt activity: 1) “please push the green button” and 2) “please take a drink from the glass of water”. The observation checklist for this activity is found in Appendix B. Participant 102 and P103 were still unable to follow these prompts when issued from the EMA, so they were withdrawn from the study.

For making a list from a one-page advertisement materials included the one-page advertisement, a pen or pencil, and a piece of notebook paper. This activity required the participant to locate various items in the ad (some more difficult to find than others), announce the cost, and write the item and the cost down on a piece of paper when prompted. The observation checklist for this activity is found in Appendix C.

Due to the schedule of activities at the adult day program, times to see clients were limited to between 9:15 and 10 A.M. and over the noon hour after the participant had lunch. Four of the five participant/caregiver dyads consented to having the sessions video-taped. During the sessions with the participant whose caregiver did not consent (P101), research assistants were present along with the PI to directly and as unobtrusively as possible observe this participant’s interaction with the device during the activity. PARTICIPANT 101 always agreed to have the
research assistants present and appeared unaffected by their presence aside from socially interacting with them before and after the task.

Each participant was taken to a room adjacent to the main activity room at the adult day program facility. He or she was seated at a small table in the room with all the required materials for the task laid out on the table. Each participant took part in one practice session to become oriented with the activity and device, as well as five sessions. During this practice session the PI also recorded the appropriate volume level of the DVR for future sessions. The PI provided instructions beforehand for the practice session and the five “official” sessions because participants were not able to recall how to use the device. The PI was required to re-orient the participant to the task before each session because they did not remember what the device was for or what they were specifically supposed to accomplish. Instructions included explanation of the study, how to start the DVR, orientation to the task materials, and how to peel off the paper backings of the stickers (if the participant was creating a seasonal decoration).

At the required time of the task, the EMA provided and initial prompt asking the participant to “Push the green button. Please push the green button.” The participants then pressed a central button on the EMA that was marked with a green foam sticker, which then automatically activated the DVR and started the series of prompts that coached them through the assigned task.

Prompts were pre-recorded and timed based on earlier (practice session) observations of how long it took the participant to complete each step of the activity. The PI and trained research assistants then monitored the person using the device during the task. The investigators observed how the person interacted with the device and whether or not the person grasped the concept of using the device. This was measured by the PGARS and the observation checklist. Practice
sessions and sessions were also videotaped and observed by the PI and two research assistants. Exceptions were that P101’s sessions were not videotaped, since the caregiver did not provide video consent.

During the interventions, the investigators only filled out one form at a time during the session. After the session, the second form would be completed from memory. During videotaped analysis, the footage was watched twice so that each form could be filled out during the session for greater accuracy. The checklist results were more accurate when based on the videotaped footage since it was possible to rewind the tape.

**Data Analysis**

The scores of each subsection from the KSBA are displayed in a bar graph for each participant. These graphs were compared against line graphs displaying the percentage of responses and correct responses to the prompts. Due to the small size of the pilot study, visual analysis was used in place of statistical analysis.

With the observation checklist, the total number of responses to prompts were tallied and divided by the total number of prompts delivered for each session. Then the total number of correct responses to prompts was tallied and divided by the total number of prompts delivered for each session. These two values were then graphed together (in separate lines) in a line graph to compare how often the participant simply responded to the EMA to how often the participant correctly responded to the EMA in each session.

Comments in the observation checklist and the PGARS were transcribed verbatim and then categorized based on the different responses made by the participants. The PGARS affect states displayed by the participants that were recorded by the PI and two trained research assistants are described in detail for each session with the average number of each affect state listed next to the specific affect state. Significant words, phrases, and themes were identified and recorded. These
comments were used to compliment the quantitative data in the Results chapter. The scale uses six affect adjectives, three positive states (pleasure, interest, contentment) and three negative states (anger, anxiety/fear, and sadness). Over the observed time period the researchers indicated frequency of each affective state.

Inter-rater reliability was accounted for by training the research assistants with the checklists and scales before the sessions began. The training included filling out the checklists and scales while watching videos of occupational therapy patients performing ADLs and watching volunteers perform the study activities in-person. Training activities also included informal discussions about the behaviors being coded. The investigators’ results were then compared and discussed between each other. Coder reliability was measured with the Kappa statistic (K) which not only looks at how frequently coders agree, but also at the number of agreements expected due to chance (Blomqvist & Hallberg, 1999). A Kappa of 0.75 was established as an acceptable level of agreement since other investigators have proposed that reliability coefficients between .60 and .80 indicate good to very good (Blomqvist, & Hallberg, 1999; Gibson & Helme, 2000). Reliability estimates for the taped study measurements were good at kappa = 0.78.

**Step Two**

**Participants in Step Two**

**Participant pair 201, caregiver (C201), participant (P201)**

Participant 201 was a Caucasian female over age 89. She had less than a ninth grade education, was widowed and had lived with her daughter for nearly 15 years. She had several chronic conditions including joint problems, poor hearing, muscle weakness, tired easily, memory difficulties, and speech or communication difficulties. All of these conditions were reported by her daughter who stated that each of these conditions had affected her mother’s
activity level severely. Her mother was almost entirely dependent with ADL tasks, with the exception of some grooming tasks and eating. Participant 201 scored a three on the MMSE, indicating severe cognitive impairment. A paid caregiver came to help three times a week and respite services helped on occasion.

Participant 201’s main caregiver is her daughter (C201) who is 69 years old and retired. She is Caucasian, completed some college with no degree and was divorced. C201 reported joint problems that moderately affected her activity level. She frequently used several types of technology including personal computers for banking, the Internet, and email, cell phone, bank ATM, CD player, microwave, a home security alarm, and the CareWatch System which monitored her mother’s exits in and out of bed, certain rooms in the house, and house exits. She stated that her technology experiences were satisfying, saved her time, and helped her connect with other people. Sometimes technology took too much of her time, but overall she liked to try out new technology.

**Participant pair 202, caregiver (C202), participant (P202)**

Participant 202 was an 81-year-old Caucasian male who lived in a home with his wife (C202). They were both retired. C202 was very active socially and her husband (P202) would also sometimes attend events with her, although he could be safely left home where he liked to read and watch television. He fell two months prior to starting the study, but had recovered nicely and was nearly finished with his home physical therapy treatments. His highest level of education was a bachelor’s degree. He scored 19 on the MMSE. C202 reported that P202 had low vision and poor hearing that had severely has affected his activity level. Joint problems, muscular weakness, a right leg that was two inches shorter than his left (he had built up tennis shoes), and memory difficulties had moderately affected his activity level. She also reported that writing, using a computer, walking, climbing stairs, getting out of chairs, bending, using the
phone, doing housework, and driving were difficult or impossible for him to accomplish and that he found technology frustrating.

Caregiver 202 was 77, Caucasian, and had completed a vocational, technical, or business school degree. She reported no conditions that affected her activity level, but reported that she found using a computer difficult. She had one for only a month and decided to sell it. She frequently used a VCR, cell phone, CD player, answering machine, and microwave. She felt neutral about technology and said it took up too much of her time.

**Participant pair 203, caregiver (C203), participant (P203)**

Participant 203 was a 76-year-old Caucasian male who was widowed and lived between his daughter (C203) and her husband’s home as well as his own trailer home. He participated in an adult day program, but was in his home by himself from the time the day program ended to when his daughter arrived to pick him up at his home and bring him to her house. He also stayed in his own home while his daughter worked on Saturdays. He had a paid caregiver who came in to help with his meals and medicines during the times when he was alone. He had a less than ninth grade education. He scored a 13 on the MMSE. Caregiver 203 reported he had low vision that did not affect his activity level, poor hearing that moderately affected his activity level and memory difficulties that severely impaired his activity level. He also had difficulty reading, writing, using a computer, preparing meals, grooming, and using the phone. Caregiver 203 reported that he found technology frustrating, but used the TV and the telephone. She also reported that he had Parkinson’s disease. The sessions took place at his trailer home.

Caregiver 203 is 58, Caucasian, completed some college and owns her own business. She was married and lived with her husband and her father. She reported no activity limitations and used technology frequently including the computer, VCR, cell phone, digital camera, band ATM,
CD player, answering machine, and microwave. She reported that she found technology satisfying, it saved her time, and she liked to try new technology.

**Study Design**

Most research on machine-based external prompting for people with memory impairments has been with people with traumatic brain injury. Machine-based external prompting for people with AD is a relatively new area. Because this is a new area of research and because capabilities both between and within subjects are variable with this population, using a single-subject design approach is a logical step to determine if using these devices in a home scenario is possible.

A single subject design includes one participant or a small group of participants observed over a period of time in which a treatment is introduced and outcome variables are controlled and observed over time (Reboussin & Morgan, 1996). In single subject designs each participant serves as his or her own control. Multiple measurements are required during each phase. These designs are commonly used in behavior modification research as well as when the size of a population may be too small for larger scale experimental research (Thompson, 2006). Single subject designs are also used when subjects fall outside of the norm because they provide more flexibility than group designs.

Thompson discusses the appropriateness of using single subject designs with people with aphasia because of the heterogeneity of this type of sample (2006). The same could be said of studying people with AD. Because of this heterogeneity, the treatment effects could differ across individuals. In group experimental designs, results are usually averaged across participants; however, in a single subject design with a heterogeneous sample this could be contraindicated, especially in the early stages of experimentation, because the treatment effects have not been strongly established. Once these effects are more established across individual subjects, then it
may be appropriate to continue the research process using group designs with larger numbers of people.

The capability of people with AD to perform daily tasks can vary from day to day, therefore demonstrating intra-subject variability. An advantage of using a single subject design with this population is that this intra-subject variability becomes clear through repeated measurement of the dependent variable as the design progresses. This type of intra-subject variability could be hidden in a group design.

Single subject designs demonstrate internal validity by controlling for extraneous variables by isolating the treatment variable as the source of treatment effects in the experiment. This aspect of single subject designs is similar to that of experimental group designs, however rather than comparing groups, the single subject design compares experimental and control conditions within a single individual. Single subject designs are also different from case studies in that controlled experiments are used in single subject designs and replication of treatment effects is required both within and across subjects (Thompson, 2006).

Generalizability to a population can only be made when subjects in a study are randomly selected and randomly assigned to experimental and control groups. However, random selection is difficult when conducting research with people with AD because it is difficult to sample the population of people with AD. Because AD can vary in severity, and function can change on a daily basis, finding consistently similar characteristics among participants can be difficult. Also it is unethical to have people with AD consent for themselves, so a caregiver must provide consent. This makes the likelihood of all members of this population to be equally likely to be selected practically impossible, so having the numbers necessary to complete group research is difficult. Most participants are recruited from local facilities or clubs in a certain geographical
area. Hypothesis testing is possible, but any statements of significance would apply only to the group that received the treatment and not to anyone else. Any generalizations are only based on non-statistical logic by the investigators conducting the study (Thompson, 2006).

This lack of external validity is a frequent criticism of single subject designs; however, there are non-statistical methods for estimating external validity (Kazdin, 1982). One of these methods is direct and systematic replication which is a part of research designs like ABAB designs (described below). The more replications that occur, the greater the effect of the treatment (Zhan & Ottenbacher, 2001). The design used in this study is called an ABAB design.

The ABAB Design

In single subject designs the letter “A” represents the baseline or non-treatment measurement, where the letter “B” denotes the intervention or treatment period. During the baseline or A phase, the target behavior is measured repeatedly. After the behavior is stable over a number of days, an intervention is introduced. The intent of this intervention is to change the target behavior. This target behavior is measured several times throughout the intervention phase. Then the investigators examine the information gathered during these phases and try to determine if there is a relationship between the intervention and the target behavior (Kazdin, 1982).

To demonstrate experimental control when utilizing this design, four things must occur: 1) the performance on the dependent variable must be stable during the first A or baseline phase, 2) when the treatment variable is introduced in the B phase, a change in the dependent variable must be evident when compared to the previous A phase, 3) when the treatment is withdrawn in the second A phase the dependent variable must return to baseline levels, and 4) when the treatment variable is re-introduced in the second B phase, the treatment effect on the dependent variable must once again be evident. When this sequence is established in the design, within-
subject replication has occurred. If this same pattern is shown across several participants, then across-subject replication has occurred (Kazdin, 1982; Zhan & Ottenbacher, 2001).

Potential Limitations of an ABAB Design

Zhan and Ottenbacher (2001) noted that irreversible effects of a treatment on the target behavior could be a limitation in an ABAB study. This becomes an ethical issue when removing the treatment leaves the subject in an undesirable state. In these cases withdrawing treatment is not ethical. However, this issue should be of relatively little concern in testing machine-based external prompting with people with AD, because carryover of behaviors is not likely with this population once the intervention is removed. This fact regarding the issue of little to no carryover after the prompting device is removed also more or less negates the need to use other types of single subject designs such as multiple-baseline designs (which can help solve the problem of long treatment effects) (Ottenbacher, 1986; Backman, Harris, Chisholm, & Monette, 1997).

Research Plan for Step Two

Procedure

Step Two of this study explored whether or not the EMA could prompt people with AD during daily tasks in the home through a single subject design intervention and direct field observations. Interviews with caregivers were also conducted to assess participants’ daily routines and determine what tasks could be prompted with the EMA. The interviews also gathered information about how caregivers and participants perceived and used technology.

Again, once the caregiver and participant with AD expressed willingness to participate in this study, the PI arranged an initial meeting in their residence to explain the study, obtain informed consent, and to administer the MMSE to determine if participants were eligible for the study based on study criteria. Caregivers were provided their own consent for the study participation and also provided proxy consent for the person with AD. Verbal assent was also
obtained at each session from the person with AD. The caregiver’s cognitive status was judged by the PI through conversation and training procedures during the initial session. Caregivers were not required to complete formal cognition tests. Demographic information, including age, sex, gender, marital status, education level and race were collected. These forms also included information regarding any other impairments the participant or caregiver may have and a checklist of activities that were marked if the participant or caregiver had difficulty doing the activities or could not do the activities at all. Finally, the forms asked about what items of technology (in checklist form) had been used before the intervention and general feelings toward technology (caregiver and participant demographic forms, Appendices F and G).

**Measurement Tools**

An observation checklist created by the PI was again used to list each specific prompt that was delivered during each session. Under each prompt were three options that could be checked: 1) response, 2) correct response, and 3) no response. There was also space for additional field note observations. Again, a “response” is defined here as when the participant acknowledges a prompt in some way either by looking at the person or device, talking to the person or device by making a comment or asking for a clarification regarding the prompt, or by performing an action as a result of the prompt. A “correct response” is defined as the participant responding correctly to the prompt. “No response” is when there is no visible or audible acknowledgement that a prompt was delivered. The checklist provided extra space for the investigator to record any vital contextual information from the session. The checklists for participants in Step Two are found in Appendices H-J.

The caregiver was trained how to use the Revised Memory and Behavior Problems Checklist (RMBPC) (Appendix K) during session one. This tool allowed caregivers to measure
problems with memory, depression, and disruptive behaviors exhibited by the person with AD (Teri, Truax, Logsdon, Uomoto, Zarit, & Bitaliano, 1992). It is the most commonly used tool to measure behavior problems in community-dwelling individuals with AD (Allen, Kwak, Lokken, & Haley, 2003). While this test is usually administered weekly, in this study the caregiver filled this out on each day a session was scheduled to gain further information about the participant’s context on those days and within each phase of the study. The 24 items on the RMBPC not only measure how often a behavioral disturbance occurs, but also how much it affected the caregiver. It has shown good overall reliability for patient behavior ($\alpha = 0.84$) and caregiver reaction ($\alpha = 0.90$). The memory-related problems subsection was also positively correlated with the MMSE ($r = .48$).

**Procedures**

At the first session of each session, a semi-structured qualitative interview was conducted with the caregiver. The PI conducted the first interview. The caregiver responses to the first qualitative interview (Appendix L) determined what ADL or IADL tasks could be feasibly prompted with the EMA and determine the target behavior(s). The PI made this determination following discussion with the caregiver. Immediately following the first session, the PI completed an activity analysis and wrote it up to be used as a prompting guide for the chosen target behavior in Phase A1.

Activity analysis is done to understand an activity by evaluating its structure, rules, environment, materials and objects, real and symbolic meaning, and action processes. When the investigator or clinician compares the analysis to a person, he or she is able to determine why the person may be having difficulty participating in the activity and find ways to help. The PI is an occupational therapist and has expertise in the ability to complete a thorough activity analysis.
The activity analysis provides the foundation for the prompting checklists found in Appendices H-J.

An ABAB single-subject study design was utilized in this part of the study. This ABAB single subject design consisted of an initial baseline observation phase (A1) lasting a minimum of eight sessions within a two-and-a-half week period to observe behavior under conditions before treatment is implemented. Typically in this type of design these sessions would be completed daily, but due to the unpredictable nature of collecting repeated measurements in persons with AD, it was thought that it might not be convenient or possible for the caregivers to meet with PI on subsequent days throughout the study period. For this reason, the above guidelines for a minimum number of sessions within a maximum time-period were established. Typically the initial baseline phase is continued until the participant’s behavior appears to be stable (Kazdin, 1982). But since behavior or task performance is labile in nature for people with AD, the investigator determined that at least eight baseline sessions were needed to observe each individual’s typical behavior patterns during the targeted task. Also, to see possible treatment effects but keep caregiver burden at a minimum, this study was limited to four phases (one baseline, one treatment, one treatment withdrawal, and a final treatment phase. Similar determinations were made in another study that investigated pain behaviors in people with dementia utilizing a single subject design (Elliott, 2006)

An example of incorporating this design phase into prompting research would be to recruit individuals with AD that have difficulty brushing their teeth. They would be observed during this baseline period of time to determine their typical behavior during this activity. This would involve recording several factors. Examples of factors might be: 1) whether or not they need a prompt to initiate the task, 2) what steps do they complete on their own and in what order, and 3)
level of quality in the completion of the tasks. These factors are examples of baseline patterns that would need to be established prior to a machine-based prompting intervention.

