

EXPLORATORY STUDY OF FAMILY VISIT PROGRAM FOR
ALZHEIMER'S RESIDENTS IN CARE FACILITIES

A Thesis

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ABSTRACT

Alzheimer's disease is a debilitating and progressive disorder. As Alzheimer's progresses, disease-driven changes occur in the individual. These changes include not only cognitive decline but also erosion of sensory perception and eventual loss of the individual's ability to interact and communicate. Communication problems experienced by those with Alzheimer's make interaction with family members and loved ones challenging.

Family visits have been shown to have a therapeutic benefit. While the quality of family visits directly correlates to the quality of life for people with dementia, continued involvement of family members with loved ones in care facilities has implications for the quality of life of the family. Although family interaction and visits are important and may be desired, decreased communication abilities of people with Alzheimer's disease often make family and loved ones uncomfortable when anticipating a visit. Too often, such uneasiness and apprehension leads to abbreviated visits, if the visits even happen at all. Accordingly, developing interventions focusing on visits between people with Alzheimer's disease and their families is appropriate. Other interventions that focus on family visits of this sort have been developed, however, the intervention studied here, the Family Visit Program, is unique in that it explores the potential of the physical environment to enhance the quality of the visit experience.

The Family Visit Program is an example of evidence-based design and includes four components: conversation corner, digital picture frame and stand, image selection process, and orientation process and communication strategies. The conversation

corner served as the setting for the visits. Designed as a seating unit, it employs an upholstered curved bench with a high back, a canopy, and partitions at each end. The digital picture frame and stand were intended to serve as the display medium for the primary source of stimulation, personally meaningful photographs. Image selection was the process by which the families sorted through family photo collections to select images likely to evoke positive reactions from the resident as well as family. Family members were asked to complete image selection prior to the preparation meeting with the researcher. The orientation process consisted of the preparation meeting held with individual families during which images were scanned and communication strategies were discussed. The presented strategies were intended to enhance the quality of interaction and flow of conversation during the visit.

This thesis was exploratory in nature. As such, the intent was not to test hypotheses but instead to identify a range of issues surrounding family visits with people with Alzheimer's disease living in care facilities. More specifically, the intent was to gain understanding about the potential of the Family Visit Program and each of its components to enhance the quality of the visit experience.

The research was conducted at Longview, an elder care facility including both independent apartments and assisted living suites, located in Ithaca, NY. This study included three groups of participants: residents of Longview, family members of those residents, and Longview staff members. Four families participated in the research, though there were five resident participants. Two staff members participated in interviews. Each family participated in one visit as part of the Family Visit Program. There were three methods of data collection in this study: video recording of visits, interviews, and field notes. These three types of data were analyzed separately.

This exploratory study was successful in attaining feedback on the potential and viability of the Family Visit Program and its components. The study demonstrates not only that the Family Visit Program components establish an appropriate framework for rewarding family interaction, but also that each component could benefit from further refinement.

BIOGRAPHICAL SKETCH

Sarah Estelle Blau attended Cornell University for her undergraduate education, studying interior design. She earned a Bachelor of Science in the field of Design and Environmental Analysis in May 2007. Sarah received the Hillier Award from the Department of Design & Environmental Analysis and made the Dean's List several semesters. Prior to coming to Cornell, Sarah attended Dobbs Ferry High School, where she participated in the International Baccalaureate program and was salutatorian of her graduating class.

Dedicated to my grandma Fran, who has always been an inspiration to me

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CHAPTER 1

INTRODUCTION

1.1 Alzheimer's Disease

Alzheimer's disease is a debilitating and progressive disorder that is the most common type of dementia. The hallmark symptom of Alzheimer's disease is a gradual decline in memory and other cognitive abilities. At first, decline is most noticeable with respect to new memories, though as damage to the brain spreads, people are likely to have increased confusion, disorganized thinking, impaired judgment, difficulty expressing themselves, and disorientation with respect to time, space, and location (Alzheimer's Association, 2008). As the disease progress further, individuals stricken with Alzheimer's will need more and more help with activities of daily living (ADL's) and eventually may lose their communication skills and be unable to recognize loved ones (Alzheimer's Association, 2008).

The significance of Alzheimer's disease is due not only to its tragic nature, but also to the sheer number of people who have it and are projected to become afflicted with it. In 2000, there were an estimated 4.5 million people in the United States with Alzheimer's disease, 93% of whom were 75 years and older (Hebert, Scherr, Bienias, Bennett, & Evans, 2003). It is estimated that 5.2 million Americans have Alzheimer's disease in 2008, 5 million of which are people age 65 and over (Alzheimer's Association, 2008). Another way of thinking about this number is that about thirteen percent, or one in eight people, age 65 and over have Alzheimer's disease (Alzheimer's Association, 2008). This increase within the last several years is not only astounding but also indicative of the future. It is expected that by the year 2050, there

could be somewhere between 11 million and 16 million people age 65 and over with Alzheimer's disease (Alzheimer's Association, 2008). This is due largely to the fact that the greatest identified risk factor for the disease is advancing age and that people are living longer today, many surviving into their 80s and 90s (Alzheimer's Association, 2008). Because of such tremendous growth, research is needed to learn more about the disease from a medical and biological standpoint, so as to determine its causes and develop a cure. It is also essential that we look at the human side of Alzheimer's—how it affects individuals and their loved ones, in order to develop interventions for those with the disease and those close to them.

Although many people with Alzheimer's are initially cared for at home by family and loved ones, the disease generally progresses to a point where this is no longer possible. Although the informal care provided at home by family members is a significant part of all care provided for people with Alzheimer's and other forms of dementia (Alzheimer's Association, 2008), providing this manner of care is difficult. The problem is that unpaid family and other informal caregivers tend to experience high levels of emotional stress and even depression, along with negative effects on their health, employment, and finances (Alzheimer's Association, 2008). Most people afflicted with Alzheimer's eventually need to move into a residential care facility as the tasks and stresses of caring at home become too difficult (Alzheimer's Association, 2008). As such, the interventions and research discussed from this point forward pertain to people with Alzheimer's living in care facilities.

1.2 Alzheimer's Disease-driven Changes

As Alzheimer's progresses, disease-driven changes occur in the individual. These changes include not only cognitive decline but also erosion of sensory perception and eventual loss of the individual's ability to interact and communicate.

1.2.1. Alzheimer's Disease-driven Changes Related to Memory and Cognitive Abilities

The hallmark sign of Alzheimer's disease is memory loss. Memory loss and other cognitive changes are due to the fact that in Alzheimer's disease and other types of dementia, increasing numbers of neurons deteriorate and die (Alzheimer's Association, 2008). Symptoms begin with progressively increasing difficulty remembering new information, a progression that is caused by loss of brain cells starting in regions of the brain involved in the formation of new memories (Alzheimer's Association, 2008). At first, an individual may notice memory lapses in his/her everyday life, such as forgetting familiar words or the location of commonly used objects (Alzheimer's Association, 2005). Next, friends, family, and other people close to the individual may start to notice difficulties that can include forgetting words or names, difficulty performing tasks, losing or misplacing valuables, and trouble with planning or organizing (Alzheimer's Association, 2005). During early-stage or mild Alzheimer's the person afflicted is likely to experience significant forgetfulness of recent events, weakened ability to perform challenging mental arithmetic, and increased difficulty completing complex tasks, among other symptoms (Alzheimer's Association, 2005). Other cognitive changes that occur with the disease include confusion, disorganized thinking, impaired judgment, difficulty expressing oneself, and disorientation with respect to time, space, and location (Alzheimer's Association, 2008).

While the effects on short-term memory occur and are noticed first, eventually Alzheimer's also comes to affect long-term memory. The rate of decline of long-term memory does, however, vary from person to person. In relatively early stages of the disease, some people may begin to have difficulty remembering their personal history while others with moderate Alzheimer's may still remember significant details about themselves and their family (Alzheimer's Association, 2005). Difficulty recalling personal history is likely to increase as the disease progresses and, although there may be some ability to distinguish between familiar and unfamiliar faces, an individual is likely to have difficulty remembering the name of a spouse or caregiver (Alzheimer's Association, 2005).

It is important to note, though, that even with the significant declines in memory and cognition associated with Alzheimer's disease, emotions still exist, as do many talents and abilities. People with Alzheimer's have been shown to demonstrate better recall for emotionally laden stimuli than for neutral stimuli (Abrisqueta-Gomez, Bueno, Oliveira, & Bertolucci, 2002; Fleming, Kim, Doo, Maguire, & Potkin, 2003) and personally significant images of people, places, and things were more likely to be recognized than nonpersonal images (Cohen, Firth, Biddle, Lewis, & Simmens, 2009). Emotions are related to a specific type of memory, implicit memory. This type encompasses procedural skills and habits, and allows for the potential of familiar cues to help invoke memories (Son, Therrien, & Whall, 2002).

1.2.2. Alzheimer's Disease-driven Changes Related to Sensory Perception and Interpretation

In addition to the aforementioned changes in memory and cognitive abilities, changes also occur in how stimuli are perceived by the senses and how perceptions are

processed in the mind of a person with Alzheimer's. Disease driven decline in sensory perception, such as with hearing, is due more to how stimuli are understood and processed than with the mechanics of auditory perception (Bakker, 2003). It is important to understand that although Alzheimer's can significantly change how people interpret what they perceive through the different senses, these changes are highly individual and anything but constant. Factors such as neuropathological changes, sensory loss, time of day, medication management, and the social and physical environment can all affect perceptions (Bakker, 2003).

In terms of vision, a number of deficiencies and difficulties have been observed. People with Alzheimer's disease often experience changes in their visual abilities including problems with depth perception, glare, and visual misinterpretations, all of which may be made worse by visual disorders (Bakker, 2003). Alzheimer's disease can also negatively affect certain basic visual abilities including color discrimination and contrast sensitivity (Cronin-Golomb, 1995). In one study looking at vision and Alzheimer's disease, the majority of subjects with the disease showed significant impairments in at least one visual function, many having multiple deficits (Cronin-Golomb, 1995). With respect to color, Wijk, Berg, Sivik, and Steen (1999) found that color discrimination in the yellow and red area of the spectrum was better than in the blue and green area, while Cronin-Golomb (1995) also found that people with Alzheimer's disease exhibited specific deficits with respect to the blue color axis and had more difficulty discriminating between blue and violet hues. Additionally, variations in lightness were easier to notice than variations in hue or color (Wijk, et al., 1999). Other findings include that basic colors (red, blue, yellow, green, black, and white) were the most easily identified and that the severity of dementia significantly influences the ability to recognize colors by their names and to use elaborate color

names (Wijk, et al., 1999). Also of interest is that color preference does not seem to be affected by age or Alzheimer's disease and that across age groups, people rank colors from most to least beautiful in the following order: blue, red, green, yellow, purple, orange, and brown (Wijk, et al., 1999).

Along with changes in vision, it is important to consider how aspects of the physical environment can affect this sense. For example, lighting level should be considered when interacting with people with dementia. To be specific, if light level is inadequate, an individual with dementia may experience agitation (Bakker, 2003). Glare, which can be problematic for people of all ages and abilities, can be particularly problematic for those with dementia as it may lead to misinterpretations, especially for individuals who have low vision (Bakker, 2003).

In addition to misinterpretations of stimuli and the environment, delusions and hallucinations are common in dementia. Delusions, fixed, false beliefs that occur in many people with dementia (Smith, 2004), can be due to the individual's misperception that he/she is living in a previous time period or to misunderstanding or misinterpreting the surrounding environment (Smith, 2004). Less common than delusions, hallucinations may also be experienced by those with dementia, most often in the form of false visions, though other senses can be affected too (Smith, 2004).

Touch can be a significant part of interacting with someone with Alzheimer's disease. Interpretation of touch is, however, highly subjective. Reactions to touch can vary from person to person and within a person from day to day or even from one moment to the next. While many people with Alzheimer's may find comfort in the warm touch of a family member, friend, or caregiver, others may not react the same way. It is best

to seek their permission before engaging in any sort of touch (Bakker, 2003). Bakker (2003) suggests that, “knowing who, when, where, and how to touch is key” (p. 49).

Given these changes in sensory perception and how stimulation is interpreted, it follows that overstimulation of people with Alzheimer’s disease can create anxiety, disorientation, and distraction (Alzheimer’s Disease and Dementia: Successful Design Interventions, 2002). Both understimulation and overstimulation can have negative outcomes (Morgan & Stewart, 1999) such as confusion, illusions, frustration, and agitation, thus making it important to consider the amount, type, and variety of stimuli (Bakker, 2003).

1.2.3. Impact of Alzheimer’s Disease-driven Changes on Ability to Interact and Communicate

With further progression into severe Alzheimer’s, cognitive impairments can reach a point where the individual loses the ability to carry on a conversation, though still sometimes uttering words or phrases (Alzheimer’s Association, 2005). Decline in ability to communicate mostly affects the semantic and pragmatic levels of language processing, which are not independent from each other, but rather work together to enable communication (Savundranayagam, Hummert, & Montgomery, 2005).

Semantics deal more with language content, specifically words and their meanings, while pragmatics deal more with language as it is adapted to situations (Savundranayagam, et al., 2005). As such, problems with the former tend to include word-finding and naming difficulties, while problems with the latter deal more with conversational errors such as talking too much and/or at inappropriate times, repeating ideas, and getting off topic (Savundranayagam, et al., 2005). Combined, these

communication problems can significantly affect the caregiving relationship and even level of caregiver burden (Savundranayagam et al, 2005).

Communication problems also make interaction with family members and loved ones challenging. Added to the previously mentioned problems is the complicating factor that Alzheimer's disease robs the individual of his/her persona, personal history, and eventually his/her ability to recognize and interact with others (Yamamoto-Mitani, Aneshensel, & Levy-Storms, 2002). While verbal communication abilities may decline, though, people with Alzheimer's are often still able to pick up on the emotional cues and facial expressions of those speaking to them, and conversely still able to express emotions and feelings, even if they cannot find the right words to do so (Bailey, 1989). The fact remains that reduction in the individual's ability to communicate is likely to play a significant role in their interaction with family and loved ones, and can make these situations quite frustrating and difficult.

1.3 Family Interaction with Individuals with Alzheimer's Disease

Families play an exceedingly important role for loved ones with Alzheimer's disease. Although there is a prevailing belief that family caregiving ends once the person with Alzheimer's moves into a care institution, the reality is that family members generally continue their involvement after the move has taken place. In fact, continued relationship with the loved one who has been institutionalized often holds much significance for family members, with visits being an integral part of the long-term relationship (Yamamoto-Mitani, et al., 2002). In their longitudinal study of family visit patterns with institutionalized elders with dementia Yamamoto-Mitani, et al. (2002) also found that establishing a pattern of frequent visits soon after the loved one is moved into a care facility is important. This study reported that the visit pattern

established in the first year after institutionalization is generally maintained, that the initial visit frequency and length seem to be self-perpetuating, and that, accordingly, efforts to maintain family involvement should start early on (Yamamoto-Mitani, et al., 2002). In another study, this one comparing family involvement with dementia residents in nursing homes versus assisted living facilities, key findings included that some family members wanted advice and encouragement, irrespective of facility type, regarding how they could be more involved in the care of their loved one and that there was a desire to spend more time with the residents (Port, Zimmerman, Williams, Dobbs, Preisser, & Williams, 2005).

Family involvement in care of nursing home residents is vital to the psychological and psychosocial well-being of the resident. As such, family visits do have a therapeutic benefit (Greene & Monahan, 1982; Port, 2004). The quality of family visits directly correlates to the quality of life for people with dementia (Burgener & Twigg, 2002). In addition to benefiting the quality of life of the resident, continued involvement of family members with loved ones in care facilities has implications for the quality of life of the family (Yamamoto-Mitani, et al., 2002). Because of their intimate knowledge of the individual, family caregivers can provide biographical and historical information for and about residents, especially those with cognitive impairments (Port, 2004; Yamamoto-Mitani, et al., 2002). In a study that looked at the experience of caregiving for residents (not specifically those with dementia) living in nursing homes, the knowledge of family context and history that family members bring to the process of caregiving enabled an identity for the resident that was otherwise unknown to staff (Kellett, 1998).

While family interaction and visits are important and may be desired, it has been noted that family members often find it difficult to participate in caring for a loved one with dementia (Kelley, Specht, and Maas, 2000). The reactions of family and loved ones to residents with dementia living in care facilities have been studied. One observation from this work is that family and friends may come together for their loved one out of a feeling of responsibility to monitor care closely and provide a connection to the resident's past. The alternate observation is that family and friends may reduce the amount of contact they have with the resident because they find visiting someone with dementia not to be rewarding personally and even emotionally distressing (Port, Gruber-Baldini, Burton, Baumgarten, Hebel, Zimmerman, & Magaziner, 2001).

Decline in status of the person with Alzheimer's, in particular deficits related to diminished abilities to communicate, account for much of the difficulty families experience in caring for and interacting with loved ones with the disease. In one study, Port (2004) found that the largest group of caregivers, nearly one third, noted that dealing with the resident's cognitive or physical status was the primary challenge they faced. Yamamoto-Mitani and colleagues (2002) note that with an individual's increasing difficulty with interpersonal interactions, visits may become quite challenging and thankless for family members, though some families may feel rewarded by trying to overcome this difficulty. Decreased communication abilities of people with Alzheimer's disease often make family and loved ones uncomfortable when anticipating a visit. People may question what sorts of things they will talk about, what they will do to pass the time and whether the experience will be tolerable as they decide whether or not to visit their loved one (Cohen, et al., 2009; Cohen, 2000). Moreover, family members may not know how to structure a visit or be familiar with techniques to communicate and interact with their loved one (McCallion,

Toseland, & Freeman, 1999). All too often, this uneasiness and apprehension leads to abbreviated visits, if the visits even happen at all (Cohen, et al., 2009; Cohen, 2000). Given the stress associated with decline in communication abilities, it is not surprising that in an exploratory study looking at family members caring for relatives with early stage Alzheimer's, Kuhn (1998) found that communication techniques were one of the top issues of interest for family members.

Given that residents of care facilities with dementia are likely to have decreased ability to engage in certain forms of contact, such as phone calls and written communication (Port, et al., 2001), visits with family and friends are of utmost importance, as they become the main vehicle for contact. However, Alzheimer's disease-driven changes in the individual affect his/her ability to interact and communicate, which in turn negatively affect the interest and ability of family members to visit. This, along with the fact that families often find visiting to become increasingly stressful and difficult (as a result of the decline in communication ability), shows a need for intervention.

1.4 Examples of Interventions and Approaches for Encouraging Communication and Interaction

There is a clear need for interventions in interaction between people with Alzheimer's disease and their families. As noted earlier, specific changes in individuals with Alzheimer's that are due to the disease greatly impact their abilities to communicate and interact, which in turn affects their families and the extent to which families want to visit and feel comfortable doing so. In the late stages of Alzheimer's, when patient deterioration and dysfunction are high, interventions that address issues of personhood and purpose can be quite important (Cohen, 2001). While the person with the disease may no longer be able to convey or experience a sense of self, his/her loved ones and

their memories of the individual become essential in preserving this sense of personhood (Cohen, 2001). Along these lines is the notion of developing interventions that transcend the medical model of problem solving which focuses only on signs and symptoms because this approach does not lend itself well to addressing quality of life and issues of personhood with respect to Alzheimer's (Cohen, 2006). Cohen (2006) suggests going beyond this "two-S patient-centered problem focus to a four-S approach that adds a person-centered focus on potential" and emphasizes "skills (or strengths) that are preserved to varying degrees and also satisfactions (areas, activities, actions that bring a satisfying or pleasurable feeling)" (p. 13-14). This viewpoint can be seen as part of the overarching perspective of nonpharmacological interventions.

While nonpharmacological interventions can be based on a range of theoretical ideas, they share in looking at the interaction among the individual with Alzheimer's, caregivers, the environment, and the system of care, rather than simply considering the patient's disease as the problem (Cohen-Mansfield, 2005). There is a precedent set in treatment plans for other chronic and progressive disorders that even if a disease cannot be cured, prevented, or substantially stopped in its progression, treatments and interventions can still help alleviate some of the symptoms and effects of having such a disease (Cohen, 2001). Cohen-Mansfield (2005) makes the case for creative approaches, saying "nonpharmacological interventions generally provide more personalized care for persons with dementia, addressing their needs, and thereby preventing or treating inappropriate behaviors or decline in function" (p. 140). It is important to note that while there may not be overarching conclusive evidence concerning the effectiveness of nonpharmacological interventions, a wide variety of approaches have been studied and used successfully, despite the inherent difficulties of doing research in this population (Cohen-Mansfield, 2005). Approaches of this sort

can include such things as one-on-one interaction to provide social support and contact, engaging people with dementia through sensory stimulation, self-affirming interventions such as reminiscence therapy, and use of memory books (Cohen-Mansfield, 2005). Just some of the many possibilities for interventions for people with Alzheimer's and their families are presented here.

A number of the interventions cited here focus on family visits, with the objective of finding ways to enhance this form of interaction for all involved. As previously noted, visits are extremely important to both residents and their families, yet may diminish in occurrence and quality with families finding it difficult to continue to have meaningful interaction. McCallion, et al. (1999) studied an intervention known as the Family Visit Education Program (FVEP), which sought to improve the quality of interaction between dementia residents in a nursing home and their loved ones. The program addressed the areas of both verbal and nonverbal communication as well as effective structuring of visits. It consisted of group sessions supplemented with family conferences to promote education that was tailored to the level of dementia of each resident, incorporating observation of interaction between families and their loved ones with feedback given to the family members. Over the course of the program, families learned about dementia and its effects, discussed and engaged in role play activities related to effective and ineffective verbal and nonverbal communication techniques, were encouraged to create and use a memory album or other aid, were able to give feedback on what was learned, had opportunities to ask questions and share their experiences, and were given suggestions specifically related to their visits. Family members indicated that the program had a significant impact on residents and commented on how it helped them, specifically noting renewed feelings of being able to communicate and/or connect with their loved ones. This study is indicative of the

idea that educating families about communication techniques can positively affect resident's mood and interactions between residents and their loved ones (McCallion, et al., 1999).

Sancier (1984) looked at the Family Support Group model, another intervention targeting families and their feelings towards a relative in a nursing home. This model consisted of four sessions, the second of which focused on visits and aimed to help family members find ways to make visits mutually satisfying. This session specifically was meant to serve as a skill-building exercise to help family members learn to deal with personal feelings during and after visits and to provide sensory stimulation for their loved ones. Families incorporated suggestions for enriching their visits, tying them in with their own personal experiences as a way to preserve their valued relationships with the residents (Sancier, 1984). While this intervention was not specific to people with Alzheimer's disease, it is still relevant to the present study for its focus on family visits and preserving the relationship between residents and their loved ones.

Other interventions have been developed that particularly focus on education of family members of people with Alzheimer's. Educational interventions which largely aim to reduce distress or burden experienced by caregivers, increase knowledge, and/or improve coping skills generally have been successful, at least in the short-term, at reducing burden, anxiety, and depression among loved ones of people with Alzheimer's (Kuhn & Fulton, 2004). One such program, known as the Alzheimer's Disease Knowledge Building Program, is comprised of a five-part curriculum that is intended to increase participants' knowledge about key medical, legal, financial, and psychosocial aspects of Alzheimer's disease and to enhance coping skills (Kuhn &

Fulton, 2004; Kuhn, 1998). This intervention was found to succeed at increasing family members' knowledge about Alzheimer's, improving their self-efficacy, and decreasing their level of distress about disease-driven memory problems seen in their loved ones (Kuhn & Fulton, 2004). It seems that when families learn about the disease and get a better understanding of how it progresses, they may be able to deal better with the significant decline seen in their loved ones.

Given the declines among individuals with Alzheimer's in their ability to communicate and the difficulties this leads to with respect to visits and interaction with family, it is clear that interventions aimed at helping family members explore different techniques for communication are vital. It has been suggested that interventions should aim to prevent further declines in communication and to maintain the highest level of communicative function, while teaching caregivers about the gradual decline of communication and exploring strategies for managing such impairments (Tonkovich, 2005). Additionally, Tonkovich (2005) points out that interventions should focus on process and strategies rather than on tasks or repetitive drills, noting that caregivers need preparation in how to cue people with dementia and how to manage specific situations. Ripich (1994) employed a set of communication suggestions known as FOCUSED, an acronym for the techniques: Face the person, Orient to the topic, Continue on the topic, Unstick communication blocks, Structure the questions, Exchange conversation, and Direct question usage. People with dementia often maintain communication success with decreased agitation and frustration when strategies are used that look at their specific communication needs and those of their loved ones (Tonkovich, 2005).

One example of an approach that incorporates techniques for communication is the Family Involvement in Care Protocol, developed by Kelley, et al. (2000), which is a research-based intervention with the goals of promoting quality care for those with dementia and aiding family members in attaining meaningful and satisfactory caregiving roles. This program involves four phases, the second of which deals with education of all caregivers with regard to principles of family caregiving for individuals with dementia, including communication and visit strategies (Kelley, et al., 2000).

In yet another example, Hansen, Patterson, and Wilson (1988) describe the Resident Enrichment and Activity Program, an intervention aimed at providing family members with a more active and meaningful role in interacting with residents with dementia. Within this program, family members were involved in the overall operation of a dementia unit in a care facility and the care planning for their relatives. Different family volunteers ran activities and programs, giving family members structured opportunities to interact with their own relative as well as with other residents on the unit. Several of the family members felt their programming to be therapeutic given that it offered residents opportunities for mental stimulation. While all of the family volunteers were primarily concerned with spending time with their own relative, they also felt positive about interacting with all the residents (Hansen, et al., 1988). This example is a fairly intensive program that actively involved families in the care of their loved ones. Such involvement may not be possible on a widespread scale.

A number of interventions focus on the use of sensory stimulation, largely as a means of engaging people, both within the context of visits and in general. One such approach involves Snoezelen Multi-Sensory Environments, which incorporate

materials and products that offer a range of sensory experiences (Snoezelen). The name “snoezelen” is a contraction of two Dutch verbs, “snuffelen” and “doezelen” which mean to seek out or explore and to relax, respectively (Snoezelen). With the many snoezelen products, various arrangements and configurations can be created based on what sort of experience is desired, ranging from multi-sensory ones to those that focus on a single sense (Snoezelen). Although Snoezelen Multi-Sensory Environments are geared toward people of all ages and abilities, a primary area of research regarding this approach pertains to its use with older adults with dementia (Snoezelen). Snoezelen environments stimulate the primary senses and can have a calming effect on those who use them, while also offering the potential for those with Alzheimer’s to connect with loved ones or caregivers (Cohen, 1999). The experience is tailored to the individual, catering to his/her specific needs and abilities, and is designed to be stimulating, while not overwhelming (Cohen, 1999). In an overview of studies looking at the use of snoezelen with people with dementia, Lancioni, Cuvo, and O’Reilly (2002) note that one of the reasons for the popularity and success of this type of intervention is that it is found to be pleasurable, friendly, and highly humane.

Other interventions using sensory stimulation may focus on specific senses. In one study regarding sensory stimulation activities with people with Alzheimer’s disease, Witucki and Twibell (1997) looked at the effects of sensory stimulation activities of music, touch, and smell and found that these activities yielded lower discomfort levels and an increase in psychological well being. The sensory stimulation activities were experienced along with social interaction (Witucki & Twibell, 1997), supporting the notion that sensory stimulation may be a useful approach during visits. Music in particular seems to have significant potential for stimulating and engaging individuals with dementia. Bakker (2003) notes the capability of music to be a powerful tool for

connecting with someone with dementia given that familiar music can invoke memories and feelings. Chavin (2002) asserts that “music is universal, but it is not a universal language,” addressing the fact that “music is powerfully able to communicate thoughts and emotions, both verbally and non-verbally” (p. 145). Music is commonly understood to differ from other means of expression and/or communication, given its high emotive quality and ability to convey mood and feeling (Chavin, 2002). From research, Chavin (2002) concludes that when used in the right way, music can influence mood, behavior, speech, interaction with others, and ability to perform daily activities. A study by Brotons and Marti (2003) looking at the effects of music therapy with respect to Alzheimer’s patients and their family caregivers (spouses) found positive changes—more than half of the caregivers observed improvement in the patients’ social behaviors and emotional state. The caregivers, too, benefited greatly from the music therapy. All participants agreed that music was positive because it helped them to relax, many mentioning that it offered them a space that was pleasant and enjoyable where they felt they could express feelings previously kept inside (Brotons & Marti, 2003).

Another approach related to sensory stimulation involves the use of images and photographs. Photographs, specifically personally meaningful ones, have been reported to have a positive effect and serve as a way to connect with older adults living in long-term care environments. Cohen, et al. (2009) asserts that personal images are more likely than non-personal ones to be recognized by and be meaningful to people with Alzheimer’s disease. Koretsky (2001) advocates for the use of photographs with older adults in care facilities with memory deficits, noting that the images can often help people remember or recognize someone familiar and whom they care about, which can be particularly important when in a place that inherently seems unfamiliar. Additionally, photographs from the past can allow people to

reminisce about pleasant times in their lives, while those from the present may help people relate to their current situation (Mizen, 2007). Albums can also help by giving information about individuals to care professionals, specifically as part of reminiscence therapy which aims to empower the individual and provide pleasure (Mizen, 2007). Koretsky (2001) notes the ability photography has given people “to freeze a moment in our lives, making it more tangible across time and space... to pass moments down to future generations” (p. 8). As such, she encourages using memory books and preserving photographs digitally not only for people to look at now, but also for generations to come (Koretsky, 2001).

This idea of preservation ties into the exceedingly important role photographs can play as a means of providing biographic information about a person with Alzheimer’s. This role is of prime importance given that with Alzheimer’s disease, people lose a significant amount of their memories, losing not only their own recollections, but also their ability to share their personal histories with others (Cohen, 2000). Along these lines, the life stories of people with dementia are too often unknown to those around them. Additionally, families struggle with how to converse and interact with someone whose ability to recall and express themselves is so diminished (Cohen, 2002). Two specific interventions focus on this idea in particular, and employ the previously mentioned “four-S” approach, incorporating areas of satisfaction and areas of strengths or preserved skills.

The first intervention, known as Therapeutic/Restorative Biographies, or TR-Bios, employs video biographies (Cohen, 2000; Cohen, 2002). TR-Bios are created using videotaped snapshots of old photographs paired with explanations and narrations by family members, allowing the biographies to incorporate both visual and auditory

stimulation. As such, TR-Bios have the potential to become dynamic home movies, using images that are selected because they are likely to tap into the person's memory. Visits can then be structured around residents and family members watching the videos together, using the images and accompanying commentaries as a way to guide their interaction. Alzheimer's care facility residents and their families can spend time together in a way that potentially reduces family anxiety about what to do during a visit. Additionally, since the TR-Bios are watched on a television screen, the images can be seen much larger than they would be as a standard photograph or in an album. An additional intended benefit to the video biographies is that staff, volunteers, and others who do not already know about an individual's personal history can learn about his/her life, thus making the caregiving experience more personal. While these videos do not claim to improve the memory of someone with Alzheimer's over time, memories seem to be enhanced during visits. This enhancement has been shown to have a positive effect on the experience of both residents and visitors (Cohen, 2002; Cohen, 2000). A secondary result of the creation of video biographies is the idea that families are left with an organized record of memories and family history, even after the person with Alzheimer's passes away (Cohen, 2000). One facet of the success of this sort of intervention is its ability to structure time in a meaningful way with pleasant and satisfying events or activities and connecting with residual memories, so as to create time intervals that might otherwise be marked with agitation and stress (Cohen, 2000). While improved mood and diminished agitation of the resident were seen in the period of time immediately following watching the video, family and staff also had high levels of satisfaction with the intervention (Cohen, 2000). This represents just one creative approach to presenting and engaging with biographical information. It goes beyond simply the use of photographs and albums, tying these

together to convey a life story in a dynamic and engaging way that family members can share in together.

Another creative intervention based on the underlying principle of presenting biographic information and promoting engagement and interaction is a game developed specifically for people with Alzheimer's disease. The game, known as Making Memories Together, aims to alter in positive ways the experience of the devastation associated with Alzheimer's for both those with the disease and their families, while also providing meaningful one-on-one interaction (Cohen, et al., 2009). Making Memories Together is a noncompetitive, collaborative game in which everybody is on the same team moving a single game piece, a small beanbag, around the board. The playing board is colorful and has four different categories of squares: people, animals, places & special events, and favorite objects. These same categories, and their respective colors, correspond to those employed in the deck of Memory Cards used to play the game. When the group lands on a space, a Memory Card of the same color is selected and discussed. Memory Cards, which have been made beforehand by family, loved ones, and possibly with the help of volunteers, incorporate a personal picture on one side and text on the other explaining the image. There is no preset ending space to the game, as it can be determined at the time of play, and there is no winning or losing in the conventional sense. It is suggested that the end of the game be associated with a special treat given to the person with Alzheimer's. A significant point about the Memory Cards is that since they have explanatory text on one side, they can function like flash cards, and prior knowledge of the image is not required in order to play the game (Cohen, et al., 2009; Cohen, 2000). This feature of explanatory text accompanying images offsets the fact that the people with Alzheimer's have increased difficulty recalling and conveying

information about their life history. Additionally, it means that the game can be played not only with family and loved ones who are likely to be familiar with this biographic information but also with staff, volunteers, and others who do not already know the background of the individual. The game actually can teach care staff about the individual whom they are caring for or spending time with, thus making the caregiving experience more personal and meaningful (Cohen, et al., 2009). This game, like the TR-Bios, can give structure to a family visit and script topics for discussion, thus decreasing the family's anxiety associated with feeling the need to come up with things to talk about and/or do. Not only are topics of discussion available with each turn during the game, but also images and cues on the Memory Cards are at hand to help spur conversation (Cohen, et al., 2009). Using both formal assessment and assessment by family members, Cohen, et al. (2009) found overwhelming support for their hypothesis that the game would enhance both the quality of life for the resident and quality of the interaction during the visit. A very high level of visitor interest was observed and also found with the positive self-assessment by the family members themselves, supporting the idea that this type of visit had significantly heightened appeal for the family. Also of note is the fact that when families had played the game for the amount of time required for the study, most did not want to stop playing, with many continuing the game for another half hour (Cohen, et al., 2009).

As evidenced here, the realm of possibilities for interventions for facilitating interaction between those with Alzheimer's and their families is practically limitless if creativity is employed and attention is given to the human and personal aspects of the disease rather than simply to its medical symptoms. Given the significance of family visits and their potential as a point of intervention, finding ways to enhance visits, making them more enjoyable and rewarding for everyone involved, is of utmost

importance. Although many thoughtful and creative ideas have been presented here, most overlook aspects of the physical environment and the role it can play in hindering or supporting visits. Research indicates that an improvement to the experience of visiting might involve providing a place to sit during visits other than the resident's bed (Port, 2004). Attention to the setting might help to encourage more family members and loved ones to take part in visiting together, something that has been noted by caregivers to be difficult (Port, 2004), and that might help alleviate some of the anxiety associated with unstructured visits. Many of the concepts relevant to the previously mentioned interventions also helped guide the development of the intervention presented here, the Family Visit Program.

1.5 Family Visit Program

The Family Visit Program consists of four components: conversation corner, digital picture frame and stand, image selection process, and orientation process and communication strategies. This program is an example of evidence-based design, meaning that the design and development of the components employ concepts interpreted from reported evidence previously described.

1.5.1 Component 1: Conversation Corner

The conversation corner is a seating unit designed as an upholstered curved bench with a high back and canopy. It is intended to be a setting for family visits within a larger public space in a care facility. The design of the conversation corner was informed by ten concepts.

Concept 1-A: Line of sight

An idea central to the design of the conversation corner is that participants be able to look both at each other and at the stimuli (images on the digital picture frame), and switch between the two with relative ease. Because the conversation corner is intended for use during visits, accommodating the ability for residents and their families to look at each other is quite important. Having eye contact when conversing, particularly with an elderly person likely to have a hearing impairment, was a logical detail to consider in the design of the conversation corner. Equally important during visits is the ability to see the central source of stimulation, images on the digital picture frame. It is the curve of the bench that accommodates the line of sight view among people sitting in the corner as well as ease of switching view to the digital picture frame. Illustration 1.1 shows the conversation corner in use during a visit and shows participants looking at each other and those looking toward the digital picture frame



Illustration 1.1 Line of Sight and Touch. The design of the conversation corner considered line of sight—related to participants being able to look at each other and at the images on the digital picture frame, as seen here. The picture also shows the potential for touch designed into the conversation corner.

Concept 1-B: Touch

Another key aspect of the conversation corner design was the opportunity provided by the continuous bench for physical contact and loving touches among family members. Touch can be a valuable part of interacting with people afflicted by Alzheimer's disease given their decline in communication ability. Touch can reinforce meaning and convey emotions even when words cannot, though reactions to touch can vary greatly from person to person (Bakker, 2003). The design of the conversation corner intends to accommodate touch through such features as the continuous curved bench. Illustration 1.1 depicts two participants touching each other, with the arm of one resident around the shoulders of another resident, his wife.

Concept 1-C: Standing support – folding armrests

Armrests were designed as part of the conversation corner to offer support for the resident when standing up from a seated position. When not in use, the armrests tuck completely into the seat back and are covered with a flap of matching upholstery, thus putting the armrests out of view and out of the way. The armrests are depicted in Illustration 1.2. This feature allows the conversation corner to avoid one of the pitfalls of long sofas, armrests only at opposing ends. When sitting in the middle seat of a sofa, there are no arms directly next to the sitter to assist in standing up from a seated position. On the other hand, armrests distributed along a sofa would not allow family and residents to sit as close together. The fact that the armrests of the conversation corner can be pulled down when needed but be out of the way when not needed, allows for the best of both worlds—one can use the armrests as support when standing, but also sit as close to a loved one as desired with the armrests folded out of the way.



Illustration 1.2 Armrests. When needed for standing support, armrests are available on either side of the middle seat. When not needed, they stow neatly into the seat back, covered by a fabric flap of matching upholstery.

Concept 1-D: Transfer from wheelchair – flip-up seats

The outer seat on each end of the conversation corner can be flipped up to allow a wheelchair to get close to the middle seat and thus enable side transfers between wheelchair and middle seat. This can be seen in Illustration 1.3. Accommodation of transfer between seat and wheelchair is necessary given the frequency of use of wheelchairs in adult care facilities.



Illustration 1.3 Flip-up Seats. The outer seats of the conversation corner flip up to accommodate transfer from a wheelchair to the middle seat.

Concept 1-E: Intimate scale

The scale of the conversation corner was designed to be intimate. The intent was to bring down the scale of the larger room where the conversation corner was located to a smaller and more intimate scale. Along these lines, the intervention aims to provide a more private setting for visits within a public space, serving as an alternative to the common practice of using resident rooms for family visits. While visits within the resident room provide desired privacy, having to sit on the resident's bed makes for an uncomfortable context for visits, particularly when more than one family member is present (Port, 2004). Because family members prefer not to come alone to visits, accommodating larger groups improves family members' perceptions of visit quality (Port, 2004). While the scale of the conversation corner is intimate, it can accommodate up to four adults.

Concept 1-F: Acoustical zone

The conversation corner was designed to enhance the ability of family members to hear conversation during visits. This enhancement is particularly important to the elderly residents, members of a population segment prone to hearing loss. The design intent was to keep the sounds of conversations in and minimize intrusion of sounds from outside of the corner, accomplished through the use of acoustically reflective wooden side panels, the high, upholstered seat back, and the fabric canopy. These features reinforce the idea of the conversation corner creating a private area within the larger context of a public space in a care facility.

Concept 1-G: Screening distractions

The design of the conversation corner was intended to help screen out competing sources of visual stimulation and distraction. Screening distractions goes hand in hand with the idea of having a central focus for the visit—the images on the digital picture frame. The design of the conversation corner aims to buffer outside distractions through use of the wood end panels, the high back, and the canopy overhead. Given the declines in cognitive abilities and sensory perception associated with Alzheimer's, controlling the level of stimulation is of prime importance as both under- and overstimulation can be problematic (Bakker, 2003). By buffering outside distractions, the conversation corner can help promote the resident's focus on displayed images.

Concept 1-H: Comfortable seating posture—height, back angle

The contour of the bench seat was designed for postural comfort during the act of viewing images on the digital picture frame. Seat height and seat depth were designed to accommodate a fifth percentile female, given that the majority of care facility residents are elderly women. Seventy four percent of nursing home residents age 65

and over are women according to the National Nursing Home Survey (as reported by National Center for Health Statistics, 2007), many of whom are of small stature. The seat back angle was designed for comfortable sitting, while ensuring that a person could lean forward with ease to see the details of images on the digital picture frame. The upholstery was intended to be sufficiently firm to prevent the occupant from sinking into the seat, as sometimes happens with conventional sofas. Excessively soft upholstery can make leaning forward and changing seating position difficult. The firmness of the upholstery can also prevent sinking so far into the seat that it is hard to stand up, another issue sometimes experienced with conventional sofas. Illustration 1.4 shows how the conversation corner allows for postural changes such as leaning back in the seat and leaning forward toward the digital picture frame.



Illustration 1.4 Seat Posture. The conversation corner allows for ease of postural change. The image on the left depicts the older woman leaning somewhat forward toward the digital picture frame, while the image on the right shows her leaning back in the seat, while still looking at the images.

Concept 1-I: Reach range

The conversation corner was intended to enable participants comfortably and easily to reach the stand/screen. Features designed to support this concept include shallow seat

depth to allow the display stand to be pulled in close to the viewer and intermediate seat back angle that is comfortable but allows the occupant to lean forward with ease to see and manipulate the display stand. A related feature is the design of unobstructed space beneath the front edge of the seat to allow rolling room for the mobile base of the stand. This feature was intended to allow the digital picture frame to be rolled within close reach range without the base of the stand hitting the furniture.

Concept 1-J: Aesthetics

The aesthetic concept for the conversation corner aimed to strike a balance between simplicity—a design that is not comprised of distracting visual elements—and sophistication—a design that does not talk down to the residents or family members and that is not childlike. Once again, this ties in with the idea of providing for an experience that is not overstimulating, while also addressing the notion that designs for those with Alzheimer’s should not be dumbed down to the point where features become juvenile and undignified. Giving the conversation corner a sense of warmth so it would feel cozy and inviting to sit in was also considered important. Ideally, the conversation corner should feel like a place people want to sit, regardless of their participation in the program. Along these lines, the way the seating unit appears from the outside should match the feeling of the experience of being in it.

1.5.2 Component 2: Digital Picture Frame & Stand

The digital picture frame and stand serve as the primary source of stimulation around which a visit is focused. The design of the digital picture frame and stand was informed by four concepts.

Concept 2-A: Focus attention with frame

The wood used to surround the digital picture frame was designed to help focus attention on the screen and the images. The wooden frame was intended to add warmth to the digital picture frame, making it seem familiar and personal. Beyond this, it was also intended to help separate the displayed images from other objects in the room that might be seen in one's peripheral view when looking at images on the digital display. This separation can help with buffering outside distractions such that focus may remain on the activity at hand. Illustration 1.5 shows the wooden frame surrounding the digital picture frame.



Illustration 1.5 Wooden Frame. The wood frame surrounding the digital picture frame creates a border and is intended to help focus attention.

Concept 2-B: Control

The idea of control was extremely important in the design of the digital picture frame and stand. Control manifested itself in a number of ways, many of which can be seen in Illustration 1.6. Large handholds built into the leading edge of the stand were intended to enable families to control the location and facing direction of the screen. The implementation of these handholds, cutouts within the stand, makes them not only easy to grab onto, but also inviting to touch, thereby encouraging interaction with the



Illustration 1.6 Digital Picture Frame and Stand—Control. The digital picture frame stand incorporates large handholds that can be used to move or rotate the stand. Arrows indicate how the stand swivels, how the digital picture frame can be tilted, and how the height can be adjusted. The five-star caster base allows the stand to be easily rolled. The remote affixed to the stand in front of the screen can be used to control the duration of image display.

stand by families and residents alike. Wheels on the base of the stand were provided so families could move and adjust with ease where the stand was located. This not only allows for the stand to be brought as close as desired for image viewing, but also to be moved out of the way when the visit is over. A swivel stem, with integral gas-lift mechanism, that connects the base of the stand and the digital picture frame can be

used to adjust the height of the screen. The swivel stem also enables families to adjust the direction the screen faces. The screen can be turned without having to adjust the whole stand, and can be done with relatively little force, thus making this feature accessible to even frail residents or young children. A hinged tilt mechanism that attaches the screen to the stand was intended to allow family members to vary the viewing angle of the screen. The forward and back navigation buttons on the remote that was affixed to the stand were provided so families could control how long each image remained on the screen. All other buttons on the remote were covered so as to reduce confusion and distraction.

Concept 2-C: Aesthetics

The wooden frame and stand for the digital picture frame used specific aesthetic concepts in their design. These included use of natural wood to add warmth and soften the otherwise technological features of the digital picture frame. The wooden frame and stand were intended to be elements that both residents and families would be attracted to and would feel comfortable interacting with. Another concept was to design features that expressed how the stand should be manipulated, thus making use of the stand and frame intuitive. The integrated handholds on the leading edge of the stand are an example of an implemented control that can be used without explanation.

Concept 2-D: Display to compensate for progressive Alzheimer's disease-driven decline in sensory capability

In this study where a goal was to compensate for progressive Alzheimer's disease-driven decline in sensory capability, three features of a 15" digital picture frame made it appropriate for use as the display medium. The features were generous image size, good image contrast because of integral lighting, and ability to control duration of

image display. With a 15” diagonal screen, the size of digital images tends to be significantly larger than the size of the original photographs. This increased size can help mitigate many of the Alzheimer’s disease-driven issues with vision described previously in this chapter. Additionally, with larger images, details that might otherwise go unnoticed can be seen and discussed. Having good image contrast due to integral lighting again helps to offset vision problems associated with the disease. Of specific importance is the fact that it negates glare, as an external source of light is not needed. As noted previously, glare is of particular concern given its potential to cause illusions and agitation for people with Alzheimer’s disease. It is relevant to mention that the non-glare surface of the screen helps reduce the likelihood of unwanted illusions and distractions. Lastly, the digital picture frame can be run in both automatic and manual slideshow modes, the latter of which was selected for use. In this mode, families can adjust the duration of image display, looking at and talking about each image for as long as desired and choosing when to advance to the next image. This allows the visits to be individualized—families can dwell on certain images longer than others as is comfortable.

1.5.3 Component 3: Image Selection Process

Image selection is a process the families were asked to go through prior to meeting with the researcher. In advance of this meeting, families were given guidelines and recommendations to direct their thinking and efforts while selecting images. The image selection process in itself is viewed to be a potentially thought provoking and emotional experience. Development of the image selection process was informed by two concepts.

Concept 3-A: Sources and quantity of images

In selecting images, families were advised to look at a variety of sources, including photographs, photo albums, and slides, as all of these could be scanned into digital images. Additionally, families were given the recommendation to choose approximately 30 images, a number that would likely suffice for a reasonable visit.

Concept 3-B: Image selection considerations

When selecting images, families were encouraged to consider the following. First, they were asked to think about the meaning of images to the resident in order to select images that will elicit a positive reaction. One of the underlying ideas of the use of images is to tap into long term memories, especially those associated with positive emotions. The use of personally meaningful images directly relates to the fact that people with Alzheimer's have been shown to respond more to personal and emotional stimuli than to that without personal significance (Abrisqueta-Gomez, et al., 2002; Fleming, et al., 2003; Cohen, et al., 2009). Families were also encouraged to think about the resident's life as a story with chapters, and to select images that represent different chapters, ranging from, for example, the resident's childhood or early life, to more recent years including children and/or grandchildren. By doing so, a more complete life story can be developed. Additionally, images from a range of times in the resident's life may increase the likelihood of image recognition and/or response. Thirdly, families were strongly encouraged to consider their own familiarity with and ability to talk about images, especially those that precede their memory, in an effort to prevent a situation in which neither resident nor family can recall anything about a picture and have nothing to say about it. Illustration 1.7 shows a subset of images selected by one family that draws from various time periods or chapters of the resident's life.



Illustration 1.7 Family images. A subset of images selected by one family that represent a number of chapters in the life story of the resident.

1.5.4 Component 4: Orientation Process & Communication Strategies

The orientation process consists of a preparation meeting held with individual families during which images were scanned and communication strategies were discussed. To facilitate this discussion, a printed copy of these communication strategies was given to the families, which they also could take home and review. The idea behind the orientation process was that having specific strategies for using images to enhance communication and interaction could make for a better flow during the visit. Additionally, given the decline in communication ability among people with Alzheimer's, having ideas for ways to interact with them might be helpful. Along with the specific list of communication strategies delineated to families, two additional resources were pointed out to them, if they had interest in reading more about

communication with loved ones with Alzheimer's disease. The two sources were *Learning to Speak Alzheimer's* (Coste, 2003) and *Talking to Alzheimer's: Simple ways to connect when you visit a family member or friend* (Strauss, 2001). Development of the orientation process and communication strategies was informed by four concepts.

Concept 4-A: Recognition ability

Image recognition—the ability to identify, name, and place into chronological context the contents of an image—is relevant but not an objective of the Family Visit Program. Conversation about images should not be dictated or limited by correct image recognition. Instead, the emphasis of the visit should be to use whatever is recognized as a basis for evoking positive emotions. To this end, families were encouraged to allow time for exploration of images by the resident in order to tap into long term memories and deeply held emotions. Family members were also encouraged not to be overly focused on making factually accurate connections for each image.

Concept 4-B: Interacting in the moment

Interacting in the moment is how people with dementia come to operate (Alzheimer's Association, 2008), given their progressively diminished short term memory.

Associated with interaction in the moment is the potential for an altered sense of reality in the minds of people with dementia (Coste, 2003). The challenge for family members is to connect with their loved ones on both of these levels. Interacting in the moment and within the resident's sense of reality were discussed with families during the preparation meeting as communication strategies. As important as it is, the idea of interacting and living in the moment can be quite hard for family members to grasp and apply during their visits with loved ones with dementia. Emphasis was given to avoiding reliance on (the resident's) short term memory and resisting the tendency of

families to correct residents if they make factually inaccurate comments. Emotional connections and enjoyment of being together supercede facts.

Concept 4-C: Agitation

Along with communication strategies, it was considered important to talk with families about agitation experienced by their loved ones. Family members were encouraged to be vigilant for signs and causes of agitation, specifically whether or not it is related to an image, and then respond accordingly. Because agitation can be caused by any number of factors, families were also encouraged to address the source of agitation and try to help the resident move beyond the feeling of agitation.

Concept 4-D: Have fun

The idea of having fun during the visit was of utmost importance in enabling a family visit to be a positive experience for all involved. A spirit of having fun relates well with all of the other communication strategies. Although the notion of having fun should go hand in hand with the idea of visiting, this may not always be the case, especially if visits become connected with feelings of anxiety and apprehension on the part of family members. Families participating in this study were encouraged to come to the visit with a mindset of having fun, anticipating that the visit will be an enjoyable experience.

1.6 This Study—Pilot Research

This thesis represents exploratory research regarding the Family Visit Program. The intent was not to test hypotheses, but instead to identify a range of issues surrounding family visits with people with Alzheimer's disease living in care facilities. More

specifically, the intent was to gain understanding about the components designed and developed as part of the Family Visit Program.

CHAPTER 2

METHODS

2.1 Introduction

This thesis represents work done as pilot research for further study of an intervention pertaining to family visits with people with Alzheimer's disease. As such, there are not set hypotheses, but rather the study serves as a way to explore the potential of the Family Visit Program.

2.2 Research Components and Design

2.2.1 Research Components

The study was comprised of four major research components: the conversation corner, the digital picture frame and stand, the image selection process, and the orientation process. These were all designed and developed using research-based concepts as delineated in Chapter 1.

2.2.1.1 Component 1: Conversation Corner

The conversation corner served as the setting for the visits. As a seating unit, it employs an upholstered curved bench with a high back, a canopy, and partitions at each end, as seen in Illustration 2.1. It can comfortably accommodate up to four adults, and allows occupants to sit in it in a variety of postures such as leaning back, leaning forward, and sitting sideways.



Illustration 2.1 Conversation Corner. The conversation corner encompasses an upholstered curved bench with a high back, canopy, and partitions at each end.

2.2.1.2 Component 2: Digital Picture Frame & Stand

The digital picture frame that was used for the study has a 15” diagonal screen and can be operated in either automatic or manual slideshow modes. For the purposes of the study manual mode was selected to allow families to go through the pictures at their own pace. This was the case for all visits except one in which technical difficulties ensued and automatic mode had to be used. With the automatic slideshow mode, each image was shown for ten seconds before advancing to the next image. In both automatic and manual modes, the set of pictures cycles back to the beginning after showing all images, allowing people to go through the images as many times as desired. The digital picture frame was controlled by a remote that was affixed to the

custom-built stand, with all but the forward and backward navigation buttons covered, so as to reduce confusion and promote intuitive use for participants. The screen and remote of the digital picture frame can be seen in Illustration 2.2.

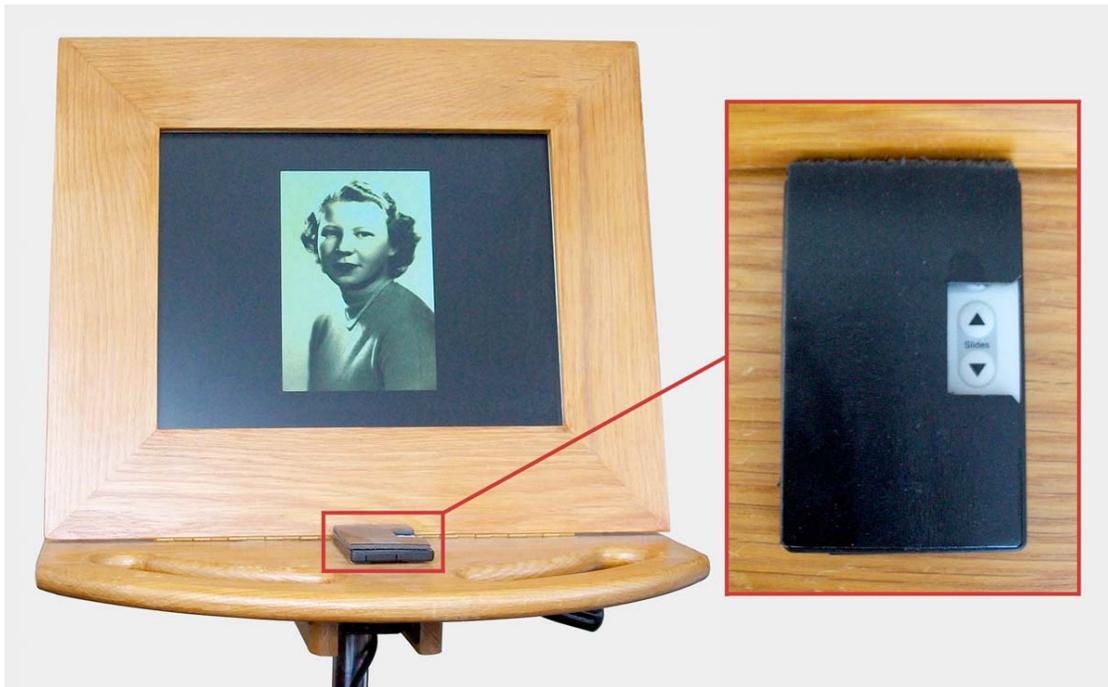


Illustration 2.2 Digital Picture Frame. The 15” diagonal screen of the digital picture frame is shown displaying an image selected by one of the families. Also shown is the wooden frame and stand with a close-up of the remote affixed in front of the digital picture frame.

The stand for the digital picture frame was also designed using concepts. It was made of oak wood that was finished with a shellac and golden oak stain mix. The stand consisted of a horizontal surface with handholds along with a wooden frame housing the digital picture frame attached with supports and a hinge. This was connected to a rolling five-star base salvaged from a drafting stool, which included the gas-lift stem that had been used to raise and lower the seat. The casters attached to the base allowed the stand to be moved by rolling and the stem allowed the height of the screen to be adjusted. The screen could be swiveled by rotating the digital picture frame on the

stem and the angle of the screen could be adjusted by tilting it on the hinged mechanism that attached the digital picture frame to the horizontal surface of the stand. Illustration 2.3 shows the digital picture frame and stand and its mobile five-star base.



Illustration 2.3 Digital Picture Frame Stand. Features of the digital picture frame stand seen here include integral handholds, gas-lift stem, hinged screen, and mobile base.

2.2.1.3 Component 3: Image Selection Process

Image selection was a process the families were asked to complete prior to the preparation meeting for the visit. In advance of the preparation meeting, families were given guidelines to direct their thinking and efforts as they selected images. The guidance provided was for families to select photographs and/or slides that they felt

would be personally meaningful to their loved ones, making the image selection process something that in itself could be a thought provoking and emotional experience. In addition to guidelines about the types of images to select, a recommendation was also made that family members select approximately thirty images, as that seemed to be a number that could offer sufficient variety during a visit without being overwhelming and/or exhausting for participants. A copy of the letter delineating suggestions for the image selection process can be found in Appendix B.

2.2.1.4 Component 4: Orientation Process & Communication Strategies

The orientation process consisted primarily of a list of evidence-based as well as tacit knowledge-based strategies pertaining to communication with people with Alzheimer's disease and other dementias. This list was discussed with family members at the preparation meeting prior to the actual visit and a copy was given to each family to review at home and share with any other family members who might be coming to visit. The compiled list of communication strategies can be found in Appendix D. At the preparation meeting, an explanation was given of features of the conversation corner and the digital picture frame stand and how to use and control each feature.

2.2.2 Research Design and Structure

The research was structured to study and evaluate the previously explained components, specifically within the context of family visits with loved ones with Alzheimer's disease living in an assisted living facility. As such, families were involved with each component of the Family Visit Program and were asked to give feedback on each component.

The process of contacting families began with a letter that briefly described the project and inquired about interest in participating in the study. The letter, a copy of which can be found in Appendix A, was followed by a phone call in an effort to make the invitation to participate in the study feel personal. During these phone conversations, if family members agreed to participate, the face-to-face preparation meeting with the family was scheduled. Prior to this meeting, the researcher corresponded with the families in a letter that gave more information about the project and included the guidelines for image selection. This letter also addressed the need for consent forms to be filled out. Included with the letter were copies of both the family and resident consent forms for them to review prior to our preparation meeting. Copies of the pre-preparation meeting letter and consent forms are located in Appendix B and C, respectively.

The next step in the process was the preparation meeting between the researcher and the family. Three of them took place at Longview, the care facility where this research was conducted (described later on in this chapter), while one was conducted at a family member's place of work. The location was chosen based on convenience for the family members. The family members brought their pre-selected photographs and slides, with the understanding that the images would be scanned at the meeting. This detail avoided the issue of the family having to entrust their valuable images to the researcher. During the meeting, the consent forms were reviewed with the family members, any questions or concerns they had about the project were answered or addressed, and each family member present was asked to sign a consent form. After the forms were signed and the images were scanned, the researcher proceeded with the orientation process for the family. This involved discussion about ways to think about using images to structure the visit. The list of communication strategies was given to

the family for review and consideration as well as for them to share with other family members who might come to the visit. A copy of the list of communication strategies is located in Appendix D. Features of the conversation corner and digital picture frame/stand were also mentioned in order to familiarize the family with those components of the study, however no images of the conversation corner or digital picture frame/stand were shown nor did any of these meetings involve interaction with the physical components. Between the preparation meeting and visit, the scanned images were cropped and adjusted, and then loaded onto a memory card that would be inserted into the digital picture frame at the time of the visit.