Once the typical behavior pattern was observed in phase A1, the first intervention phase (B1) was initiated. To create equivalence with the first phase, this phase also lasted eight sessions within a two-and-a-half week period. In this phase the PI incorporated the use of the EMA rather than one-on-one in-person prompting with the participant.

Following intervention phase B1, a withdrawal phase (A2) took place. During this phase the prompting technology intervention was removed and baseline conditions were re-established. This phase lasted a minimum of four sessions (if behavior returned to baseline levels rapidly or if the target behavior remained stable within the phase) to a maximum of 8 sessions.

Following the withdrawal phase (A2), a final intervention phase (B2) took place in which the prompting technology was re-introduced. This phase is also lasted a minimum of four sessions to a maximum of eight sessions.

The second qualitative interview took place on the last day of the study. This interview examined the thoughts and opinions of the caregiver regarding the study protocol (how it affected him or her as a caregiver and how it affected the person with AD) and the prompting technology intervention itself (EMA) (Appendix I). C203 did not complete this interview because P203 was always seen while C203 was at work (at her request), and she was not physically present during any of the sessions. Because the PI wanted the caregivers to provide their honest perceptions, another investigator conducted these interviews. This investigator was an occupational therapist with a Ph.D. in rehabilitation science.

Sessions were videotaped for viewing by another trained observer on the research team to ensure that behaviors had been measured accurately and consistently and to minimize bias. This
observer was an occupational therapist with a Ph.D. in rehabilitation science who was trained in all protocols of this study. The training included filling out the checklists while watching videos of occupational therapy patients performing ADLs. Training activities also included informal discussions about the behaviors being coded. The investigators’ results were then compared and discussed between each other. Coder reliability was measured with the Kappa statistic (K) once again, with kappa equaling 0.81, indicating strong reliability.

**Participant 201 (P201) Protocol**

Following the intake interview with the caregiver it was determined that having P201 wash her face and brush her hair would be feasible activities to try to use the EMA. While in-person prompts varied depending on her needs in the session, for the treatment phase with the EMA, steps were developed to prompt her through the tasks of washing her face and brushing her hair based on the most frequently used prompts from phase A1. These prompts are found in Appendix H.

This participant was seen three times a week at 11:30 AM. This time was chosen by the caregiver since paid help was present on those days and that was the typical time of day when P1 woke up and started her morning ADL routine. This way she would be up and already in the bathroom for the sessions and it would not disrupt her typical routine as much.

**Participant 202 (P202) Protocol**

Participant 202 fell approximately three months previous to his study participation and had a home exercise program from his physical therapist. The caregiver and PI concluded that the task that would work the best for him (as well as the caregiver) would be to have the EMA prompt him through his home exercise program. The specific prompts are listed in Appendix I.

Participant 202 was seen everyday, typically during the mid-morning hours; however, sometimes this needed to be modified to early or late afternoon on days when he and his
caregiver had other engagements. He performed his exercises at the kitchen counter since it provided a place of stabilization and provided him with space to complete his exercises.

**Participant 203 (P203) Protocol**

Participant 203 had difficulties remembering and thoroughly completing the tasks of brushing his teeth, shaving, and combing his hair. He spent most of the day Monday through Friday at an adult day program, but was alone on Wednesday through Friday evenings from 4 PM until about 7:30 PM on those days as well as all day on Saturday. He had caregivers come help him with his medicines and meals during those times, but his caregiver requested that he be seen while he was alone, so another person could come check on him. So he was seen at 6 PM on the weekdays and during the day on Saturday.

He brushed his teeth, shaved, and combed his hair at the bathroom sink. The list of prompts he required are found in Appendix J.

**Analysis of the Data**

The PI recorded the following information from each video-recorded session: 1) number of prompts delivered, 2) number of responses to prompting, 3) number of correct responses to prompting, 4) number of occasions where the participant displayed no response to prompting, time required to complete the task, and 6) number of times the PI had to verbally (if in a “B” phase) or physically (in either an “A” or a “B” phase) intervene for each session. The number of prompts delivered and time required to complete the task were used to create the prompting sequence on the EMA and were not formally analyzed. A verbal intervention refers to having to provide an in-person prompt during a “B” phase. A physical intervention is when the PI had to physically intervene for safety reasons or to provide a visual example of how to complete a prompted task.
The percentage of responses to delivered prompts (either in-person prompts or machine-delivered prompts, depending on the study phase) and the percentage of correct responses for each session were graphed and analyzed according to the method described below.

**Single Subject Design Analysis**

Single subject designs are usually visually analyzed based on a graphic presentation (Edmans & Lincoln, 1989). The graphic presentation provides a way to analyze the target behavior both in detail and with efficiency (Tawney & Gast, 1984). Reliability or consistency of the effects of the intervention is also able to be viewed in this manner (Kazdin, 1982).

Visual analysis is the most used and accepted form of data analysis to interpret single subject designs (Parsonson & Baer, 1984). However, statistical tests may occasionally be used to evaluate the reliability of findings, especially in cases with variable or trend-affected baselines (Greenwood & Matyas, 1990; Kazdin, 1982).

The simplest form of graphic presentation is a line graph with a horizontal x axis (representing time) and vertical y-axis (representing behavior: frequency, rate, amount, etc.), drawn at right angles (Ottenbacher, 1986; Harbst, Ottenbacher, & Harris, 1991). As the design is implemented, the subject performance of the behavior is plotted at the intersection of the y-axis and the time in which the behavior occurs (x-axis). A series of points emerges as the design progresses and the points are connected, forming data paths. Participant data are graphed over the course of the entire study. Several characteristics of the data are examined in visual analysis. These characteristics are either related to the magnitude of change across phases (mean and level) or the rate of change (trend and latency). Overlap of data points between phases and stability within a phase should also be analyzed (Harbst, Ottenbacher, & Harris, 1991; Lagrow & Prochnow-Lagrow, 1983).
A change in mean refers to a shift in the average rate of performance between phases. A change in level refers to the shift of behavior between the end of one phase and the beginning of the next phase. Since the trend or the slope of the data shows whether behavior systematically increases or decreases over time, a change in trend may be revealed when the intervention is applied or withdrawn.

Most studies want to demonstrate treatment effectiveness by looking for a change in level and mean. However, for this study, changes in mean and level were not necessarily expected to become higher (indicating an increase in performance of the target behavior) during treatment phases, rather, the means and levels were expected to, at the very least, remain stable to indicate that use of the EMA did not relate to decreased performance of the target behavior. Table 3-1 demonstrates how change in level is determined. If the first value of the next phase is smaller than the last value of the first phase, then a decrease in level between phases has occurred. If the first value of the next phase is larger than the preceding value, then there is an increase in level between phases.

Likewise, while the trend (slope) of the data is typically expected to either increase or decrease during the intervention phases, the hope in this study was that the slope would at least stay the same or move in a positive direction (increase) indicating no change in task performance or an increased ability to perform a task. The latency of change refers to the period between the onset or termination of one phase and subsequent changes in behavior and is assessed by examining level and trend changes together. Therefore, the latency of change reveals how long after an intervention is applied it takes to change behavior. The closer this change takes place to the change in experimental condition, the more clear the effect of the intervention (Ottenbacher, 1986).
The slope or trend for each phase can be calculated in Excel after graphing the points for one phase. Excel will draw a trend line after the points are selected and can display the equation when that option is chosen. The magnitude of the level change and the change in slope are examined together. First, the investigator must determine if the change was in the intended direction. Again, most studies would look for a change in the slope direction or level to determine if there has been a change in the target behavior, but in this study, no change or an increase in responses to prompts or correct responses to prompts in the treatment phases is acceptable. Figure 3-2 demonstrates an example of a trend line.

Rapidity of change between phases must also be considered. If the period of latency is short, meaning the behavior changes quickly (and in the intended direction), the intervention effects on the target behavior are strengthened. If the latency periods are slow, meaning, there is a smaller level of change and the slope changes in the unintended direction the intervention effects are not as strong. However, in this study a minimal change in slope is acceptable.

Other factors to consider when visually analyzing single subject graphical data are stability (variability of performance within a phase) and overlap (the consistency of the effect across phases or baselines). When a large fluctuation in a series of data points is noticed graphically, variability is evident (Ottenbacher, 1986). These two factors demonstrate the reliability of an effect. To determine stability of data between phases the number of data points that fall between 15% above and 15% below the mean must be calculated. In this study, this was calculated by first calculating 15% of the mean for each individual phase. This value was then added and subtracted from each data point to provide a set of values that would have the same trendline as the original data, but represent the range 15% above and 15% below the original data set. Then, all three data sets were graphed in Excel with their respective trend lines. Figure 3-2
demonstrates an example of this. In this example all data points fall within 15% above and 15% below the mean indicating 100% stability of the data points in Phase A1 for P202.

Overlap of data between phases is determined by looking at the number of data points in each phase and looking to see if any of those data points or within the range of the data points in the adjacent phases. For example, in Phase A1 of P201’s trial where percentage of responses were determined the data points ranged from 82-100%. In Phase B1 the responses ranged from 59-96% which demonstrated that six points overlapped between Phases A1 and B1. Typically the effectiveness of the intervention is strengthened when there is no overlap between data points, but in this study this is not necessarily the case since the goal was to see if the treatment in the “B” phases was as effective as the “A” phases.

There are some disadvantages to visual analysis. One of these is that low inter-observer agreement among raters can occur due to ill-defined decision rules regarding graphical data interpretation (Harbst, Ottenbacher, & Harris, 1991; Bloom, Fischer, & Orme, 1995). Several studies report this issue and make the statement that these visual analyses should also be supplemented with statistical methods (Harbst, Ottenbacher, & Harris, 1991; Sharpley, 1986; Johnson & Ottenbacher, 1991). If the change from baseline to treatment is pronounced and patterns are clear in the visual data this may not be necessary, but when patterns are not so pronounced, statistical methods could be useful (Bloom, Fischer, & Orme, 1982).

Use of statistical methods are particularly important if there is an unstable baseline since a stable baseline is necessary to effectively measure against any intervention phases (Kazdin, 1982). For visual analysis to pick up treatment effects, the changes in a subject’s performance must be substantial, and if these changes are more subtle, small treatment effects may not be
discovered. Also, if extraneous variables are not carefully controlled, visual inspection of intervention effects could also go undetected (Ottenbacher, 1992).

**Qualitative Analysis of Step Two**

Interview responses were recorded with a digital voice recorder and transcribed verbatim into Word documents, read thoroughly, and then coded. Interview responses and comments in the observation checklist were categorized by significant words, phrases, and themes. These responses and comments were used to compliment the quantitative data in the Results chapter.
Table 3-1. Demographics/MMSE scores of participants in Step One

<table>
<thead>
<tr>
<th>Participant #</th>
<th>Age</th>
<th>Gender</th>
<th>Race</th>
<th>MMSE score</th>
<th>Level of completed education</th>
<th>Marital status</th>
<th>Lives with</th>
</tr>
</thead>
<tbody>
<tr>
<td>101</td>
<td>89</td>
<td>Female</td>
<td>Caucasian</td>
<td>14</td>
<td>Associates degree</td>
<td>Widowed</td>
<td>Daughter</td>
</tr>
<tr>
<td>102</td>
<td>76</td>
<td>Male</td>
<td>Caucasian</td>
<td>2</td>
<td>9th Grade</td>
<td>Married</td>
<td>Spouse</td>
</tr>
<tr>
<td>103</td>
<td>83</td>
<td>Male</td>
<td>Caucasian</td>
<td>7</td>
<td>Doctorate</td>
<td>Married</td>
<td>Spouse</td>
</tr>
<tr>
<td>104</td>
<td>Above 89</td>
<td>Female</td>
<td>Caucasian</td>
<td>16</td>
<td>Some college</td>
<td>Widowed</td>
<td>Daughter</td>
</tr>
<tr>
<td>105</td>
<td>83</td>
<td>Female</td>
<td>Caucasian</td>
<td>19</td>
<td>High school</td>
<td>Divorced</td>
<td>Son</td>
</tr>
<tr>
<td>Study phase</td>
<td>Duration</td>
<td>Actions</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>-----------------------------</td>
<td>-----------------------------------------------</td>
<td>----------------------------------------------------------------------------------------------------------------------------------------</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>A1- Baseline observation</td>
<td>8, 1-hour sessions within 2 ½ week period</td>
<td>Session 1: consent obtained, demographic measures obtained, qualitative interview of caregiver takes place, caregiver training on RMBPC takes place, PI observes target behavior and develops activity analysis Sessions 2-8: Target behavior is observed by PI and videotaped. PI completed an observation checklist and recorded field notes Caregiver completes RMBPC</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>B1- Intervention</td>
<td>8, 1-hour sessions within 2 week period</td>
<td>Sessions 1-8: PI utilizes prompting technology rather than personal one-on-one prompting, Caregiver fills out RMBPC, Target behavior videotaped by PI, PI completed an observation checklist and recorded field notes.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>A2- Withdraw intervention</td>
<td>4-8, 1-hour sessions</td>
<td>All sessions: see description for phase A1 sessions 2-8.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>B2- Re-introduce intervention</td>
<td>4-8, 1-hour sessions</td>
<td>All sessions: see description for phase B1. On the last day an exit qualitative interview of the caregiver also took place.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Table 3-3. Calculating the level of change between phases

<table>
<thead>
<tr>
<th></th>
<th>A1 to B1</th>
<th>B1 to A2</th>
<th>A2 to B2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Last value in first phase</td>
<td>82</td>
<td>96</td>
<td>100</td>
</tr>
<tr>
<td>First value in next phase</td>
<td>59</td>
<td>100</td>
<td>92</td>
</tr>
<tr>
<td>Difference (last value of the first phase - first value of next phase)</td>
<td>23 point decrease</td>
<td>4 point increase</td>
<td>8 point decrease</td>
</tr>
</tbody>
</table>
Figure 3-1. The electronic memory aid (EMA).
Figure 3-2. Example of trend line produced in Excel.
Figure 3-3. Example of calculating the stability of data points within Phase A1 for P202.
CHAPTER 4
RESULTS

This chapter presents the results first of Step One, then Step Two. In Step One the results of the KSBA (filled out by the caregiver) are displayed first. The results of the two specific aims of Step One are displayed through descriptions of the individual sessions and observations of affect as measured by the PGARS. In Step Two results for the two specific aims are presented through descriptions of graphical representations of the data and excerpts from field notes. The two overall research questions of this study will be examined in the Chapter 5.

Step One Results

Individual Descriptions of Performance with the Device

The following section examines each participant individually through a description of his or her performance and interactions with the EMA during the sessions. First a bar graph depicting the behavioral profile (as measured by the KBSA) of each participant is presented, followed by a session description table. For P101, P104, and P105 a graph comparing whether or not the participant responded to the prompt and whether or not the participant responded to the prompt correctly is displayed. PARTICIPANT 102 and P103 were withdrawn early in the sessions and do not have this graph.

Participant 101 (P101) MMSE = 14

Participant 101 (P101) completed the task of making a seasonal decoration in all five sessions. She displayed pleasure (2.33 times), anger (0.66), anxiety/fear (2.66), interest (3.66), and contentment (2). Pleasure was evident through smiling and laughing before and after the intervention. She remarked after the activity that “It’s a little silly” and then laughed. Anger was noted when her mouth occasionally turned down. (On the PGARS this facial expression had to be categorized as “anger,” but it was perceived as boredom or concentration, not anger, by the
investigators. This will be discussed in more detail in Chapter 5). The raters either described this display as a “grimace” or “pursed lips”. Signs of anxiety/fear included “furrowed brow”, “facial expression of worry”, and “leg jiggling”. She verbally expressed her anxiety by making comments such as “Should we start over?”, “Oh, fiddle”, and “Why me?” during the intervention. Signs of interest were “eyes follow object”, “intent fixation on object or person”, and “facial, motoric or verbal feedback to other”. She engaged in the activity and the conversation before and after the intervention. Signs of contentment were “comfortable posture” and “sitting”. At the end of the task she asked, “If that answered some kind of question for you?” and remarked “It’s interesting.”

In session 2, she displayed signs of pleasure (1.66), anxiety/fear (1.66), interest (4.33) and contentment (2.66). Pleasure once again was evident through smiling and laughing briefly before and after the intervention. A sign of anxiety/fear was most obvious through “motoric restlessness.” The participant stood up twice before the intervention began, and the second time she had to be prevented from leaving the room by the PI. Despite her desire to do something else before the activity, the participant displayed several signs of interest during the activity including “intent fixation on object or person”, “facial, motoric or verbal feedback”, “eye contact maintained”, and “eyes follow object”. Signs of contentment were “comfortable posture”, “smooth facial muscles” and “sitting” once the intervention began.