During the preparation meeting, one visit was scheduled for each family. These visits took place some time between one week and one month following the preparation meeting, depending on the family members' schedules. When families came to Longview for their scheduled visit, they met with and brought their loved ones to the conversation corner in the lounge. The families briefly talked about the project with their loved one(s), who then were asked to sign the consent forms, some needing the help of their family to do so. Sitting in the conversation corner, the families then had their visit, looking at images on the digital picture frame and talking about them. These visits were both video and audio recorded, with the researcher and her assistant(s) present. Families had been told that they need not worry about getting through all the pictures and that they could stop at any point, but all families did look through all of their images.

Immediately following the visit, the researcher conducted a short interview with the resident(s) in the conversation corner. The resident interview consisted of questions about their visit experience, specifically visiting in the conversation corner and

looking at images on the digital picture frame. After the resident interview, the family members were interviewed either in or near the conversation corner. It was originally intended for residents not to be present at all during the family interview, but in reality, all remained present, though some were in another part of the room or not paying attention. The family interview was longer than the resident interview and again included questions about the visit experience, but also included questions about the other components of the program. At a later date, Longview staff members were also interviewed. The questions asked to staff were related to the program as a whole along with its components, and specifically about the conversation corner and reactions to its presence in the lounge. Copies of the interview questions asked to each participant group can be found in Appendix E.

When families initially decided to participate, they agreed to have one visit, with the option of having more after the first visit had taken place. From a research point of view, it was desirable for families to have more than one visit. The thinking was that multiple visits in the conversation corner would enable family members to become more comfortable with the different components of the program or to use them differently over time. Another idea was for families have a visit again using the digital picture frame/stand but within another type of seating context, such as a more conventional grouping of chairs or a sofa. This would have introduced a control into the study, and would have helped in identifying which features of the Family Visit Program were most effective. After completing the first visit, several of the families expressed interest in having another. However, due to busy schedules and timing, no second visits took place.

At a date following the completion of the visits, each family was sent a letter of thanks for their participation, along with CD's containing digital copies of their scanned images, digital copies of any still photographs taken during their visit, and copies of any video and audio recordings of the visit. These mementoes were viewed as an incentive, of sorts, for families to participate, as they could serve as a keepsake of the later years of their loved one's life. This proved to be particularly meaningful given that the resident of one of the families passed away several months after participating in the study.

2.3 Participants

This study included three groups of participants: residents of Longview, family members of those residents, and Longview staff members.

Four families participated in the research, though there were five resident participants. A list of potential resident and family participants was compiled by Longview staff with knowledge of the underlying ideas of the research project. The criteria used by the staff in identifying possible participants were that the residents had moderate confusion/memory loss and had family members who come to visit them at Longview. This list initially included 22 families to whom a letter giving a general explanation of the project and inviting them to participate was sent. As previously mentioned, a copy of this letter is included in Appendix A. By the time follow-up phone calls were made, six families had been taken off the list for a variety of reasons. The remaining fifteen families were then called to give further explanation of the study, answer any questions and/or concerns, and inquire about interest in participating. Approximately ten of the families were not home and/or did not answer when called the first time, and so a second attempt was made. Four families explicitly declined participation, largely

due to disinterest and/or living too far away (distance). Three families initially agreed, and a fourth was interested, but lived far away, and referred the researcher to a sibling who lives locally. This sibling agreed to participate, yielding a total of four families. Of these four families, most of them were excited about participating, had previously started compiling images, and/or used images in their interaction with their loved one(s) living in Longview prior to being contacted to participate in this study. The family participants included children of the resident (two sons and one daughter), daughter-in-laws (two), a granddaughter, and great-grandchildren (one boy and one girl). Incentives for families to participate in the study included the motivation the study gave for them to engage in research of their family history. Another incentive was the CD they would receive of digitized images of the family photographs they selected as well as copies of the video and audio recordings of any of their visits that took place as part of the study.

Although there were four families, there were five resident participants, as one of the families included a husband and wife couple who both reside at Longview. The five residents were composed of four females and one male, all of whom had been identified by the staff of Longview to have some degree of confusion/memory loss. The residents were in various stages of dementia and cognitive decline, and for the purposes of organizing collected data, they were ordered by Longview staff in terms of progression of dementia.

Staff members were also interviewed at a date following the completion of all the visits. Two staff members who work on the fourth floor participated, both female. Their selection was based on them working at the time the researcher went to conduct the interviews and their willingness to participate.

2.4 Setting

The research was conducted at Longview, located in Ithaca, NY. Longview is an elder care facility that includes both independent apartments and assisted living suites, along with a variety of services and amenities. This study focused specifically on residents living in the assisted living area on the fourth floor. The conversation corner was situated in the main lounge on the fourth floor. The lounge is a public space used primarily by the residents of the fourth floor. It consists of different areas and furniture arrangements including sofas and chairs oriented around a television, seating by a fish tank, a piano, a table and chairs with puzzles, and other chairs and sofas in a conversation grouping. The space has a central fireplace and is easily accessed by the stairs from the ground floor as well as the corridors leading to the resident rooms and staff areas. The reason for putting the conversation corner into the lounge and conducting the visits in a public space was to look at ways of creating a more intimate and private environment or setting within a larger, public context. Although smaller rooms that are intended to serve as private spaces for visits (outside of the resident room) are scattered throughout Longview, these were not as desirable a location within which to place the conversation corner and conduct the study of the Family Visit Program. These smaller spaces were not as frequently used or populated by residents on a day-to-day basis compared to the main lounge, and thus would have precluded the study from assessing the physical components of the Family Visit Program with respect to creating a more intimate and private setting within a larger context and area that has at least moderate traffic.

The conversation corner was first situated in one corner of the lounge near a window and facing a wall. It was believed that this orientation would be preferred for visits as a means of reducing distraction and promoting focus toward the digital picture frame.

A few weeks later, the conversation corner was reoriented to face into the room, in an effort to make it more inviting and open to residents using the lounge. Illustration 2.4 shows the conversation corner in its final position and orientation within the lounge. The conversation corner was set up in the lounge prior to any visits taking place in hope that residents (both those participating in the study and those not) and their families might become aware of and comfortable with it prior to actually conducting a visit in it. The digital picture frame and stand were brought in specifically for each visit, as there was no lockable storage that could be accessed by the researchers at various times of day when the visits took place.



Illustration 2.4 Conversation Corner at Longview. The conversation corner situated in one corner of the fourth floor lounge at Longview.

2.5 Data Collection

There were three methods of data collection in this study: video recording of visits, interviews, and field notes.

Video recording was employed to document interactions among participants during family visits. This was done with a digital video camera, which recorded video along with sound. The video camera was set up on a tripod approximately ten feet from the conversation corner in a position that allowed for all participants to be seen at once, while trying to minimally obstruct use of the lounge. The video camera was set up at the beginning of each visit by the researcher and/or assistants, and once positioned, remained stationary throughout the duration of the visit, with the exception of needing to change the battery during Family D's visit. As the position of the video camera had been set such that all participants were in view, there was no need to adjust the camera during the visits. Limited adjustment of the camera during visits was also intended to minimize attention being drawn to the fact that the visit was being recorded, a potential source of distraction during the visit. In addition, a digital camera was used to take higher-quality still images of some of the visits.

Post-visit interviews were conducted separately with residents and family members. Immediately following the visits, interviews with the residents took place, while they were still sitting in the conversation corner. Following the post-visit conversations with residents, more extensive interviews were conducted with the family members, also in or near the conversation corner. Interviews were conducted with staff members at a date following the completion of all of the visits. Notes were taken during the interviews and audio recordings were also made for the purpose of transcribing the responses.

The researcher's subjective observations related to uses of and reactions to each of the components of the Family Visit Program were recorded as field notes. These were made during visits and the interviews that followed.

2.6 Data Analysis

Video recordings, interview responses, and field notes were analyzed separately.

2.6.1 Video Analysis

Video footage of each visit was analyzed separately for each participant. The analysis was done second by second and duration of each observed behavior was recorded using the following categories: attention, posture/orientation of body, self-initiation—interaction with the stand, emotion indicators—smiling/laughing, along with touch and gesture. Within each category, subcategories were used to further refine the analysis. The video analysis processes organized by categories and subcategories are described below.

2.6.1.1 Attention

Because the Family Visit Program intended to use personally meaningful images as the central focus and source of stimulation for interaction during visits, it was relevant to document where participants directed their attention during the visit. The videos were analyzed in terms of the focus of each participant's attention. This analysis was done by recording the amount of time in seconds over the course of the visit that each participant spent looking at and with attention directed toward the following subcategories: pictures/digital picture frame stand, the family (for residents), the resident (for family), elsewhere, another family member (for family and only if more than one family member participated), another resident (for residents and only if more than one resident participated), and no category was assigned if the person was blocked from view in the video or if their attention could not be determined for some other reason. There were some occasions when more than one subcategory was marked, for instance when someone was either glancing in one direction, but during

the same second also looked at something else. When determining percentage of time for the different subcategories, time intervals for which more than one subcategory was marked were counted in both subcategories. This yielded total percentages for some participants that were greater than one hundred, though not by much. Most of these totals were less than 101%, with the highest total percent being 112%.

2.6.1.2 Posture/Orientation of Body

Given that the design of the conversation corner was intended to provide a comfortable seating posture while making it easy for participants to interact with the digital picture frame/stand and with each other, it was appropriate to look at each participant's posture and body orientation during the visit. The videos were also analyzed in terms of the posture and orientation of each participant's body, specifically how each person was leaning throughout the visit. The subcategories used were: leaning forward/toward pictures/stand, leaning toward family (for residents), leaning toward residents (for family), leaning back in seat, leaning towards another family member (if more than one family participated), leaning towards another resident (only if more than one resident), and no category was assigned if the person was blocked from view. In analyzing the posture and orientation of participants there were times when it was not possible to assign postures to only one subcategory (such as leaning back in seat), because the leaning posture observed fit into a combination of more than one subcategory (such as leaning back in seat and leaning toward resident). When this type of condition was observed, the times were counted in all subcategories marked, thus yielding total percentages for some participants higher than one hundred. After discussing whether or not to leave the data of multiple categories out or where to assign the time, it was determined that counting these time periods in all subcategories marked would more accurately represent what happened. The alternative would have

been to add new categories that were composed of combinations of other categories, thus complicating the data. In this case, total percentages were generally higher than they were for attention, and ranged from 100% to 173%.

2.6.1.3 Self-Initiation—Interaction with the Stand

Decline in the ability to self-initiate is a characteristic of the progression of Alzheimer's. Design has the potential to encourage and facilitate self-initiated actions. Features were designed into the digital picture frame stand to encourage self-initiation. It was appropriate then to look for any evidence that the resident took initiative. It was also appropriate to place instances of resident self-initiated action into a total context of self-initiation taken by all participants in the visit. The specific indicator of self-initiation employed was time spent interacting with, controlling, or manipulating the stand and/or screen. For each participant, all interactions with the screen/stand were noted within the following subcategories: pointing to/touching the screen/stand, pulling the stand/screen closer, pushing the stand/screen farther, rotating the screen, and tilting the screen. For each person, all forms of interaction with and manipulation of the stand were added together and the percentage of time spent physically interacting with the stand compared to the total time of the video of the visit was then calculated.

2.6.1.4 Emotion Indicators—Smiling/Laughing

Because the larger purpose of the Family Visit Program was to turn family visits into a positive, rewarding experience for all participants, it was relevant to look for evidence of positive emotions. This entailed recording instances when participants smiled and/or laughed. For each participant, all instances of smiling/laughing and their

duration were recorded, and the percentage of the total time each person spent smiling/laughing was calculated.

2.6.1.5 Touch and Gesture

The design of the conversation corner deliberately allowed for touch between participants, as touch can be a natural and comforting part of interacting with loved ones. All instances of touch and gesture were recorded for each participant as part of the video analysis using the following subcategories: touch directed toward family (for residents), touch directed toward the resident (for family), touch directed toward another family member (for family and only if more than one family member participated), touch directed toward another resident (for residents and only if more than one resident participated), and touching or gesturing relating to self. The duration of all instances of touch and gesture were recorded for each participant, with notes made regarding what sort of movement occurred. The percentage of time associated with instances of touch and gesture were also calculated.

2.6.1.6 Documentation of Video Analysis

The behaviors of each participant were logged using data sheets with rows corresponding to each of the subcategories, and color-coding used to differentiate among categories (attention, posture, interaction with stand, and emotion indicators). Figure 2.1 shows an example of the color-coding used for video analysis of family participants. An example of color-coded data sheets for participants in one family (the Family A resident and daughter) can be found in Appendix F.

	Time (min) 0
	(sec) 00
Family:	
Touch/Gesture:	
Touching resident (initiated by family)	
Touching another family member - only if 2+ family members	
Touching/gesturing to self	
Smiling/laughing or other emotional indicators	
Attention/Line of Sight:	
Attention focused on pictures/stand	
Attention focused on resident	
Attention focused on another family member - only if 2+ family members	
Attention focused elsewhere	
Posture/Orientation of Body:	
Leaning towards pictures/stand	
Leaning towards resident	
Leaning towards another family member - only if 2+ family members	
Leaning back in seat	
Interaction w/ stand/pictures:	
Pointing at/touching screen	
Pulling the stand/screen closer	
Pushing the stand/screen farther	
Turning the stand	
Tilting the screen	
	Time (min) 0
	(sec) 00

Figure 2.1 Video Observation Categories. This example shows the color-coding of categories and subcategories used for video analysis.

Video analysis was done separately by the researcher and two assistants, who then all came together to compare individual analyses and record a single, master copy. The three raters generally had high levels of agreement, though no reliability calculation was done. When disagreements arose among the individual analyses, for example when two raters had marked a given subcategory and one rater had marked a different subcategory for a specific behavior, the three raters together watched the time interval in question and discussed observations until consensus was reached. On several occasions where behaviors were challenging to analyze, for example with respect to posture, it was necessary for the raters to use a previously analyzed time interval, of which the analysis had been agreed upon, as a basis for reaching consensus. With the example of posture, use of a previously analyzed and agreed-upon time segment was especially useful and necessary given that there could be a range of positions and postures that could be classified as a given subcategory and a fine line between what

distinguishes postures to be classified as one subcategory versus another. This process promoted consistency among raters in the analysis of each participant's behavior across the total length of the visit recording.

2.6.2 Interviews

Interview responses were transcribed from the audio recordings made of the interviews with each participant group (residents, families, and staff). The responses for each question were grouped together such that similarities and differences in responses among participants/families would be apparent.

2.6.3 Field Notes

Field notes were made regarding each of the components of the Family Visit Program. Some of these observations were made during the actual visit and others were based on replay of the visit recording. Observations were compiled and organized according to the concepts used in the development of the components, allowing for similarities and differences between how different families interacted with the components to be noted and aspects of the components that could benefit from further consideration to be identified. For example, no family was observed to use the flip-up seat feature of the conversation corner, indicating the need for consideration of an enhanced visual cue.

CHAPTER 3

FINDINGS & RESULTS

The findings and results are organized in the following way. First, general visit information is given, including the number of participants per family, the number of images used during visits, and the duration of visits. Next, results are organized in terms of method of data collection and will be presented as follows: video analysis, interview responses, and field notes. The findings from this study do not provide conclusive evidence of a specific hypothesis. Hypothesis testing was not the intent. Instead, the study was conceived of as pilot research, an exploration to gain understanding about the potential of the Family Visit Program and each of its components.

3.1 General Visit Information

The residents who participated in this study were ordered in terms of ascending level of dementia. The staff of Longview determined the order based on their knowledge of the residents' cognitive conditions. Within Family D, there were two residents, a couple, both of whom had dementia, but at different levels. The female resident of Family D had the most progressed dementia of all the resident participants, while her husband's dementia was more at a level along the lines of that of the residents of Family A and Family B.

The families were composed of varied numbers of people and generations, as depicted in Figure 3.1. Family A had two participants, comprised of one resident and her daughter. There were four participants for Family B, which included one resident, her

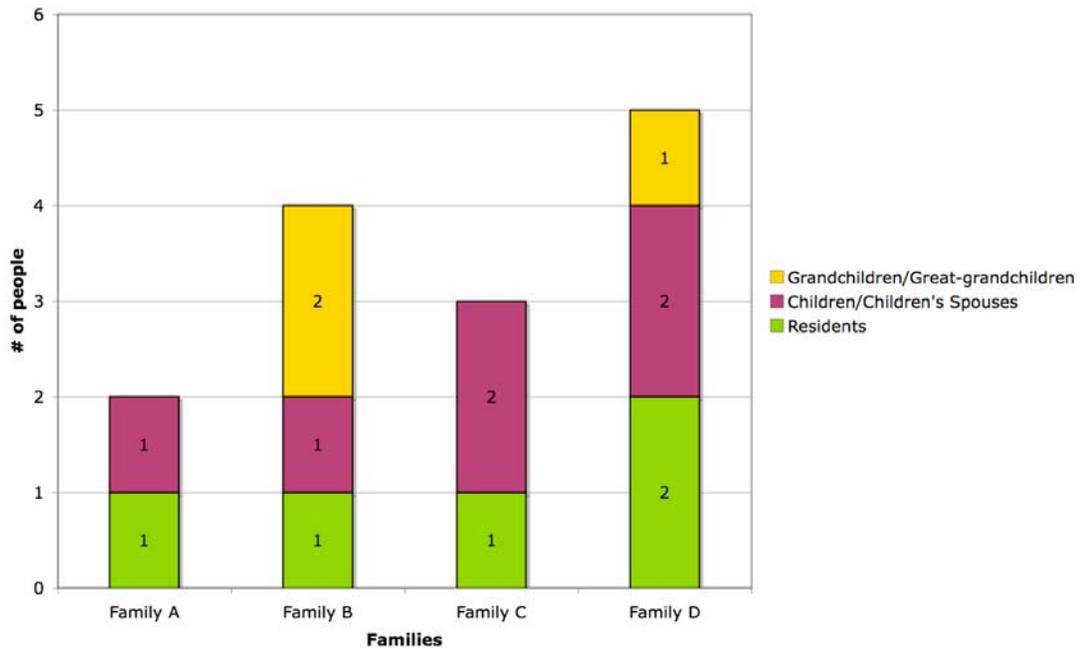


Figure 3.1 Number of Participants per Family and Composition of Families

son, and two great-grandchildren. Family C had a total of three participants and was composed of one resident, her son, and her daughter-in-law. Family D included five participants total, specifically two residents (wife and husband), their son, their daughter-in-law, and their granddaughter.

The families selected different numbers of images to use during their visits. As seen in Figure 3.2, Family A selected 33 images, Family B 14 images, Family C 45 images, and Family D 36 images.

The families also differed in terms of the duration of their visits. Family A’s visit lasted approximately 42 minutes while the duration of Family B’s visit was approximately 19 minutes. It is important to note that Family B experienced technical difficulties with the digital picture frame and remote and were unable to use the

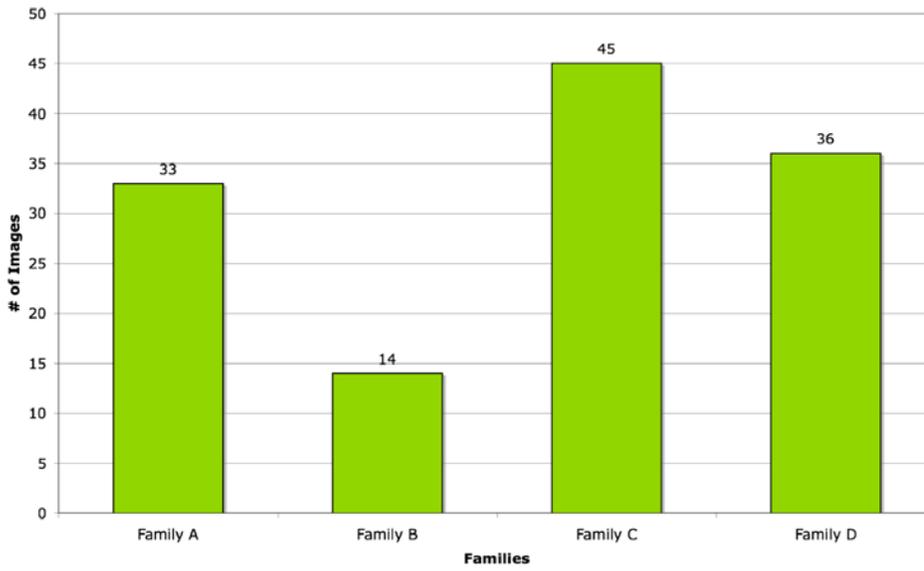


Figure 3.2 Number of Images Selected

remote to control the images. They had to use the digital picture frame on automatic slideshow mode and thus could not control how long images remained on the screen.

With automatic slideshow mode, the images changed after only 10 seconds. Family C's visit was approximately 60 minutes long. Family D's visit lasted approximately 75 minutes, though due to technical difficulties with the video camera and its batteries, only about 34 minutes of the visit were video recorded. Figure 3.3 shows this information graphically. No quantitative comparison was possible between the duration of visits as part of the Family Visit Program and duration of regular visits engaged in by the families given that regular visits were not observed as part of this study.

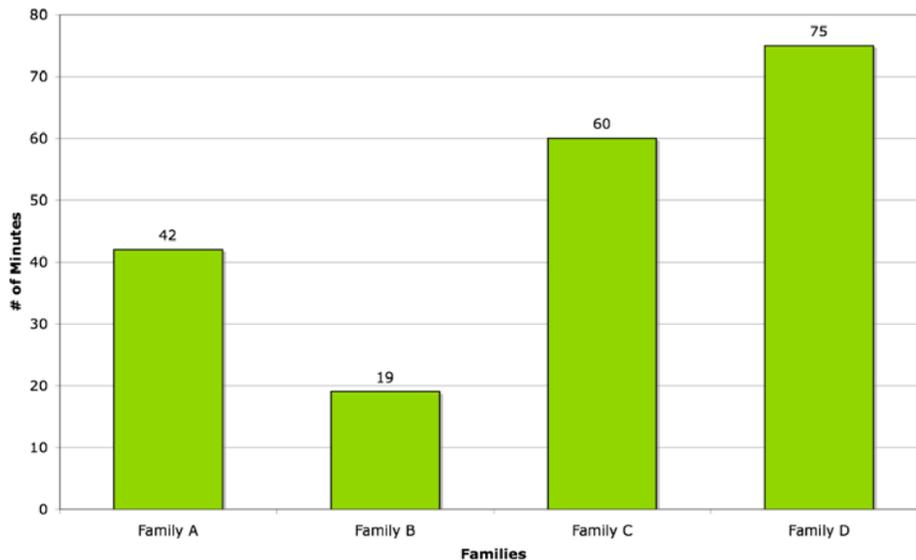


Figure 3.3 Duration of Visit

3.2 Video Analysis

Video footage of each visit was analyzed separately for each participant. The analysis was done second by second with respect to the following categories: attention, posture/orientation of body, self-initiation—interaction with the stand, emotion indicators—smiling/laughing, along with touch and gesture.

3.2.1 Attention

The videos were analyzed in terms of the focus of each participant’s attention in the manner described in the previous chapter, with the exception of the daughter-in-law of Family D. She was not included in this part of the analysis because she was not actually sitting in the conversation corner, but instead on the seat of a walker adjacent to the conversation corner. More importantly though is the fact that, given her position, the video camera could record only her profile and did not reveal with certainty the object of her visual focus, only the general direction in which her head was turned which could indicate she was looking at any number of people or objects. For a complete table documenting attention for all other participants, see Appendix G.

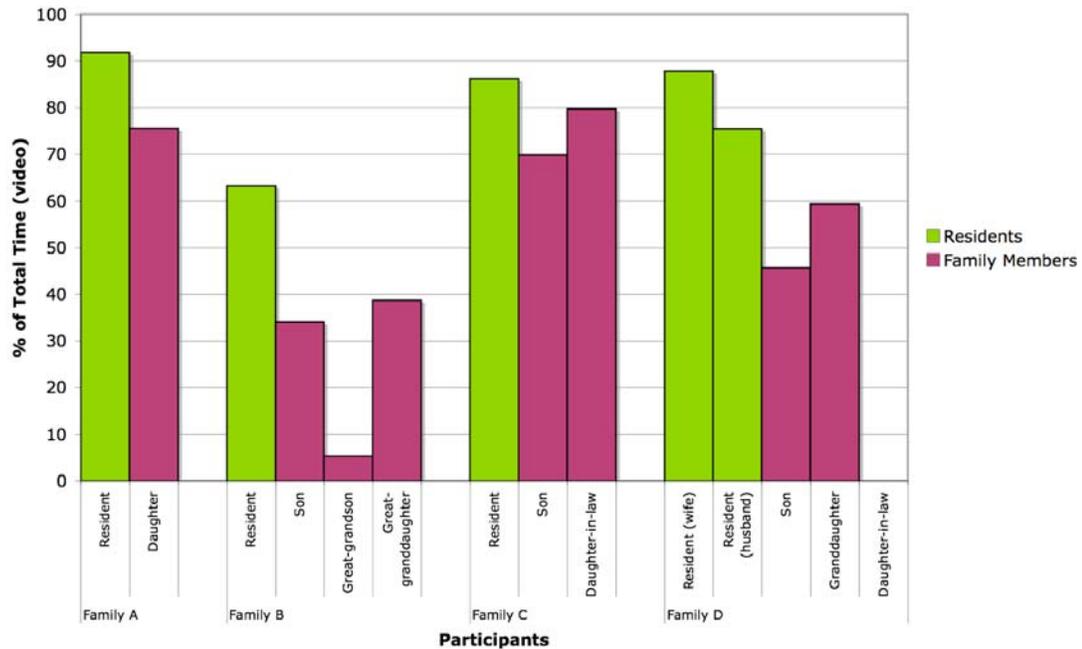


Figure 3.4 Attention Toward Picture/Digital Picture Frame Stand

Figure 3.4 graphically depicts the percentage of time each participant spent looking at the images on the digital picture frame or at the stand. Within each family, the resident(s) spent a larger percentage of time with their attention focused on the pictures/stand than did the family member(s), though the extent of this difference varied among the four families. All of the residents spent more than 60% of the time with their attention focused on pictures/stand, ranging from 63.2% to 91.9%, with a mean of 72.7% and a median of 86.2%. There was greater variation in the percentage of time that the family members spent with their attention focused on the pictures/stand, ranging from 5.2% to 79.7%, with an average of 51.0% and a median of 52.5%. For Family A, the resident spent 91.9% of the time with attention focused on pictures, while the daughter spent 75.6% of the time. Within Family B, the resident spent 63.2% of the time looking at the images, while the son and great-granddaughter respectively spent 34.0% and 38.6% of the time with their attention directed towards

the pictures. In contrast, only 5.2% of the great-grandson's attention could be attributed to being focused on the pictures, though for 81.9% of the time, no category could be marked due to his face being blocked by the digital picture frame. As a group, Family C spent most of their time looking at the images, with less difference between the percentage of time for the resident as compared to that for each of the family participants. The resident's attention was focused on the pictures/stand 86.1% of the time, while the son's was 69.8% of the time, and the daughter-in-law's 79.7% of the time. Greater disparity was seen within Family D as the resident wife and husband respectively spent 87.8% and 75.4% of the time looking at the images. The son, though, spent 45.6% of the time with his attention focused on the pictures and the granddaughter spent 59.4% of the time.

In contrast to the high levels seen for the amount of time spent with attention focused on the pictures/stand, much lower percentages of time were seen for attention directed toward family member(s) by the residents and toward resident(s) by the family members. All participants spent less than 50% of the time focused on family/residents, with all but one spending less than 30%. This can be seen in Figure 3.5. The range for the resident's attention toward family was 3.2% to 23.6%, while the mean was 11.6% and the median was 10.9%. For the family member's attention toward residents, the range was 2.8% to 48.6%, the mean was 17.0%, and the median was 13.9%. For Family A and Family C, the family participants spent more time with their attention focused on the residents than did the residents with their attention focused on their families. The resident in Family A spent 4.3% of the time with her attention directed toward her daughter, whereas the daughter spent 20.8% of the time with her attention directed toward her mother. For Family C, the resident spent 10.9% of the time

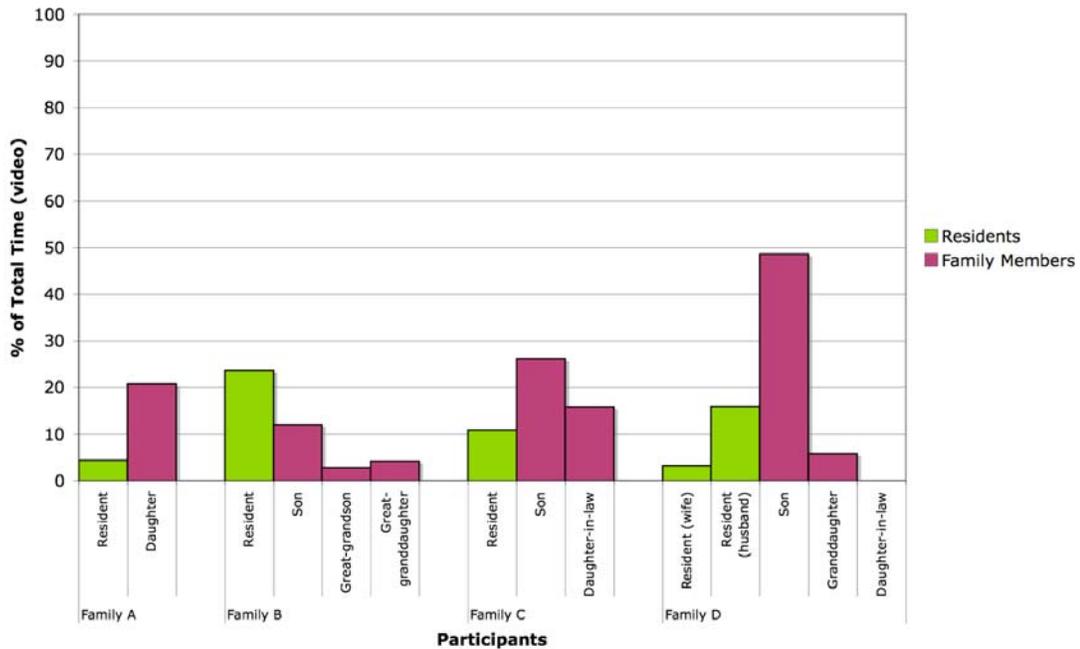


Figure 3.5 Attention Toward Family/Resident, Respectively

looking at her son and/or daughter-in-law, while the son and daughter-in-law respectively spent 26.1% and 15.8% of the time focusing on the resident. In Family B, the resident actually spent a greater percentage of time focused on the family than any of the family members did looking at her – the resident focused on family for 23.6% of the time, while her son looked at her only 12.0% of the time. The great-grandson and great-granddaughter respectively spent 2.8% and 4.1% of the time focused on the resident. It is important to note, though, that the son’s attention was focused on either of the great-grandchildren for 9.3% of the time and that the focus of his attention could not be determined for 41.6% of the time, primarily due to his face being blocked by the digital picture frame. For Family D, the resident wife’s attention was directed toward the family members 3.2% of the time, while the resident husband spent 15.9% of the time with his attention focused on the family members. Additionally, the wife and husband respectively spent 4.2% and 4.0% of the time with their attention focused on each other. The son of Family D, though, spent 48.6% of the time looking at either

or both of his parents, while the granddaughter's attention was focused on the residents for only 5.8% of the time.