During the third session P101 displayed signs of pleasure (2.33), anxiety/fear (3.66), sadness (1.33), interest (2.66), and contentment (2.66). Pleasure once again was displayed through smiling and laughing after the intervention. She also joked “That’s all the artwork for today.” Anxiety/fear was displayed as sighing, “motoric restlessness”, and “repeated motions”. She brought her hand to her mouth and tapped her feet while waiting for the prompting to begin.
She displayed a sign of sadness when her “mouth was turned down at corners” and by having her “eyes/head turned down”. She turned away from the PI prior to the intervention before their conversation was over. She exhibited interest during the intervention through “intent fixation on object” and “motoric feedback”. She also had a “comfortable posture” and sat throughout session. After being asked if she could be seen again, the participant said, “I don’t know if I want to keep doing this. I don’t know if I should.”

Session 4, consistent with session 3, P101 displayed pleasure (3), anxiety/fear (2.66), sadness (0.33), interest (4), and contentment (1.33). She smiled, laughed and crinkled her eye during her conversation with the PI before and after the intervention. She displayed “motoric restlessness” and “repeated motions” by bringing her hand to her hair, mouth and ear while she was waiting for the prompting to begin and during the intervention. One rater noted sadness by a display of her mouth being turned down at the corners. Interest was present during the intervention and conversation before and after by “eyes follow object”, “intent fixation”, “facial, motoric or verbal feedback to other”, and “eye contact being maintained with the object”. Consistent with the other sessions, the participant displayed contentment by having a comfortable posture and by sitting.

In the final session P101 exhibited pleasure (1), anxiety/fear (1), sadness (2), interest (2.66), and contentment (2.33). A slight smile was recorded after the intervention. Anxiety/fear was present in brief “hand wringing” and signs of sadness were “eyes/head down turned” and “face expressionless”. She stared blankly. She appeared sedated during this session and moved slower than in the other sessions. During the intervention her “eyes followed object” and she had “intent fixation on object”. Contentment was present as “comfortable posture”, “smooth facial muscles” and “sitting”. She dozed off briefly during this session.
Participant 101 displayed approximately two signs of pleasure, anxiety/fear, and contentment throughout the five sessions. Overall signs of interest were exhibited the most often, an average of 3.5 times. The signs of interest were present both before and after the intervention during the conversations with the PI as well as during the intervention while she completed the activity. The two displays of contentment corresponded to sitting and having comfortable posture throughout the intervention. The signs of pleasure were displayed before and after the session. All of the displays of affect are summarized in Table 4-2.

Qualitative comments

Qualitative data from the investigators’ comments revealed that she did not ask many questions during the activity when she was confused, but would explain her difficulties after the session. There were times when she seemed skeptical of the EMA saying that “she understands its all foolishness” and is “not usually suspicious.” While she agreed to participate, she did not always appear to enjoy it. Most of her amusement only arose from self-deprecation. For example, she would frequently make jokes about herself or her performance during the task. She was often distracted by objects in the room and the stickiness of the stickers for the note cards.

Participant 102 (P102) MMSE = 2

In session 1, P102 displayed signs of pleasure (3), anxiety/fear (2), sadness (1), interest (3.33), and contentment (2.66). There were no signs of anger displayed in this first session. Signs of pleasure included “smile” and “laugh”. The signs of pleasure were present upon initial meeting and instructions. The signs of anxiety/fear included “motoric restlessness” and “repeated motions” in the form of foot tapping and fidgeting with objects. These displays of anxiety/fear were exhibited during the intervention while he was waiting between prompts. Toward the end of the task he asked, “Is this almost done?” Examples of interest included “intent fixation on object” and “facial, motoric or verbal feedback to other”. He would look at the device from time
to time and even read the time on the display screen; however, his feedback was limited to his conversation before and after the intervention with the PI. The participant did not display feedback with the EMA. Contentment was displayed in the form of “comfortable posture” and “sitting” and was present throughout the session.

For session 2 the activity was changed to a two-step task: taking a sip of water. All six affective states were present in this session: pleasure (3), anger (0.33), anxiety/fear (1), sadness (0.66), interest (3.33), and contentment (2). The participant displayed pleasure by smiling, laughing and nodding during the greeting and conversation with the PI. Only one rater indicated a sign of anger, a grimace, when he was asked if he was thirsty. Sadness was displayed by his “eyes/head down”, and his “face expressionless” during the session. Examples of signs of interest included an “intent fixation on object”, “motoric and verbal feedback”, and “turn body or move toward object” (leaning towards the device). These displays of interest were present in conversation and during the intervention. As in session 1, the participant displayed contentment by having “comfortable posture” and “sitting” throughout the session.

Qualitative comments

Participant 201 did not respond to any of the prompts from the EMA. He would respond to verbal prompts from the principal investigator but they had to be repeated or supported with visual prompts. He appeared interested in the EMA by “leaning toward the device” and “reads numbers in the device,” but he did not react to any of the prompts. Not following any of the directions created long periods with no activity, making him bored and restless. When he was asked questions, his answer would often be “I don’t know.” Upon consulting the day program staff, they said that in the last few months he responded to requests in Spanish better, but that lately he was not responding to requests in Spanish either.
Participant 103 (P103) MMSE = 7

After the practice session with P103, the PI decided that he would only perform the taking a sip of water activity. The participant displayed pleasure (2.66), anger (0.33), anxiety/fear (1), interest (3.33), and contentment (1) during the session. Pleasure was displayed in the form of smiling and laughing which was present throughout the entire session. The raters recorded interest as “intent fixation on object” when he was looking at the device, “visual scanning”, and “facial and verbal feedback”. He said “okay” and “ooh” during the instructions as well as muttered nonsense sentences. Contentment was displayed throughout the entire session by “sitting”. The raters noted that prior to the session that he had been complaining of back pain, but no sign of pain was exhibited during this session. The participant was withdrawn from the study after one session due to his cognitive impairment which reduced his ability to interact with the EMA.

Qualitative comments

Participant 103 only completed one session when it was decided to stop his intervention. His attitude was positive throughout and did not show any aggressive behavior, although his caregiver did report a symptom in that group. He sometimes understood that commands came from the EMA, but did not follow its instructions. When the PI would repeat the command verbally, he would sometimes respond with a nonsensical phrase.

Participant 104 (P104) MMSE = 16

Participant 104 displayed all six affective states in all but one session. In session 2 there were no signs of sadness. Contentment was present throughout every session as “comfortable posture” and “sitting”. Participant 104 periodically displayed two facial expressions consistently throughout the sessions. Her mouth turned in and down which might have been due to the curvature of her lower teeth. This facial expression was most often described as “grimace”
(anger) or “mouth turned down at corners” (sadness). Additionally, she periodically raised one eyebrow while squinting with the other eye. This facial expression was recorded as “tight facial muscles” or “furrowed brow” (anxiety). In the first session she showed pleasure (3), anger (0.33), anxiety/fear (2), sadness (0.66), interest (4.33), and contentment (3). She smiled and laughed prior to the intervention while being oriented with the activity. One rater noted a sign of anger by having “pursed lips” that moved side to side while she wrote. Anxiety/fear was displayed through “furrowed brow” which was described as raised brow and eyes wide while listening to the instructions from the PI. A sign of sadness was present prior to the activity because the participant had her “eyes/head turned down” while waiting for the prompting to begin. Interest was displayed by “eyes follow object”, “intent fixation”, “eye contact maintained”, and “visual scanning”. The participant nodded along and said “ooh” while receiving the instructions. She maintained eye contact with the PI during instructions and focused on the EMA during the intervention.

In the second session she displayed states of pleasure (2.66), anger (1.33), anxiety/fear (2.66), interest (4.66), and contentment (2). She smiled and laughed during conversations with the PI before and after the intervention. She displayed anxiety/fear with raised and furrowed eyebrows as well as “tight facial muscles”. Signs of interest included “eyes follow object”, “intent fixation on object or person”, “eye contact maintained”, and “turn body or move toward person or object”. She leaned into the device while it was providing prompts and looked from one object to another on the table during her orientation with the activity.

During session 3, P104 displayed pleasure (2), anger (1), anxiety/fear (1), sadness (0.33), interest (4), and contentment (1.33). She smiled and laughed while going over instructions with the PI. She pursed her lips, a sign of anger, while writing and peeling off the backs to stickers for
the card. She displayed “tight facial muscles”, anxiety/fear, when she raises one eyebrow and squinted with the other eye. This facial expression was present at various times throughout all five sessions. Signs of interest included “eyes follow object”, “intent fixation on object or person”, “visual scanning”, and “turn body or move toward object or person”. She also displayed interest by asking questions during the instructions and while performing the steps of the activity.

In session 4, examples of pleasure (2), anger (0.66), anxiety/fear (1.33), sadness (0.33), interest (3.33), and contentment (1.66) were present. The participant smiled before the intervention and between steps. She, also, laughed and asked, “Is that all?” Anger was indicated by a grimace. The grimace was a common facial expression and could be contributed to the curvature of her teeth. One rater used “mouth turned down at corners” (sadness) to describe this same expression. Anxiety/fear state was from a “furrowed brow”, where she raises one eyebrow and squints with the other eye. Interest was displayed by “intent fixation on object”, “motoric feedback”, and “eye contact maintained”. She pointed at and interacted with the items for the activity and focused on the PI during the instructions.

In session 5 the participant displayed pleasure (1.66), anger (1), anxiety/fear (3), sadness (0.33), interest (4), and contentment (2). The participant smiled and then laughed when the intervention was over. Anger was indicated by “pursed lips” and sadness was indicated by a down turned mouth. These facial expressions were used to describe the way her mouth turns in and down periodically. Anxiety/fear displays included the way she raises one eyebrow as previously described, as well as, a sigh while waiting for the intervention to begin, and “tight facial muscles” from her mouth. Signs of interest included “intent fixation”, “move toward
object”, “visual scanning”, and “motoric feedback”. She looked around at everyone in the room and leaned into the device while it provided prompts.

Participant 104 displayed signs of interest more often than any other display of affect throughout the five sessions an average of four times. Signs of pleasure, anxiety/fear, and contentment were present an average of two times throughout the session. She displayed signs of anger and sadness infrequently. Often only one rater reported any indicator of sadness in the sessions. A summary of P104’s affective states is provided in Table 4-8.

Qualitative comments

She would ask many questions before the EMA started to make sure she understood the activity completely before starting. She was often interested in the purpose of the study and would ask the investigators “what’s this for?” at least once per session. These questions were judged to be more from interest than suspicion due to her pleasant demeanor and active listening.

Except for the first session when participant 104 was confused on the purpose of the intervention, Figure 4-6 shows that she was fairly consistent in her responses and correct responses. Many times she would only understand half of the command and ask the investigators for a confirmation or repeat of the prompt. She had a tendency to squint one eye and raise her eyebrows. While it was at first assumed to be a sign of frustration or concentration, repeated sessions showed that it might be an act of habit and unrelated to the EMA.

Participant 105 (P105) MMSE = 19

Participant 105 completed all five sessions. In the first three sessions her activity was to create a greeting card, and in her last two sessions her activity was made more challenging by having her create a simple shopping list from items in an advertisement. Information for the participant’s affect was not recorded for session 2 and 3 because of issues with the video recording, and at these sessions there was only one researcher present who filled out only the
observation checklist. During all sessions this researcher (the PI) sat in view of the participant and therefore was able to observe affect during the intervention and wrote comments on the observation checklist. The participant’s behavior was consistent at every session. Throughout all of the sessions the participant never displayed a sign of sadness. Signs of contentment were consistent with “comfortable posture” and “sitting”. She also displayed “lack of tension in her limbs”, “smooth facial muscles” and leaned back.

In session 1, the participant displayed pleasure (2.66), anger (0.33), anxiety/fear (1.66), interest (4), and contentment (1.66). She smiled and laughed and said, “It seems kind of ridiculous to talk to a device.” She also nodded along when receiving the instructions from the PI. Anger was indicated by a grimace when she was having a hard time understanding or hearing a prompt. Anxiety/fear was indicated by “motoric restless” and “repeated motions”; she tapped her fingers while waiting for the prompting to begin. Signs of interest included the following: intent fixation on object, facial, motoric or verbal feedback, turn body or move toward person or object, and eye contact maintained. She leaned into the device, verbally responded both to the device and the PI, and looked to the PI for feedback.

During session 4 she displayed pleasure (2.66), anger (0.33), anxiety/fear (1), interest (4.33), and contentment (2.66). Before the intervention she talked and smiled a lot with the PI discussing subjects such as her children and books. She laughed after remarking that she thought of the device as a person she did not like very much. She displayed anger by knitting and lowering her brows during the intervention. She very briefly exhibited anxiety/fear through “tight facial muscles” while looking for an item in the advertisement. She displayed interest through “eyes follow object”, “intent fixation on object or person”, “visual scanning” while
looking through the ad, and “turn body or move toward object or person”. She turned around to ask PI for help during the activity and became very alert once the intervention began.

In the final session she displayed similar signs of pleasure (2.33), anger (0.33), anxiety/fear (1.33), interest (5), and contentment (3). Signs of pleasure were found before the intervention when she smiled and laughed. Anger once again was present as “knit/ lowered brows” briefly during the intervention, and anxiety/fear was present as sighing while waiting and being startled when she heard the fist prompt. Signs of interest included the following: eyes follow object, intent fixation on object, facial, motoric or verbal feedback to the PI and the device, turn body or move toward person or object, and eye contact maintained. She leaned into the device and picked up the ad to look at it closer.

Participant 105 displayed an average of four signs of interest throughout the sessions more than any other affective state. An average of more than two signs of both pleasure and contentment were present in the sessions. Signs of sadness were not observed in any of the three sessions. The average number of signs of each affective state can be found in Table 4-10.

Qualitative comments

Unlike the others in the study, she seemed to have a better grasp on the nature of the project. She understood that the sessions were mainly geared toward assessing the EMA, not her abilities, and was more comfortable doing the activities. Figure 4-8 shows that she consistently responded to all the prompts. She was often impatient during the long pauses since she completed the prompts quickly and wanted to know what was next. Her ease with the projects allowed the PI to increase the level of difficulty from making a seasonal decoration to making a shopping list from an advertisement. This latter activity increased her engagement with the EMA. For example, she became frustrated when it went too fast or was joyful when she found an object in the advertisement, whereas with the seasonal decoration task she was more indifferent.
Although she would talk to the EMA, she felt self-conscious about it at times, saying “am I talking to this stupid thing?” and “[it] seems a bit ridiculous talking to this thing.” These skeptical comments would always be followed with a laugh, making it understood that she thought it was more silly than suspicious. She would often ask the PI for reassurance. Even when the PI would sit behind her to prevent P105 from asking direct questions, P105 would still turn around to ask them. While doing a prompted task, she would often repeat to herself the directions or the object she was looking for.

**Affect Summary for All Participants**

The average number of signs of each affective state for all participants was consistent with the findings for the individual participants. Contentment was displayed by all participants as “comfortable posture” and “sitting”. Pleasure was often evident through “smile” and “laugh” usually seen before and after the intervention. The participants 102, 104, and 105 displayed several signs of interest throughout all of their sessions. Anger and sadness were seen the least often which was also the case for each participant in each session. Signs of anxiety/fear had the most variability throughout the different sessions.

**Overall Comments**

While on occasion participants would sometimes recognize the research staff or even the device and activity, they still needed directions on what to do with the supplies and required information on the purpose of their participation prior to each session. On occasion, these directions were required more than once during a session. For example, instructions and the purpose of the session would be explained to the participant prior to each session, and the participant would sometimes ask when finished, “Why am I doing this?” or “What is the purpose of this?”
All participants interacted socially with research staff before and after the activity. Except for P103, none of the caregivers reported that the participants “can’t sit still, restless, fidgety.” However, all of the participants presented this symptom at least once during the intervention. All participants were surprised when the intervention was over, usually thinking that it was shorter and simpler than what they expected.

Results for Step Two

The primary aims of this step of the study were to: 1) explore whether someone with AD is able to use the EMA in his or her home environment and 2) test whether or not an EMA can be helpful for a variety of daily tasks. These aims were evaluated by comparing participants’ performance on a specific task during baseline task performance with in-person prompting versus task performance with EMA-provided prompting. The specific tasks were individualized and determined by the PI and the caregiver for each participant. Four main methods were used to observe changes in performance. First, the percentage of responses to prompts was recorded along with the percentage of correct responses to prompts. These two factors were graphed together and described. These descriptions of the graphs included changes in mean, latency of change, overlap of data between phases, and the stability of data within each phase. Field note excerpts from the prompting sessions were also included, and the results of the RMBPC described.

Participant 201 (P201), Caregiver 201 (C201)

The session prompts can be found in Appendix H. During a typical session C201 and the paid caregiver were present. However, there was also a small puppy in the house at all times, and it was common to have at least one visitor present. Caregiver 202 reported that several people stopped by throughout the day, and that visitors were a routine part of their lives since she did not get to leave the house very often.
Percentage of Responses and Correct Responses to Prompts for Participant 201

The prompts for the activities are found in appendix H. Figure 4-12 displays the percentage of responses and correct responses for each session during baseline (A1 and A2) and intervention (B1 and B2) conditions. Although graphed together for the sake of comparison, the percentage of responses and percentage of correct responses results were discussed separately.

Percentage of Responses for Participant 201

Mean: During the initial baseline phase (A1), the mean percentage of responses to prompts displayed by the participant during her session was 93%. This mean decreased to 70% after the introduction of the EMA in the second phase (B1). Upon return to one-on-one prompting in phase A2, the mean percentage of responses to prompts increased to 83% and then decreased to 73% when the EMA was re-introduced in phase B2.

Level changes and trend are analyzed together to determine the latency of change between phases. Latency: There was a 100 point decrease in level between phases A1 and B1. The slope went from 1.4 in phase A1 in the intended direction to 7.1 in phase B1. Between phases B1 and A2 there was a 29 point decrease in level with the slope changing from 7.1 to -2.7 in the unintended direction in phase A2. Another decrease of 9 points occurred between the last two phases with the slope continuing in the unintended direction (slope in B2 = -6.4). Overlap: One data point overlapped between A1 and B1, 7 points overlapped from B1 to A2, and 6 points overlapped between A2 and B2. Stability: There was 100% stability in the data points in phase A1, 50% stability in phase B1, 88% stability in phase A2, and 75% stability in phase B2.

Percentage of Correct Responses to Prompts for P201

Mean: During the initial baseline phase (A1), the mean percentage of responses to prompts displayed by the participant during her session was 47%. This mean decreased to 12% after the introduction of the EMA in the second phase (B1). Upon return to one-on-one
prompting in phase A2, the mean percentage of responses to prompts increased to 33% and then decreased to 27% when the EMA was re-introduced in phase B2. **Latency:** There was a 47 point decrease in level between phases A1 and B1 with the slope of 7.1 in B2 in the intended direction demonstrating an increase in correct responses to prompts over time. Between phases B1 and A2 there was a 13 point change in level with the slope moving in the intended direction. Between A2 and B2 a 15 point decrease in level occurred, however, the slope went down and leveled off in phase B2 (A2 slope= 1.5, B2 slope 0.1). **Overlap:** There was no overlap in data points between phases A1 and B1. Four points overlapped between phases B1 and A2, and all points in B2 overlapped with phase A2. **Stability:** There was 75% stability in the data points in phases A1 and A2. Phases B1 and B2 had 38% stability.

**Revised Memory and Behavior Problems Checklist (RMBPC) Results for 201**

**Mean:** During the initial baseline phase (A1), the mean total on the RMBPC during phase A1 was 11. This mean decreased to 8 after the introduction of the EMA in the second phase (B1). Between phases A2 and B2, the mean total remained the same at 14. **Latency:** Changes in level were minimal between the phases with the level decreasing by three points between phase A1 and B1 and the slope changing from -0.06 to 0.8. There was a 5 point decrease in level between phase B1 and A2 with the slope switching direction from 0.8 to -0.2. From phase A2 to phase B2 there was a one point decrease and almost no change in slope (B2 slope = -0.1). **Overlap:** Five data points overlapped between phase A1 and B1. Two points overlapped between phases B1 and A2, and all data points in phase B2 overlapped with phase A2. **Stability:** There was 38% stability in the data points in phases A1, B1, and B2, while phase A2 had 76% stability. The pattern described is presented in Figure 4-10.
Additional Information from Field Notes

With P201, the PI had to physically intervene at least twice in every session, no matter what phase of prompting was taking place. These interventions usually involved pointing at an object, but sometimes the PI would have to hand her the wash cloth or turn the sink faucet on or off. She also required several verbal prompts to continue with the task in each study phase.

Several extra verbal prompts were required to help her complete the tasks during the phases with the EMA. Participant 201 did not have the capability to obey the command to “push the green button”, so the PI always did that. The EMA also had to be kept out of her visual field or she would become distracted by it and just look at it rather than listen to it. On two occasions with the EMA she attempted to leave the room while it was prompting her. She would sometimes tell the device she completed a certain task already and the PI had to intervene. Sometimes she would converse with it and report back what she was doing or that she heard the prompt. In phase B2, session 2, after the EMA delivered the final prompt, she looked at the PI, then waved her hand in the direction of the EMA and whispered, “Don’t pay no attention to that.” In phase B2, session, 3, after the EMA delivered the second to last prompt to “Make sure you get the back” (referring to brushing the back of her hair) she replied, “Yes!”, then said, “That lady’s gettin’ on, getting’ on…” with a furrowed brow. After the final prompt she looked toward the device, then looked at the PI and stuck out her tongue at the device.

Throughout all four phases, the task of brushing her hair seemed more automatic and intuitive for her than washing her face. When asked to wash her face, she would frequently wash her hands or wipe her hands with the washcloth.

Participant 202 (P202), Caregiver 202 (C202)

Prompts for P202 are found in Appendix I.
Figure 4-11 displays the response rates of P202 to prompting during all four phases.

**Mean:** During the initial baseline phase (A1), the mean percentage of responses to prompts displayed by the participant during his session was 93%. This mean decreased to 89% after the introduction of the EMA in the second phase (B1). Upon return to one-on-one prompting in phase A2, the mean percentage of responses to prompts rose to 98% and then decreased to 97% when the EMA was re-introduced in phase B2. **Latency:** There was a 23 point decrease in level between phases A1 and B1; however, the trend in A1 had a slope in the unintended direction (slope = -2.2) and once phase B1 started the trend went in the intended direction with a slope of 3.8. Between phases B1 and A2 there was a small four point increase in level with the slope leveling off to 0.8. From phase A2 to B2 there was an eight point decrease, but only a slight change in slope (A2 slope = 0.8, B2 slope = 1.2) demonstrating a slow latency of change.

**Overlap:** Six points overlapped between phases A1 and B1. One point overlapped between phases B1 and A2. Four points overlapped between A2 and B2. **Stability:** There was 100% stability in the data points in phases A1, A2, and B2, while phase B1 had 87.5% stability.

**Percentage of Correct Responses for Participant 202**

**Mean:** During the initial baseline phase (A1), the mean percentage of responses to prompts displayed by the participant during his session was 72%. This mean increased to 78% after the introduction of the EMA in the second phase (B1). Upon return to one-on-one prompting in phase A2, the mean percentage of responses to prompts increased again to 89% and then increased to 92% when the EMA was re-introduced in phase B2. **Latency:** There was a 29 point decrease in level between phases A1 and B1. Again the trend in A1 was in the unintended direction (slope = -2.4) but in phase B1 after the initial point decrease the slope went in the intended direction (slope = 4.4). Between phases B1 and A2 there was a 19 point increase that
eventually came back down making the slope of -4.2 which is conflicting since after the initial increase the data leveled off. Between phases A2 and B2 there was a one point decrease accompanied by a change in trend in the intended direction (slope = 27). **Overlap:** Seven points overlapped between phases A1 and B1. Three points overlapped between B1 and A2. All four points overlapped between the last two phases. Three points overlapped between A2 and B2. **Stability:** There was 71.4% stability in the data points in phase A1, 50% stability in B1, and 100% stability in A2 and B2.

**RMBPC Results for P202**

**Mean:** During the initial baseline phase (A1), the mean total on the RMBPC during phase A1 was 16. This mean decreased to 13 after the introduction of the EMA in the second phase (B1). In phase A2, the mean total increased to 16 and then increased slightly to 18 in the last phase. **Latency:** Changes in level were minimal between the phases with the level increasing by one point between phase A1 and B1 and the slope changing from -0.9 to 0.4. There was a 3 point increase in level between phase B1 and A2 with the slope switching direction from 0.4 to -0.9. From phase A2 to phase B2 there was a one point increase and a change in slope from -0.9 to 1.6. **Overlap:** All data points in phase B1 overlapped with the data from phase A1. All data points in phase A2 also overlapped with the data from phase B1. Three points from phase B2 overlapped with data from phase A2. **Stability:** There was 75% stability in phases A1 and A2, 63% stability in phase B1, and 100% stability in the last phase. The pattern of RMBPC responses are presented in Figure 4-12.

**Additional Information from Field Notes**

During phase A1 (prompts detailed in Appendix I), session 2, P203 needed two visual prompts, both prompts were for proper form during leg exercises (one for prompt number 8, the other for prompt number 11). In session 3 he required a visual prompt for prompt number 11 and
another for correct form during prompt number 17. In session 4 he required a visual prompt for number 8. In session 5 he needed a visual cue for posture and correct form between prompts 14 and 15. In session 7 he needed a visual prompt for posture and form during prompt 5. He argued with the PI about changing his posture, and needed a visual prompt to persuade him to change what he was doing. In session 8 he needed a visual prompt to after prompt 11.

In phase B1, session 1, he completely ignored the first prompt to push the green button and the PI had to remind him to listen to the device and do what it asked. He required eight extra verbal prompts from the PI during this first session. Also, in addition to the PI trying to guide him, his wife was also present in the room and was telling him in a loud voice to do what the device asked. He seemed confused during this session. During session 2 he pushed the green button, but needed the PI to verbally prompt him to listen and follow the instructions that were delivered by the EMA (at first he just looked at it). The PI asked if he could hear it and he replied that he could, but it sounded “screechy”, so after adjusting the volume the PI repeated the prompt he missed. He required additional verbal prompts for activities 7, 8, 11, and 14. During prompt 15 when the EMA says, “Keep your leg straight” he yelled, “I’m keeping straight here!” then said, “I’m in an argument with this thing.” The PI had to verbally correct his form for prompts 17 and 18.

Prior to session 3, the PI had a male occupational therapist record the prompts to see if P203 would be able to hear them better. The PI had to verbally prompt him in addition to the EMA after prompts 2, 5, 11 and 18. He yelled at the EMA, “Be quiet! I’m keeping it straight!” after prompt 12 and then again after prompt 15 when he told it, “Shut up! I am!” During session 4 the PI had to verbally prompt him to correct his form or posture after prompts 3, 11, 12, and 19. He required a visual prompt after prompt 11 when the PI’s additional verbal prompt did not
help. During session 5, P203 completely missed the first prompt to push the green button because he was distracted by his wife talking to someone on the other side of the room even though the device was placed in front of him, so the PI asked him to push the green button. The PI needed to visually prompt him after prompt 11, and verbally prompt him to fix his form or movement after prompts 5, 12, and 17. In session 6 he required verbal prompts for correct form after prompts 5 and 18, and required a visual prompt after prompt 17 from the EMA. In session 7, he required a visual prompt again after prompt 11 was delivered. After prompts 14 and 17, the PI had to verbally prompt him to fix his posture. After prompt 19 was delivered he yelled at it saying, “I’m going slow! Shut up! Guess he didn’t answer back.” During the last session of phase B1, the PI had to provide a verbal for proper positioning and form after prompts 2, 11, 18, and 19 and a visual prompt after prompt 3.

During phase A2, session 3, when the PI prompted him to correct his posture he argued with her and a visual prompt was required to convince him to change his posture. In session 4 he needed a visual prompt to complete the 11th prompt correctly.

During phase B2, session 1, on four occasions when he completed a prompted task he immediately asked, “Now what do I do?” Each time the PI would tell him to wait for instructions from the EMA. The PI also had to provide visual cues for him to change his form during tasks 14, 17, and 18. During session 2, on two occasions he performed the prompted task and started to walk away. The PI intervened both times and told him to wait until the EMA told him he was finished. He also needed a visual prompt for his form for task 17. During session 3 the PI had to provide additional verbal and visual prompting after prompt 11 was delivered. P203 was argumentative, but did eventually change what he was doing. During session 4 the PI had to verbally prompt him to fix his posture after prompts 14 and 18.
Overall Comments

Prior to starting the first B phase of the trial after the PI explained that the EMA would be providing him with instructions to complete his exercises, he stated, “I’d rather you did it,” but he did eventually agree to use the device. The first two sessions in which the device was used (phase B1, sessions 1 and 2) the PI’s voice was the recorded voice on the EMA, however, he seemed to have difficulty hearing the prompts and stated that the voice sounded “screechy,” so the prompts were re-recorded using a male voice which appeared to work better for him. Throughout the sessions with the EMA he would sometimes argue with the device or yell at it. For example, in phase B2, session 2 when it stated, “Remember to go slow,” he yelled, “I’m going slow! If I go any slower I won’t be moving!” During all four phases of the session he would sometimes turn to the PI and ask for re-assurance that he was doing a task correctly.

Participant 203 (P203), Caregiver 203 (C203)

Prompts for P203’s sessions are found in Appendix J.

Percentage of Responses for P203

Mean: During the initial baseline phase (A1), the mean percentage of responses to prompts displayed by the participant during his session was 100%. This mean decreased to 89% after the introduction of the EMA in the second phase (B1). Upon return to one-on-one prompting in phase A2, the mean percentage of responses to prompts increased to 97% and then decreased to 95% when the EMA was re-introduced in phase B2. Latency: There was a 56 point decrease in level between phases A1 and B1 (prompts were delivered too fast by the EMA in the initial B1 session). However, the slope went in the intended direction (slope = 4.5). There was an 11 point decrease between phase B1 and A2 with a slight change in slope (slope = 3.3). There was no change in level between phases A2 and B2 and minimal change in slope indicating a slow latency of change. Overlap: Five points overlapped between phases A1 and B1. Four
points overlapped between phases B1 and A2 as well as between A2 and B2. **Stability:** There was 100% stability in the data points in phases A1, A2, and B2, while phase B1 had 62.5% stability.

**Percentage of Correct Responses for P203**

**Mean:** During the initial baseline phase (A1), the mean percentage of responses to prompts displayed by the participant during his session was 86%. This mean decreased to 68% after the introduction of the EMA in the second phase (B1). Upon return to one-on-one prompting in phase A2, the mean percentage of responses to prompts increased to 81% and then decreased to 78% when the EMA was re-introduced in phase B2. **Latency:** There was a sharp decrease in level between phases A1 and B1 because of faulty prompting, but with a slope of 7 in the intended direction the data resumed higher levels. Following a 22 point decrease in level between phases B1 and A2, the slope (= 8.1) followed a similar trend to that in phase B1. Another 22 point decrease occurred between phases A2 and B2, but only a slight change in slope from 8.1 to 6.6 occurred indicating slow latency of change. **Overlap:** Four points overlapped between phases A1 and B1 as well as between phases B1 and A2. Three points overlapped between A2 and B2. **Stability:** There was 100% stability in phase A1. Phase B1 demonstrated 37.5% stability, mainly due to the outlying first data point of the phase. Phases A2, and B2 were both 75% stable, but each of both of those phases had only one point just outside of 15% below the mean of the phase.

**RMBPC Results for Participant 203**

Because of her schedule C203 requested that to complete the RMBPC only once a week (P203 was seen four times a week). C203 stated that P203’s behavior was relatively stable from day to day, so the PI agreed to this option. Therefore, changes in slope could only be determined for the first two phases (phases A2 and B2 only had one data point each). However, in this case
the slope for the full range of data throughout all phases is also determined to establish stability throughout the four phases.

**Mean:** During the initial baseline phase (A1), the mean total on the RMBPC during phase A1 was 31. This mean decreased to 27 after the introduction of the EMA in the second phase (B1). There are no mean figures for phases A2 and B2 because each only had one data point, but those points were 27 and 26, respectively. **Latency:** Changes in level were minimal between the phases with the level decreasing by five points between phase A1 and B1, but the slope remained the same for both phases indicating slow latency of change (both slopes = 0.25). There was no change in level between phase B1 and A2. Latency cannot be reported for the remainder of the data since each of the last two phases only had one data point. The overall slope of the entire data set through all four phases was -0.2 indicating an overall decline in reported behaviors over the course of the study. **Overlap:** There was no overlap between phases A1 and B1, but the data point in phase A2 overlapped with the data in phase B1. The data point in phase B2 was only one point less than the point in phase A2. **Stability:** There was 100% stability in phases A1 and B1. Stability cannot be reported for the two final phases since there was only one data point in each of those phases. However, the data throughout all four phases was 100% stable. The pattern of RMBPC responses are presented in Figure 4-14.

**Additional Information from Field Notes**

In phase A1 the PI needed to physically intervene on two occasions. The first occasion (session number 1) involved the PI pointing to the participant’s toothpaste when verbal cues did not help him locate it (he had attempted to put shaving cream on his toothbrush). On the second occasion (session 4), a visual prompt (pointing to the object) was required twice so P203 could locate the toothpaste (tried to use shaving cream on toothbrush again). On one occasion (session 5) P203 attempted to put toothpaste on his razor, but was verbally re-directed. On two occasions
(sessions 1 and 8) P203 requested to use the toilet, so the PI stepped out mid-session and resumed prompting session when he was finished. On a few occasions P203 asked if he was doing the task correctly.

In phase B1, session 1, P203 tried to put shaving cream on his toothbrush and required verbal prompting to use toothpaste. In this first session with the EMA the prompts were delivered too fast and the PI needed to supplement verbal prompts to continue the session and keep up with the device. In session 2 (the timing of the prompts had been adjusted), P203 once again tried to put shaving cream on his toothbrush, and then attempted to shave with his toothbrush and required verbal prompting. In this session he also nodded at the EMA and stated, “pretty clever” and then looked directly at the EMA and said “What else you want?” He then said, “That’s pretty neat.” In session 3 the PI had to stop the device while the participant went to the bathroom, but then started it again when he finished so the session could be completed. During a lull between prompts he started to leave, but the PI asked him to stay, and he did. In session 4 the PI had to verbally prompt him to use toothpaste after he did not respond to the prompt that requested he use toothpaste, but he said, “yeah, I already did.” The PI asked him to do it again, and he did. After the EMA prompted him to use shaving cream, he continued to shave without it, so the PI said, “Can you use shaving cream? It asked you to use shaving cream.” He responded, “Yeah, I heard,” but then he put the shaving cream on his face. He again tried to leave during a lull in the prompting and the PI stopped him. After the prompt to comb his hair, he combed it and immediately exited and the PI again asked him to come back. When the EMA gave the final prompt for him to make sure he combed the back, he says, “yeah, yeah, I did” and told the device “shhhhhhh.” In session 5 when it prompted him to shave he said, “I shaved already,” and the PI asked him if he would mind shaving again, and he proceeded to
shave. The PI had to ask him to use shaving cream, and he complied. He again tried to leave
during a lull in prompting (this time in a different place) and the PI asked him to stay. At the last
prompt he said he already combed the back of his hair and ran his hand over it and left
immediately. During session 6 the PI had to ask him to use toothpaste when he did not respond
to the prompt. After the prompt that asked him to shave was delivered, he started to walk out of
the room, but the PI reminded him that it asked him to shave and he returned. (His daughter had
entered the house, and he was distracted by that). In session 7 the PI had to point to his
toothpaste again because he tried to put shaving cream on his toothbrush. After the last prompt to
comb the back of his hair, he started to comb his face, but fixed what he was doing with no
additional prompting. In session 8 before the PI introduced the session he said, “I push the green
button, right?” When the EMA prompted him to use shaving cream he started using the
toothpaste, and the PI had to prompt him to re-direct him.