3.2.2 Posture/Orientation of Body

The videos were analyzed in terms of the posture and orientation of each participant's body, specifically how each person was leaning throughout the visit, as previously described. The daughter-in-law for Family D was not included in this part of the analysis because she was not actually sitting in the conversation corner but, instead, on the seat of a walker adjacent to the conversation corner. As such, her leaning was more difficult to observe and mark within the categories, and also did not reflect someone sitting in the conversation corner, but rather someone sitting farther away who inevitably had to make more and larger movements to stay part of the interaction. For a complete table of leaning and posture for all other participants, see Appendix H.

Figure 3.6 shows the percentage of total time participants spent leaning back in the seat. For each family, the resident spent more time leaning back than did each family participant, though the difference is greater for some families than it is for others. The range for residents was 53.4% to 92.2%, while the mean was 74.1% and the median was 71.4%. There was more variation in the percentage of time family members spent leaning back. For family members, the range was 5.2% to 74.8%, the mean was 37.2% and the median was 38.0%. For Family A, the resident spent 71.4% of the time leaning back, while her daughter spent only 42.5% of the time doing so. For Family B, the difference between how much time the resident and her son spent leaning back is much smaller. The resident did so for 71.2% of the time, while her son sat in this position for 70.2% of the time. The great-grandson and great-granddaughter respectively spent 10.9% and 52.4% of the time leaning back in the seat. The great-

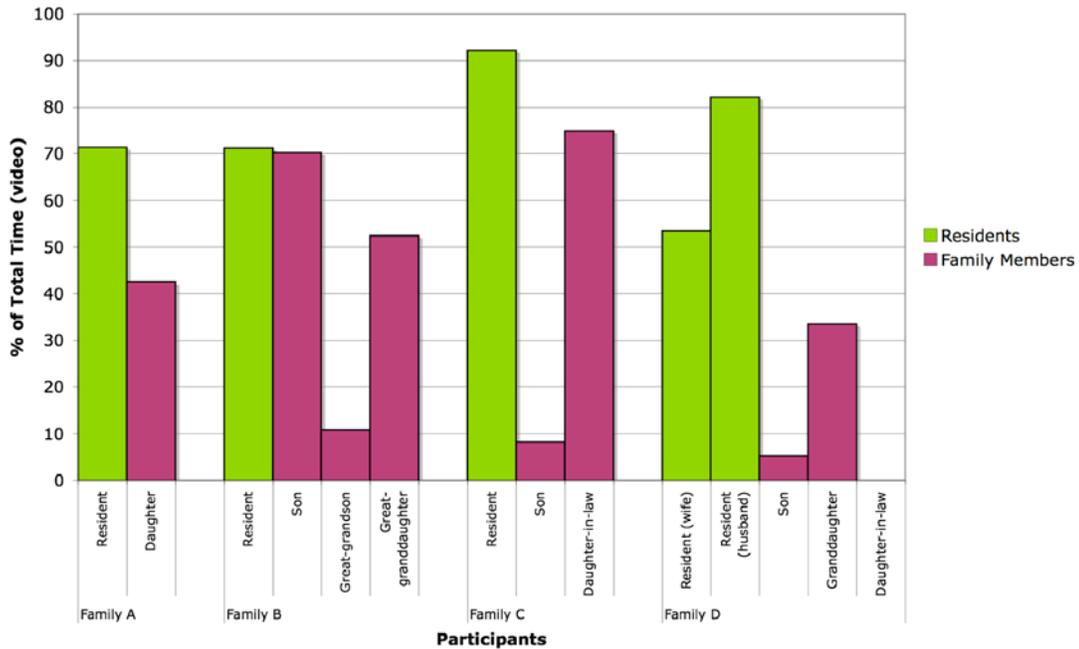


Figure 3.6 Leaning Back in Seat

grandson, though, spent 82.2% of the time during the visit standing, while the great-granddaughter spent only 11.0% of the time standing. With respect to Family C, the resident spent 92.2% of the time leaning back in the seat, while there was a large difference in the percent of time spent in this position by each of the two family members. The son spent only 8.2% of the time leaning back, while the daughter-in-law spent 74.8% of the time doing so. Within Family D, there was also considerable difference in the percentages of time spent leaning back between the residents, and also between the family members, with the family members still spending less time in this position than the residents. The wife and husband (residents) respectively spent 53.4% and 82.1% of the time leaning back in the seat. Their son, though, only leaned back for 5.2% of the time, while the granddaughter did so for 33.5% of the time.

3.2.3 Self-Initiation—Interaction with the Stand

Video analysis relating to self-initiation was specifically focused on time spent interacting with, controlling, or manipulating the stand and/or screen as noted in the

preceding chapter. For a complete table of physical interaction with the stand for all participants, see Appendix I.

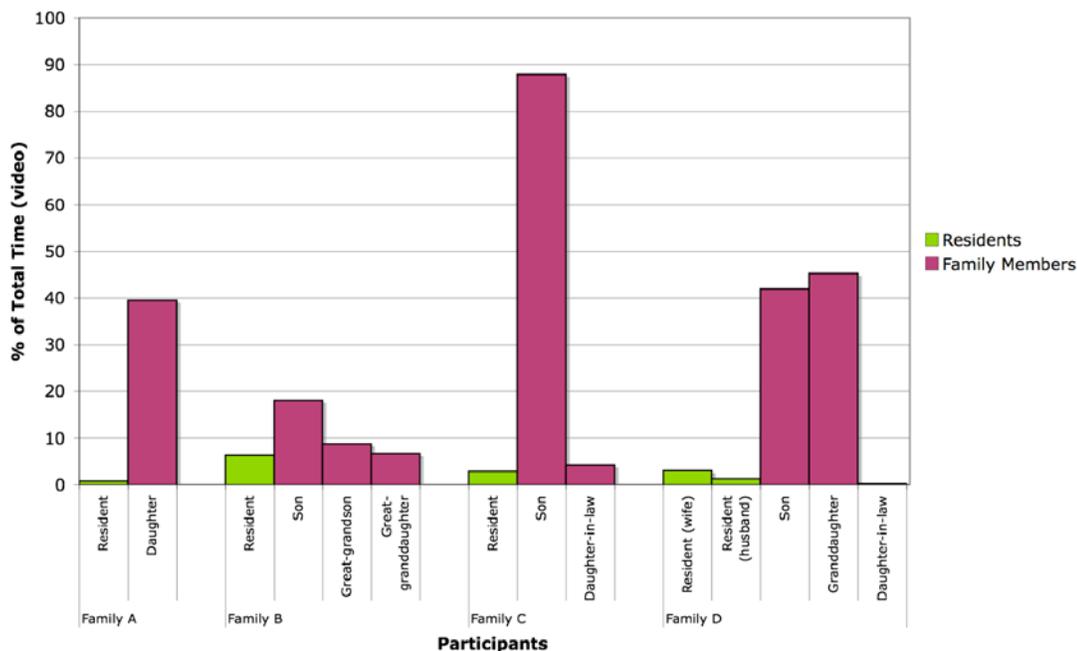


Figure 3.7 Interaction with/Control of Stand

Figure 3.7 depicts the percentage of time each participant spent interacting with the stand during the visit. For all families, the family participants tended to spend more time interacting with the stand and/or controlling it than did the residents, generally with one family member in particular doing so. All five residents spent less than 10% of the time interacting with the stand, four spending less than 5% of the time. There was much more variation between the family members, as the range for how much time they spent interacting with the stand was 0.1% to 87.9%. The mean for family members was 28.0% and the median was 18.0%. The difference in percentage of time spent by a family member compared to resident is more stark for Families A, C, and D than it is for Family B. For Family A, the resident spent .72% of the time interacting with the stand, while the daughter spent 39.5% of the time doing so. With respect to

Family C, the resident spent 2.9% of the time touching or otherwise interacting with the screen/stand, whereas the son spent 87.9% of the time doing so, and the daughter-in-law 4.2%. The son's high level of interaction is due in part to the fact that he spent a lot of time with one or both hands resting on the stand, even when he was not always specifically using the remote to switch the pictures. In Family D's visit, the wife and husband (residents) respectively spent 3.0% and 1.3% of the time interacting with the stand. The son and granddaughter respectively spent 41.9% and 45.3% of the time physically interacting with the stand, while the daughter-in-law spent only .1% of the time doing so. The daughter-in-law, though, was not sitting in the conversation corner, but rather was a bit further away from the stand than the rest of Family D, which may have precluded her, to some extent, from physically interacting with the stand. In contrast, for Family B, the resident spent 6.3% of the time interacting with the stand, while the son spent 18.0% of time, the great-grandson 8.7%, and the great-granddaughter 6.6%. It is important to note, though, that Family B experienced technical difficulties and had to use the digital picture frame in automatic slideshow mode, and thus did not need to spend time using the remote and controlling the navigation while viewing the pictures, a task that most likely would have been engaged in by the son. Additionally, because of the technical difficulties, the son did touch the stand a lot at first and looked for what the problem might have been and how to fix it.

3.2.4 Emotion Indicators—Smiling/Laughing

Emotion indicators, specifically smiling and laughing, were part of video analysis. All instances of smiling/laughing and their duration were recorded, and the percentage of the total time spent smiling/laughing was calculated. For a complete table of

smiling/laughing for all participants, see Appendix J. The percentage of time spent smiling/laughing for each participant is depicted in Figure 3.8.

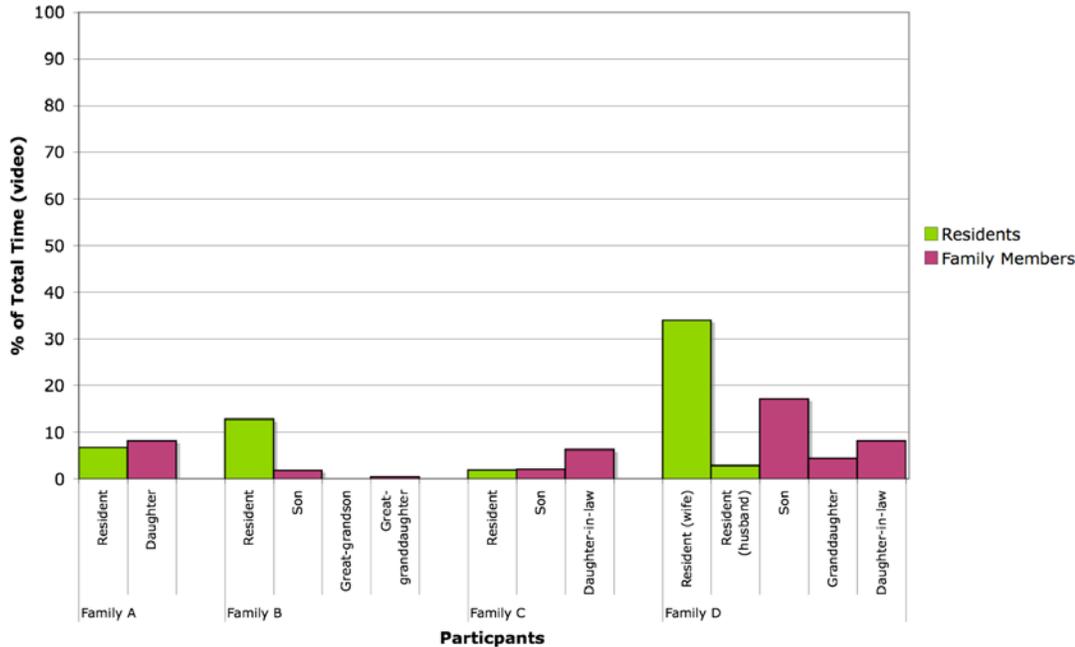


Figure 3.8 Smiling/Laughing & Other Emotion Indicators

There was no consistency among the four families—in some families it was the resident(s) who spent more time smiling/laughing, while for other families it was the family member(s) who spent more time doing so. For residents, the range was 1.9% to 34.0%, the mean was 11.6%, and the median was 6.7%. Meanwhile, for family members, the range was 0% to 17.1%, the mean was 5.4%, and the median was 4.4%. For three of the families, all participants spent less than 13% of the time smiling/laughing, while the other family had one participant who spent over 30% of the time, and another who spent just over 17% of the time. For Family A, the resident smiled/laughed for 6.7% of the time, while her daughter did so for 8.1% of the time. With respect to Family B, the resident smiled and/or laughed 12.8% of the time, while it was recorded that the son and great-granddaughter respectively did so for 1.8% and

0.5% of the time. No instances of smiling/laughing were recorded for the great-grandson, though given that he was blocked from view for much of the time (as noted earlier), there may have been smiles that could not be recorded. With respect to Family C, the resident spent 1.9% of the time smiling and/or laughing while the son spent 2.1% of the time doing so, and the daughter-in-law 6.3%. Family D had the most variation among its members, as the wife and husband (residents) respectively spent 34.0% and 2.8% of the time smiling exhibiting signs of emotion. Variation was also seen among the family participants, as the son spent 17.1% of the time smiling/laughing, while the granddaughter spent 4.4% of the time doing so, and the daughter-in-law, 8.2%.

3.2.5 Touch and Gesture

Video analysis also looked at touch and gesture for each participant. All instances of touch and gesture, and their duration, were recorded in the manner described in the previous chapter. Additionally, notes were made regarding what sort of movement occurred for each occurrence. The percentage of time associated with instances of touch and gesture was calculated. For a complete table documenting touch and gesture for all participants, see Appendix K.

One aspect of this category of analysis included touching that occurred between family members and residents, touching among family members (when applicable), and touching among residents (when applicable). The most touching that occurred was between the Family B son and great-grandchildren. The son spent 19.2% of the time touching another family member, while the great-grandson and great-granddaughter respectively spent 24.2% and 30.2% of the time doing so. Much of this was due to the fact that the great-grandchildren were climbing, sitting, or leaning on the grandfather

throughout the visit. The other family in which significant amounts of touching occurred, was Family D. The most notable touching occurred between the resident wife and husband. The wife spent 5.0% of the time touching her husband, while he spent 11.3% of the time touching her. The son of Family D spent 2.9% of the time touching either of his parents. The other families exhibited minimal amounts of touching.

The other aspect of this category of analysis looked at touches and gestures participants made that related to the self or that did not specifically relate to anyone else. While some instances of this type of gesturing or touch could be evidence of self-initiation, the sub-category itself was too broad, as it also included small movements such as fidgeting. For this reason, this data was not revealing. The percentage of time recorded for all participants was fairly similar, with the range being 8.7% to 29.2%.

3.3 Interview Responses

Interviews were conducted with all participants and the responses to these interviews are presented below, organized by participant group. Responses are summarized for residents, family members, and then staff.

3.3.1 Interviews with Residents

Immediately following each visit, interviews were conducted with the resident(s) in the conversation corner. As previously noted, there were a total of five residents, as one family included a resident husband and wife couple. Summaries of the responses to these questions are given below.

A few questions were asked regarding whether the residents enjoyed the visit. All of them answered affirmatively, with one going into detail about how much she enjoyed it. She stated, “I almost cried when I saw those pictures, it brought back memory... It was just remarkable”.

Next, the residents were asked questions about qualities of the conversation corner, including whether or not it was cozy, comfortable, intimate, and inviting, along with whether or not they liked the materials. They all answered positively about the corner being cozy, with one person saying that it was “cozy enough” and another saying that “it was nice.” They all also found it comfortable to sit in. Although one of the residents found the corner not to be intimate, all others did find it to be intimate. One added that the conversation corner made her feel like she and her husband “wanted... to sit and hold hands and [this feeling] brought back the memory of... our son [as] a baby”. The three residents who found the corner to be intimate also said that it was inviting, though to various degrees. One resident was not asked specifically about whether the conversation corner felt intimate or inviting, as she had given minimal responses to previous questions that were similar in nature. In terms of liking the materials, one resident said no, while the others answered affirmatively, but to different extents, ranging from “yeah... beautiful, beautiful” to “yes... I can’t get too excited about it”.

When residents were asked about their ability to hear what family members were saying when sitting in the conversation corner, all but one answered positively. For one resident, though, the question had to be repeated because she either did not hear or did not understand the question the first time. The one resident who answered negatively about being able to hear what family members were saying had hearing

difficulty in general. In terms of feeling distracted by other things going on in the lounge during the visit, all but one said that they were not distracted, while one said, “I don’t know”.

The residents were then asked about the digital picture frame and stand. In terms of enjoying looking at images on the digital picture frame, they all answered affirmatively. Two in particular were quite enthusiastic about the way images were displayed. In terms of whether or not the stand was easy to manipulate, one said yes and two said that they did not move it, though one of them commented that everyone else who did move it did not have any trouble. One of the residents was again not asked this question given her limited responses to previous questions.

In terms of desire to have future visits in the conversation corner and looking at images on the digital picture frame, all but one said yes, with enthusiasm. Other comments included one resident particularly expressing interest in having another visit, specifically after her daughter suggested the idea of having her sons (the resident’s grandsons) come too, and another resident remarking about how much she and her husband really enjoyed the experience and that they would definitely participate again. One resident was not explicitly asked these questions because of limited responses to previous questions along with the perception that she was no longer engaged or interested in the conversation.

The level of dementia among residents did not seem to relate to the responses to interviews. The resident who was the least verbally responsive was classified as being the second least progressed, while the resident who was the most verbally responsive and visibly excited was classified as the one most progressed into dementia. Of

interest is the fact that the resident who was most verbally responsive was part of the resident couple who participated. Her experience during the visit as well as her ability and interest in talking about the visit may be related to having her husband there with her.

3.3.2 Interviews with Families

Post-visit interviews with family members were conducted following those with residents and also took place in or near the conversation corner. The number of family members per visit ranged from one to three. All of these participants' responses are summarized below. The interviews with the family members were more extensive and included a significantly greater number of questions than the interviews with residents. These questions were grouped among the following categories: the visit experience, the conversation corner, the digital picture frame and stand, the orientation process and communication strategies, and summary questions.

3.3.2.1 The Visit Experience

The first category of questions was intended to probe generally into perceptions of the visit experience and participation in the Family Visit Program. When asked to compare the quality of the visit to previous visits (not in the conversation corner) both in terms of their own experience and their perception of their loved one's experience, all families answered that they found the visit enjoyable and that they thought the residents did as well. Two families identified as a positive quality that the visit was focused, presumably more so than previous visits. Other things that were mentioned about this visit compared to previous visits included the following: that having the images made the visit less stressful, that the visit was more satisfying because it was more intentional and had fewer distractions, that family members and residents were

able to get more out of pictures than in other circumstances, and that the visit seemed to have a specific purpose other than that of a chore to bring something to or do something for the loved one. Three of the families commented on the fact that they thought their loved ones really seemed to enjoy the visit, including that they were “really paying attention, keeping track of things, engaged” and “more animated than... they’ve been lately”. By contrast, one family commented that the visit experience revealed significant decline in the resident’s memory. Decline was seen in the resident’s ability to recognize close family members, even those regularly looked at in pictures.

The next few questions were about whether/how participation in the Family Visit Program affected length of stay during the visit and desire to visit in the future. Three of the four families said that engagement in just one activity inherent in the structure of the program made the time pass quicker than in previous visits and/or that the visit facilitated interaction for the entire stay. The fourth family, the one comprised only of the resident and her daughter said the program did not really affect the length of stay. Three of the four families felt that the visit made them want to come again and do the same or a similar sort of thing in future visits, while one family felt that the program and visit did not make any difference and that they already come as much as they can. The latter family, consisting of the son and daughter-in-law of the resident, had been somewhat skeptical about the program from the beginning. A member of one family who felt that the program and visit increased the desire to have future visits (of this sort) specifically identified that it encouraged her to “really stay focused, really have visits, rather than check in”. Another family compared the visit to similar things they had done in the past related to looking at pictures, and said that there was “something

about doing it this way that sort of kept the focus on it. It felt like we were going to go from beginning to end”.

The next question asked families to identify the specific feature(s) of the Family Visit Program (conversation corner as setting, digital picture frame and stand as focal point, or orientation process) that made the biggest impact on the quality of the visit. All of the families commented about the digital picture frame and stand, specifically with regard to being able to look at the pictures on a screen rather than in a photograph. They appreciated in particular that the screen made the pictures larger. Families also mentioned that the handles on the stand allowed it to be moved and turned with ease. Three of the families commented about the setting (i.e. the conversation corner), specifically saying that it did cut out some of the distractions in the lounge, gave some privacy, and kept everyone together and focused. A member of one family mentioned that the communication strategies (as part of the orientation process) were helpful to think about, especially since she felt that that communication was neither hers nor her mother’s strong point.

3.3.2.2 Conversation Corner

The second category of questions dealt specifically with the conversation corner and its performance as the visit setting. The first two questions were about initial reactions to the conversation corner as well as if/how these impressions changed after sitting in it and experiencing it. One family expressed having little reaction to the corner at first, but thought that it seemed interesting. Three of the families mentioned that they had experienced curiosity and interest as to what the corner was, thinking of it sort of as a mystery. One family in particular commented that it seemed big and somewhat odd-looking while also adding that it just seemed like a place to sit. This family also noted

that they had seen it previously when it was turned around (facing the wall) and had thought that the experience with the corner facing in that direction would have been more personal, with less “extraneous noise from the tv and folks wandering and walking around”. Another family added that some of their curiosity about the corner was related to how it looks in the context of the room, which she thought might be different if it had been a built-in or permanent piece of furniture. Other initial reactions included references to a confessional and the fact that the design elicited a lot of giggles, in particular after one family’s loved one said, “why is there women’s underwear up there?” One of the family members mentioned having seen the corner several times, and that he was so curious that he sat in it and found it sterile and uninviting when he was by himself. He also said that when he sat in it and it was facing the wall, “you could sort of get a sense that it had some idea of keeping other distractions out... but it was hard for us to imagine how that would work.” However, this family found the experience in it during their visit to be quite different—“The nice thing about it I would say is that it faded into the background very well. It was invisible while we were all talking together, and so I think that’s a good thing.” They also said that while the corner seemed sort of odd when they had sat in it without anything to focus on, they found it to be enveloping when they were looking at images on the digital picture frame. Another family corroborated the idea of the conversation corner fading into the background by saying, “I was unaware of the seat; I was more focused on the pictures. It didn’t bother us at all.” One family participant commented that he had no change in opinion, while someone from another family thought that her impressions were different after experiencing it, commenting specifically on how she felt that the conversation corner “creates a little private area, which is nice for visits” and that “it cuts out on the distractions in an open, public setting.”

When asked if the conversation corner had felt like a place they wanted to go and sit for a visit with their loved one(s), one family said yes, while the others were more inclined towards negative responses. One family commented that it seemed a bit sterile or industrial, while another said that they were not drawn to it. A third family said that before the visit, they could not envision sitting and visiting in the corner. Along these lines, the families were then asked if they thought the conversation corner was inviting. One family said yes, while two others commented that they felt once they were in it and/or had gotten started looking at the images, the corner was fine, but that it was not really inviting when looking at it from the outside. One of these families elaborated, saying that they thought “part of it is the very tall back and very straight lines” and that “from the outside, as a place to go, it just looks really hard... and not something that I would want to go into.” A member of another family thought that the corner seemed inviting because it offered the opportunity to sit together in close proximity to each other without having chairs in the way. Yet, another member of the same family chimed in, “But you’re not facing each other either, I mean when we’re talking, Mom’s gotta turn her head both ways... I don’t think it’s quite as personable as if we were looking at or facing each other.” All of the families expressed that they enjoyed sitting in the conversation corner with their loved ones. One family in particular said that the corner was physically comfortable and that it felt cozy.

The next few questions were the same ones asked to the residents relating to qualities of the conversation corner, including if it was cozy, comfortable, and intimate, along with whether or not the family members liked the materials. All of the families said that they found the conversation corner cozy, one person attributing this perception to the general shape of the seating unit and another ascribing her perception of coziness

to the top (canopy) and side pieces. Everyone also said the conversation corner was comfortable to sit in, though one family felt the cushions were a little too stiff and were ready to get up (after sitting in it for about an hour and a half). In terms of intimacy, three families answered affirmatively, while a member of the other family said, "I don't know if I'd go so far as intimate because there's still such a wide, open space in front." Two of the families said they were satisfied with the materials. All of the members of one family really liked the wood, adding that they felt it added warmth, but were split with respect to their opinions regarding the fabric. One of them felt neutral about the fabric choice, while the others felt strongly about not liking the color of it. They commented that "the mustard yellow... looks flat and hard." A member of another family also disliked the color of the fabric, noting a personal preference for blues and greens and commenting that the colors of the fabric and maybe even the wood seemed too light.

Next, families were asked how well they felt the conversation corner supported interaction, specifically in terms of acoustical qualities of its design. One family felt that the design of the corner did not have any effect, as they felt the seating configuration caused their loved one to speak facing forward, rather than towards them. However, two of the other families thought the design did a good job, even taking into consideration that they each had a loved one who was hard of hearing. One family stated that it seemed that their loved one had an easier time hearing them in the conversation corner than in other circumstances. One family offered little response to questions about the acoustic quality of the conversation corner design.

The next set of questions dealt with whether or not people felt distracted during their visit. Also asked was how well the conversation corner buffered outside distractions,

both auditory and visual. Three of the families did not experience significant acoustical or visual distractions during their visit, noting that there was not much, if anything, else going on in the lounge at that time. Some noted that they heard someone's alarm going off, a few doors slamming, and that the group had some potential visitors, but found none of these distracting. One family noted that rather than being distracted, they felt they were the distraction, given that a staff member came over to see what they were doing. Yet a member of another family commented about not being visually distracted because "the pictures were way too interesting to be looking at anything else." One family included a member who was acoustically distracted by the television and other residents who came by, but another member who did not feel as distracted by these things because of how focused she was on the images and the visit. All of the families also answered that their loved ones did not really seem distracted either. One family elaborated, saying that they felt their loved ones stuck with the conversation and looking at the pictures much better than when they had brought other media in the past. The members of this family went on to say that they even had expected their loved ones to fall asleep, or be "focused on other stuff, with attention wandering off, and that didn't happen here." Three of the families felt that the conversation corner did help to buffer at least some of the outside distractions, one family participant noting specifically that if the side piece had not been there, he thought he would have been glancing at the television screen from time to time to see what was going on.

Lastly within this category of questions, families were asked if they had any concerns regarding the design of the conversation corner and what they might change about it. Although none of the families said they had any specific concerns, two of the families made a point to mention the color of the fabric (though another family had discussed

fabric color as previously noted in an answer to another question). Suggestions included using a neutral, possibly floral design, “or a more cheery color, or a brighter color... like a deep green or something,” along with the notion that “a softer color would make it more comfortable looking” given the firmness of the cushions. Another comment was that the walls could be bigger. One family spoke specifically about issues pertaining to wheelchair transfers and the existing arms. They said, “You almost need a bar or something like that, to help people get up and into” the seating unit and felt that the arms “are too low and they don’t look like they’re going to bear your weight”. A suggestion they made was to use “something that looks and acts like the kind of grip you’d have in a bathroom, a grab bar,” but added that it wouldn’t have to be there all the time. It turns out that this family had not understood that the arms folded out of the seat back of the conversation corner, but once made aware of them, still felt that they were too low and too far for their loved one to reach, and above all, that they did not look strong enough. This family also commented on the canopy, which they felt was a good idea, as they suggested it may help to focus attention and enhance the feeling of coziness. However, they felt that having something with rounder lines at the top would help the conversation corner seem more “pod-like,” and therefore reactions would be more positive. This was contrasted with their view that the flat surfaces and straight lines of the upholstery make the conversation corner appear more sterile and less inviting.

Families were also offered the opportunity to give any additional comments relating to the conversation corner. One family participant brought up her surprise by the positioning of the seating unit, as she had seen it on a previous occasion when it was turned to face the wall, as well as her thought that it would have been a very different experience if it had been oriented in another direction.

3.3.2.3 Digital Picture Frame & Stand

The third category of questions dealt specifically with the digital picture frame and stand relative to the experience of viewing images. First, families were asked about how much they enjoyed looking at images on the digital picture frame as well as how much they perceived their loved ones to enjoy the experience. All of the families said that they really liked the frame and stand, with one participant going so far as to say, “I want one.” Another family commented that “it was fun” and that the displayed images were “the real highlight of the experience.” Although all of the families felt that their loved ones enjoyed looking at the images on the digital picture frame, one family commented that they “thought she would show a little more interest, a little more emotion.”