In phase A2, session 1 he picked up his razor when the PI asked him to brush his teeth, so
she had to prompt him to his toothbrush. In session 2 he attempted to shave with his comb and
needed to be prompted to use his razor. In session 3 he attempted to use shaving cream on his
toothbrush again, so the PI had to prompt him to find his toothpaste.

In phase B2, session 1 after the device prompted him to brush his teeth he said, “ok,
whatever you say.” He tried to leave during a lull in prompting, but then turned around to use the
toilet, so the PI stopped the EMA and stepped out until he finished. During session 2 the PI had
to intervene to have him put toothpaste on his toothbrush and to ask him to shave. There were
lulls in prompting, but in this session he waited and looked at the EMA until it gave him the next
prompt. In session 3 during a lull in the prompting he asked if he should push the green button.
In session 4 he attempted to use shaving cream on his toothbrush again and needed verbal
prompts to locate his toothpaste. After brushing his teeth, he asked, “Should I push the green button again?” and the PI reminded him to just wait for the next prompt. When the EMA asked him to shave, he said, “I don’t want to shave,” but the PI asked him to do it and he did. During a pause before the next prompt he leaned in toward the device and said, “Get lost!” but then turned toward the PI and smiled. When the prompting was completed and the device said, “You’re finished. You look great!” he said, “Oh boy, I like that! How does he know? He can’t see me!”

**Overall Comments**

Throughout all four phases, P203 frequently liked to demonstrate what he was doing directly at the camera and would narrate. For example, when the EMA asked him to wipe the shaving cream off his face he would turn to the camera and say, “This is a towel. You wipe your face with it.” He did this at least once in almost every session. Also if he ignored a prompt and was verbally prompted by the PI, he would frequently reply, “Ok, but only because you asked me to. I wouldn’t do this for just anybody.”
Table 4-1. Description of performance of P101 with the EMA

<table>
<thead>
<tr>
<th>Task #</th>
<th>Performance description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Introduction/practice session</td>
<td>P101 was hard of hearing and said she forgot her hearing aids that day. She completed all tasks on the MMSE, with the exception of the last task where she experienced difficulty copying a drawing. She verbally explained how she wanted to go about completing the drawing (and her idea was an appropriate one), but was not able to translate that idea to her hand to draw. She wrote a long, complete sentence and said, “I could have written, ‘The cat is black.’ But this is more like a story.” She completed her EMA training with the “advertisement” activity. The prompts seemed to be delivered too fast, and the task was a little too complex for her, so the “seasonal decoration” activity was used during her “official” sessions.</td>
</tr>
<tr>
<td>Session 1 attempt</td>
<td>She was sitting in a wheelchair today, and the staff said we could try to work with her, but she was overmedicated. She was dozing in the wheelchair when we went to pick her up. She fell asleep on the way into the room. We then gently roused her, and she woke up, but fell asleep again during the brief instructions. The PI decided to wait to have her first session later on that week.</td>
</tr>
<tr>
<td>Session 1</td>
<td>The PI oriented her to the task and the supplies for the “seasonal decoration” activity. She responded to 7/11 tasks, of those she responded to 5/11 correctly. She required one in-person verbal cue to figure out what to do with marker cap (the PI then decided to take all caps off of writing utensils thereafter). She became confused about where the stickers should go and expressed confusion as to why she had to do the task.</td>
</tr>
<tr>
<td>Session 2</td>
<td>She responded to all commands correctly, but was distracted when first brought into the room by other objects. She was re-oriented to the task and practiced pulling off the backing on a sticker prior to task performance.</td>
</tr>
<tr>
<td>Session 3</td>
<td>The initial prompt on the device did not go off at the designated time, so the PI gave the initial prompt (could not re-set device due to time limitations at the facility). She responded to 5/11 commands, of those 1/11 were correct. She said “I’m not sure I understand” at one point. The volume was set the same as before and her hearing aids were in, but may not have been turned up. She also seemed confused and agitated today.</td>
</tr>
<tr>
<td>Session 4</td>
<td>She responded to 11/11 commands with 11/11 of those being correct. She was alert today and asked how often she would have to do this.</td>
</tr>
</tbody>
</table>
Table 4-1. Continued.

<table>
<thead>
<tr>
<th>Session 5</th>
<th>She responded to 10/11 commands, of those, 8/10 were correct. Her responses were slower and more delayed today, which may account for incorrect responses.</th>
</tr>
</thead>
</table>


Table 4-2. Summary of P101 affective states

<table>
<thead>
<tr>
<th>Affective state</th>
<th>Session 1: Average number of signs</th>
<th>Session 2: Average number of signs</th>
<th>Session 3: Average number of signs</th>
<th>Session 4: Average number of signs</th>
<th>Session 5: Average number of signs</th>
<th>Total Average number of signs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pleasure</td>
<td>2.33</td>
<td>1.66</td>
<td>2.33</td>
<td>3</td>
<td>1</td>
<td>2.07</td>
</tr>
<tr>
<td>Anger</td>
<td>0.66</td>
<td>None</td>
<td>None</td>
<td>None</td>
<td>None</td>
<td>0.13</td>
</tr>
<tr>
<td>Anxiety/fear</td>
<td>2.66</td>
<td>1.66</td>
<td>3.66</td>
<td>2.66</td>
<td>1</td>
<td>2.33</td>
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<td>Sadness</td>
<td>None</td>
<td>None</td>
<td>1.33</td>
<td>0.33</td>
<td>2</td>
<td>0.73</td>
</tr>
<tr>
<td>Interest</td>
<td>3.66</td>
<td>4.33</td>
<td>2.66</td>
<td>4</td>
<td>2.66</td>
<td>3.47</td>
</tr>
<tr>
<td>Contentment</td>
<td>2</td>
<td>2.66</td>
<td>2.66</td>
<td>1.33</td>
<td>2.33</td>
<td>2.2</td>
</tr>
</tbody>
</table>
Table 4-3. Description of performance of P102 with the EMA

<table>
<thead>
<tr>
<th>Task #</th>
<th>Performance description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Introduction/</td>
<td>P102 came in and recognized one of the undergraduate research assistants immediately (she volunteered at the facility a few months previously). The PI completed the MMSE with P102, but he seemed to immediately respond to everything with “I don’t know”. He seemed to have low interest in completing the questions, and just seemed to want to rush through them. However, he was very pleasant and socially interacted the whole time smiling and laughing with the investigators. He did not respond to prompts to make the “seasonal decoration” during training on the device.</td>
</tr>
<tr>
<td>practice session</td>
<td></td>
</tr>
<tr>
<td>Session 1</td>
<td>Initially he was sitting with his eyes closed on the couch but when the PI went to get him but he became alert and willing to come in the room. The PI again explained the EMA to him what he would be doing and showed him the materials he would need. He said ok and nodded. When the device told him to push the green button, he needed an in-person prompt, and then he pushed the button with the end of the marker and held on to the play button. He held the button down until verbally and physically prompted to stop. The PI then reminded him to listen to the prompts and moved to a different area of the room. He proceeded to sit and fidget with the one of the materials from the activity. He looked at the device when it said something, but did not follow the commands issued. When asked if he could hear the device he said, “yeah, I hear.” He read numbers from the LCD screen on the device but did not follow the commands. He eventually rested his head in his hands and sat until the prompts were finished.</td>
</tr>
<tr>
<td>Session 2</td>
<td>Today he came in the room smiling and joking. The PI oriented him to the task. This time a “drinking water” task was used involving 2 commands. He did not follow the prompt to push the green button, so the PI verbally prompted him. He said “ok”, but did not push the button. The PI ended up pushing the button to start the task. He did not respond to the second prompt. When the device spoke he would look at it, but would not follow the command that was issued. He fidgeted in his chair until the session was over, but left the room smiling and joking.</td>
</tr>
</tbody>
</table>

* sessions were determined to not be appropriate with this participant due to severe cognitive impairment and possible language difficulty and were discontinued after session #2
<table>
<thead>
<tr>
<th>Affective State</th>
<th>Session 1: Average number of signs</th>
<th>Session 2: Average number of signs</th>
<th>Total average number of signs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pleasure</td>
<td>3</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Anger</td>
<td>None</td>
<td>0.33</td>
<td>0.17</td>
</tr>
<tr>
<td>Anxiety/fear</td>
<td>2</td>
<td>1</td>
<td>1.5</td>
</tr>
<tr>
<td>Sadness</td>
<td>1</td>
<td>0.66</td>
<td>0.83</td>
</tr>
<tr>
<td>Interest</td>
<td>3.33</td>
<td>3.33</td>
<td>3.33</td>
</tr>
<tr>
<td>Contentment</td>
<td>2.66</td>
<td>2</td>
<td>2.33</td>
</tr>
</tbody>
</table>
### Table 4-5. Description of performance of P103 with the EMA

<table>
<thead>
<tr>
<th>Task #</th>
<th>Performance description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Introduction/practice session</td>
<td>P103 was very verbal, but did not often speak in sentences; rather, he mainly jumbled words and syllables. He required verbal and physical cues to sit at the table, but once there, sat there comfortably. He was easily distracted and had to be re-directed. A few times, when asked a question he replied, ‘well, that depends on the situation,’ or ‘well it could be several things.’ He was then shown the device and allowed to practice with it and hit the green button. He seemed rather interested, and nodded and smiled when told that he would get directions from the device. He did follow a command, but when a subsequent command was issued he balked at the device when it ‘spoke’ and said “who did that?” He did not follow the remaining electronic prompts, and required in-person verbal prompts to complete the task. He needed numerous prompts to stand up when he was finished. He laughed and smiled throughout and made jokes, but it was evident he was confused or uneasy at times by his body language (balking). He also laughed, “is it going to punch me in the face?” The PI decided the first session would be the two-step “drinking water” task.</td>
</tr>
<tr>
<td>Session 1</td>
<td>P103 was oriented to the task and task materials. He did not respond to the initial prompt to push green button. He did not respond to an in-person verbal prompt to push button either, so the PI pushed the button. When the EMA asked him to take a drink of water, he stuck his tongue out at it and simulated a dog panting, but did not follow the command. His demeanor was pleasant throughout task (smiling and laughing), but he complained of a backache initially.</td>
</tr>
<tr>
<td>Session 2</td>
<td>* Activity was not deemed appropriate for this participant due to decreased cognition and sessions were discontinued at this point.</td>
</tr>
<tr>
<td>Affective state</td>
<td>Session 1: Average number of signs</td>
</tr>
<tr>
<td>----------------</td>
<td>-----------------------------------</td>
</tr>
<tr>
<td>Pleasure</td>
<td>2.66</td>
</tr>
<tr>
<td>Anger</td>
<td>0.33</td>
</tr>
<tr>
<td>Anxiety/fear</td>
<td>1</td>
</tr>
<tr>
<td>Sadness</td>
<td>None</td>
</tr>
<tr>
<td>Interest</td>
<td>3.33</td>
</tr>
<tr>
<td>Contentment</td>
<td>1</td>
</tr>
<tr>
<td>Task #</td>
<td>Performance description</td>
</tr>
<tr>
<td>----------------------------</td>
<td>--------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Introduction/ practice session</td>
<td>P104 trained on the “seasonal decoration” activity with 1 sticker. She responded to 8/8 prompts correctly, however, some verbal responses were given to her when she asked a question. She would look to the PI for re-assurance with the task at times and seemed a little nervous about doing things correctly.</td>
</tr>
<tr>
<td>Session 1</td>
<td>P104 completed the “seasonal decoration” activity with 1 sticker. She responded to 8/8 prompts and 7/8 were correct.</td>
</tr>
<tr>
<td>Session 2</td>
<td>Today she completed the “seasonal decoration” activity with 2 stickers. She was re-oriented to the task and materials. She responded to 11/11 prompts and 8/11 were correct. Occasionally she looked to the PI for re-assurance during the activity.</td>
</tr>
<tr>
<td>Session 3</td>
<td>P104 was re-oriented to the activity and responded to 10/11 prompts. 9/11 of her responses were correct. One missed prompt she may not have heard because she said “what am I supposed to do?”</td>
</tr>
<tr>
<td>Session 4</td>
<td>She responded to 10/11 tasks and 8/11 of these were correct. Asked many questions today during the task. There was less time today between the re-orientation and the start of the actual activity.</td>
</tr>
<tr>
<td>Session 5</td>
<td>After re-orientation to the activity she responded to 11/11 prompts. All were correct considering the specific directions, but she put one sticker on upside down.</td>
</tr>
<tr>
<td>Affective state</td>
<td>Session 1: Average number of signs</td>
</tr>
<tr>
<td>-----------------</td>
<td>-----------------------------------</td>
</tr>
<tr>
<td>Pleasure</td>
<td>3</td>
</tr>
<tr>
<td>Anger</td>
<td>0.33</td>
</tr>
<tr>
<td>Anxiety/fear</td>
<td>2</td>
</tr>
<tr>
<td>Sadness</td>
<td>0.66</td>
</tr>
<tr>
<td>Interest</td>
<td>4.33</td>
</tr>
<tr>
<td>Contentment</td>
<td>3</td>
</tr>
<tr>
<td>Task #</td>
<td>Performance description</td>
</tr>
<tr>
<td>---------------</td>
<td>-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Introduction/ practice session</td>
<td>She responded to 7/8 responses and 6/8 were correct. After 3 of the prompts she asked a question. One time she responded to a prompt by saying “I ain’t through yet!” and chuckling.</td>
</tr>
<tr>
<td>Session 1</td>
<td>She completed the “seasonal decoration” task with 2 stickers since the activity with 1 sticker was fairly easy for her during training. She responded to 11/11 prompts, however it was difficult to determine if the response was appropriate because she always directly questioned the PI about the prompt, but the final product of the task demonstrated that 9/11 were correct. The PI answered her questions in order for her not to miss the rest of the prompts. Next time, the PI decided she needed to be out of P105’s visual field, so she would not rely on her so much.</td>
</tr>
<tr>
<td>Session 2</td>
<td>The PI sat out of 105’s visual field this time and did not verbally answer any of her questions during the actual prompting task. Sometimes she asked the question to the device or seemed to be speaking aloud to herself to “talk through” the task. She responded to 11/11 prompts and 9/11 were correct.</td>
</tr>
<tr>
<td>Session 3</td>
<td>P105 was in a positive mood today, conversational, and remembered doing the seasonal decoration activity (during activity said, “seems like I’ve done this before…”). She responded to 11/11 prompts and 9/11 were correct. She missed the same prompts as last time, so perhaps she did not comprehend the prompts correctly or the prompts were unclear. She still asked questions, but not as many. At the end she asked what this was for and how many others were doing it. The PI decided to try a more complex task next time since this activity was very easy for her and did not really interest her.</td>
</tr>
<tr>
<td>Session 4</td>
<td>The PI changed the activity to making a shopping list from a 1-page advertisement. The participant looked at the advertisement before the activity and just was naming what was in the pictures. During the actual activity she ended up responding to every prompt, but in one section the prompts were delivered too fast and she needed one verbal cue from the PI to complete the task (the object she was supposed to locate was one she said she saw on the page prior to the activity, but during the actual activity she said she could not find it until the PI gave her a verbal prompt). She did end up responding to everything correctly. At the end while she was talking to the PI she laughed and said that she thought of the device as a person she did not like very much.</td>
</tr>
</tbody>
</table>
Table 4-9  Continued.

Session 5  
P105 remembered the PI and remembered that she was supposed to listen to the device for instructions, so minimal instructions were needed today. She was glad it was her last time doing this; however, she seemed more comfortable with the PI and liked to sit and chat with her prior to and when the session was finished. The PI sat behind her again and answered only one of her questions (it was for clarification on what word was said). She responded to 11/11 prompts correctly. At one point she stated, “Am I talking to this stupid thing?” and laughed. For this set of prompts the PI recorded some of the prompts twice in a row and that lessened the number of questions P105 asked. The PI also asked her if having the prompts said twice was helpful after the session, and she said that it helped her think about what she was supposed to do more. There was loud music playing in the other room, so the distraction level was high today, but she still did very well and seemed unaffected by the noise.
Table 4-10. Summary of participant 105 affective states

<table>
<thead>
<tr>
<th>Affective State</th>
<th>Session 1: Average number of signs</th>
<th>Session 4: Average number of signs</th>
<th>Session 5: Average number of signs</th>
<th>Total Average number of signs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pleasure</td>
<td>2.66</td>
<td>2.66</td>
<td>2.33</td>
<td>2.56</td>
</tr>
<tr>
<td>Anger</td>
<td>0.33</td>
<td>0.33</td>
<td>0.33</td>
<td>0.33</td>
</tr>
<tr>
<td>Anxiety/fear</td>
<td>1.66</td>
<td>1</td>
<td>1.33</td>
<td>1.33</td>
</tr>
<tr>
<td>Sadness</td>
<td>None</td>
<td>None</td>
<td>None</td>
<td>None</td>
</tr>
<tr>
<td>Interest</td>
<td>4</td>
<td>4.33</td>
<td>5</td>
<td>4.44</td>
</tr>
<tr>
<td>Contentment</td>
<td>1.66</td>
<td>2.66</td>
<td>3</td>
<td>2.44</td>
</tr>
</tbody>
</table>
Table 4-11. Summary of affective states for all participants

<table>
<thead>
<tr>
<th>Affective state</th>
<th>Average number of signs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pleasure</td>
<td>2.40</td>
</tr>
<tr>
<td>Anger</td>
<td>0.42</td>
</tr>
<tr>
<td>Anxiety/fear</td>
<td>1.85</td>
</tr>
<tr>
<td>Sadness</td>
<td>0.42</td>
</tr>
<tr>
<td>Interest</td>
<td>3.81</td>
</tr>
<tr>
<td>Contentment</td>
<td>2.13</td>
</tr>
</tbody>
</table>
Figure 4-1. KSBA behavior profile for P101.
Figure 4-2. Responses to prompts for P101.
Figure 4-3. KSBA behavior profile for P102.
Figure 4-4. KSBA behavior profile for P103.
Figure 4-5. KSBA profile for P104.
Figure 4-6. Responses to prompts for P104.
Figure 4-7. KSBA profile for P105.
Figure 4-8. Responses to prompts for P105.
Figure 4-9. Responses to prompts for P201.
Figure 4-10. Frequency of responses from the RMBPC for P201.
Figure 4-11. Responses to prompts for P202.
Figure 4-12. Frequency of responses from the RMBPC for P202.
Figure 4-13. Responses to prompts for P203.
Figure 4-14. Frequency of responses from the RMBPC for P203.
CHAPTER 5
DISCUSSION

Major Findings

The major findings of Step One are discussed followed by the major findings of Step Two. Caregiver and participant attitudes toward prompting (Research Question 2) are addressed throughout the discussion of Steps One and Two. Factors related to the ICF are examined. This is followed by a discussion addressing the limitations of the EMA. This chapter concludes with overall study limitations and suggestions for future research.

Step One

The first specific aim of this step of the study was to determine if people with AD would be able to follow the instructions provided by an external prompting device. The hypothesis was that participants with AD would be able to follow the instructions provided by the external prompting device. The results from this small sample demonstrate that people with a moderate cognitive impairment have the capability to follow prompts issued by an electronic prompting device. However, in these sessions the investigator provided the initial setup and was always present. If the device were to go off at random times during the day with no warning, the result might not be the same. In this step of the study it was not possible to try to execute prompting in this way.

Other studies have shown that people with severe impairments are able to follow prompts issued from an external device, (Mihailidis, Barbenel, & Fernie, 2004; Mihailidis, Fernie, & Cleghorn, 2000) but in Step One, this was not what was found. The five people with a severe cognitive impairment (MMSE score of less than 10) included in Step One of this study were not able to use an electronic device. While they often had awareness, and even interest in the device, what the device was saying did not translate into following a command issued from the device.
One participant demonstrated confusion by saying, “Who did that?” Of the five participants, the two participants with severe cognitive impairment were unable to grasp the concept of the device. They would look at the device or even react to it when it “spoke”, but did not follow through with any type of appropriate action.

In Step One, participants with moderate cognitive impairment were able to use the device and follow the prompts successfully, but they required a new orientation to the device and task each time. However, the study participant with the highest cognitive level (per the MMSE) did require less instruction over time, even when completing a different task.

The second specific aim was to determine if the external prompting device could help people with AD in successful completion of a specific leisure or IADL task (making a seasonal decoration or making a list from a 1-page advertisement). The hypothesis was that following training on use of the prompting device, people with AD would be able to do this. This study did find that of the three participants who were able to follow commands issued from the device, all were successful in completing the task assigned to them. These three participants demonstrated this, and on at least one occasion, each of these participants was able to complete the task following 100% of the prompts accurately. However, while successful, they were not always consistent in their performance of the task.

Those who could follow prompts from the device often wanted reassurance that they were doing the task correctly. Some would just verbally make a comment about hoping they were doing the task correctly, while others would turn their face toward the PI or toward a research assistant looking for some affirmation or directly asked if they had completed a step correctly. As sessions went on, the PI placed herself completely out of the person’s visual field. However, one participant still completely turned around and asked her questions.
It also became apparent during the sessions that some people might benefit from hearing a prompt twice. Since the machine-delivered prompt was not preceded by a visual or auditory indicator prior to delivery, some participants missed part of the prompt. By delivering the prompt a second time immediately following the initial delivery of the prompt seemed to help the participant process how they were supposed to respond. Delivering some prompts twice was attempted in the last two sessions with one participant. By doing this, the number of questions she asked the investigator or asked the device decreased.

Affect in Step One was measured through the PGARS. Signs of interest were displayed most often by all five participants in this study. In the PGARS interest, pleasure and contentment comprised the positive aspects of affect. Overall, the participants displayed positive affect in response to the intervention. Their engagement, displayed by signs of interest, showed that they could benefit from the prompting provided by the EMA. Signs of anger and sadness, two aspects of negative affect, were rarely displayed by the participants. The participants did not appear to be angered or saddened by the intervention; contrarily, they appeared to enjoy the sessions. None of the participants displayed extreme negative signs of affect as a result of their interaction with the EMA.

Regarding the KSBA, having a low MMSE did not necessarily predict that a participant would have a high number of caregiver reported behavioral symptoms. For example, the participant with the lowest MMSE score had the least amount of reported behavioral symptoms. The participant who had the highest MMSE score had some of the most reported behavioral symptoms. Thus, cognitive impairment was not predictive of the amount of behavioral symptoms a caregiver reported for a person in this study.
The most commonly affected behavioral domains included “attention/concentration/memory” and “daily activities”. This explained some of the participants’ problems in remembering the purpose of the activity, even when it was explained to them a few minutes prior, and how they were surprised at how short the activity was. The participant whose caregiver marked “overly dependent, wants more guidance than usual” was the participant who required the most reassurance. The participants who had more trouble with the projects were the ones that had “can’t concentrate, pay attention for long” reported.

No one had any caregiver reported symptoms of paranoid behavior, which was reflected during their sessions by pleasant demeanors and cooperation. The only one who had reported behaviors in aggression and misperceptions/misidentifications did not demonstrate any of these symptoms during his sessions, but this may not have been noticed due his short duration within the study. One participant sometimes expressed wariness toward her participation in the study, but no behavioral symptoms were reported for her in this area.

All five participants had unique behavioral symptoms. Some of these symptoms were demonstrated in the sessions, such as short attention span and perseveration, while others were not detected at all, such as aggressive behavior. Certain symptoms present in the sessions could have contributed to some participants’ difficulty using the EMA, such as “no longer uses some common objects properly.” However, another participant whose caregiver had also marked this behavioral symptom interacted very successfully with the EMA. Therefore, there was not one specific symptom or group of symptoms that influenced a participant’s overall success or lack thereof with the EMA.

There were some symptoms that could influence a participant’s consistency and focus with the EMA. Those that had “can’t concentrate, pay attention for long” symptoms reported by
their caregivers demonstrated the most inconsistent rates of responses. Also, while the specific symptom may not predict a person’s consistency, the amount of reported symptoms may. Those participants with the highest symptoms reported in “attention/concentration/memory” had more inconsistency than those who had less symptoms reported in that category.

**Step Two**

Since one participant scored so low on the MMSE, the PI was hesitant to enroll her in the study, but after talking with the caregiver and observing her complete the tasks of washing her face and brushing her teeth, the PI decided that her experiences could provide some valuable information regarding machine-based prompting, especially since other studies have enrolled people with similar MMSE scores. She was different than the severely impaired participants in Step One in that she actually could respond to prompts issued from the device. This is where patterns of behavior must be considered. In the case of this participant, she completed routine tasks which seemed to come more naturally to her than other tasks. In the case of the participants with severe cognitive impairments in Step One, they performed a novel task by making a seasonal decoration which may not have been interesting or natural to them. As far as taking a sip of water was concerned, while this was a typical daily task, what was not typical was the context. Typically a person is not taken to a separate room and asked to take a sip of water. These factors could have contributed to their inability to understand the prompts.

The graphical data in Chapter 4 for two participants initially seemed to support that the EMA provided nearly the same prompting capabilities as in-person prompting did, however, the graphs do not take the field notes or contextual information into account.

Sometimes certain prompts were not expressed effectively on the EMA. One participant consistently required visual prompting for completing a leg extension exercise during his sessions, even during in-person prompting phases. This demonstrated that the verbal prompt was
faulty or did not supply enough information for the person to understand. Some tasks were
difficult to prompt because if they were broken down too much the person would not know what
was going on or would try to go ahead with what they thought they were supposed to do. The
prompts also could not deliver too much information at once or the participant became confused.

In Step Two the RMBPC results did not appear to have much impact on the performance
of the participants during their sessions. This was especially true with two participants whose
RMBPC totals changed very little over the course of the study. One participant’s scores were less
stable, and while her performance was also not stable, the two factors (based on visual analysis)
did not seem to correlate.

In the two follow-up interviews with two caregivers, both said they did not think the
device would be helpful to them. Both caregivers were present for the entire process and saw
how frequently the PI had to intervene, and since she had to be there anyway and could not leave
the person unattended, they did not think it would make helping the participant with tasks any
easier. Both caregivers mentioned how important personal contact was, and that they thought
that if they had the capability to do something there was no reason why they should not do it.
They admitted to being frustrated at times in their caregiving experiences, but did not think this
was a reason to substitute personal care. This was especially the case with the caregivers who
were adult daughters of the person with AD. Both mentioned at some point during the interview
that they had a sense of obligation to their parents and felt it was their duty to take care of them.
One caregiver mentioned that she thought the device would be helpful if she could record her
voice so her mother could hear it, especially since her mother would call for her every time she
left her sight. In their exit interviews both caregivers expressed that the main benefit of the study
was having someone new come in everyday to provide extra stimulation to the environment and provide some respite while the participant engaged in the study activity.

Affective States Before and After the Intervention

This study discovered patterns in which the affective states were displayed. Signs of pleasure, most commonly smiling and laughing, were displayed by all of the participants in every session before and/or after the intervention during their conversations with the PI. Rarely were these signs present during the intervention. This can be partially attributed to the nature of the activity. The participants were required to listen to and follow instructions from the EMA in order to complete a task. The intervention required concentration which does not typically lead to displaying obvious signs of pleasure. One participant displayed pleasure during her first session by asking “Am I talking to this stupid thing [the EMA]?” and then laughing which is contradictory because she laughed while calling the EMA “stupid”. Signs of anxiety/fear were occasionally noted by the raters before the intervention began usually including leg jiggling or repeated motions while they were waiting for the alarm on the EMA to go off.

Affect During the Intervention (in Parts One and Two)

During the intervention the participants most often displayed anxiety/fear and interest. Even though the participants exhibited some signs of interest that did not necessarily mean that they were engaged in the activity. Two participants would look at the device and the supplies on the table but did not do anything with them. Two participants displayed anxiety during their sessions. They expressed concern for completing the activity appropriately. One even asked to start over in one session when she did not understand the device.

Machine-based Prompting and the ICF Model

The severity of the cognitive impairment seemed to determine whether or not a person could follow the prompts issued from the EMA. In this study, participants with an MMSE score
of less than 10 either could not follow the prompts at all or required so many additional verbal and visual prompts that machine-based prompting really would not have been helpful to either the person with AD or the caregiver. Those who had moderate AD had an awareness that they were being prompted by a device, but also did not understand that they needed prompting for certain tasks. To their knowledge, they performed their routine tasks acceptably.

A person’s capability to attend to a task also made a difference as to whether or not the device could successfully prompt them. On occasion, if the timing was not “just right” the participant would lose interest and try to leave the room. Context aware devices may be able to alleviate some of this problem, since these devices utilize algorithms and decision trees that can change the course of prompting as the participant’s prompting needs change. Ultimately, in this sample, if the participant did not want to do the task, the EMA could not convince them to do it.

The presence of the PI also had significant impact on the results, especially in Step Two. One participant sometimes seemed unable to differentiate between the PI and the EMA, but sometimes she seemed to view the voice from the EMA as a third person and called it “that lady” on one occasion. Another participant stated that he preferred it when the PI prompted him. This was also evident in how he reacted to prompts. Sometimes he yelled at the EMA when it told him to do something, but he never yelled at the PI. He would sometimes argue with her when he thought he was doing things correctly, but he never yelled at her.

This leads to the next issue: self awareness. If prompted by a machine, the machine needs to have the intelligence to know that the person is doing an activity correctly. One participant often thought he was doing everything the way he should, which was a source of frustration when the device would remind him to “stand nice and tall” or “slow down.” If an exercise felt difficult he would modify it so it was easy, which defeated the purpose of having him do
strengthening exercises. He did not understand this concept, and it had to be explained to him on numerous occasions so he would cooperate with some of the prompts. This was also an issue with another participant since he would often do as the prompts asked but would pick up the wrong object. The PI needed to be there for safety to make sure he did not misuse his razor or put shaving cream in his mouth via his toothbrush. Also, if he did not want to complete a task he simply would say “I did that already” rather than do what the device asked. Having a person to hold both of these participants accountable for correct completion of tasks made a difference. Also, the fact that the PI was a new person made a difference. Because she was a new face, participants argued with her less than they did with their caregivers (per caregiver feedback).

The context of the activity where machine based prompting took place was also an issue. At the moment context aware devices are tested in laboratory environments. These environments will not transfer well to many home environments. One participant would more than likely not listen to a prompt if it were delivered without set-up or instructions since on more than one occasion when the EMA was placed directly in front of him and issued a prompt; he ignored it if he were paying attention to something else. In the home of one participant there was so much activity, that had she been able to consistently follow prompts, one could not guarantee that she would hear a prompt.

Co-morbidities must also be considered. One participant who had a hearing impairment said the PI’s voice on the EMA was not very understandable to him, in fact, it was irritating. When a male voice was used, the lower frequency was easier for him to hear and understand. Another had Parkinson’s disease in addition to AD. He demonstrated intention tremors that made some of the fine motor tasks in his grooming routine (like putting toothpaste on a toothbrush) difficult. Because of the Parkinson’s disease he had a shuffle to his gait, which would sometimes
cause him to trip. He also had a tendency to take out his hearing aids when he was sitting on the
couch and had to be reminded to put them in prior to the session. Had the PI not provided the
“set-up” situation prior to the prompt he may not have heard the prompt.

**Limitations of Current EMAs**

Finding an electronic device currently available on the market that was capable of
providing prompts proved difficult. Most prompting devices target populations other than people
with AD such as people who have traumatic brain injuries or multiple sclerosis. Even the devices
that claimed to help people with dementia would have been too complicated for participants in
this study since they needed orientation to the task and materials at each session. It would be
highly unlikely for any of the participants in this study to carry a device with them at all times
because they did not possess the awareness that they needed prompting for tasks.

The EMA that ended up being used also had many limitations. First, the fact that two
devices had to be combined was a limitation. The VoiceCue© could only deliver a prompt every
five minutes and only had three volume options. The digital voice recorder required participant
feedback in order for it to start and prompts had to be timed based on the PI’s observations
during either the practice session (Step One) or the baseline phase (Step Two). In both steps,
sometimes the timing was off. However, in some cases this could not be truly fixed because
while generally the participants completed the steps of a task at a certain rate, sometimes they
would progress faster or slower than the prompt delivery allowed which either led to participant
confusion (prompts too fast) or participant boredom and inattention (prompts too slow).

Another problem with the EMA is that the participants referred to the intervention as
“silly” and “foolishness”. One participant asked, “Am I talking to this stupid thing?” and then
laughed. Another participant demonstrated signs of frustration while interacting with the EMA
since she sometimes had difficulty hearing and comprehending the instructions from the EMA
immediately. She would ask to start over or explain why she did the activity a certain way if she was not sure she had completed the steps correctly. In Step Two all participants tried to leave at least once if there was a lull between prompts. All participants in Step Two expressed annoyance toward the device on at least two occasions. The only exception was when one participant referred to the device and said, “That’s pretty clever.”

**Limitations**

The small sample size of the pilot study limited generalization to the overall population with AD. Convenience sampling was used for participant selection, so the results were neither random nor possible to generalize to the entire population of people with AD. In Step One, possible participants who had more impairing behavioral symptoms would not be suited for the adult day program and were therefore not available during participant selection.

Due to safety reasons, all sessions had at least one investigator in the room with the participants. This may have influenced how the participants behaved and acted with the EMA. This also allowed participants to ask questions during the session, which the investigators answered to avoid participant distress or confusion. Having a caregiver nearby to answer questions might not be feasible or practical in a real world setting.