Families were then asked whether or not they found the digital picture frame to be an appropriate medium for looking at images. All of the families agreed that it was a great way to look at pictures, namely mentioning that they liked that the images were generally bigger than photographs in an album. One family said that they felt the pictures were more vibrant and possibly even clearer. Another liked that the digital picture frame was manually controlled, and found that “it’s more sharable” than printed pictures. This family also compared using the digital picture frame to using a laptop to look at images with their loved ones, which was something they had done in the past. They found that the digital picture frame and stand worked much better, largely because of the integration of the two elements, and the use of handles that are “meant to be held onto” and to be used to bring the stand closer. A member of another family said that it might be nice if the pictures were further enlarged and offered the idea of using an even larger monitor.

Along these lines, families were also asked if the digital picture frame was easy to control. Three of the families answered affirmatively, though a member of one family expressed some concerns about the remote control and its cover. This family member found that his eleven-year-old daughter, who was the one primarily in charge of changing the pictures, was distracted by picking up the cover of the remote and looking at the other buttons. After inquiring about using the remote without the cover, this family member did agree that it would have been even more distracting without it, but also mentioned that the sense of the buttons was inherently “backwards, that down shouldn’t mean next... it should be left and right instead of up and down, and even if they are up and down, it’s in the wrong direction.” He also asserted that the remote/control “really needs two big buttons” and not to have anything else there. Another comment from this family was that the picture changing was too slow and “should be sub-second”. The fourth family had experienced technical difficulties with the digital picture frame, and actually was not able to control the speed of the pictures changing for most of their visit. Accordingly, this family found the digital picture frame only to be somewhat easy to control.

Next, families were asked about ease and intuitiveness of manipulation of the stand. All of the families agreed that they found the stand easy to manipulate, citing actions including moving it around and adjusting the angle of the screen, as well as using the handles to turn the stand. One family specifically commented about “the big handles that you could grasp,” such that the screen “wasn’t going to fall off the table like a laptop would”. They liked that the handles were really meant to be held onto and could be used to move or turn the stand.

Families were then asked to express any concerns and give any suggestions regarding the design of the stand. Two families commented about the base of the stand, both with regard to accommodating feet. One of these families thought that having something to put your feet on, such as a ring around the bottom, would be a good addition, while the other family spoke more specifically about how the legs of the stand got in the way of their loved one's feet when they pulled the stand closer to her. The latter family suggested either removing part of the five-star caster base or widening it. Although one family had reported adjusting the tilt of the screen, another was not as satisfied with this control. They liked that it was possible, but felt that the tilt adjustment was "a little bit iffy" and consistently felt like the tilt mechanism would not hold if it were adjusted. They suggested making the mechanism stronger to enhance the perception of the tilt capability. This family also was particularly fond of the wood noting that it added warmth and said, "the handles are stellar."

3.3.2.4 Orientation Process & Communication Strategies

The fourth category of questions dealt specifically with the orientation process and the communication strategies that had been printed, given to, and discussed with the families during the preparation meeting. Before describing answers to this category of questions it is relevant to note that one of the four families that participated in the study did not give any substantive responses throughout this section of the interview. The orientation process was enhanced by family members taking an active role during the preparation meeting conversation about communication strategies and by reviewing the strategies prior to visiting. The family who responded minimally to the questions about the orientation process did not take the desired initiative.

Families were asked what they thought of the orientation process and to what extent they found it to be helpful or to have made a difference in the quality of their visit. All of the families who answered thought that the orientation process was a good thing, being both a useful and necessary component to the project. One family said that they found the strategies to be “helpful, but hard to stick to” and felt that if they had not initiated conversation, their loved one would not have spoken, given the progression of her mental deterioration. They did, though, find the communication strategies as presented in the orientation process to be effective. However, this family did not feel that the orientation process in general made a difference in their visit because they often get out pictures and talk to their loved one about them. One of the members of another family thought that the ideas presented made sense and that these were helpful to have in mind during visits. He added that some of the things he had remembered from the orientation process, including focusing on emotions and facial expressions in pictures, were things he found his parents to pick up on right away—“That’s really what they were, at least part of the time...focused on”. A member of another family felt that the orientation process had helped her to “pull a little bit more out of the conversation” than she might normally. Based on their experiences and thoughts regarding the orientation process, families were asked if they had any suggestions for improving it. One family suggested incorporating role-playing about communication strategies into the orientation process. This family also pointed out the need to reassure families that there is no right or wrong kind of visit. Another family suggested knowing more about how advanced resident’s memory loss is, explaining that they felt that “you come to a point where...[a visit is] no longer helpful.” They also mentioned the idea that their loved one is “in the moment, and then it’s forgotten” and expressed doubts as to whether repeatedly talking about the people in pictures

with their loved one was really helping, and whether it was something they did for themselves or for her.

3.3.2.5 Summary Questions

The final category included summary questions that dealt largely with the visit experience as a whole and offered an opportunity for anything not previously talked about to be discussed. First, families were asked if they learned anything from the experience. A member of one family reported feeling that “you can try new things,” while a member of another family expressed having more of a “realization for where she’s at [mentally],” adding that that was difficult. A member of another family responded, “that I enjoy my visits with my mother and that I need to take more time to enjoy them...enjoy just the visit”. Another family felt that “this is a nice way to be prepared for a visit, to bring a bunch of media like this”, adding that they were already looking into ways to digitize images that their loved ones had not seen in a long time.

Families were then asked if there was anything they would want to change about the visit experience. While two families could not come up with any suggestions, one said that they wished they had more images. (This family had only selected fourteen images to be scanned.) A member from the fourth family mentioned spending more time selecting pictures. He elaborated, explaining, “some pictures were really hard to pick out—the slides, of which I have hundreds, were just too hard without a projector to go through and choose things”. He also mentioned that just having many of the slides digitized (which was something they planned to have their daughter do in the near future) would have helped tremendously. After the researcher posited the idea of having a projector available at the time of scanning, the family member said he thought that would not necessarily be that useful. He responded further by stating that

slide selection is something that he would prefer to do ahead of time and not necessarily in the presence of the researcher, given that a significant amount of time had been spent thinking about different aspects of the pictures, including both how the images relate to each other and how family members would relate to each other and to his parents while viewing the images.

As a follow-up, and a general summarizing question, families were asked if they would want to have another visit in the conversation corner. All of the families said yes, though one was not particularly enthusiastic. This family felt that they would probably get even less of a response in the future and added that they thought that a year or two ago, earlier in the progression of the resident's dementia, participating in the Family Visit Program would have been better and more worthwhile. The other families were quite excited about another visit, along with the idea of scanning additional images. One family even brought up the idea of using digitized movie clips, while a member of another family said that she thought it would be fun to bring her sons for a visit of this sort. When given the chance to give any additional comments, one family participant mentioned that she felt the experience was good and that it had inspired her to do two things, "one, work on having visits with mother that are more than just checking in, and two, work on family history and her stories and make sure that we document those or that I know those." She also added that this visit experience gave her a benchmark in terms of her mother's memory, noting, "she couldn't remember some things and could remember others".

3.3.3 Interviews with staff

Interviews were conducted with two staff members, at a date following the completion of all the visits. These interviews included questions about the conversation corner

when not in use for the study as well as those about the orientation process and the conversation corner with digital picture frame/stand when in use for the study, if staff members had observed the latter two categories. A summary of their responses to these questions is as follows.

First, staff members were asked what their initial reactions were to the conversation corner. One of them thought that the unit seemed very large, especially for the space. She recounted, “The residents would go by and ask what it was. They said it looked like a love seat and then we would explain that it was for an experiment and that the college students would be in to work with families”. She also expressed concern among staff as to how long the project was going to take, as it seemed to them that the conversation corner was there for a long time. The other staff member commented that the conversation corner reminded her of “a funeral home thing, or...a Catholic confessional a little bit.” Both staff members responded that they had sat in the conversation corner, and agreed that their reactions did change after having done so. One expressed what drew her to sit in it in the first place—“I guess I just wanted to see what it would feel like, and how a resident would feel if they sat there”. She said that she found it comfortable to sit in, but remembers thinking that there was not anything to look at and that there should have been pictures or something when the conversation corner was first brought into the lounge and was oriented toward the wall. The other staff member recounted, “it’s just like a big sectional sofa with a back to it, or a screen sitting behind you.” The staff members were then asked if their reactions changed after the conversation corner was moved by staff members and reoriented in the lounge. Both answered affirmatively, though one elaborated on sentiments regarding the change in orientation, stating that it was initially turned

around “so that when you sat in it, you were with people, it wasn’t like you were by yourself”.

Staff members were then asked about whether the introduction of the conversation corner affected the work of staff and/or staff members’ interaction with residents. Both of them agreed that its presence did not affect the work of staff, citing that “it was just over in the corner.” As far as its effect on staff interaction with residents, one of the interviewees said not at all. The other, though, brought up the fact that the residents asked a lot of questions about what it was. In response, the staff encouraged them to go over and sit in it. However, after realizing that there was nothing for them to look at, the staff felt it necessary to put magazines in that area of the room. The next questions were related to whether the conversation corner influenced residents’ behavior in and use of the lounge, both in its initial placement and orientation, and after it was rearranged. Both staff members that were interviewed answered that residents still went into the lounge and used it in the same way, but that residents were curious about what it was and asked questions about it. The staff members also expressed that the residents seemed to get used to the conversation corner by the time it was rearranged, and that “once in a great while, you might see somebody sit there”.

The next part of the interview gave the staff members the opportunity to express any concerns or suggestions regarding the design of the conversation corner. One of interviewees again expressed her feelings that it is big and mentioned that someone “felt it looked like a Catholic confession”. She posed the question of whether “it wouldn’t be the same if you just had chairs turned”, and added that dividers might also work because they could be set up and taken down when necessary, would not be expensive, and could even be decorated. The other staff member expressed feelings

that the lounge was not the best location for the conversation corner. She acknowledged that they had been aware of and involved in the project from the beginning, and that they understood that part of the research was to put it in a public place to see how it can minimize distractions, but felt that this was not a good place in the building for it. She did think there was an appropriate location, but that that space was already separated from the lounge and public activity.

The rest of the questions were based on the staff members having observed and/or been aware of any of the interactions with the families, including the orientation process and use of the conversation corner and digital picture frame/stand as part of a visit. As such, before any specific questions were asked about either of these components, the staff members were asked if they had witnessed or been aware of any of the interactions with the families. One of them did not know that any visits had taken place, but after being told that four visits had occurred, she commented that after a while, residents “just used it as the couch... and if we had little get-togethers, they all sat there” and that they would listen to music among other things. She added that the residents seemed to like it and that they said the conversation corner was a nice, big, soft place to sit. The other staff member had been aware of interactions with families and said that the staff knew about the visits but made an effort to stay away, as they were busy doing their work and were told that whoever was down in the lounge was talking. The more specific questions regarding any observations made of the orientation process and the visits were not asked given the limited knowledge these staff members had of the interactions with families.

3.4 Field Notes

The following is a summary of field notes made relative to each component of the Family Visit Program. These observations are intended as a complement to the other data collection methods for assessing participants' responses to concepts employed in the design of the components. As such, the field notes are organized around the four components of the program (conversation corner, digital picture frame and stand, image selection process, and orientation process and communication strategies) and the concepts used in developing each component.

3.4.1 Component 1: Conversation Corner

Concept 1-A: Line of sight

An idea central to the design of the conversation corner is that participants be able to look both at each other and at the stimuli (images on the digital picture frame), and switch between the two with relative ease. The extent to which the design of the conversation corner, as constructed, was observed to facilitate switching between looking at family members and viewing stimuli varied depending on the number of people present. Illustration 3.1 shows the conversation corner in use during visits of a family that included two people and of a family of five people.

The Family A visit was comprised of only two adults, the resident and her daughter. The two sat close to each other, towards the middle of the conversation corner, but with some space between them. This space seemed to allow them to have an easier time alternating between looking at the images and at each other when they wanted to, without forcing head turning to be uncomfortable. The daughter seemed to adjust her seating position more so than did her mother. Given that the mother spent most of the



Illustration 3.1 Group Size. The conversation corner can be used by family groups of different sizes. The visit depicted on the left includes just two people, while the visit depicted on the right includes five people, only four of whom could be physically accommodated within the conversation corner.

time looking at the pictures, it was the daughter who did most of the head turning as she alternated between looking at her mother and the images on the screen.

The Family B visit consisted of two adults, the resident and her son, and two small children, the resident's great-grandchildren. The son was sitting at one end of the conversation corner and the resident was sitting almost in the center, a little to the other side. The great-grandchildren were situated between them. Although as a group they generally turned their heads to look at each other, and did so apparently without having to strain or feel uncomfortable, most of the time was spent looking at the pictures, especially for the resident. The son's attention was diverted at times by the great-grandchildren who were climbing on or otherwise touching him, but he was easily able to turn his head and switch the focus of his attention among his mother, the screen, and the children as desired.

The Family C visit was comprised of three adult participants: the resident, her son, and her daughter-in-law. The resident sat in the middle, with her son on her right side and

her daughter-in-law on her left side. The daughter-in-law sat somewhat closer to the resident than did the son, who sat closer to the wood end panel. They all appeared able to look at each other, but the family members did so more than the resident did. This may be due to the increased difficulty the resident appeared to have in turning her head. The family members consistently made an effort to look at the resident's face particularly when talking to her. Effort was required because she was sitting back in the seat and facing the stand. The resident did at times turn her head to look at her son and daughter-in-law, but generally stayed facing straight ahead. The son's choice not to sit right up next to his mother, but rather with a bit of space between them seemed to be done to make it easier for the two of them to see each other without having to turn so deliberately. All family members appeared to be able to look at the images on the screen with ease and without having to drastically alter their sitting positions. Some leaning occurred, along with some turning of the stand, but no major difficulties were observed. Although the son was initially sitting a bit further away from his mother than was the daughter-in-law, as the visit went on, he seemed to lean and get a bit closer to his mother, which seemed at least in part to be done in order to see the pictures better. They all leaned forward towards the stand at different times, presumably to get a closer look at a detail in the image that was displayed. The resident spent the most time looking at the images, while the family also spent significant time doing so, but also went back and forth between looking at the screen and the resident and, on occasion, at each other.

The Family D visit had five participants, only four of which could be accommodated in the conversation corner. This family included two residents, husband and wife, who sat in one half of the conversation corner, with the husband in the outer part of the seat and his wife (the one with more progressed dementia) sitting closer to the middle.

Their granddaughter sat next to her grandmother and their son sat next to his daughter, at the other end of the seat from his father. The daughter-in-law sat on the seat of the father's walker, right next to the conversation corner on the other side of the father, almost as if the curve of the bench had continued. Given that she was not actually in the conversation corner, she was somewhat removed from the group and had to make more of an effort than the others to look at the pictures. She did however appear to have the easiest time looking at everyone else. The radius of the curve of the seating unit may not have been tight enough for a group this size as evidenced in the amount of time that the son spent leaning forward and sitting towards the front edge of the seat, presumably to be able to switch easily between looking at the images and looking at his parents. Interestingly though, the fact that the son was often leaning/sitting a bit forward did make it easier for his parents to look at him without having to adjust their sitting position. The family members would definitely turn toward the group, and specifically the residents, when talking to them. The residents also sometimes looked at each other, specifically when talking primarily to one another. To do so, they had to turn significantly, and often the husband would lean into the corner (away from his wife) to see her more easily. As a group, they did not seem to have difficulty seeing the images, even when sitting back, though they probably could not all see very well at the same time given the size of their group. As such, they took advantage of rolling and, even more so, of turning the stand so everyone could have a chance to look. At different points, all of the family members did lean a bit forward towards the screen and more towards the center of the seat, seemingly to get a better look at the screen. The daughter-in-law in particular had to do this as she was sitting the furthest out and was the most removed, due to the walker she was using as a seat being almost in line with the edge of the stand. The son and father also leaned more so than the mother and the granddaughter, as the latter were the most centrally located. In general, the group,

especially the residents, spent a lot of time looking at the images, evidence that they found them to be quite interesting, captivating, and enjoyable.

Observations: Although the curve of the conversation corner appeared to enable all participants to look at each other and at the images, some participants were observed to be straining to maintain their desired line of sight. Although line of sight concerns remain constant, the size of the group sitting in the conversation corner can affect how well the design supports the ability for participants to look at each other, at the images, and to switch between the two with ease.

Concept 1-B: Touch

Another key aspect of the conversation corner design was the opportunity the continuous bench provided for physical contact and loving touches among family members.

Although only a few instances of touching were observed during all four visits, when it did happen, it tended to be quite tender. For Family B, touching occurred between the family members in that the great-grandchildren were consistently climbing on or interacting with and touching their grandfather, the resident's son. The children also started touching each other a little bit, specifically towards the end of the visit, as they became restless. What seemed to be the sweetest and most significant instance of touch for this family was between the resident and her great-granddaughter. At one point the great-granddaughter leaned on the resident, they looked at each other, and the resident playfully poked the little girl's belly. The two really appeared to make a connection, even for just a brief moment, and both seemed to smile and enjoy it. The family that included the resident couple, Family D, also exhibited a few sweet

instances of touching, especially that which occurred between the two residents. At various times, they held hands, or he placed his arm around her, or she put her hand(s) on his leg. These behaviors exemplified that they were a happy couple and seemed to show how much they were enjoying the visit and spending time with their family. Illustration 3.2 depicts an instance when the residents were touching, with the husband's arm around his wife. During this family's visit, the son also touched his mother a few times, mostly as a way to get her attention. He did so when she started having a side conversation just with her husband, while the other family members were trying to encourage group conversation. Additionally, there was one instance in which the son put his hand on his mother's leg as a consoling gesture when she did not remember that a sibling of her husband, whom she asked about, had passed away several years earlier. There were some brief instances of touching between the family members, specifically the son and granddaughter, usually having something to do with her controlling the navigation through the pictures.



Illustration 3.2 Touch. This picture depicts the resident couple of Family D touching, with the husband's arm around his wife's shoulders.

The other two families exhibited even fewer instances of touching. For Family A, the only time the daughter reached out and physically touched her mother was when the

mother started coughing. Otherwise, they sat fairly close to each other and at times definitely leaned their bodies or inclined their heads or bodies towards each other, without actually touching. With respect to Family C, the only observed instances of touch were when the daughter-in-law whispered to the resident, usually to give her an answer to a question that the son had just asked, and when the daughter-in-law leaned behind the resident to whisper to her husband about not asking so much about whether the resident remembered or could tell them who the people were in the pictures. They all sat fairly close together, especially the daughter-in-law and the resident, and both family participants did at times tilt their heads or lean their bodies toward the resident. Observations: The fact that any touching occurred at all during any of the visits meant that the design of the conversation corner with a continuous bench seat did allow for physical contact and certainly did not inhibit it.

Concept 1-C: Standing support—folding armrests

Armrests were provided to offer support for the resident when sitting down and standing up. Given that the presence of armrests can dictate how close people can sit together and what kinds of seating postures they assume, the armrests were made to fold into the back cushion, revealing an unobstructed surface.

None of the families used the armrests, some not even realizing that they were there. In general, when residents were standing up from the seat, they used their family members and/or walkers for support. Although no one used the armrests to help them get up, the fact that they were out of the way certainly affected how the families interacted. Because the seat could be seen as one long bench, without defined seat divisions, families were able to choose how they wanted to be configured within the conversation corner, and could adjust their positions and postures as well throughout

the visit. For Family A, comprised of just mother and daughter, having an open curved bench enabled them to sit close to each other, without having to be right up against each other. This arrangement allowed them to retain enough space between them such that they could comfortably look at each other as well as the pictures and talk to each other without being too close for comfort. For Family D, even though all five of them could not be accommodated by the conversation corner, the four who did sit in it would not have been able to fit as easily, if at all, if the armrests had been permanently down. In Family B with the great-grandchildren, not only could the children move around on the seat without any obstacles or tripping hazards, but also the great-granddaughter at times became fascinated and occupied with the velcro flaps covering the armrests (that were stowed within the seat back).

Observations: It was apparent that with the armrests folded away people sat different distances apart and assumed a variety of seating postures. Because participants did not pull the armrests down, it was not possible to observe the effectiveness of the armrests in assisting residents with sitting down or standing up. While having the armrests out of the way appeared useful, the velcro flaps covering them in the stowed position obscured the armrests to the point that they were not intuitive to use and people were not aware of their existence.

Concept 1-D: Transfer from wheelchair—flip-up seats

The outer seat on each end of the conversation corner flipped up to allow a wheelchair to get close to the middle seat and enable side transfers between wheelchair and middle seat.

None of the families were observed to utilize the flip-up seat feature. Only one of the residents who participated in the study used a wheelchair. This resident transferred between the wheelchair and the conversation corner seat, but was not observed to use the flip-up feature. Instead, the son assisted her in these transfers.

Observations: The reason the flip-up seat feature was not used is unknown. Part of the reason may have been due to the latch not being visible from a seated or standing position. If this were the case, the placement and ergonomics of the latch would need further consideration.

Concept 1-E: Intimate scale

The scale of the conversation corner was designed to be intimate. The intent was to bring the scale of the larger room where the conversation corner was located, in this case, the fourth floor lounge, down to a smaller and more intimate scale.

Although responses to this concept were difficult to observe given that this idea really deals with how people feel when in the conversation corner, family members during each of the four visits sat fairly close to each other and seemed to be interacting as if in an intimate setting. The height of the canopy, one of the design elements used to define scale, did appear to be too tall for people when seated. Because the canopy is so far above people's heads, it is likely to be perceived as not much lower than the ceiling of the room itself. Along these lines, although the high back appears enveloping, it may also be too tall to give a convincing sense of intimacy.

Observations: To the extent that the handling of scale in the design achieves intimacy, scale seems to be more successful in the horizontal than in the vertical. The curve of

the bench implies intimacy and promotes sitting close to each other while the height of the seat back, combined with that of the canopy, is out of scale with the seated participants.

Concept 1-F: Acoustical zone

The conversation corner was designed to enhance the ability of family members to hear conversation during visits. The design intent was to keep the sounds of conversations in and minimize intrusion of sounds from outside of the corner.

All of the families appeared to be able to hear what was being said during their visit. Participants did not talk excessively loudly. Even those residents who had hearing impairments seemed to be able to hear their families, without having to ask for many comments to be repeated. The resident of Family B was the one among all resident participants who exhibited the greatest amount of hearing difficulty, and this was most evident during the post-visit interview. In Family D with husband and wife residents, the woman had excellent hearing while the man was somewhat hearing impaired. He did not appear to have excessive difficulty hearing what others were saying during the visit, but did ask for some comments to be repeated. His requests did not seem excessive nor did the conversation corner appear to be exacerbating his hearing problem. Although his wife spoke softly, by sitting right next to her husband she could speak directly toward his ear. His participation in family conversation was limited, potentially because he could not hear and did not speak up to say so, or because he simply did not have anything to add or did not feel like talking. Because of his wife's excellent hearing, she picked up on sounds coming from beyond the lounge, including a door slamming and someone's alarm clock going off. The conversation corner did not appear to buffer these external sounds. The family talked about these noises and

commented on how great the mother's hearing was. After filling the father in on what had happened (as he had not heard the sounds), the family quickly got back into looking at the images and talking about them. With respect to Family C, the mother was somewhat hearing impaired, but did not appear to be having a difficult time hearing her family while in the conversation corner. Moreover, although she also spoke at a low volume, her family was still able to hear what she was saying. Towards the end of this visit, some other residents in the lounge started watching the television with the volume turned up. While it seemed as though the family could hear the TV, they certainly could not see it, which may have prevented the TV from being too much of a distraction. The family continued with their visit, and finished going through the pictures.

Observations: The acoustical qualities of the conversation corner appeared to facilitate conversation within it, but the design was limited in its ability to buffer outside sounds, especially those that were loud. Additionally, no observations were made as to whether or not, or to what extent, the conversation corner was able to shield the sounds of the conversation from the space around it.

Concept 1-G: Screening out distractions

The design of the conversation corner was intended to help screen out competing sources of stimulation or other outside distractions.

During the visits of three of the families, there was little other activity in the lounge and therefore no significant distractions. During Family A's visit, no other residents or staff even came into the lounge, while during Family B's visit the only other person to enter the lounge was a staff member. She came over to the conversation corner and

asked the resident and family what they were doing. They talked to her and showed her the picture they were looking at. This interruption did not seem to be perceived by the family as a negative distraction, but rather as a pleasant part of the visit. They neither ignored her nor seemed to be bothered by her coming over. In fact, it seemed as though they were happy to show her and tell her what they were doing since they were having a good time. During Family D's visit, the most significant interruption was when a couple of other residents came over to see what the family was doing. The family showed these other residents the digital picture frame and spoke to them briefly about it, and did not seem to be disturbed and certainly not annoyed by the disruption. Even though these other residents stayed in the vicinity and walked around for a bit, the family quickly regained their focus and returned to the flow of their conversation, as they really seemed to be enjoying looking at the images. This family also experienced a few additional rather minor sources of distraction. These were sounds coming from beyond the lounge, including a door slamming and someone's alarm clock going off, each of which the mother pick up on and noted. The family acknowledged these sounds and the mother's exceptional hearing. These distractions did not seem to last more than a few seconds each at the most, after which the family got right back into the images. It seemed that their focus was so drawn to the screen and the images that they could easily brush off any sounds or interruptions that might have become major distractions.

Family C appeared to be the most easily distracted, even though the disturbances that occurred during their visit were not significantly different than those that occurred during the visits of the other families. This family was the only one that reacted noticeably to the inevitable distractions of the presence of the researchers, the video and audio recording equipment, and the underlying idea that they were being

observed. This family, most notably the daughter-in-law, would at times look around, most likely for the researchers. The daughter-in-law exhibited this behavior more so in the beginning of the visit or right before she whispered comments to her husband about not asking the resident so many questions about identifying people in the pictures. These seemingly nervous behaviors did appear to diminish as time went on, as the daughter-in-law may have become more comfortable or more engrossed in the visit and the images. Another more specific instance of distraction occurred when some other residents came over and talked to the researchers. The family, including the resident, seemed distracted by this because they could probably hear what was being said and see it in their peripheral vision. The resident even sat up taller to look over the stand to see what was going on. This was, though, a relatively quick interruption, and the family continued with their visit. Additionally, towards the end of the visit, a staff member turned the television on for some other residents in the lounge and the volume was fairly loud. The family seemed to be able to hear it, as the son in particular seemed to glance up in the general direction of the television and noticeably change his body language. However, because of the wood end panels on the conversation corner, he could not see the screen, which may have helped reduce the level of distraction. The daughter-in-law's back was toward the direction of the television, so she also could not see it.

Observations: Because there were not many distractions during the visits, it was hard to judge the extent to which the conversation corner was able to screen distractions. Additionally, it seemed as though different people might react differently to distractions based on a number of factors, including how involved or engaged they were in their visit. Along these lines, the position and orientation of the conversation corner might also affect its ability to screen outside distractions. For example, if it

were turned to face the corner of the room, it might even preclude some distractions from occurring, as other residents might be more hesitant to come over and talk to the family.

Concept 1-H: Seating posture

The contour of the bench seat was designed for postural comfort during the act of viewing images on the digital picture frame. In the design of the conversation corner, seat height, seat depth, and seat back angle were all considered, along with the firmness of the upholstery.

All of the families appeared to be comfortable sitting in the conversation corner. They seemed to be able to see the images even while leaning against the seat back, but also seemed to be able to lean forward or in any other direction with ease when desired. Alternately stated, no one appeared to get stuck in the leaning back position.

There were seating behaviors that were not anticipated when designing the conversation corner, but that ended up being accommodated by the design. One example occurred during the Family A visit. Because the seat cushion was not as deep front to back as most sofa cushions the daughter was able to sit with her right foot on the floor and her left leg bent and resting on the seat cushion, as depicted in Illustration 3.3. This enabled her to turn her body toward her mother, a position that allowed her comfortably to look at and pay attention to the pictures and her mother, and to switch easily between the two. The behavior just described was facilitated not only by the shallow seat depth but also by the curve of the seat. The curve of the seat slightly reduced the degree to which family members must turn their heads in order to look at each other.



Illustration 3.3 Seating Position—Family A. The shallow depth of the seat cushion allowed the daughter of Family A to sit with her right foot on the floor and her left leg bent and resting on the seat cushion.

During Family B’s visit, although the resident and her son did not noticeably change their positions, the great-grandchildren did a significant amount of moving around. They were somewhat restless, did not want to sit still and were observed to engage with the seat in a number of ways including sitting on it in various positions, leaning on it, kneeling on it, and even standing on it.

In the Family C visit, all of the participants seemed to be comfortable sitting in the conversation corner looking at the screen, but the family participants did appear to adjust their positions more so than did the resident. In part, this may have been because they were alternating between looking at the resident and at the images. The daughter-in-law in particular was observed to fidget and make small position and posture adjustments including moving her hands on her lap and making small

modifications to how she was sitting. These behaviors may have been due at least in part to being physically uncomfortable or to being somewhat nervous.

With respect to Family D, comprised of five people, the conversation corner could accommodate only four of them. Although they all tended to sit back while looking at the images, at times individuals would lean forward toward the stand to get a closer look at the display screen. It was observed that both the son and the father who were sitting in the end seats on opposite sides of the conversation corner would sometimes change posture a bit and lean more into the end panel. This behavior apparently was in order to get a better view of the family, in particular the mother, while talking.

Illustration 3.4 shows the son sitting toward the front edge of the seat and with his body leaning forward and toward the end panel while he looks towards his parents.

They then would go back to sitting more towards the middle presumably to be able to



Illustration 3.4 Seating Position—Family D. The son of Family D is depicted sitting toward the front edge of the seat, with his body leaning forward and toward the end panel while he looks towards his parents.

look at the images. Additionally, as a group, the four sitting in the conversation corner did not seem to make many position adjustments, as there was not a lot of extra room for them to move around.

Observations: Decisions about seat contour—seat back angle, seat height, and seat depth—and upholstery firmness in the design of the conversation corner were observed to be appropriate and effective in accommodating a broad range of postures and behaviors, even those that were not anticipated.