There were also limitations to the PGARS measure used in Step One. The PGARS was a modified scale created by Lawton et al. (1996) from the Philadelphia Geriatric Center Positive and Negative Affect Rating Scales (Lawton et al., 1992). The Philadelphia Geriatric Center Positive and Negative Affect Rating Scales contained 10 affective states (Happy, Interested, Energetic, Content, Warmhearted, Sad, Annoyed, Worried, Irritated, and Depressed) which were cut down to six for the PGARS to lessen the burden on the rater. Even though the reduction of the affective states from 10 to six reduced the burden and complication on the raters, it forced the raters to report displays of affect into categories that did not match their perceptions. This was
especially problematic for the signs of anger, anxiety/fear, and sadness. The raters consistently noted for the signs of anxiety/fear that none of the participants were “fearful” at any time during the intervention. Additionally, signs of anger were often described either as boredom, confusion or both by all of the raters. Boredom was commonly noted whenever the participants had to wait a significant amount of time for the alarm to go off on the EMA or if there was a significant amount of time between steps. Often participants would display signs of different affective states simultaneously. For example, a participant might have smiled, a sign of pleasure, while their leg was jiggling, a sign of anxiety/fear.

Originally the PI had hoped to have the caregivers utilize the EMA, but due to difficulty recruiting participants and after talking with the caregivers who were willing to participate, it was decided that the only way for the current study to be carried out would be if the PI worked with the device rather than the caregiver. None of the caregivers the PI spoke to were interested in testing the device themselves. Had the device already been proven to work with easy instructions this may have been different.

Lastly, the conclusions that emerged from the sessions were based on the patterns found by the investigator. The subjective nature of this analysis could be biased due to the personal investment of the researcher with the project.

**Conclusions**

Findings related to the EMA were as follows:

- Behavior issues did not directly translate to the participants experiencing difficulty using the EMA.
- Cognitive impairment was not predictive of the amount of behavioral symptoms described by the caregiver.
- Aspects of the tasks that need to be monitored include a safety during the tasks, proper positioning of the participant during the tasks, making sure the participant uses objects required for the task correctly, and thorough completion of each step of the task.
- A male voice may be easier to understand for those with a hearing impairment.
• Having prompts delivered more than once helps the participant understand the prompt.
• Visual prompts provided through a monitor or some other form may be required.
• The initial prompt must be strong enough or repeated enough to gain the attention of the participant.
• Some participants displayed a possible learning effect during their sessions.

Suggestions for further research include:

• having a larger sample size and including participants with a wider range of behavioral symptoms,
• using stronger statistical methods to examine if a correlation exists between behavior and task performance of specific ADLs with the EMA,
• performing more single subject designs to determine if participants with dementia demonstrate a learning effect when using an electronic prompting device,
• focusing interventions on people with mild to moderate dementia who realize that they require prompting to complete some tasks,
• holding focus groups or in-depth qualitative interviews with caregivers to determine their feelings toward electronic prompting,
• taking the information obtained from this study and applying it to the continued development context aware device that have better capabilities to adjust to participant needs.
APPENDIX A
PROMPTS FOR SEASONAL DECORATION ACTIVITY

Participant #: 100
Date: Trial #: Activity type: Seasonal decoration
Time of day: Day of the week:

1) Please press the green button on the device in front of you.
   ___ response
   ___ response was correct
   ___ no response
   Comments:

2) Do you see these items?
   ___ response
   ___ response was correct
   ___ no response
   Comments:

3) Please pick up the pumpkin sticker.
   ___ response
   ___ response was correct
   ___ no response
   Comments:

4) Peel off the backing on the pumpkin sticker.
   ___ response
   ___ response was correct
   ___ no response
   Comments:

5) Place the pumpkin sticker on the front of the card.
   ___ response
   ___ response was correct
   ___ no response
   Comments:

6) Now, turn the card over.
   ___ response
   ___ response was correct
   ___ no response
   Comments:
7) Please pick up the pen.
   ___ response
   ___ response was correct
   ___ no response
Comments:________________________________________________________________________

8) Write your name on this side of the card with the pen
   ___ response
   ___ response was correct
   ___ no response
Comments:________________________________________________________________________

Comments:________________________________________________________________________
APPENDIX B
PROMPTS FOR DRINK OF WATER TASK

Participant #: _100________
Date:_________    Trial #: _________________ Activity type: __drink of water__
Time of day:______________ Day of the week:___________

1) Please press the green button on the device in front of you.
   ___ response
   ___ response was correct
   ___ no response
Comments:______________________________________________________________

2) It’s time to take a drink of water. Please take a drink of water.
   ___ response
   ___ response was correct
   ___ no response
Comments:______________________________________________________________

Comments:________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
APPENDIX C
PROMPTS FOR MAKING A LIST FROM AN ADVERTISEMENT

Participant #: _100_______ Date:________________ Trial #: _________________ Activity type: _List______
Time of day:______________ Day of the week:_______________

1) Please press the green button on the device in front of you.
   ___ response
   ___ correct response
   ___ response was correct
   Comments:______________________________________________________________

2) Today we are going to make a shopping list. The items you will need are right in front of you.
   You will see a page from an advertisement, a sheet of paper, and a pen.
   Do you see these items?
   ___ response
   ___ correct response
   ___ response was correct
   Comments:______________________________________________________________

3) Tell me is there a picture of toilet paper in the ad?
   ___ response
   ___ correct response
   ___ response was correct
   Comments:______________________________________________________________

4) Tell me, how much does the toilet paper cost?
   ___ response
   ___ correct response
   ___ response was correct
   Comments:______________________________________________________________

5) Please write the word “toilet paper” on the sheet of paper in front of you.
   ___ response
   ___ correct response
   ___ response was correct
   Comments:______________________________________________________________

6) Write the cost of the toilet paper down too.
   ___ response
   ___ correct response
   ___ response was correct
   Comments:______________________________________________________________
7) Tell me, are there any potato chips in the ad?
   ___ response
   ___ correct response
   ___ response was correct
Comments:____________________________________________________________________________

8) Tell me, how much do the potato chips cost?
   ___ response
   ___ correct response
   ___ response was correct
Comments:____________________________________________________________________________

9) Please write “potato chips” on the next line of the paper.
   ___ response
   ___ correct response
   ___ response was correct
Comments:____________________________________________________________________________

10) Write the cost of the potato chips down, too.
    ___ response
    ___ correct response
    ___ response was correct
Comments:____________________________________________________________________________

11) Tell me, is there coffee in the ad?
    ___ response
    ___ correct response
    ___ response was correct
Comments:____________________________________________________________________________

12) Tell me, how much does the coffee cost?
    ___ response
    ___ correct response
    ___ response was correct
Comments:____________________________________________________________________________

13) Please write “coffee” on the next line of paper?
    ___ response
    ___ correct response
    ___ response was correct
Comments:____________________________________________________________________________
14) Write down the cost of the coffee as well.
   ___ response
   ___ correct response
   ___ response was correct
Comments:____________________________________________________________________

15) That concludes our list for today. You are finished and may put your pen down. Thank you!
   ___ response
   ___ correct response
   ___ response was correct
Comments:____________________________________________________________________

Overall session comments:
____________________________________________________________________________
____________________________________________________________________________
____________________________________________________________________________
____________________________________________________________________________
____________________________________________________________________________
____________________________________________________________________________
____________________________________________________________________________
____________________________________________________________________________
____________________________________________________________________________
KINGSTON STANDARDIZED BEHAVIORAL ASSESSMENT

Kingston Standardized Behavioral Assessment:

Daily activities:
No longer takes part in favorite pastimes (or greatly reduced).
Reduced personal hygiene
If left on his/her own, doesn’t eat properly.
Unsafe in daily activities, if left unsupervised.
No longer uses some common objects properly.
Unable to handle personal finances.
Is unable to perform usual household tasks.
Gets confused in places other than home.
Overly dependent, wants more guidance than usual.
Trouble appreciating subtleties in conversations (e.g. recognizing humor).
Difficulty judging the passing of time.
Wanders aimlessly.
Hides things.
Hoards objects.
Fails to recognize family or friends.
Incontinence of urine/feces in clothes in daytime.
Voids in non-toilet areas.

Attention/Concentration/Memory
Can’t concentrate, pay attention for long.
Misplaces things more than usual.
Has difficulty organizing his/her time or daily activities.
Forgets activities, conversations of only a short time before.
Forgets important everyday information.

Emotional Behavior
Shows little or no emotion.
Mood changes with no apparent reason.
Expresses inappropriate emotions, either type or intensity.
Makes uncharacteristically pessimistic statements.

Aggressive Behavior
Verbally abusive at times.
Uncharacteristically excitable, easy to upset: reacts catastrophically.
Attempts to hit/strike out at others.

Misperceptions/Misidentifications
Claims an object/possession looks similar to, but is not the real one.
Claims a family member looks similar but is the not the true one.
Thinks present dwelling is not their place of living.
Thinks people are present who aren’t.

Paranoid Behavior
Suspicious of family and friends.
Suspicious about money issues.
Accuses others of stealing his or her things.
Accuses spouse of infidelity.
Expresses suspicion around taking medication.

**Judgment/Insight**
Shows poor judgment in social situations.
Shows poor judgment about driving.
Shows uncharacteristic change in his or her concern about money.
Poor choices in dressing. (E.g. wears clothes that are inappropriate for season or temperature, wears the same clothes for days.)
Makes inappropriate sexual advances.
Shows less self control than usual.
Unable to identify personal safety risks.

**Perseveration**
Repeats same actions over and over.
Repeats same words or phrases.
Repeatedly shouts or calls out.

**Motor Restlessness**
Desire to pace or walk almost constantly.
Can’t sit still, restless, fidgety.
Tries doors, windows.

**Sleep/Activity/Sundowning**
Falls asleep at uncharacteristic times.
Gets up and wanders or awakens frequently at night, more than usual.
Sleeps more.
Behavior more agitated or impaired in late afternoon.

**Motor/Spatial Problems**
Poor coordination seen in limb/finger movements.
Slowness of movement.
Unsteadiness when walking.
Has trouble dressing, especially with buttons or shoelaces.
Difficulty judging object sizes or how near an object is from themselves.

**Language difficulties**
Reads far less frequently than previously.
Substitutes some words for others.
Does not watch or follow television.
Does not speak unless spoken to (e.g. Does not participate in conversations.)
Often cannot find the right word.
Trouble pronouncing words.
Does not understand simple commands, explanations.
Does not produce meaningful speech.
APPENDIX E  
MODIFIED PHILADELPHIA GERIATRIC CENTER AFFECT RATING SCALE

Over this 10-minute observation period, rate the extent or duration of each affect state by circling the most appropriate choice. The indications are named for illustrative purposes. Please circle any indicators you use. You may use other indicators but if you do, please write them down.

**Pleasure**

*Signs:* Smile, laugh, stroking, touching with “approach” manner, nodding, singing, arm or hand outreach, open-arm gesture, eye crinkled  

<table>
<thead>
<tr>
<th>Never</th>
<th>&lt;16 sec</th>
<th>15—59 sec</th>
<th>1—5 min</th>
<th>&gt;5min</th>
<th>Can’t tell</th>
</tr>
</thead>
</table>

**Anger**

*Signs:* Clench teeth, grimace, shout, curse, berate, push, physical aggression or implied aggression, like fist shaking, pursed lips, eyes narrowed, knit brows/lowered  

<table>
<thead>
<tr>
<th>Never</th>
<th>&lt;16 sec</th>
<th>15—59 sec</th>
<th>1—5 min</th>
<th>&gt;5min</th>
<th>Can’t tell</th>
</tr>
</thead>
</table>

**Anxiety/Fear**

*Signs:* Furrowed brow, motoric restlessness, repeated or agitated motions, facial expression of fear or worry, sigh, withdraw from other, tremor, tight facial muscles, calls repetitively, hand wringing, leg jiggling, eyes wide  

<table>
<thead>
<tr>
<th>Never</th>
<th>&lt;16 sec</th>
<th>15—59 sec</th>
<th>1—5 min</th>
<th>&gt;5min</th>
<th>Can’t tell</th>
</tr>
</thead>
</table>

**Sadness**

*Signs:* Cry, tears, moan, mouth turned down at corners, eyes/head down turned and face expressionless, wiping eyes, horse-shoe on forehead  

<table>
<thead>
<tr>
<th>Never</th>
<th>&lt;16 sec</th>
<th>15—59 sec</th>
<th>1—5 min</th>
<th>&gt;5min</th>
<th>Can’t tell</th>
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</thead>
</table>

**Interest**

*Signs:* Eyes follow object, intent fixation on object or person, visual scanning, facial, motoric or verbal feedback to other, eye contact maintained, body or vocal response to music, wide angle subtended by gaze, turn body or move toward person or object  

<table>
<thead>
<tr>
<th>Never</th>
<th>&lt;16 sec</th>
<th>15—59 sec</th>
<th>1—5 min</th>
<th>&gt;5min</th>
<th>Can’t tell</th>
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</thead>
</table>

**Contentment**  (less intense than pleasure)

*Signs:* Comfortable posture, sitting or lying down, smooth facial muscles, lack of tension in limbs, neck, slow movements  

<table>
<thead>
<tr>
<th>Never</th>
<th>&lt;16 sec</th>
<th>15—59 sec</th>
<th>1—5 min</th>
<th>&gt;5min</th>
<th>Can’t tell</th>
</tr>
</thead>
</table>

Comments:
APPENDIX F
CAREGIVER QUESTIONNAIRE

Confidential Study Participant Number: _________

1. Age: ______

2. Gender:
   1. Male    2. Female

3. Race:
   1. Black    4. Asian
   2. White     5. Native American
   3. Hispanic  6. Other ____________________________________________

4. Level of Completed Education:
   1. Less than 9th Grade        5. Vocational, technical, or business school degree
   2. 9th to 12th grade, no diploma   6. Associate degree
   3. High School Graduate       7. Bachelor’s degree
   4. Some college, no degree    8. Graduate or professional degree

5. Marital Status:
   1. Married        4. Single
   2. Widowed        5. Other __________________________________________
   3. Divorced

6. Living Arrangement
   1. Live alone    2. Live with someone    3. Other ________________
7. Please identify if you have any of the conditions listed in the left hand column of the table by placing an “X” in the column labeled “I Have this Condition.” Once you have identified the condition, please select how much that particular condition has affected your level of activity, by marking the appropriate column on the right. The table continues onto page 3. A sample is provided in the first row. Use the terms below for considering the impact of the condition on your activity level:

- **Mildly Affected**: *I do activities more slowly, but I can do most of what I use to do. Sometimes I use devices to help.*
- **Moderately Affected**: *I require some help with some activities.*
- **Severely Affected**: *I require a great deal of help with a number of activities. It would be difficult to live alone without the help I receive.*

<table>
<thead>
<tr>
<th>Type of Condition</th>
<th>I Have this Condition</th>
<th>Condition Has Not Affected Activity Level</th>
<th>Condition Has Mildly Affected Activity Level</th>
<th>Condition Has Moderately Affected Activity Level</th>
<th>Condition Has Severely Affected Activity Level</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Sample) Tire Easily</td>
<td>X</td>
<td></td>
<td></td>
<td>X</td>
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<tr>
<td>Low vision</td>
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<td>Blind</td>
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<tr>
<td>Joint Problems</td>
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<tr>
<td>Poor Hearing</td>
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<tr>
<td>Deaf</td>
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<tr>
<td>Muscular Weakness</td>
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<tr>
<td>Back Problems</td>
<td></td>
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<tr>
<td>Difficulty with Hand Tasks</td>
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<tr>
<td>Type of Condition</td>
<td>I Have this Condition</td>
<td>Condition Has Not Affected Activity Level</td>
<td>Condition Has Mildly Affected Activity Level</td>
<td>Condition Has Moderately Affected Activity Level</td>
<td>Condition Has Severely Affected Activity Level</td>
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<tr>
<td>Paralysis of Legs</td>
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<tr>
<td>Paralysis of Arms</td>
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<tr>
<td>Tire Easily</td>
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<tr>
<td>Memory Difficulties</td>
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<tr>
<td>Learning Disability</td>
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<tr>
<td>Speech or Communication Difficulties</td>
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<tr>
<td>Other:</td>
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<tr>
<td>Other:</td>
<td></td>
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</tr>
</tbody>
</table>

8. The following activities are difficult or impossible for me to perform: (Please check all that apply)

___ Reading
___ Writing
___ Using a Computer
___ Bathing
___ Preparing meals
___ Getting on and off the toilet
9. **How much income do you have a year?** *(please circle the letter that identifies yearly income category).*

Yearly

A  0-$10,000  
B  $10,000- $20,000  
C  $20,000- $30,000  
D  $30,000- $40,000  
E  $40,000- $50,000  
F  $50,000- $60,000  
G  $60,000- $70,000  
H  $70,000- $80,000  
I  $80,000- $90,000  
J  $90,000- $100,000  

If over $100,000, please estimate your annual income in the space provided.