Concept 1-I: Reach range

The conversation corner was intended to enable participants comfortably and easily to reach the stand/screen. Features such as seat depth, seat back angle, and unobstructed space beneath the front edge of the seat, allowed for ease and comfort in leaning forward and in rolling the stand within close reach range.

No major issues with reach range were observed. All of the family members who sat within the conversation corner appeared able to reach the stand or point to the screen without difficulty or reaching strain. None of the families seemed to have problems with the mobile base fitting under the conversation corner, but foot placement frequently obscured the ability of the observer to determine if the stand had been moved to an optimal position relative to the viewers.

Observations: Seat depth and seat back angle in the design of the conversation corner facilitated reach range. While the design of the conversation corner accommodates reach range, foot interference with the mobile base of the digital frame stand reduces the effectiveness of this accommodation.

Concept 1-J: Aesthetics

The aesthetic concept for the conversation corner was about striking a balance between simplicity—a design that is not comprised of distracting visual elements—and sophistication—a design that does not talk down to the residents or family members and that is not childlike. Giving the conversation corner a feeling of warmth, so it would feel cozy and inviting to sit in, was also considered important.

Although all of the families appeared to be comfortable sitting in the conversation corner, it was difficult to make observations regarding their feelings about its aesthetics. Certainly, none of the families seemed to be distracted by the upholstery or any other elements of the conversation corner, with the exception of the great-granddaughter, who for a short time became fascinated with the velcro of the panel covering the armrests when they were tucked into the seat back. For Family D, the resident couple appeared to be hesitant when they first approached the corner. Once the visit started, though, neither the family members nor the residents seemed to focus on the conversation corner at all, as they were engrossed and captivated by the images. The conversation corner did not appear to distract them at all or detract from their experience or ability to interact in any way. The perceived nervousness and fidgeting of the daughter-in-law from Family C seemed to be more related to the idea of being observed by researchers than by any aspect of the conversation corner itself. This family also did not seem to be distracted or offended in any way by the aesthetics of the conversation corner. Although none of the families showed any signs of distraction with respect to the conversation corner itself, this certainly does not automatically translate into them having positive feelings towards its aesthetics.

Observations: The fact that initial reactions to the design of the conversation corner evoked hesitation suggests that the design should be softened. It is relevant to note, though, that once people sat in the conversation corner, they appeared less focused on aesthetics, and more on their favorable opinions of the quality of the spatial experience. Ideally, the aesthetics and actual feel of the seating unit would align.

3.4.2 Component 2: Digital Picture Frame & Stand

Concept 2-A: Focus attention with frame

The wood used to enclose the digital picture frame was designed to help focus attention on the screen and the images. Not only was the wooden frame intended to add warmth to the digital picture frame, but also to help separate the displayed images from other objects in the room that might be seen in one's peripheral view when looking at images on the digital display.

All of the families were observed to focus much of their attention on the images displayed on the digital picture frame. The wooden frame seemed to help in this regard. The frame appeared to be an appropriate size for attracting and focusing attention, as it created a buffer of sorts between the image and peripheral distractions. In Family B, the resident and her son both remained focused on the images for most of the visit. Of more significance is that, at certain times, even the two young great-grandchildren stayed engaged in looking at the pictures. With respect to Family A, both the resident and her daughter seemed interested and able to focus easily on the digital picture frame and images, within the context of the wooden frame and stand. At some point towards the end of their visit, the resident asked her daughter about the frame and stand, which could indicate that its presence was significant given that the

resident made a point to mention it and acknowledge it. The frame seemed to help attract and hold the focus of Family D as they viewed the images. This family was comprised of five people, and so having the frame to define the edge of the screen and create a border may have been especially beneficial as the frame also helped make the screen a larger entity on which to focus. Even though the granddaughter's attention wandered more than that of other members of this family, she definitely appeared to be engaged and focused on the images and the screen at certain points throughout the visit. Within this family, the residents in particular were completely interested in the pictures and engrossed in looking at them on the digital picture frame. For Family C, the frame again seemed to help focus their attention on the pictures. The family members spent the majority of their time looking at the images (or at each other) and relatively little time looking around the room for other stimulation. The frame also made the screen larger in that it took up more visual space, which seemed to help block out other things going on in the room beyond the screen. For example, at one point when several other residents came over and talked to the researchers, the family seemed to be distracted and the resident even sat up taller so she could peer over the screen to see what was going on. Although she did this when the frame was present, had the frame not been there, the level of distraction could have been even higher and the group may not have been able to get back into looking at the images as quickly.

Observations: The design of the wooden frame for the digital picture frame appears to help focus viewers' attention on digital images.

Concept 2-B: Control

The idea of control was extremely important in the design of the digital picture frame and stand. Control manifested itself in a number of ways, as previously explained.

The handholds were observed to be conveniently located. Not only were they used by all families to adjust the rotation of the screen but were also commonly used as a resting place for hands between clicks of the navigation buttons.

The mobile base did enable families to locate the stand where they desired, but a significant problem was observed. This was in the relationship between the mobile base and people's feet. For Family C in particular, there were a few instances when a family member tried to pull the stand closer to the group, but could not because its base and peoples' feet/legs, especially those of the resident, were colliding. This resident had at least one of her feet on the base at times, seemingly because there was nowhere else for her feet comfortably to go. This became a serious problem when the resident moved her foot that was resting on the base and unintentionally pushed the stand, almost causing it to fall over. The son was able to grab the stand before it toppled. Some members of Family D also rested their feet on the base intermittently, apparently without problems. There was only one instance of a foot causing the stand to move, when the male resident's foot was on the stand base and he inadvertently moved his leg, pulling the stand closer. This caused his wife to have to adjust the position of her legs, but this too seemed not to be problematic.

The stand's swivel stem and tilt mechanisms both worked as intended, although Family B was the only group to employ the tilt mechanism. This family adjusted the tilt so that the screen was fully upright, which was later determined to be the reason the remote did not function properly (as it cannot transmit through the wooden frame). Family D seemed hesitant of the tilt mechanism, noting that it needed to be tightened, an operation that required use of a screwdriver. The other two families did not use the

tilt mechanism at all. All families were observed to use the swivel feature of the stand as they periodically adjusted the facing direction of the screen. Family D, the largest group, was observed to be the most frequent user of the swivel feature as they rotated the screen among family members to enable all to see images. In Family A, while the son made most of the adjustments, the great-grandchildren at times turned the stand, sometimes seemingly inadvertently.

The navigation buttons on the remote control worked but some issues were observed. Family B experienced technical difficulties and thus was unable to control the amount of time the image remained on the screen. As such, the family had to look at the images on automatic slideshow mode, for which the images switched after only ten seconds. It can reasonably be said that for at least some, if not all, of the images, the family probably would have wanted them to remain up for a longer duration of time, given that there appeared to be more things to talk or ask questions about than could be done in the ten-second period. Additionally, it is likely that with more time, the resident might have been able to recognize more people and features, or at least there would have been more time for the images to sink in and be processed. There were at least a few instances when the resident had just started talking about an image when the screen switched to the next picture. Given this time constraint (along with the limited number of pre-selected photographs), this family looked through the whole set of images a few times, which did allow them to talk a bit more about some of the images, but certainly not in an ideal way. If they wanted to continue what was said during the previous viewing of an image, they had to rely on everyone's ability to remember earlier parts of the conversation, something that the structure of the visit and design of the program were trying to avoid.

None of the other families experienced technical difficulties with the remote and thus they were all able to control how long they spent looking at each image and vary the amount of time according to how much conversation was spawned. These families also did not seem to experience any difficulties using the navigation buttons on the remote other than having to figure out the direction to which each button corresponded.

For Family A, comprised of just the mother and daughter, the daughter did the majority of the manipulation of the frame and stand. While the daughter seemed comfortable using the buttons on the remote, the resident appeared comfortable only pointing to and touching the screen or stand. For Family D with five participants, the granddaughter was the person who basically did all of the navigation through the pictures using the buttons on the remote. This seemed to help keep her attention on the images to some extent, though she definitely did play around with the remote cover, at times lifting it up and looking at the other buttons. This family certainly seemed to vary the amounts of time spent on individual pictures, and there were at least a few occasions in which an image sparked someone to tell a story. For Family C, the son was the primary, if not the only, one to use the buttons on the remote to navigate through the pictures, and no issues related to this control were observed.

Observations: All features of the digital picture frame stand appeared to work as intended although improvements are needed. Problems were observed with the mobile base—its stability and interference with feet—and the intuitive nature of some controls.

Concept 2-C: Aesthetics

The wooden frame and stand for the digital picture frame used specific aesthetic concepts in their design. These included use of natural wood to add warmth and soften the otherwise technical features of the digital picture frame. Another concept was to design features that expressed how the stand should be manipulated, thus making use of the stand and frame intuitive.

Observable indicators of participant's responses to the aesthetics of the digital picture frame stand were difficult to identify. Apparent comfort with the stand was considered one indicator. All of the families appeared to be comfortable with the stand and its accessibility as evident in the frequency with which participants, including the residents, touched the handles of the stand. Even the great-grandchildren in Family B pointed to the screen and touched the stand, specifically grabbing onto the handles. It seemed in general as though the stand really invited participants to touch it and engage with it, maybe helping them to connect with the pictures. Enjoyment of the digital pictures was considered an indicator that the aesthetic quality of the stand was familiar and did not divert attention from the intended source of stimulation, the images. All of the families focused attention on the digital images and for one family in particular, Family D, the resident couple exhibited excitement about looking at the digital pictures.

Observations: The aesthetic qualities of the digital picture frame stand, including the use of natural wood and features that express their use, appeared to be viewed positively by family and residents alike.

Concept 2-D: Display to compensate for progressive Alzheimer’s disease-driven decline in sensory capability

In this study, where a goal was to compensate for progressive Alzheimer’s disease-driven decline in sensory capability, three features of a 15” digital picture frame made it appropriate for use as the display medium. The features were generous image size, good image contrast because of integral lighting, and ability to control duration of image display.

The size of the images seemed to be appropriate for all of the residents as evident in their ability to focus on the images and not be inclined to seek out other sources of visual stimulation throughout the room. For Family B, the resident seemed interested and engaged in the visit and often pointed to the pictures. She actively talked to the staff member who came over about what the group was doing. During Family A’s visit between mother and daughter, image size also seemed adequate as the resident was able to sit back and look at the pictures without having to strain. She leaned forward to study details at times, but did so with apparent ease. This medium appeared to provide her with sufficient stimulation such that she were not distracted or looking for other sources of stimulation in the room. For Family C, the images seemed to hold the resident’s attention, even though she did not exhibit much of a (verbal) response to all of the images. For Family D, consisting of five participants, the size of the digital picture frame was adequate for the two residents. They were able to look at the pictures together without having to be right on top of each other or having to exclude their family members, as might be the case with a photo album that could be too small and cumbersome to view as a group. The pictures were large enough to hold the residents’ attention and allow them to avoid distractions or straying interest to competing stimuli.

Contrast and integral lighting seemed to be adequate, although both were affected by viewing angle. The ideal viewing angle was within 30 degrees on either side of the centerline of the screen. Family A adjusted the tilt of the screen in order to place the resident's line of sight within the optimal viewing angle of the screen. Once this adjustment was made, she appeared to have no problem seeing images. Family D rotated the screen for the residents who then leaned their bodies at times, apparently in an effort to get a better look.

Ability to control duration of image display was important because extended display periods minimized the need for residents to remember things talked about during a conversation. Even for Family B, who experienced technical difficulties and could not control the dwell time for each image, the resident seemed to find the digital picture frame to be an otherwise appropriate medium. It was apparent that at various times, the resident would have benefited from additional time with a given picture to talk more about it. The three other families were able to control dwell time and use the idea of having a constantly present stimulus as a basis for conversations. The Family A resident was able to look at an image for as long as was desired or needed for recognition or questioning. Although the members of Family C at times appeared to use the pictures and the idea of a constantly present image as a starting point for conversation, there was relatively little verbal response from the resident, making it difficult to judge her ability to see and process images. The digital picture frame also seemed to work well as an image-viewing medium for Family D consisting of five people. Having a constantly present image allowed sufficient time for the residents to thoroughly examine each picture, take it in, process it, and usually recognize at least some aspect of it.

Observations: The digital picture frame was observed to be an appropriate image display medium to help compensate for progressive Alzheimer's disease-driven decline in sensory capability. Considering the use of an even larger screen might be worthwhile.

3.4.3 Component 3: Image Selection Process

Concept 3-A: Sources and quantity of images

In selecting images, families were advised to look at a variety of sources, including photographs, photo albums, and slides, as all of these could be scanned into digital images. Additionally, families were given the recommendation to choose approximately thirty images.

Only one family, Family D, brought slides in addition to a proportionately larger number of printed photographs. The three other families brought only photographs. While most of the families seemed to choose pictures from a variety of albums or collections, one family, Family B, brought in only one album, with possibly an extra picture or two. This family had not pre-selected the images to be used from the album, but rather went through the album during the preparation visit and selected them on the spot, evidence that they had not put in the desired effort beforehand. This family only selected fourteen images, which appeared not to be enough at the time of the visit. This, though, may have been due mostly to the fact that this family experienced technical difficulties and was unable to control how long each image remained on the screen. As such, and given the fact that the automatic slideshow settings changed the image every ten seconds, the group cycled through the selected pictures fairly quickly. Although the family went through the whole set of pictures a few times, they were not

able to dwell on images for as long as they wanted. During and after the visit, the son expressed that he thought he had chosen more images, and definitely wished that he had selected more. Some of this desire to have a greater number of images may have been due to how much he saw his mother enjoying the experience, and even how much he may have enjoyed it as well. Families A, C, and D selected 33, 45, and 36 pictures respectively. Although it had been explained to the families that they should not feel pressure to get through the complete set of images, but rather just to look at and talk about the digital pictures for as long as was comfortable, each family did look through all of their pictures during their visit. While most of the families appeared to enjoy the images so much that they would have been happy to look at more, one of the families, Family C, appeared to be fixated on the idea of getting through the task of looking at the images, specifically focusing on finishing the set. In this way, the family members seemed relieved, in a sense, when they got back to the beginning of the set of images.

Observations: The recommended number of images, thirty, was observed to be appropriate in terms of sustaining meaningful interaction for the duration of the visit, without causing the visits to be excessively long.

Concept 3-B: Image selection considerations

When selecting images, families were encouraged to consider the following ideas. First, they were asked to think about the meaning of images to the resident in order to select pictures that would elicit a positive reaction. Second, families were encouraged to think about the resident's life as a story with chapters and to select images that represent different chapters ranging from, for example, the resident's childhood or early life to more recent years including children and/or grandchildren. Third, families

were strongly encouraged to consider their own familiarity with and ability to talk about images, especially those that precede their memory, in an effort to prevent a situation in which neither resident nor family can recall anything about a picture and have nothing to say about it.

In general, most of the families appeared to put a significant amount of effort into their image selections and seemed to keep the considerations described above in mind when choosing pictures to include. For Family D, the son was probably the primary family member involved in image selection, as he was the one who attended the preparation meeting and he was the one who talked the most about the topic of image selection in the post-visit interview. He appeared to have put a substantial amount of effort into picking a variety of images that spanned his parents' lives. Additionally, he seemed to choose pictures that related to or that depicted specific stories that he thought would elicit positive reactions and that he wanted to talk about. It was also observed that he made a point to select specific images that he thought his parents had not seen in a long time and that they would really enjoy. His image selection choices appeared to have been made with deliberate intention. He selected images with which he was quite familiar and was able to talk about them with ease. It appeared that he had not only put thought into image selection, but also into what might be said about each image, as a means of preparing for the visit and having a backup, of sorts, in case conversation lulled. The set of images selected can be seen as successful given that the residents visibly enjoyed and were excited about looking at the digital pictures, commenting on the fact that they had not seen certain images in a long time and how they never thought they would see some of them again. Another thing to note was the son's enthusiasm about image selection, as it was clear that he understood it to be an opportunity to influence the quality of the family visit in a positive way. Additionally,

this process appeared to give him an appreciated motivation to sort through the family's fairly large collection of slides, and have them digitized. At least part of his enthusiasm was probably related to the fact that as a family they were already in the mindset and process of going through images and even digitizing old family movies.

Family A also showed significant enthusiasm and excitement with respect to image selection. The daughter in this family seemed to put considerable thought into the image selection process prior to the initial preparation meeting. She chose pictures from throughout her mother's life, ranging from when her mother was a Girl Scout to when she was a high school student doing a radio interview, to when she was protesting in Washington D.C., to when she was serving on civic committees. Considerable thought and intention also went into image sequence when the daughter was given the opportunity to arrange them at the preparation meeting. She seemed to be sufficiently familiar with the images, as she could talk about them, and expressed significant interest and enthusiasm in further delving into family pictures, stories, and history to increase her own familiarity. The images selected by the daughter were successful in that the resident was observed to be quite interested and excited about looking at them, and really appeared to enjoy herself while talking about the pictures.

With respect to Family C, the images selected seemed to cover a variety of times or chapters in the resident's life and definitely included a range of family members. Additionally, the family appeared to make an effort to choose images that the resident would react positively to and enjoy looking at. Positive responses did occur, to the extent that they could be observed, given that the resident exhibited limited (verbal) response capability. Although there was not a huge amount of excitement on the resident's part, there were not any negative reactions either. The family was familiar

with the images and what was depicted, which allowed them to be able to talk about the pictures and identify people, even when the resident could not do so.

Concerning Family A, the son chose pictures that his mother appeared to enjoy seeing and that presumably were significant to her. These images covered a variety of parts of his mother's life. The son, though, seemed to focus more on pictures from her early life and with only fourteen images selected, did not cover many chapters of her life. In part, this lack of coverage may be due to selecting images just from one album, which is likely to have contained pictures that spanned only a limited amount of time. The son seemed familiar enough with the pictures and was able to identify people and answer questions when his mother inquired or faltered.

Observations: The recommendations for thoughtful gathering of images appeared to provide useful guidance to families during the image selection process. Families who appeared to have put significant thought and effort into the image selection process were observed to be fully engaged in and enjoying the visit.

3.4.4 Component 4: Orientation Process & Communication Strategies

The orientation process consisted of a preparation meeting held with individual families during which communication strategies were introduced and discussed. A printed copy of these communication strategies was also provided to families for use during the meeting as well as to review at home.

The level of interest in discussing the communication strategies varied among the families—some engaged in discussion with enthusiasm, while others did not show much concern. With respect to Family B, the son did not appear to be very interested

in the communication strategies or thinking of ways to use the images as the basis for interaction. At the preparation meeting, he said that he had forgotten his glasses and, therefore, could not read the sheet during the discussion of communication strategies. As a result, this discussion was quite brief. Moreover, it appeared that he did not look over the printed copy before the actual visit. For Family C, both family members attended the meeting and participated in the discussion of communication strategies. During the dialogue, both family members commented about the progression of the resident's dementia and expressed skepticism about the potential for the visit to be successful (though "success" within the context of this research was never defined explicitly, but was solely based on the subjective experience of families). Along these lines, the family members expressed their belief that the visit would be a lost cause and that their loved one was not the ideal resident to reap benefits from participating in the study. Nonetheless, the recommended communication strategies were discussed and the family members, especially the daughter-in-law, did ask a few questions and expressed thoughts about strategies. The daughter-in-law, more so than the son, showed some interest in and was receptive to the ideas presented and appeared to make at least a bit of an effort to use the strategies during the actual visit. The son generally seemed to ignore the strategies, except when he was reminded of them by his wife. After the visit, this family indicated that they found the communication strategies interesting but hard to adhere to, especially considering the decline of their loved one. They seemed to have made up their minds in a way about the communication strategies even before really trying to use them or to think of additional ways of enhancing communication with their loved one.

In contrast, the other families were observed to take more of an active interest in thinking about the communication strategies. In Family A, the daughter appeared to be

quite interested in discussing these strategies. At the preparation meeting, she sought to understand the recommendations, asking for examples and making it a real discussion rather than just a one-sided presentation of ideas. For Family D, only the son attended the preparation meeting, even though there were other family participants. He seemed to be interested in talking about the communication strategies and also posed questions and asked for examples. A productive and thoughtful conversation occurred, and at the actual visit it was evident that he had talked to his wife about the communication strategies or given her the sheet describing them, as she too seemed familiar with them when we spoke during the post-visit interview.

Observations: The presented strategies appeared to be useful in assisting families, some more so than others, to explore ideas that go beyond their preconceived notions for how to communicate with their loved one during visits.

Concept 4-A: Recognition ability

Image recognition—the ability to identify, name, and place into chronological context the contents of an image—is relevant but not an objective of the Family Visit Program. Conversation about images should not be dictated or limited by correct image recognition, but rather the emphasis of the visit should be to use whatever is recognized as a basis for evoking positive emotions.

The families varied in terms of how much this concept appeared to come through in their visits, with some family members focused primarily on identification and others trying to embrace recognition when it happened, but not trying to force it, and being content even when recognition did not occur. Family C in particular seemed to try to get the resident to recognize, remember, and identify people, things, and scenarios

depicted in the images, even though this line of thinking was difficult for the resident. Some time was allotted for exploration of the images, and at certain points the resident could identify some people or things, but really only when questioned or coaxed, and usually the information ended up being supplied by the family. When a new image was brought up, the son tended to ask his mom if she recognized the person or people in the picture. Although the family seemed a bit preoccupied with recognition, at times the daughter-in-law, more so than the son, did try to go beyond that, but often not for long, especially given that the resident was generally unresponsive. The family tried to engage the resident and talk about things that were not necessarily specific to remembering precisely who was in the picture or what happened, but rather things about emotions or appearances of people. For example, they talked about why a woman in one of the pictures looked so big, the answer being that she was pregnant. They also talked about seasons, as there were some pictures of the same house at different times of year. Even with these efforts, the resident was not very verbally responsive, so it is unclear how much the family's emphasis on emotions instead of facts may have helped. It may have been less frustrating for the resident, given the anxiety that can be raised by not knowing the answers to questions, if she could have been allowed simply to look at the pictures and enjoy them. Additionally, the family may have found her limited responses to be somewhat discouraging, thus making it hard to keep up attempts to talk about the images in ways beyond just who is in them and what they are doing. With regard to Family B, who experienced technical difficulties, they were able to talk to some extent about the pictures, but were significantly limited by the ten-second dwell time imposed on them by the automatic slideshow mode. This time frame did not allow for as much exploration of the images as seemed to be desired. In general, though, the group started out talking about recognition, but did branch off into less factual aspects of images.

The two other families seemed to work with the residents' ability to recognize images, but appeared to accept the residents' cognitive decline and were not limited by the residents' lack of ability to recognize images. Family A, comprised just of mother and daughter, talked a lot about the pictures and different elements of them. The daughter allowed her mother time to recognize people, things, or scenarios in pictures, while acknowledging lapses in her mother's memory and not being stifled or discouraged by them. The resident's recognition and memory of the content of images varied from being able to identify some immediately to having difficulty being able to identify others quickly or without help. The daughter was able to help her mom make connections and the two women were able to talk about the images with ease. The conversations, although initially started by the images, were not limited to them. Talking about image content often continued and tied into talking about other things. This did not go on for too long though, and the conversations were generally tied back to the images, especially if there was a lull, or when the mother and daughter proceeded to the next picture. At one point when looking at a picture of the kitchen in the house where the mother used to live and where the daughter currently lives, the two women talked about the image and the things in the kitchen as shown in the picture, but also about how the kitchen has not changed very much since the picture was taken and still looks pretty much the same twenty years later. In addition, at times the resident recognized her own difficulty remembering certain things, voicing her frustration. When this occurred, the daughter tried to minimize the resident's frustration and anxiety related to not being able to remember things by talking about it. The daughter made an effort to let her mother express her feelings and tried to validate those feelings. It is important to note that interaction between mother and daughter was not brought down by the mother's lapses in memory. They were quickly able to resume looking at images and enjoying their time together.

Family D, comprised of the resident couple, their son, daughter-in-law, and granddaughter, talked a lot about the pictures and different aspects of them ranging from the specific event taking place in the image to other elements or objects in the pictures. The family allowed the residents time to recognize and sometimes identify things or people in the images, but the family was certainly not solely reliant on the residents' fact recognition ability to stimulate conversation. Often, family members would say something about the picture, which might spark a memory or otherwise engage the residents to comment or ask questions and, at times, even to point or reach out to the screen. The family was also not stifled by lapses in the residents' memories, but rather was able to supply additional information or talk about things in the images that were not dependent on recognition of specifics such as who is in the picture, or where it is. Comments were made about emotions and expressions on peoples' faces, about hairstyles, and about the style and size of handbags in the pictures as part of talking about the images without relying on factual recognition. Additionally, there was an instance when the mother asked about how one of her husband's siblings, who was depicted in the image, was doing. The fact was that this person had died at least several years earlier. The family dealt with this topic with relative ease as the son put his hand on his mother's leg, and calmly explained that his dad was the only one of his siblings still living. She became quite sad and may have cried briefly, but as a group, they were able to move past this situation fairly quickly and continue on with their visit.

Observations: When families applied the recommendation to go beyond the resident's ability to recognize the content of images the visits appeared to flow with ease and enjoyment for all participants. When families did not appear to apply this

recommendation, the visits were observed to be somewhat stressful. The flow of visits appeared to be interrupted by image identification questions asked to the resident.

Concept 4-B: Interacting in the moment

One of the key ideas touched upon in the orientation process and communication strategies was that of interacting in the moment, since this is how a person with dementia comes to operate. This idea, along with that of trying to interact within the resident's sense of reality, was discussed with families during the preparation meeting as a communication strategy. As important as it is, the idea of interacting and living in the moment can be quite hard for people to grasp and apply in their interactions with loved ones with Alzheimer's.

In contrast to the Family C visit, during which the focus appeared to be on trying to get the resident to recognize and identify people, things, and scenarios in the images, two of the other families particularly seemed to apply the concept of interacting in the moment. Both of these families appeared simply to enjoy being together and visiting. In both of these visits, the fact that the resident could not remember some things came up, but the families did not let these memory lapses get the better of the visit. In Family A's visit, the resident and her daughter talked about how the mother felt about not being able to remember and were able to do so without getting too upset. They were then able to continue having a great time looking at the images together. With respect to Family D, when the mother asked about a sibling of her husband, it was explained to her that this person had actually died at least several years earlier. When this was explained to her, she became quite sad, seeming to realize that she was not remembering things. In this situation too, the family acknowledged the mother's

feelings and responded with sympathy, and soon the group was able to resume looking at the images and enjoying their time together.

Observations: Families who appeared to grasp the concept of interacting in the moment were observed to experience genuine enjoyment during the visit with their loved one and momentarily set aside the reality of their loved one's decline.

Concept 4-C: Agitation

Along with communication strategies, it seemed important to talk with families about agitation. Family members should be vigilant for signs and causes of agitation being experienced by their loved ones, specifically whether or not it is related to an image, and then respond accordingly.

Few instances of agitation were observed among residents as they participated in this study. For two of the families no agitation was observed, though towards the end of one visit, the resident of one of these families (Family C) said something about the son being a jerk. However, it was not clear if this was really related to anything, and even if it was, the resident did not appear to be particularly agitated. During Family A's visit, the resident was distracted when she had to cough, but her daughter attended to her and the visit soon resumed. The coughing spell seemed to be completely unrelated to the visit, was fairly quickly resolved, and did not become an instance of emotional agitation. This same resident did, though, express some frustration about not being able to remember things, but she and her daughter talked about these memory lapses openly and calmly. This calm processing of memory decline enabled the mother's feelings of frustration to fade away, keeping them from tainting the positive nature of the visit or the experience as a whole. For Family D, about fifteen minutes into the

visit the mother needed to go to the bathroom. She did not appear to be agitated, but did express urgency about needing to go at that point. Her son helped her up and back to her room, and when they returned, the family quickly resumed their visit. Later on in the visit, the mother got quite sad when it was explained to her that one of her husband's siblings, whom she thought was still alive, had passed away at least several years earlier. The family, specifically the son, as well as her husband, consoled her. As a group, they then went on to another picture and were able to continue with the visit, her spirits lifting as they went along. This episode was not completely related to the image itself, but rather to their conversation about this image. Additionally and more importantly, this also was not so much an instance of agitation as it was an expression of sad emotions.

Observations: The only instances of negative reaction during visits appeared to be those of sadness and frustration, and not of agitation. The fact that any such reactions occurred, points to the importance of strategies for dealing with negative responses.

Concept 4-D: Have fun

The idea of having fun during the visit was of utmost importance in enabling a family visit to be a positive experience for all involved. A spirit of having fun relates well with all of the other communication strategies.

All of the families seemed to exhibit at least a few signs of enjoying their visit and having fun, some families more so than others. Three of the families in particular seemed to have fun over the course of their respective visits. For Family B, which included the small children, both of the adults laughed and the son joked around a little. For example, with regard to a picture of the resident and her husband when they

were young, the son called her a “ret hot mama,” which the resident and her son, and even a staff member who came by at that point, got a kick out of, smiling and laughing about it. Additionally, the presence of the small children appeared simultaneously to be a source of distraction, particularly for the son, and a source of joy, particularly for the resident. There was an instance when the great-granddaughter leaned up against the resident and the resident playfully poked the girl’s belly. The two looked at each other quite sweetly and smiled. Family A, consisting of the mother and daughter, also genuinely seemed to have a really good time during their visit. They both laughed and smiled throughout the visit, enjoying each other’s company while looking at and talking about the pictures together. Family D, consisting of the resident couple and their son, daughter-in-law and granddaughter, also seemed as a group to enjoy the visit and have fun looking at the images with each other, though the granddaughter appeared at times not to be very interested or engaged, and seemed to get bored by the end of the visit (which was over an hour long). In spite of this, residents and family members alike smiled and laughed, joking around and telling stories that everyone enjoyed. The residents, especially the mother, really seemed to get a kick out of seeing the images, older ones in particular when she and her husband were younger and when their kids were babies or small children. The residents were simply delighted to get the opportunity to look at these pictures, especially with each other and the other family members. All in all, this too seemed to be quite a positive experience for all involved.

For Family C, although there were instances in which each of them smiled and/or laughed indicating that on some level or for at least part of the time they were enjoying the visit, overall, they seemed not to have that positive of a reaction to the visit. Even from before the visit, at the preparation meeting, this family expressed negative feelings about the pending visit, not really thinking that the communication

strategies and use of images would work that well given the progression of their loved one's dementia. Additionally, during the visit, this family seemed to be focused largely on getting the resident to remember things, to the point where they appeared to be losing sight of the idea of just enjoying spending time together. The daughter-in-law in this family also appeared a bit nervous, more so at first, but fading somewhat as the visit went on. Often, her smiles and laughs seemed to be more related to this nervousness and possibly a feeling of being judged than to her actually having a good time. These expressions were usually accompanied by her behavior of nervously looking out and around the room, generally at or toward the researchers. This was also the only family who, at the end of the visit, seemed to exude a sense of "ok, we're done with it, we got through it" rather than a sense that they had just done something that really was enjoyable and fun, the impression that was gleaned from observing two of the other families in particular.

Observations: Even though families were prompted to have fun and enjoy their visit, not all families appeared to thoroughly do so. It was observed that when one member of a family had a negative attitude or mindset, it was more difficult for the group as a whole to have fun. It was also observed that when one member of a family was having fun, their attitude was contagious, even if only briefly.

3.5 Summary of Findings

The sources of data collected in this study were video analysis, interview responses, and field notes. In this summary, categories of findings that were evident in more than one data source are presented.

The first category addressed features of the conversation corner. One feature was aesthetics. While the field notes showed that participants were not distracted by the aesthetics of the conversation corner, the interview responses painted a more complete picture of reaction to the aesthetics. Interview responses showed that families' initial reactions to the appearance of the conversation corner were not favorable. Interviews with staff members also revealed negative opinions about the appearance of the conversation corner (based on comments by other staff members and residents), with references made to a Catholic confessional and a funeral parlor. Families expressed that the conversation corner was not particularly inviting and looked somewhat hard and sterile, though, they noted that once sitting in the conversation corner and visiting with their loved ones, the aesthetics were not distracting. The conversation corner faded into the background, allowing families to focus on the images and the visit itself. It was observed that family interactions were warm and intimate. Families commented on the conversation corner as an intimate setting within the larger, more public context of the lounge.

Another feature was the design of the armrests to flip up into the seat back. The matching upholstery panel covering the armrests appeared to obscure them to the point that people did not recognize that the armrests even existed. This was evidenced by the fact that no family was observed to use the armrests. The one acknowledgement of their existence was by the great-granddaughter of Family B who played with the velcro of the flap covering the armrest. The interview responses confirmed that family members were not aware of the presence of the armrests. A member of one family even suggested the addition of some sort of armrest to assist with sitting down and standing up.

A beneficial feature made possible by the flip-up armrests was that the conversation corner was available as a continuous bench. The benefit as found in field notes was the occurrence of behavior that is accommodated by a continuous bench, namely that of sitting close to each other. Even touch, although infrequently recorded through video analysis, did occur and when it did, was observed to be a sweet and tender contributor to the quality of the visit. The continuous bench of the conversation corner was found to allow touch to occur when people felt it was appropriate.

The next feature of the conversation corner addressed was comfortable seat posture when sitting back or leaning forward toward the digital picture frame. Video analysis related to leaning indicated that most of the participants spent much of their visit leaning back, suggesting that they found the contour of the seat to be comfortable. The data on leaning also showed that people were able to lean forward toward the stand, suggesting that the upholstery was firm enough to allow this behavior. Field notes confirmed these findings, as participants were observed to be comfortable and easily able to adjust their seating postures and positions. Interview responses further corroborated that both residents and family members found the conversation corner to be comfortable.

Another category of findings pertained to the digital picture frame and stand. There was broad evidence to suggest that the digital picture frame was a suitable medium for looking at images during visits. The video analysis data on attention showed that participants spent a considerable amount of time focused on the digital picture frame. This was especially true for residents, which suggests that the digital picture frame and its images were visible and engaging enough to hold attention and focus throughout the visit. Field notes confirm this finding, as both family members and residents were

observed to be looking at and talking about the images. It was apparent that the visits were in fact largely based on the images as the central stimulation source. While responses to interview questions regarding the digital picture frame further emphasized the positive experience and enjoyment of using it to look at images, these comments also shed some light on what made the digital picture frame appropriate for use in this context. The primary feature that was identified was the generous screen size. Families found that images were generally larger than when viewed in a photo album, making them easier to share as a group. Along these lines, it was noted that the images appeared more vibrant and possibly clearer, further enabling all participants to see them.

The three sources of data indicate that participants appreciated the range of controls available on the digital picture frame and stand, though some controls were found to be more successful than others. The integrated handholds in the leading edge of the stand were found to be successful. While video analysis relating to interaction with the stand showed that in all families at least some touching of the stand occurred, field notes indicate that much of this touching was directed at the handholds. The handholds were often used not only to turn the stand, but also to move it, and sometimes just as a resting place for hands. Interviews confirmed that people saw the handholds as something that could be grabbed onto and that they found to be innovative.

The mobile base of the stand was found to be somewhat successful, but also to have some issues. Movement of the stand by families was documented through both video analysis and field notes. The only issues with the mobility of the stand were with the five-star caster base itself, and not specifically with how it moved. There were a number of observations of peoples' feet colliding with the base, once almost resulting

in the toppling of the stand. This issue was also commented on during the interviews. Families suggested the integration of a foot ring, given that it seemed inevitable that feet would interact with the base.

Two controls of the stand were found to be less successful. The first, control of screen tilt, was observed to be used only by one family. Another family commented on it during the interviews, saying that they had been aware of the tilt, but that they did not use the control because they perceived the mechanism not to be strong enough to hold screen angle once adjusted. Lack of use and lack of comment from the other two families suggest that the tilt control was not made obvious by the design. The second problematic control was the remote which was used to adjust duration of image display. One family experienced technical difficulties with the remote and could not use it all. Observations indicated that for the other three families use of the remote worked fairly well once people learned which button advanced to the next image and which button brought them to the previous picture. However, in the interviews, it became apparent that the buttons on the remote were in fact a more important issue than the observations indicated. One family was quite vocal about their feelings that the up and down buttons did not match their concept of advancing to the next image or going back to the previous one, along with the inherent distraction of the presence of the whole remote (even though much of it was covered). This family also brought up the issue of the delay being too long between when a button was pressed and when the image changed, something that was not at all apparent to the researcher when observing the visits, and something that is inherent to the digital picture frame itself.

The third category of findings relate to communication strategies, specifically, interacting in the moment. This particular communication strategy can be hard for

families to grasp because of the learned reliance on short term memory as a basis for interaction in day-to-day life. If embraced, though, the idea of interacting in the moment has significant potential for connecting with someone with dementia. It was observed that some families more than others were open to the use of the suggested communication strategies and to the idea of adapting communication style to the cognitive ability of loved ones. Those who were more open to and interested in this aspect of the Family Visit Program appeared to thoroughly enjoy their visit and the experience of looking at images and interacting with the resident. A few families commented that the experience had reminded them of the importance of visiting, that is, visiting with the intention of mutually rewarding interaction rather than just for the purpose of checking in, bringing something to the resident, or taking care of something for the resident. One family member commented that the experience made her remember how much she really enjoys spending time with her mother and that it emphasized the need to take more time to enjoy the actual visits. This certainly ties in with the concept of interacting in the moment and highlights the fact that even with the progression of Alzheimer's there is still a person inside.

The final category of findings pertains to the communication strategy and underlying idea of the Family Visit Program to make visits enjoyable for everyone involved. One way in which this was measured was through video analysis of instances of smiling/laughing. While most participants did not spend a great percentage of time smiling or laughing, the sheer presence of any instances of such emotional expression can be seen as more important and indicative. It is reasonable to suggest that the occurrence of any smiling/laughing is an indication that a participant was enjoying (at least part of) the experience. This is supported by interview responses from family members as well as residents. Most family members reported that they greatly enjoyed

the visit and looking at images with their loved ones, though, family members were not equally enthusiastic about the visits being pleasurable. At least part of the enjoyment experienced by family members may be due to a sense that the resident was more engaged and involved in the interaction and more animated than in previous visits. Those family members who reported a lower level of enjoyment also were the ones observed to have a negative mindset, presumably related to being fixated on progression of their loved one's dementia. Even when people were negative going into the visits, they still enjoyed the visits on some level, though it appeared to be more difficult for the group as a whole to do so. While interview responses from residents were brief, all residents affirmed that they had enjoyed the visit, some more emphatically than others. Although all participants were observed at some point throughout the visits to be exhibiting signs of having fun, it was apparent that there was variation in level of enjoyment. Confirmation of enjoyment was also evident in the fact that many participants were interested in and quite enthusiastic about the prospect of having additional visits under the Family Visit Program.

CHAPTER 4

DISCUSSION

4.1 Development of the Family Visit Program Study

This thesis represents exploratory research regarding the Family Visit Program. The intent was not to test hypotheses, but instead to identify a range of issues surrounding family visits with people with Alzheimer's disease living in care facilities. More specifically, the intent was to gain understanding about the components designed and developed as part of the Family Visit Program.

4.1.1 Resident Side of Interaction

The starting point for the conception of interventions explored in this study was the fact that emotionally-laden sensory stimulation can be therapeutic for people with Alzheimer's disease. From there the interventions were shaped by the thought that this type of stimulation is most effective when paired with human interaction. Without human interaction, the individual must self-initiate to engage with stimuli. With human interaction, compensation for disease-driven decline in ability to self-initiate is provided to the person with Alzheimer's in the form of scaffolding. This line of thinking led to the creation of the Family Visit Program, an intervention for facilitating mutually rewarding visits between family members and their loved ones with Alzheimer's living in residential care facilities. One of the purposes of this study was to explore the viability of Family Visit Program components in providing rewarding stimulation for the resident with Alzheimer's.

4.1.2 Family side of interaction

The needs of residents were only part of the concern in the creation of the Family Visit Program and its components. Of equal concern was how the visit experience affects family members. Parallel to the individual progressing into Alzheimer's, the family members are dealing with the slow loss of their loved one to the disease. Reactions of family members can be avoidance of meaningful interaction and denial that it is still possible to connect with the loved one at an emotional level. The Family Visit Program components were intended to provide a common meeting ground where meaningful interaction can occur between family members and their loved one with Alzheimer's. The second purpose of this study was to explore the viability of Family Visit Program components in providing rewarding visit experience for family members.

4.2 Intervention Components

The components of the Family Visit Program were: conversation corner, digital picture frame and stand, image selection, and orientation process and communication strategies. This exploratory study was successful in attaining feedback on the potential and viability of the components of the Family Visit Program and its components. The study demonstrates not only that the Family Visit Program components establish an appropriate framework for rewarding family interaction, but also that each component could benefit from refinement.

4.2.1 Component 1: Conversation Corner

The conversation corner was designed as the setting for visits. Because no previous research addressed issues related to the physical environment or setting for visits, it is not possible to put the current findings into a context of other studies. However, the

fact that the conversation corner is a seating unit that is located outside of the resident room and that can accommodate up to four adults relates to findings by Port (2004) that the presence of a place to sit during visits other than the resident's bed would be desirable and that having more family members or loved ones participate in visits could make them less difficult for family caregivers.

While the conversation corner was determined to be successful in terms of supporting interaction during visits, the findings and feedback attained in this study revealed that certain elements of the design would benefit from further consideration. The radius of the curve of the bench should be examined in order to strike a balance between reducing the effort needed for sitters to look alternately between each other's face and the digital picture frame screen and providing adequate space for legs and feet. The armrests should also be given further consideration. While the availability of armrests to provide support when sitting down or standing was a good idea, the implementation of armrests as folding, stowable features of the seating unit was not as successful. One of the main issues was that families did not realize that the armrests even existed. Additionally, even when the armrests were exposed, certain family members expressed their view that the armrests were not at the desired height and appeared too weak to actually bear weight. However, the unobstructed bench resulting from having the armrests out of the way was quite successful in allowing family members and residents to sit close to each other and even touch each other when desired. The challenge then is to conceive of a design solution that makes the armrests more intuitive to use, while retaining the ability to move them out of the way. An enhanced visual cue to the location of the armrests when in the stowed position would be helpful, such as a fabric tab that can be pulled to bring the armrests down. The flip-up feature of the outer seats was also well intentioned, but not completely effective in its

execution. Taking into consideration the difficulty of transferring between a wheelchair and the conversation corner and making such a transition easier through provision of the flip-up feature in the two outer seats is important. However, if people do not use a feature of this sort, or are unaware of how to access it, then its existence becomes futile. The latch on the underside of the seat is not something families are likely to come across on their own or that is easily accessed. A visual cue and more accessible latch release would enhance legibility of the flip-up seat feature.

The design of the conversation corner was intended to foster a sense of intimacy, though the use of scale to do so is more successful in the horizontal than in the vertical plane. The continuous curved bench connotes intimacy and promotes sitting close to each other. On the other hand, the height of the seat back and canopy overhead are out of scale with the seated participants. While the high seat back and canopy were intended to help insulate the experience of sitting in the corner by keeping outside distractions and sounds out while promoting conversation and interaction within, vertical scale should be modified to promote the feeling of intimacy.

Reduction in vertical scale is also likely to have a positive effect on the aesthetics of the conversation corner. Along these lines, the opinions family members held about the appearance of the conversation corner were out of sync with their impressions of actually sitting in and visiting within the seating unit. A worthwhile endeavor is to diminish this disconnect. The conversation corner should be seen as a special place in which families and residents want to visit. Another facet of the disconnect between the appearance and experience of the conversation corner relates to the upholstery. While the firmness of the seat was found to be comfortable and to accommodate changes in posture, the appearance of the upholstery, which is rigid and harsh, does not evoke a

feeling of comfort. Softening the edges of the cushions such that they do not read as straight, hard lines and instead appear to be plush would be helpful in this regard.

4.2.2 Component 2: Digital Picture Frame & Stand

The digital picture frame and stand were used to display personally meaningful images, which served as the central source of stimulation for visits. In this study, the use of digital pictures as stimulation was found to be successful. This finding was in accordance with Koretsky (2001) and Mizen (2007) who advocate for using photographs with older adults in care facilities with memory deficits, for example as a way to help people remember or recognize someone familiar or to remind people of pleasant memories. While memory books and photo albums are commonly recommended and used by people with Alzheimer's and their families, the current study is unique in its use of a digital picture frame to display images. This innovation is similar to the method of display used in an intervention known as Therapeutic/Restorative Biographies (Cohen, 2000; Cohen, 2002) in which video biographies are created from videotaped snapshots of old photographs and are watched on a television screen, allowing images to be seen significantly larger than when viewed as a standard photograph or in an album. However, the use of a digital picture frame mounted on a mobile stand in the current study enables the relatively large digital image to be brought within arm's reach of the viewer. This reach range affords a kind of interaction with images—pointing—that is not possible with a television screen located beyond reach, as is the case in the previously mentioned research. The successful use of stimulation paired with social interaction (during visits) seen in the present research relates to the work of Witucki and Twibell (1997) in which sensory stimulation (music, touch, and smell) was paired with social interaction and yielded lower discomfort levels and an increase in psychological well being. This connection

is relevant even though the types of stimulation are not the same for both studies and outcomes related to level of discomfort and psychological well being were not sought in this study.

Both family members and residents responded positively to the digital picture frame and stand, though there are certain features that could be improved upon. Families found the digital picture frame to be an appropriate medium for viewing images. With respect to the digital picture frame itself, participants found that the screen size allowed images to be shown larger than they otherwise would appear in an album, a finding related to research on Therapeutic/Restorative Biographies which used a television screen as the method of display for videotaped photographs (Cohen, 2000; Cohen, 2002). The use of an even larger digital picture frame screen might be considered in order to further enhance visibility of images. The presence of the wooden frame and stand was found to enhance the experience of using the digital picture frame. The design of the wooden frame appeared to help focus viewer's attention on digital images, and add cohesion to the integration of the digital picture frame with the mobile stand.

The digital picture frame and stand incorporated a number of controls which participants appreciated and appeared to find useful. Some of these controls worked better than others. The mobile base of the stand, while useful in its ability to be rolled and moved with ease, collided with participants' feet at times when it was pulled in very close. During one of these instances, the stand was kicked and came close to toppling to the ground. This indicates that the five-star base might benefit from incorporating an intentional place for feet, a footrest, and having longer spokes that extend farther out to provide a more stable base for the stand.

Even though most of the controls relating to the stand and screen were intuitive, the screen tilt mechanism and navigation buttons on the remote could benefit from further consideration. While there is nothing wrong with how the tilt adjustment works, there is no visual cue that tilt is something that can be adjusted, unlike the handholds that clearly indicate that the stand is something that can be grabbed onto and moved. The current navigation buttons, which are small and represented by up and down arrows, represent a control mechanism where significant improvement is possible. Larger buttons placed side by side that are keyed to screen refresh that moves left to right for the next image and right to left for the previous image would make the use of buttons for navigation more intuitive. Along these lines, it would be ideal for the delay between pressing a button and having the next image appear to be minimized.

4.2.3 Component 3: Image Selection Process

The image selection process was seen as an important component of the Family Visit Program. While other interventions and research have assessed use of images, none of them have evaluated the selection of images other than to assert that personal images are more likely than non-personal ones to be recognized by and be meaningful to people with Alzheimer's disease (Cohen, 2009). Although this assertion is important relative to selecting personally meaningful images, it is not adequately specific given that family image collections tend to include images all of which can be predicted to be personal in nature. The current study offered specific ideas and recommendations for family members to consider when compiling a set of images, one in particular being that of selecting (personally meaningful) images that family members believe will elicit positive reactions from residents. Given the lack of previous research or documentation related to recommendations for image selection, the findings from this study cannot be put into an evidence-based context.

The recommendations made to families for choosing images appeared to have provided useful guidance in the selection process. While it was impressed upon families that they not feel as if they had to get through all of the images during the visit, all of the families did look through their complete set of images. Most of the families seemed as if they would have been happy to continue looking at images had more been loaded onto the digital picture frame. Though, with more images there is the potential for fatigue. As such, the recommendation to compile approximately thirty images was observed to work.

4.2.4 Component 4: Orientation Process & Communication Strategies

The main purpose of the orientation process and communication strategies was to help family members think about ways to use the images to support positive interaction. The recommended strategies were aimed at opening the minds of family members to thinking about how communication can be adapted to the cognitive abilities of the resident. The idea of educating families with respect to communication and visit strategies is not new, but in previous studies in which educating families was a part of an intervention to enhance visits (McCallion, et al., 1999 and Kelley, et al., 2000) the method of education was not evaluated. Accordingly, it is difficult to compare the findings related to the orientation process in this study with those of other studies.

The orientation process and communication strategies appeared to be useful in terms of their content. However, skepticism expressed by the family members of one resident with more advanced dementia brings up an important idea of incorporating strategies for family interaction with less responsive residents. Strategies could be incorporated that target residents of varied levels of Alzheimer's disease, which would expand the population for which the Family Visit Program might be useful.

Additionally, more emphasis could be placed on helping families understand the idea of adapting communication strategies over time and as the disease progresses.

While the content of the orientation process worked reasonably well, the presentation of this material might benefit from further consideration. Given that a number of the recommended strategies may not be intuitive to family members and may take some effort to really grasp (such as interacting in the moment and not dwelling on factual recognition), it would be useful for this information to be presented in such a way that incorporates examples. One option that actively engages the family members and gets them starting to think along the lines of the communication strategies is role play. This method of education has been used in an intervention known as the Family Visit Education Program, in which families discussed and engaged in role play activities related to effective and ineffective verbal and nonverbal communication techniques (McCallion, et al., 1999), though no evaluation of this education method was reported. Along with role play, it might be useful to show examples of how the communication strategies could be used with actual images, perhaps from the family's own set of selected images. Together these ideas might help family members get a better grasp on the communication strategies, which might enhance the ability and willingness of families to incorporate such techniques in their interactions with their loved ones.

4.2.5 Potential for Future Assessment of Individual Components

While the components were all used together in this study and found to work well together, there is potential for their individual use, or for their use along with other sources of stimulation. Further study to examine the use of individual components and combinations of them would be beneficial for refinement of the Family Visit Program and maximizing its benefit. Further study could also explore variations of the specific

interventions employed in the present study. For example, within the context of using the conversation corner as the setting for visits, other sources of sensory stimulation could be considered, especially given the limitation that use of images on a digital picture frame requires that all participants, including both family members and residents, not have vision impairments. Depending on the sensory abilities of family members and residents, it might be useful to adapt the Family Visit Program for use with another source of stimulation. For example, another source of stimulation that could be considered is music, as it can be a powerful tool for connecting and communicating with someone with dementia (Bakker, 2003) at least in part because of its high emotive quality and ability to convey mood and feeling (Chavin, 2002). It is possible that another piece of furniture could be developed specifically to support use of music as a source of stimulation, just as the wooden stand used in this study was developed to house the digital picture frame.

4.3 Challenges of Evaluation and Evaluation Methods

The interplay of issues in the implementation of the Family Visit Program is complex. There were issues of ergonomics in the design of the conversation corner and digital picture frame stand, technological issues in control of the images on the digital picture frame, educational goals in preparing families to interact and changing the mindset of families coming into the interaction, and aesthetic issues in the appearance and meaning of the conversation corner and digital picture frame stand when viewed by residents, family, and staff. Behavioral reactions to the intervention components are numerous and varied.

With so many issues and behavioral reactions, it is not surprising that evaluating an intervention of this sort is complex. Some of what was learned from this study was the

range of outcomes that could be measured in future studies. This exploratory study gained a small window onto satisfaction-type outcomes such as enjoyment of visits by both residents and family members and interest in pursuing further visits. Although there is also the potential for outcome assessments related to therapeutic benefit, such as reduction in resident agitated behaviors and family emotional acceptance of the progressive loss of their loved one, procedures for assessments of this type of outcome could not be gleaned from this study.

The methodology used in this study involved identifying behaviors and reactions to describe and quantify what was happening during visits. Attention, posture, self-initiation, emotion indicators, along with touch and gesture were identified behaviors and reactions measured in the analysis of video footage of visits.

Attention is a difficult thing to ascertain. Visual attention in particular seemed appropriate to study with regard to this intervention given that the use of images as a focus for visits relies heavily on visual stimulation. Even with a focus on only one aspect of attention, it remained a facet of visits that was challenging to measure. In this study, a participant's attention was determined by the direction he/she was looking. However, it is important to consider that direction of gaze may not always match with where one's attention actually is focused. It certainly was possible for study participants to be looking at one thing while thinking about another and conversely to be paying attention and thinking about something while not looking at it. The potential disconnect between direction of gaze and attention raised by these issues may be even more likely among people with Alzheimer's, given the significant changes in cognition and sensory perception associated with the disease. As such, other methods of verifying attention might be considered.

In this study, posture was used as a way of assessing comfort. Moreover, posture may be useful in looking at engagement. Posture was analyzed in terms of what direction each participant's body was leaning and/or facing over the duration of the visit. At times, this was difficult to categorize. Sometimes there were clear distinctions between a person leaning in one direction rather than another, while at other times, the differences could be quite subtle. Additionally, a specific posture or position is not necessarily absolute, but rather someone may appear to be leaning in one direction or another depending on the context of body positions engaged in before and afterwards. In this way, specific postures may be less significant than the amount and types of changes in posture in determining level of comfort and engagement. Additionally, perception of posture can be affected by the observer's angle of view of participants in that certain changes in direction of leaning or body position may be more obvious than others.

Where there was a desire to promote self-initiation through the components of the Family Visit Program, such initiation was not observed across all residents and was difficult to ascertain. Although not the only possible indicator of self-initiation, physical interaction with the stand was the one indicator of self-initiation used in this study. Self-initiated responses can also be verbal in nature or involve a physical movement that is not directed toward the stand, but rather to oneself or another participant. In the present study, looking at self-initiation only from the perspective of interaction with the stand is likely not to paint the full picture. An additional complicating factor may be that self-initiation is only one facet of engagement, and although desired in this study, self-initiation may not always be a feasible goal for interventions related to improving interactions between people with Alzheimer's disease and their families.

Emotion indicators related to happiness, specifically smiling and laughing, were looked at for each participant. This study aimed to elicit positive feelings and memories as part of stimulation and engagement. While emotions other than happiness are certainly significant, smiling and laughing are relatively easy to detect. As such, these proved to be useful and uncomplicated indicators of emotion. However it is important to note that people certainly can be happy and enjoying themselves even if not smiling or laughing. What seems more important than the number of times or the duration of smiles and laughs is their presence at all, as this can be seen as indicating enjoyment in the moment. Of additional interest is the idea of enjoyment being contagious, such that seeing a family member or resident smiling or laughing may enhance one's own enjoyment of the visit. While participants may experience a range of emotions during visits, only happiness, as indicated by smiling or laughing, was included. This underscores the emphasis of eliciting and evoking positive emotions during visits. However, it does not acknowledge other emotional expressions that may be just as significant.

Touch and gesture were also assessed for each participant. One indicator employed was the recording of the frequency and duration of instances of touching between participants. This indicator was useful in terms of documenting the fact that the conversation corner allowed for instances of touch to occur. While the number of instances was not very great, the qualities of the instances of touch were quite telling. These moments added a sweetness and tenderness to the visits, and were important because they relate to the person-centered underpinnings of the research. The other indicator employed was the documenting of touches or gestures that were not related to another participant, but that were directed more so toward oneself. There were some behaviors in this category that were definitely gestures as part of conversing, or

physical movements as part of a reaction to the conversation or an image, which could be indicators of self-initiation or engagement in the visit. However, there were also less significant behaviors, such as fidgeting or small movements of one's hands in his/her lap, and a much greater number of such instances. While such movements may be useful to record as a general observation of an individual's behavior over the course of a visit, the documentation of every instance proved not to be necessary, and in fact detracted from the record of larger movements and gestures.

4.4 Limitations and Future Research

4.4.1 Sample Size

In thinking about limitations of this study, it is important to note that as exploratory research the goal was not to test specific hypotheses but rather to identify a variety of issues relating to family visits with residents of care facilities who have Alzheimer's disease. While exploratory research of this sort does not allow for the proving or disproving of hypotheses, this type of research still has significant value. It allows questions and issues to be raised and is able to suggest directions for research in the future. It is important to acknowledge that characteristics of empirical research that may be seen as limitations may inherently be part of doing exploratory research. For example, small sample size, which would be a significant limitation of empirical research, is of less concern for an exploratory study such as this one.

4.4.2 Control Condition

More important than small sample size is the fact that no control condition existed, thus precluding the ability to present causal findings. The lack of a control condition is tied to the fact that each family only took part in one visit as part of the study.

Attempts were made for at least one family to partake in an additional visit, however no additional visits were possible due to time constraints and busy schedules. It is important, though, to note that three of the families were interested in having another visit, two particularly enthusiastic and excited about it. This speaks to the idea that families saw the Family Visit Program and its components as positive in supporting effective, rewarding, and enjoyable visits. Certainly, future research regarding this intervention should consider multiple visits and isolating the use of components. A second round of visits might have allowed families to be more comfortable with the different components or to include more family members. Another idea was for families to have another visit using the digital picture frame and stand, but sit in a seating arrangement of conventional furniture found in the lounge rather than in the conversation corner. This would have allowed more definitive assessment of the relative contribution made by the conversation corner to the perceived value of the Family Visit Program.

4.4.3 Setting and Participants

Another aspect of consideration is the context within which the Family Visit Program was conducted. Although Longview identified residents with memory loss/cognitive impairment from among all assisted living residents as potential participants in the study, it may be of interest in the future to engage as a test site a care facility that specifically serves those with Alzheimer's disease. Along these lines, it might be useful to look at how the Family Visit Program can be used with people in different stages of Alzheimer's. In implementing the program, it is of utmost importance that staff members and residents be consulted and made aware of the program before the conversation corner is moved into the facility. It is vital that introduction of the

conversation corner not be seen as taking away resident and staff ownership of a semi-public space within a residential care facility.

4.4.4 Data Collection

This study employed three methods of data collection: video recordings, interviews, and field notes. All of these methods were found to be appropriate, but some aspects of them could use further consideration and could probably be improved upon.

4.4.4.1 Video Recordings

The video recordings were an extremely important part of data collection, given the involved video analysis done with these recordings. As such, it would have been helpful to position the camera closer so as to obtain a better, more detailed view of what was happening and to place the camera in a more consistent place relative to the conversation corner, such that the angle of view would have been similar across visits. When setting up the video camera, it is important to adjust it to a height that captures a view of all participants, especially to ensure that the digital picture frame does not obstruct a recorded view of any participant as happened a number of times in this study. This was problematic because it affected the ability to discern direction of attention and also, at times, interaction with the stand. Use of a higher quality video camera is recommended and is likely to mitigate some of the issues raised here, as well as provide for the potential to create sufficiently clear still images from the video recording.

4.4.4.2 Interviews

Both family members and residents were interviewed immediately following each visit. Although interviewing the family members made sense in terms of getting

feedback on the various components of the program, interviewing residents was important for different reasons. Interviewing residents may have had a normalizing effect. If they had not been interviewed, they may have felt more like they were just being studied and that they did not have a say in what was happening. Giving residents a chance to express themselves and asking their opinions validates them as people and as worthwhile contributors to the research. There was at least one resident who had enjoyed the visit experience very much and had many positive feelings to express, confirming that the interview served as an effective outlet for that expression. It was evident, though, that despite efforts made to simplify and reduce the number of questions asked to residents, some of the questions still appeared to be too complex for residents to understand and answer meaningfully. Additionally, some of the questions about the qualities of the conversation corner in particular, such as whether or not it was cozy, comfortable, intimate, and inviting, were observed to be redundant within the context of conversing with the residents. These terms probably were too similar for this population to discern them separately. In general with the resident interviews, most did not give elaborate answers to the questions, and the short, often one-word answers given were likely not to be reliable answers. For the reasons stated above though, this effort was important.