____________________

10. **How many people altogether live on this income (that is, it provides at least half of their income)?**  

11. **Please check the technologies that you frequently use:**
(Please check all that apply)

___ Personal Computer
   ___ For banking
   ___ For surfing the Internet
   ___ For sending emails

___ VCR
___ Cell phone
   ___ For surfing the Internet
   ___ For sending text messages

___ Digital camera
___ Bank ATM
___ CD Player
___ Answering machine
___ PDA – (personal digital assistant)
   ___ For scheduling
   ___ For an address book
   ___ For sending emails
   ___ For surfing the Internet

___ Microwave
___ Home security Alarm
___ PERS – (personal emergency response system)
   ___ Have a necklace/pendant style
   ___ Have an armband style

___ Home environmental control unit
   ___ voice input
   ___ keyboard input

___ Other (please describe)

______________________________________________________________________________________

12. How would you rate your overall experience with technology?
(Please check all that apply)

___ Satisfying
___ Saves me time
___ Feel ‘neutral’ about technology
___ Frustrating
___ Takes too much of my time
___ Helps me connect with other people
___ Makes me feel detached from other people
___ I like to try out new technology
___ I do not like to try new technology
APPENDIX G
PARTICIPANT QUESTIONNAIRE (TO BE FILLED OUT BY CAREGIVER)

Confidential Study Participant Number: __________

1. **Age:** ______

2. **Gender:**
   1. Male  2. Female

3. **Race:**
   1. Black  4. Asian
   2. White  5. Native American
   3. Hispanic  6. Other ____________________________________________

4. **Level of Completed Education:**
   1. Less than 9th Grade  5. Vocational, technical, or business school degree
   2. 9th to 12th grade, no diploma  6. Associate degree
   3. High School Graduate  7. Bachelor’s degree
   4. Some college, no degree  8. Graduate or professional degree

5. **Marital Status:**
   1. Married  4. Single
   2. Widowed  5. Other ______________________________________________
   3. Divorced

6. **Living Arrangement**
   1. Live alone  2. Live with someone  3. Other ________________
7. Please identify if your spouse, sibling, or parent has any of the conditions listed in the left hand column of the table by placing an “X” in the column labeled “I Have this Condition.” Once you have identified the condition, please select how much that particular condition has affected their level of activity, by marking the appropriate column on the right. The table continues onto page 3. A sample is provided in the first row. Use the terms below for considering the impact of the condition on your activity level:

- **Mildly Affected**: *I do activities more slowly, but I can do most of what I use to do. Sometimes I use devices to help.*
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<table>
<thead>
<tr>
<th>Type of Condition</th>
<th>Have this Condition</th>
<th>Condition Has Not Affected Activity Level</th>
<th>Condition Has Mildly Affected Activity Level</th>
<th>Condition Has Moderately Affected Activity Level</th>
<th>Condition Has Severely Affected Activity Level</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Sample)</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tire Easily</td>
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<td>Low vision</td>
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<td>Blind</td>
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<td>Joint Problems</td>
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<td>Poor Hearing</td>
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<td>Deaf</td>
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<td>Muscular Weakness</td>
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<td>Back Problems</td>
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<td>Difficulty with Hand Tasks</td>
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<td>Type of Condition</td>
<td>Have this Condition</td>
<td>Condition Has Not Affected Activity Level</td>
<td>Condition Has Mildly Affected Activity Level</td>
<td>Condition Has Moderately Affected Activity Level</td>
<td>Condition Has Severely Affected Activity Level</td>
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<td>Paralysis of Legs</td>
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<td>Paralysis of Arms</td>
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<td>Tire Easily</td>
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<td>Memory Difficulties</td>
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<td>Learning Disability</td>
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<td>Speech or Communication Difficulties</td>
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<td>Other:</td>
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8. **The following activities are difficult or impossible for your spouse, sibling, or parent to perform:** *(Please check all that apply)*

   ___ Reading
   ___ Writing
   ___ Using a Computer
   ___ Bathing
   ___ Preparing meals
   ___ Getting on and off the toilet
___ Getting dressed
___ Shopping
___ Walking
___ Climbing Stairs
___ Managing Bowel/Bladder Tasks
___ Grooming (ex. combing hair)
___ Getting out of chairs
___ Bending
___ Using the telephone
___ Doing housework
___ Holding eating utensils
___ Driving
___ Other __________________________
___ Other __________________________
___ Other __________________________

11. **Please check the technologies that your spouse, sibling, or parent has used or uses:**

*Please check all that apply)*

___ Personal Computer
   ___ For banking
   ___ For surfing the Internet
   ___ For sending emails

___ VCR
___ Cell phone
   ___ For surfing the Internet
   ___ For sending text messages

___ Digital camera
___ Bank ATM
___ CD Player
___ Answering machine
___ PDA – (personal digital assistant)
___ For scheduling
___ For an address book
___ For sending emails
___ For surfing the Internet

___ Microwave
___ Home security Alarm
___ PERS – (personal emergency response system)
    ___ Have a necklace/pendant style
    ___ Have an armband style
___ Home environmental control unit
    ___ voice input
    ___ keyboard input
___ Other (please describe)

_________________________________________________________________
_________________________________________________________________

12. **How would you rate their overall experience with technology?**
    *(Please check all that apply)*

___ Satisfying
___ Saves me time
___ Feel ‘neutral’ about technology
___ Frustrating
___ Takes too much of my time
___ Helps me connect with other people
___ Makes me feel detached from other people
___ I like to try out new technology
___ I do not like try new technology
1) It’s time to wash your face. Please pick up the washcloth.
   ____ Response
   ____ Correct response
   ____ No response
   Comments:______________________________

2) Can you pick up the washcloth?
   ____ Response
   ____ Correct response
   ____ No response
   Comments:______________________________

3) Pick up the washcloth.
   ____ Response
   ____ Correct response
   ____ No response
   Comments:______________________________

4) Turn on the faucet and wet the washcloth. Please wet the washcloth.
   ____ Response
   ____ Correct response
   ____ No response
   Comments:______________________________

5) Turn off the water and wring out the washcloth.
   ____ Response
   ____ Correct response
   ____ No response
   Comments:______________________________

6) Wring out the washcloth.
   ____ Response
   ____ Correct response
   ____ No response
   Comments:______________________________

7) Now wash your face. Please wash your face.
   ____ Response
   ____ Correct response
   ____ No response
   Comments:______________________________
8) Wash your face.
   ___ Response
   ___ Correct response
   ___ No response
   Comments:________________________________________________________

9) Are you washing your face?
   ___ Response
   ___ Correct response
   ___ No response
   Comments:________________________________________________________

10) Good job. Please put the washcloth down by the sink. Put the washcloth down by the sink.
    ___ Response
    ___ Correct response
    ___ No response
    Comments:________________________________________________________

11) Good. Now pick up your hairbrush. Please pick up your hairbrush.
    ___ Response
    ___ Correct response
    ___ No response
    Comments:________________________________________________________

12) Please brush your hair. Brush your hair.
    ___ Response
    ___ Correct response
    ___ No response
    Comments:________________________________________________________

13) Make sure you get the back.
    ___ Response
    ___ Correct response
    ___ No response
    Comments:________________________________________________________

14) You look great! Set the brush down. Set the brush down.
    ___ Response
    ___ Correct response
    ___ No response
    Comments:________________________________________________________

You’re finished!
APPENDIX I
PROMPTS FOR P202

1) [Name], it’s time to push the green button. Please push the green button.
   ___ Response
   ___ Correct response
   ___ No response
   Comments:________________________________________________________

2) Go to the kitchen counter. Please go to the kitchen counter.
   ___ Response
   ___ Correct response
   ___ No response
   Comments:________________________________________________________

3) Stand with your feet parallel to the counter. Stand with your feet parallel to the counter.
   ___ Response
   ___ Correct response
   ___ No response
   Comments:________________________________________________________

4) You are going to start by rocking back on your heels and then forward on your toes. Back on your heels and forward on your toes. Heels, toes, heels, toes.
   ___ Response
   ___ Correct response
   ___ No response
   Comments:________________________________________________________

5) Really bring up those toes and heels.
   ___ Response
   ___ Correct response
   ___ No response
   Comments:________________________________________________________

6) Ok. Stop.
   ___ Response
   ___ Correct response
   ___ No response
   Comments:________________________________________________________

7) Now, stay where you are and bring your right knee up so it’s parallel with the floor. Raise your right knee. Keep raising your right knee.
   ___ Response
   ___ Correct response
   ___ No response
   Comments:________________________________________________________
8) Go nice and slow. Go nice and slow.
   ___ Response
   ___ Correct response
   ___ No response
   Comments:________________________________________________________

9) Keep going.
   ___ Response
   ___ Correct response
   ___ No response
   Comments:________________________________________________________

10) Ok. Stop.
    ___ Response
    ___ Correct response
    ___ No response
    Comments:________________________________________________________

11) Now it’s time to do the same thing with your left knee. Do the same thing with your left knee.
    ___ Response
    ___ Correct response
    ___ No response
    Comments:________________________________________________________

12) Keep going.
    ___ Response
    ___ Correct response
    ___ No response
    Comments:________________________________________________________

13) Go nice and slow.
    ___ Response
    ___ Correct response
    ___ No response
    Comments:________________________________________________________

14) Ok. Stop.
    ___ Response
    ___ Correct response
    ___ No response
    Comments:________________________________________________________
15) Now stay there. You’re going to place your right foot behind you, keeping your leg straight. Lift your right leg up behind you keeping your leg straight. Lift your right leg up behind you.

   ___ Response
   ___ Correct response
   ___ No response
   Comments:________________________________________________________

16) Make sure you keep your leg straight. Keep your leg straight.

   ___ Response
   ___ Correct response
   ___ No response
   Comments:________________________________________________________

17) Go nice and slow.

   ___ Response
   ___ Correct response
   ___ No response
   Comments:________________________________________________________

18) Ok. Stop.

   ___ Response
   ___ Correct response
   ___ No response
   Comments:________________________________________________________

19) Now do the same thing with your left leg. The same thing with your left leg.

   ___ Response
   ___ Correct response
   ___ No response
   Comments:________________________________________________________

20) Keep your leg straight.

   ___ Response
   ___ Correct response
   ___ No response
   Comments:________________________________________________________

21) Go nice and slow.

   ___ Response
   ___ Correct response
   ___ No response
   Comments:________________________________________________________
22) Ok. Now stay there. Stay there.
   ___ Response
   ___ Correct response
   ___ No response
Comments:________________________________________________________

23) This time you are going to bend both knees to do a deep knee bend. Bend both knees and do a deep knee bend.
   ___ Response
   ___ Correct response
   ___ No response
Comments:________________________________________________________

24) Make sure you stand nice and tall.
   ___ Response
   ___ Correct response
   ___ No response
Comments:________________________________________________________

25) Remember to go slow.
   ___ Response
   ___ Correct response
   ___ No response
Comments:________________________________________________________

26) Ok. Stop.
   ___ Response
   ___ Correct response
   ___ No response
Comments:________________________________________________________

27) Good. Now go to the end of the counter and wait for instructions. Go to then end of the counter and wait for instructions.
   ___ Response
   ___ Correct response
   ___ No response
Comments:________________________________________________________________________
APPENDIX J
PROMPTS FOR P203

1) Can you push the green button? Please push the green button.
   ___ Response
   ___ Correct response
   ___ No response
Comments:________________________________________________________

2) It’s time to brush your teeth? Please brush your teeth.
   ___ Response
   ___ Correct response
   ___ No response
Comments:________________________________________________________

3) Please put toothpaste on your brush. Put toothpaste on your toothbrush.
   ___ Response
   ___ Correct response
   ___ No response
Comments:________________________________________________________

4) Now it’s time to shave. Show how you shave.
   ___ Response
   ___ Correct response
   ___ No response
Comments:________________________________________________________

5) Please use shaving cream. Use shaving cream.
   ___ Response
   ___ Correct response
   ___ No response
Comments:________________________________________________________

6) Did you get the spots under your jawbone on your neck? See if you got the spots under your jawbone and on your neck.
   ___ Response
   ___ Correct response
   ___ No response
Comments:________________________________________________________

7) Did you get all of the shaving cream off your face and neck? Make sure you get all of the shaving cream off of your face and neck.
   ___ Response
   ___ Correct response
   ___ No response
Comments:________________________________________________________
8) Now it’s time to comb your hair. Please comb your hair.
   ___ Response
   ___ Correct response
   ___ No response
Comments:________________________________________________________

9) Make sure you get the back. Make sure you get the back.
   ___ Response
   ___ Correct response
   ___ No response
Comments:________________________________________________________

You look great! You’re finished.

Comments:
APPENDIX K
REVISED MEMORY AND BEHAVIOR PROBLEMS CHECKLIST

The following is a list of problems individuals sometimes have. Please tell us if any of these problems have occurred during the past 24 hours. If so, how much has this bothered or upset you when it happened? Use the following scales for the frequency of the problem and your reaction to it. Please read the description of the ratings carefully.

How often?: 0= never occurred, 1= not in the past 24 hours, 2= 1-2 times, 3= 3-6 times, 4= > 6 times, 9= don’t know/not applicable.

How disturbing?: 0= not at all, 1= a little, 2= moderately, 3= very much, 4= extremely, 9= don’t know/not applicable

1. Asking the same question over and over again. 0 1 2 3 4 9 0 1 2 3 4 9
2. Trouble remembering recent events (e.g. items in the newspaper or on TV). 0 1 2 3 4 9
   0 1 2 3 4 9
3. Trouble remembering significant past events. 0 1 2 3 4 9 0 1 2 3 4 9
4. Losing or misplacing things. 0 1 2 3 4 9 0 1 2 3 4 9
5. Forgetting what day it is. 0 1 2 3 4 9 0 1 2 3 4 9
6. Starting, but not finishing, things. 0 1 2 3 4 9 0 1 2 3 4 9
7. Difficulty concentrating on a task. 0 1 2 3 4 9 0 1 2 3 4 9
8. Destroying property. 0 1 2 3 4 9 0 1 2 3 4 9
9. Doing things that embarrass you. 0 1 2 3 4 9 0 1 2 3 4 9
10. Waking you or other family members up at night. 0 1 2 3 4 9 0 1 2 3 4 9
11. Talking loudly and rapidly. 0 1 2 3 4 9 0 1 2 3 4 9
12. Appears anxious or worried. 0 1 2 3 4 9 0 1 2 3 4 9
13. Engaging in behavior that is potentially dangerous to self or others. 0 1 2 3 4 9

14. Threatens to hurt oneself. 0 1 2 3 4 9

15. Threats to hurt others. 0 1 2 3 4 9

16. Aggressive to others verbally. 0 1 2 3 4 9

17. Appears sad or depressed. 0 1 2 3 4 9

18. Expressing feelings of hopelessness or sadness about the future (e.g., “Nothing worthwhile ever happens,” “I never do anything right.”). 0 1 2 3 4 9

19. Crying and tearfulness. 0 1 2 3 4 9

20. Commenting about death of self or others (e.g. “Life isn’t worth living,” “I’d be better off dead”). 0 1 2 3 4 9

21. Talking about feeling lonely. 0 1 2 3 4 9

22. Comments about feeling worthless or being a burden to others. 0 1 2 3 4 9

23. Comments about feeling like a failure or about not having any worthwhile accomplishments in life. 0 1 2 3 4 9

24. Arguing, irritability, and/or complaining. 0 1 2 3 4 9
Interview Template
Participant Number: _____________________

I’d like you to take a minute and carefully reflect upon this first question before answering. How would you describe a typical day in your household?

Please describe any routines you carry out with your (spouse, sibling, parent).

Does your (spouse, sibling, parent) ever have difficulty completing everyday activities?

Which activities?

How often does this happen?

Please describe how you react when this happens?

Could you describe how you feel when your (spouse, sibling, parent) displays this behavior?

Do you attempt to help guide your (spouse, sibling, parent) through this particular activity if they get stuck?

Please describe what types of prompts or cues you use or how you prompt or cue them through the task. (if applicable)

Do you prefer to prompt your (spouse, sibling, parent) through the task or do you prefer to do the task for them?

Why?

Could you give me examples of behaviors that the person you care for displays that are particularly frustrating or worrisome?

How often do you have to intervene to help your (spouse, sibling, parent) with a daily task?

How long has/have this/these behavior/s been an issue if it/they has/have?

What types of technology do you own? Like VCRs, DVD players, computers, etc.?

How comfortable are you with the technology you own?

What do you use this technology for?
Could you describe any opinions you might have regarding technology?

Do you think technology that provides prompting or cuing could be helpful for you?

How do you feel about someone coming into your home on such a regular basis?
APPENDIX M
FOLLOW-UP INTERVIEW

Interview Template
Participant Number: _____________________

I’d like you to take a minute and carefully reflect upon this first question before answering. How has participating in this study influenced your experience of care giving, if it has?

How has participating in this study affected your life in general?

How has it been having someone come into your home every month?

Could you tell me about your experiences working with the prompting technology?

Did you find the technology helpful?

Do you have any suggestions that would make using the technology easier?

How has participating in this study affected ________ (relative), if it has?

How has having someone come into your home every month affected ________(relative)?

I’d really be interested to know how you feel about this study coming to a close.
LIST OF REFERENCES


BIOGRAPHICAL SKETCH

Megan Witte graduated from the College of Saint Mary in Omaha, Nebraska, with her degree in occupational therapy in 2002. She is a doctoral candidate in the rehabilitation science doctoral program with a concentration in social and behavioral integration and geriatrics. Prior to coming to the University of Florida, she practiced occupational therapy in an inpatient rehabilitation setting at Madonna Rehabilitation Hospital in Lincoln, Nebraska. She currently practices part-time at Oak Hammock, in Gainesville, Florida. In 2004 she was a visiting scholar at the University of Sydney in Sydney, Australia researching and lecturing as part of the Home Modification and Maintenance Information Clearinghouse team. She also served as an occupational therapist advisor for the AlzOnline project, teaching classes and answering questions on home safety and home modifications for caregivers of people with dementia.