With respect to interviews with family members, it was originally intended that the residents would not be present. In actuality, all of the residents were in the vicinity of the interview with family members, though some residents were certainly not paying attention. There were instances when it seemed that family members may have felt somewhat uncomfortable about answering some of the questions in front of their loved one, and so further consideration might be given to the extent that the presence of the residents affects these interviews. The reason many of the residents stayed, though,

resonates with some of the reasons it is important to interview the residents, in that they did not want to feel as if anything was being hidden from them.

The interviews with staff were aimed at obtaining opinions and feedback from staff regarding the various components of the Family Visit Program, the conversation corner in particular. The two staff members interviewed for this study did not have much knowledge of or interaction with the Family Visit Program, and their responses were not particularly informative. It would have been helpful to interview a greater number of staff members, especially those who had been more aware of and receptive to the study. It was clear that a significant portion of the staff, and even residents, were not happy with the introduction of the conversation corner in particular. It is important to have staff be on board with the program, as their own feelings and opinions about it may influence those of residents and families.

4.4.4.3 Field Notes

The field notes made during visits complemented the other sources of data. While this aspect of data collection was quite rich in content, it would have made sense to have a list of the concepts used in developing the components of the Family Visit Program on hand when making these observations. This is in contrast to the procedure employed in this study, with field notes made at the time of the visit, and then later categorized according to the concepts. Additionally, only one researcher made these observations, allowing for the possibility that important factors and behaviors were not noticed or recorded. However, this potential limitation seemed to be offset by the existence of video recordings which were used to clarify and expand upon observations and notes recorded at the time of the visit. An additional concern to work around in future studies was the presence of more than one researcher during visits. This presence may

have further augmented any nervousness or discomfort on the part of participants of being watched and/or recorded while they visit.

4.4.5 Data Analysis

The process of video analysis was time consuming and tedious, probably at least in part because it was developed as part of the study. As it turned out, more information was recorded in this analysis than was used. Some of the behaviors and actions recorded were not significant indicators of any of the outcomes nor did they specifically relate, as previously noted, to any of the concepts. The analysis covered every second of the visit from beginning to end. Despite the effortful nature of this analysis, it did prove to be useful in documenting behaviors over the course of visits. One idea for simplifying this process is to discard some amount of time video recorded at the beginning and at the end of the visit. This would shorten the length of the video recording to be analyzed, and would also take into consideration that it may have taken a few minutes for participants to acclimate to the setting and the visit and that participants may have become fatigued by the end of the visit. An alternative might be to select a specific amount of time to analyze for all visits, though consideration would have to be given to make sure that the selected interval is representative of the visit as a whole.

Analysis of the audio track of visit recordings could have been useful in looking at, for example, types of statements made by residents, the extent to which these were self-initiated, and the extent to which statements added to the conversation. Audio analysis might also be useful in terms of evaluating the effectiveness of the orientation process and communication strategies. The challenge remains for the researcher to define the indicators of factors such as self-initiation.

4.5 Looking Towards the Future

This exploratory study shows much promise for future research, refinement, and implementation of the Family Visit Program, its components, and comparable interventions. While other interventions have been developed to help people with Alzheimer's disease and their families, some even focusing on family visits, this study is unique, as previously mentioned, in that it explores the potential of the physical environment to make a difference in the visit experience. This unique contribution suggests that we go beyond the notion of "four-S" approaches (Cohen, 2006), and consider "five-S" approaches, those that address setting, in addition to signs, symptoms, skills, and satisfactions.

APPENDIX A

The following is a copy of the initial letter sent to families inviting them to participate in the Family Visit Program. This letter was printed on Longview letterhead and was signed by Mark Macera, Executive Director, Longview.

Dear (name of family) Family,

We are writing to invite you to participate in a research project related to family visits with residents of Longview. The focus of the research is to work with family members and residents to make visits as rewarding as possible. This work is being done for the Master's Thesis of Sarah Blau, a graduate student in design in Cornell University's department of Design & Environmental Analysis. She is working with Professors Eshelman and Becker who are in this department.

The premise of the research is that as residents age and some of their abilities decline, visits between family members and their loved ones can become somewhat frustrating. Memory declines, attention span may be shorter, and communication may not flow as easily. This study is exploring the potential of the design of the space where families interact with their loved one, and the use of family images, to help provide a positive focus for visits.

The Family Visit Program in which we are inviting you to participate involves the following steps. The first step involves Sarah Blau working with you to select positive family images from your own collection of photos, slides, etc. Once the images are selected, they can be used by the resident and family member(s) in sitting together and talking and reminiscing about the photos and the memories they may trigger in a comfortable setting. The second step involves a short orientation session with Sarah to discuss some ways of using the images that might make the conversation flow more easily. The third step is to simply use the selected images in one of your visits. In the final portion of the visit, Sarah would meet with you to get your impressions of the visit, and ask you to complete a short survey about your experience. She would also sit nearby during the visit, with your permission, so she can get a sense of how the images and space in which the visit occurs are used.

We are contacting you now inviting you to participate in this study. We believe the results of the study can help us and other facilities like ours as we continue to think about how we can provide the most rewarding and positive visit experience possible. Please let Resident Services, Marilyn Strassberg or Claudia Stoscheck, at 375-6320

know if you are interested in participating. If you respond favorably, Ms. Blau will be in contact with you. Sarah will be calling in January after the New Year to answer questions you may have, and to see whether you would like to be involved. Thank you.

Sincerely,

Mark Macera

APPENDIX B

The following is a sample of the letter sent to families prior to the preparation meeting. This letter was printed on Cornell University Department of Design & Environment Analysis letterhead.

May 5, 2008

Dear (names of family members) family,

This letter is being sent to you based on our recent conversation and your willingness to take part in a research project related to family visits with residents of Longview that I am doing for my Master's thesis at Cornell.

Since the project is about visits in which images are used as a focus for interaction and/or conversation, the first step involves selecting positive family images. You are being asked to do this prior to our first meeting, at which point the images will be scanned. Possible sources of family images might be photo albums or slides. Think about the significance of images to the resident so as to select images that will elicit a positive reaction. Additionally, you may want to think about the resident's life as a story and identify chapters that you feel are significant for the resident (for example from the resident's childhood and early life, from more recent years including children and/or grand children, etc.). Consideration should be taken when selecting old images depending on how familiar you are with the images and your ability to talk about them. Try to select at least 30 images and bring them to the preparation meeting we will be having.

As mentioned in our conversation, it is a matter of Cornell University policy that the family member(s) and residents who chose to participate in our study must sign a consent form. These forms basically set out what the project is about and how you are being asked to participate. The purpose of the form is simply to have a written record that the study was explained to those participating, and that they understand what is involved and agree to participate. As such, I have included copies of the family and resident consent forms for you to review prior to our preparation meeting. Please look over both forms and at our upcoming meeting ask any questions you have before you sign the family consent form, if you still choose to participate. Please talk with your loved one about the form and the visit beforehand. If they so choose, they can sign the form with you before the visit or on the day of the visit itself.

I look forward to meeting with you at our upcoming preparation meeting on Thursday, May 8 at 7:30 pm at Longview.

If you have any questions or need to reach me before then, you can call me at 914.874.4128.

Thank you,

Sarah Blau

APPENDIX C

Included in this appendix are copies of the consent forms for each of the participant groups in this study—residents, family members, and staff members.

Cornell Research Project at Longview – Family Visit Program Resident Consent Form

We are doing a research project related to family visits with residents of Longview and finding ways to make these visits more enjoyable and rewarding for everyone. We are asking you to help because you are a resident of Longview and your family has agreed to participate.

You can ask questions about this research project at any time. If you decide at any time that you don't want to continue, you can ask us to stop.

If you agree to be in our study, you will have a visit with your family in a specially designed conversation corner, located in the lounge on the 4th floor. In the conversation corner, you will sit with your family, look at images on a digital picture frame, and can talk about them. Your conversation during the visit will be recorded, with your permission. After the visit, we will ask you some questions about your experience and feelings. Your answers to these questions also will be recorded, again, with your permission.

There are no right or wrong responses to the images you will be looking at with your family. You are free to talk about anything that comes to mind. There are also no right or wrong answers to the questions you will be asked after the visit. We are only interested in finding out more about your visit and your feelings about the experience.

If you sign this paper, it means that you have read this and that you agree to be part of this research project. If you do not want to take part in the project, don't sign the paper. Even if you agree now, you can always change your mind later if you decide that this project isn't something you want to take part in. Being part of the project is up to

you, and no one will be upset if you don't sign this paper or if you change your mind later.

Statement of Consent: I have read the above information, and have received answers to any questions I asked. I consent to take part in this research project.

Signature: _____

Date: _____

In addition to agreeing to participate, I also consent to the photographing and/or recording of the family visit as well as the discussion with the researcher after the visit.

Signature: _____

Date: _____

I consent to the use of images and/or video clips of me in reports, publications, and/or presentations made of this project.

Signature: _____

Date: _____

Cornell Research Project at Longview – Family Visit Program Family Consent Form

You have been invited to participate in a research project related to family visits with residents of Longview. You are being invited because you responded positively to a letter sent to you by Longview and expressed interest in participating. Please read this form carefully and ask any questions you may have before agreeing to take part in the study.

Project: The purpose of the research is to work with family members and residents to make visits as rewarding as possible. Underlying this focus is the observation that as residents age and their abilities decline, visits between residents and their family members frequently become frustrating for both parties. Short-term memory may decline, attention span may become shorter, and communication may not flow as easily as in the past. This study explores the potential of the design of the space where families interact with their loved one and the use of family images to provide a positive focus for more rewarding visits.

What's Involved: If you agree to participate, you will be taking part in the Family Visit Program which involves several components. First, we will work with families to identify positive images from family photo collections which then will be digitized and uploaded to a digital picture frame. Next, we will lead families through a short orientation process and discuss ways of using the images as the basis for interaction with their loved one. With these pre-selected images loaded into a digital picture frame, you will engage in a visit within the specially designed conversation corner. This interaction will be observed and video recorded. Following the visit, both residents and their families will be asked for their impressions of the visit and the conversation corner itself. During the post-visit session, families will be given the opportunity to review the video recording for additional reflection of the experience. Staff may also be present or in the vicinity of the conversation corner during the visit

and will be asked their impressions of the research project and they have agreed to keep the conversations private.

Risks & Benefits: There are no specific risks associated with this research, as the family visits being studied are much like other family visits, differing only in that they take place in the specially designed conversation corner and involve looking at pre-selected digitized family images. These visits will be observed and, although some of the conversations may be sensitive, the names and identities of all participants will remain anonymous and confidential. The underlying benefit to you of participating is the potential for family visits to be more rewarding. Your family will also receive a digitized format of the selected images as well as a copy of the video recording of the visit for personal use. Additionally, your participation in the study will help guide further development of a program that makes family visits for others more rewarding, and that could be implemented in similar facilities.

Compensation: There is no monetary compensation for participating in this study, though as previously mentioned, your family will receive a digitized copy of the selected images as well as a copy of the video recording of the visit for personal use.

Taking part in this research project is completely voluntary. If you choose to participate, you are free to withdraw at any time, with the choice as to whether any information collected before that point may be used. If you decide not to participate in any phase of the project, this will have no effect whatsoever on your relationship and interaction with the staff and management of Longview. The staff and management of Longview know of and support the goals of the study, and understand that participation is completely voluntary.

All findings reported will remain confidential. The names and identity of all participants will remain anonymous and confidential in any and all reports, publications, and presentations that may be made of this project, unless signed consent is given. Names will be recorded on interview sheets, for the sole purpose of matching residents with family

members. Research records will be kept in a locked file to which only the researchers have access. Some data will be recorded using a digital camera, camcorder, and/or digital voice recorder, specifically related to how the conversation corner and digital picture frame stand are actually used during the visit. The visit will be video and audio recorded such that after the visit you may review the recordings for further reflection on the experience. In the post-visit session the questions you will discuss with the researcher will be audio recorded. All audio recordings are exclusively for the purpose of transcribing responses, as this represents the bulk of the actual research data. These records will be destroyed within 10 years. If signed consent is not given, photo and/or video images may only be used with pixelated faces, to prevent identification. As mentioned above, the content of all conversations (as observed or heard by researchers or staff) will be kept private and confidential.

If you have any questions, please ask them now. The researchers for this project are Professors Paul Eshelman and Frank Becker and graduate student Sarah Blau, all from Cornell's Department of Design and Environmental Analysis. If you have any questions later, please contact Sarah Blau at seb67@cornell.edu or at 914.874.4128. If you have any questions or concerns regarding your rights as a subject in this study, you may contact the Cornell University Institutional Review Board (IRB) at 607.255.5138 or access their website at <http://www.irb.cornell.edu>.

You will be given a copy of this form to keep for your records. A copy of this consent form will also be kept by the researchers for at least three years beyond the end of the study. For your information, the consent form was approved by the Cornell University IRB on March 31, 2008.

Statement of Consent: I have read the above information, and have received answers to any questions I asked. I consent to take part in this research project.

Signature: _____

Date: _____

In addition to agreeing to participate, I also consent to the photographing and/or recording of the family visit as well as the discussion with the researcher after the visit.

Signature: _____

Date: _____

I consent to the use of images and/or video clips of me in reports, publications, and/or presentations made of this project.

Signature: _____

Date: _____

Cornell Research Project at Longview – Family Visit Program Staff Consent Form

You have been invited to participate in a research project related to family visits with residents of Longview. You are being invited because of your familiarity and relationship with the 4th floor residents of Longview. Please read this form carefully and ask any questions you may have before agreeing to take part in the study.

Project: The purpose of the research is to work with family members and residents to make visits as rewarding as possible. Underlying this focus is the observation that as residents age and their abilities decline, visits between residents and their family members frequently become frustrating for both parties. Short-term memory may decline, attention span may become shorter, and communication may not flow as easily as in the past. This study explores the potential of the design of the space where families interact with their loved one and the use of family images to provide a positive focus for more rewarding visits.

What's Involved: For your information, the project, entitled the Family Visit Program, involves several components. First, we will work with families to identify positive images from family photo collections which then will be digitized and uploaded to a digital picture frame. Next, we will lead families through a short orientation process and discuss ways of using the images as the basis for interaction with their loved one. With these pre-selected images loaded into a digital picture frame, families and residents will engage in a visit within the specially designed conversation corner. This interaction will be observed and both residents and their families will be asked for their impressions of the visit and the conversation corner itself. Your role in this project is simply to answer questions related to your opinions and observations of the designed pieces used in the study (conversation corner & digital picture frame stand) and of other components of the Family Visit Program. Given that some of the conversations you may hear may be

personal and of a sensitive nature, it is important to note that you must agree to keep all conversations private and confidential.

Risks & Benefits: There are no specific risks associated with this research, other than those encountered in day-to-day life. Although there may be no direct benefits to you, your participation in the study will help guide further development of a program that makes family visits more rewarding, and that could be implemented in other facilities.

Compensation: There is no monetary compensation for participating in this study.

Taking part in this research project is completely voluntary. If you choose to participate, you are free to withdraw at any time, with the choice as to whether any information collected before that point may be used. If you decide not to participate in any phase of the project, this will have no effect whatsoever on your relationship and interaction with other staff and management of Longview. The staff and management of Longview know of and support the goals of the study, and understand that participation is completely voluntary.

All findings reported will remain confidential. The names and identity of all participants will remain anonymous and confidential in any and all reports, publications, and presentations that may be made of this project, unless signed consent is given. Names will not be recorded on interview sheets. The questions you will discuss with the researcher will be audio recorded, exclusively for the purpose of transcribing responses, as this represents the bulk of the actual research data. Research records will be kept in a locked file to which only the researchers have access. As mentioned above, for the sake of confidentiality of the study and other participants, it is necessary that all conversations observed or heard be kept private.

If you have any questions, please ask them now. The researchers for this project are Professors Paul Eshelman and Frank Becker and graduate student Sarah Blau, all from Cornell's Department of Design and Environmental Analysis. If you have any questions later, please contact Sarah Blau at seb67@cornell.edu or at 914.874.4128. If you have any questions or concerns regarding your rights as a subject in this study, you may contact the Cornell University Institutional Review Board

(IRB) at 607.255.5138 or access their website at <http://www.irb.cornell.edu>.

You will be given a copy of this form to keep for your records. A copy of this consent form will also be kept by the researchers for at least three years beyond the end of the study. For your information, the consent form was approved by the Cornell University IRB on March 31, 2008.

Statement of Consent: I have read the above information, and have received answers to any questions I asked. I consent to take part in this research project.

Signature: _____

Date: _____

In addition to agreeing to participate, I also consent to recording of the discussion with the researcher.

Signature: _____

Date: _____

APPENDIX D

The following is a copy of the recommended communication strategies that were discussed with family members during the preparation meeting. This handout was also given to family members to review at home prior to the visit.

Cornell Research Project at Longview – Family Visit Program Communication Strategies

- First and foremost the visit should be fun for everyone.
- Focus on emotions more so than facts in the course of talking about images. Try asking the person in the photograph appears happy.
- Let the conversation flow without feeling the need to correct the resident about facts. The positive energy of the interaction is more important than the factual accuracy. To avoid emphasis on accuracy, try to connect the conversation to the resident's world rather than to your reality.
- Recognizing that the resident's short term memory may be declining, be conscious of the resident's ability to keep up with the conversation. In instances where conversation enters a lull because it seems that you are relying on short-term memory of what was just said, try to return the focus of the conversation to the image.
- To reduce reliance on short-term memory and capitalize on the resident's remaining long-term memory, try to keep conversation focused on the image. Having the stimulus there and visible eliminates the need to rely on short term memory as a means of interaction. The underlying idea is to distinguish between short-term and long-term memory.
- Keep in mind the idea that decline in short-term memory lends itself to the notion of interacting in the moment.
- If you sense that the resident is becoming agitated, ask the resident what is bothering her or him and then move on if something in the image is the source of negative reaction.

- If an image doesn't seem to spur conversation, it can be just as fun to look at the image and make up a story rather than trying to connect the image with factual memories.
- Don't get hung up on getting through all the images. Allow a reasonable amount of time for the resident to process the image and conversation, and move on to another image when it appears that conversation related to an image has lulled.
- Feel free to engage the resident through touch as well as sight and sound. A hand stroking an arm or a hug can sometimes say more than words. Try to read how the resident feels about this. If she or he doesn't seem to want to be touched at the moment, there is no need to push it.
- Be aware of things that may be potentially distracting even though the conversation corner is designed to minimize it.
- If you have any questions or would like clarification or further explanation about any of these ideas, feel free to ask now, or contact Sarah Blau at seb67@cornell.edu or 914.874.4128.
- Additional references about communication strategies and visits in general include the following:
 - *Talking to Alzheimer's: Simple ways to connect when you visit a family member or friend* by Claudia J. Strauss (New Harbinger Publications, 2001)
 - *Learning to Speak Alzheimer's* by Joanne Koenig Coste (A Mariner Book, Houghton Mifflin Company, 2003)

APPENDIX E

The following is a copy of the scripts for interviews with each participant group in this study—residents, family members, and staff members.

Interviews with Residents:

The following questions will be asked to residents participating in the Family Visit Program immediately following a visit that has taken place in the conversation corner, while still sitting in the conversation corner.

Conversation corner and digital picture frame stand when in use for this study:

Did you enjoy the visit you had with your family in the conversation corner?

Did you enjoy sitting with your family in the conversation corner?

Did you find it cozy?

Is the conversation corner comfortable to sit in?

Does the conversation corner feel intimate?

Does the design of the conversation corner feel inviting?

Do you like the materials used in the conversation corner?

Were you able to hear what your family members were saying when sitting in the conversation corner?

Did you feel distracted by other things going in the lounge while visiting with your family in the conversation corner?

Did you enjoy looking at images on the digital picture frame?

Was the digital picture frame and stand easy to manipulate?

Would you like to have another visit in the conversation corner?

Would you like to have another visit in the conversation corner looking at images on the digital picture frame?

Other comments:

We would like to thank you for participating in the Family Visit Program. As you know, the underlying purpose of this study is to learn how to make family visits more rewarding. Your participation has been valuable in this study. If you wish, the findings of the study will be made available to you.

Interviews with Family:

The following questions will be asked to family members immediately following a visit that has taken place in the conversation corner as part of the Family Visit Program, ideally while still sitting in the conversation corner (preferably no longer in the presence of the resident).

The visit experience:

How would you compare the quality of this visit to other visits you have had on previous occasions (not in the conversation corner) in terms of your experience?

How would you compare the quality of this visit to other visits you have had on previous occasions (not in the conversation corner) in terms of your perception of your loved one's (the resident's) experience?

How did your participation in the Family Visit Program influence the length of stay during your visit?

How did your participation in the Family Visit Program influence your desire to visit in the future?

What features of the Family Visit Program do you think made the biggest impact on the quality of the visit (conversation corner as setting, digital picture frame and stand as focal point, orientation process)? Please explain why you think this was so.

Conversation corner:

What were your initial reactions to the conversation corner?

What were your impressions of the conversation corner change after sitting in it and experiencing it?

Did the conversation corner feel like a place you wanted to go and sit in for your visit with your loved one (resident)? Why or why not?

Is the conversation corner inviting? Why or why not?

Did you enjoy sitting with your loved one in the conversation corner? Why or why not?

Did you find it cozy? Why or why not?

Is the conversation corner comfortable to sit in? Why or why not?

Does the conversation corner feel intimate? Why or why not?

Are you satisfied with the materials used in the conversation corner? Why or why not?

In terms of acoustical qualities in the design of the conversation corner, how well do you feel the conversation corner supported interaction?

Did you feel acoustically distracted by other things going in the lounge during your visit in the conversation corner? Please explain.

Did you feel visually distracted by other things going in the lounge during your visit in the conversation corner? Please explain.

Did your loved one seem distracted by other things going on in the lounge during your visit in the conversation corner?

How well did you find the conversation corner to buffer outside distractions?

Do you have any concerns regarding the design of the conversation corner?

If you could change aspects of the design of the conversation corner, what would they be and how would you change them?

Other comments:

Digital picture frame & stand:

To what extent did you enjoy looking at images on the digital picture frame with your loved one?

To what extent did you perceive your loved one enjoying the experience of looking at images on the digital picture frame?

Did you find the digital picture frame to be an appropriate medium for looking at images? Why or why not?

Was the digital picture frame easy to control? Please describe any difficulties experienced.

Was the digital picture frame stand easy to manipulate? Please describe any difficulties experienced.

Was manipulation of the digital picture frame stand intuitive? Please explain.

Do you have any concerns or suggestions for the design of the digital picture frame stand?

Other comments:

Orientation Process:

What did you think of the orientation process?

Did you think the orientation process was effective? Please explain why or why not.

Did you think the orientation process made a difference in your visit? Please explain why or why not.

Do you have any suggestions for improving the orientation process? If so, please describe.

Other comments:

Summary questions:

Have you learned anything from this experience? If so, what have you learned?

Is there anything about the experience you would want to change? If so, please describe.

Do you feel that you would want to have another visit in the conversation corner? Why or why not?

Other comments:

We would like to thank you for participating in the Family Visit Program. As you know, the underlying purpose of this study is to learn how to make family visits more rewarding. Your participation has been valuable in this study. If you wish, the findings of the study will be made available to you.

Interviews with Staff:

The following questions will be asked to staff members. The first set of questions (about the conversation corner when not in use for this study) will be asked before any visits have taken place in the conversation corner as part of the Family Visit Program. The other sets of questions (about the orientation process and the conversation corner/digital picture frame stand when in use for this study) will be asked at a point in time following visits that have taken place in the conversation corner as part of this study.

Conversation corner when not in use for this study:

What were your initial reactions to the conversation corner when it was first placed in the lounge?

Have you sat in the conversation corner?

Did your reactions change after sitting in the conversation corner? Please describe why or why not.

Did your reactions change after the conversation corner was moved from its initial placement and orientation in the lounge? Please describe why or why not.

How does the introduction of the conversation corner into the lounge affect the work of staff?

How does the presence of the conversation corner in the lounge affect staff members' interaction with residents?

How did the initial placement and orientation of the conversation corner influence residents' behavior in and use of the lounge?

How did the conversation corner after it was rearranged influence residents' behavior in and use of the lounge?

Do you have concerns and suggestions for the design of the conversation corner? If so, please describe.

Other comments:

Orientation process:

Did you have occasion to observe the Family Visit Program orientation process? If so, what did you think of this process?

Do you have any suggestions for improving this process? If so, please describe these suggestions.

Were you able to form an opinion about what difference the orientation process makes for the quality of family visits? If so, please describe your opinion.

Other comments:

Conversation corner and digital picture frame stand when in use for this study:

Did you happen to observe family visits occurring in the conversation corner as part of the Family Visit Program?

If yes, how did you observe the conversation corner to work as a setting for family visits as part of the Family Visit Program?

If yes, how did you observe the digital picture frame stand to work as a focal point for conversation during family visits as part of the Family Visit Program?

Have you observed any changes in behavior of residents after their participation in the Family Visit Program, which involved use of the conversation corner? If yes, please describe these changes.

Other comments:

We would like to thank you for participating in the Family Visit Program. As you know, the underlying purpose of this study is to learn how to make family visits more rewarding. Your participation has been valuable in this study. If you wish, the findings of the study will be made available to you.

APPENDIX F

This appendix is a sample of one set of completed color-coded video analysis sheets for both the resident and daughter of Family A. This sample documents the participants' behaviors during the first 11 minutes of the visit. The duration of behaviors was marked in seconds and often notations were made related to specific behaviors. As such, these notations are also color-coded to reflect which category or sub-category of analysis they are related to. Color coding was intended to minimize confusion when there were multiple notations in a given second while allowing notations to be paired correctly with the documented behavior. Notations applied to the full duration of a marked behavior, for as long as a color is marked and until a white space in that row appears or until another notation is made.

Colors are associated with the categories of analysis as follows:

Light Orange, Brown, & Purple—Touch/Gesture

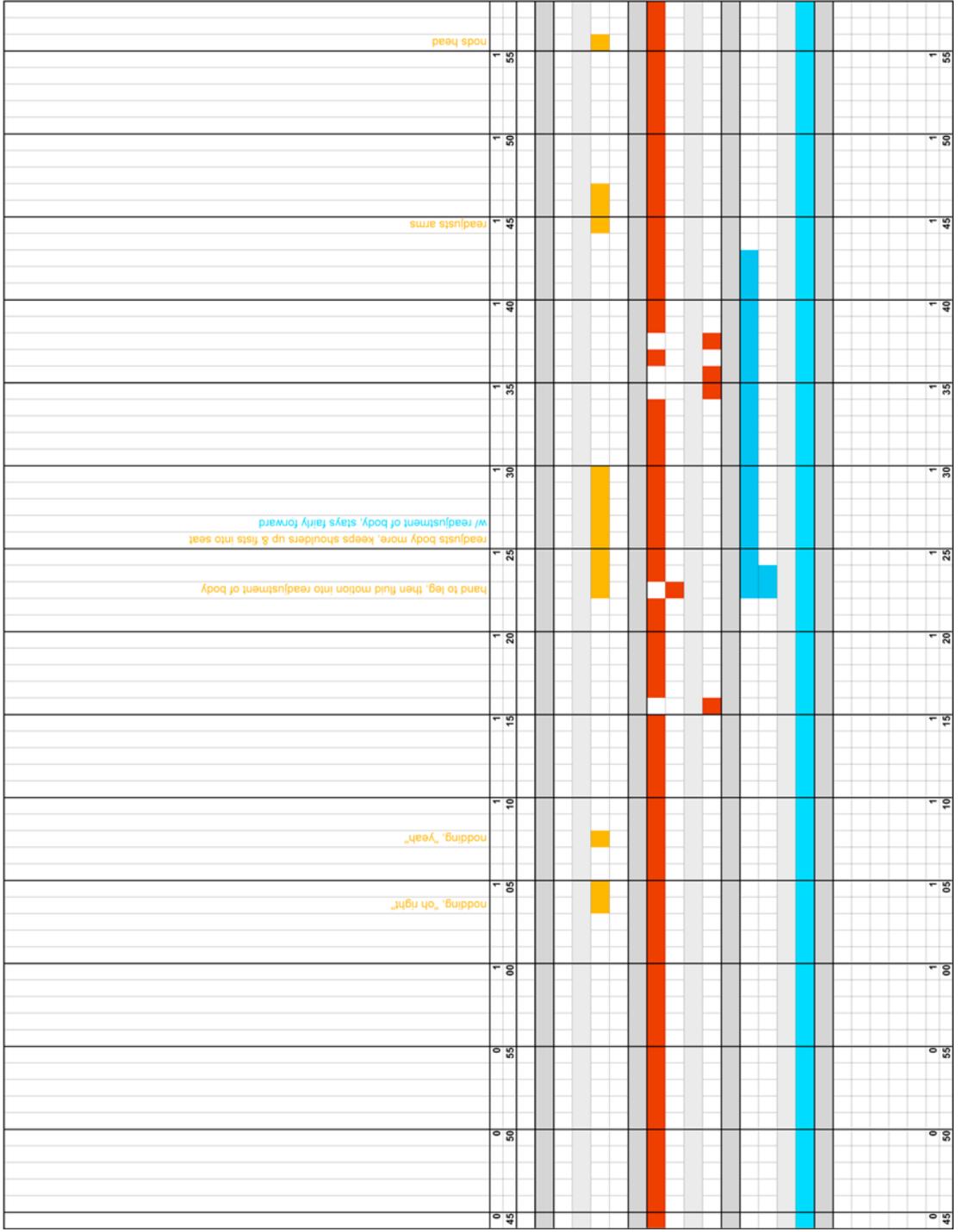
Dark Orange—Smiling/Laughing

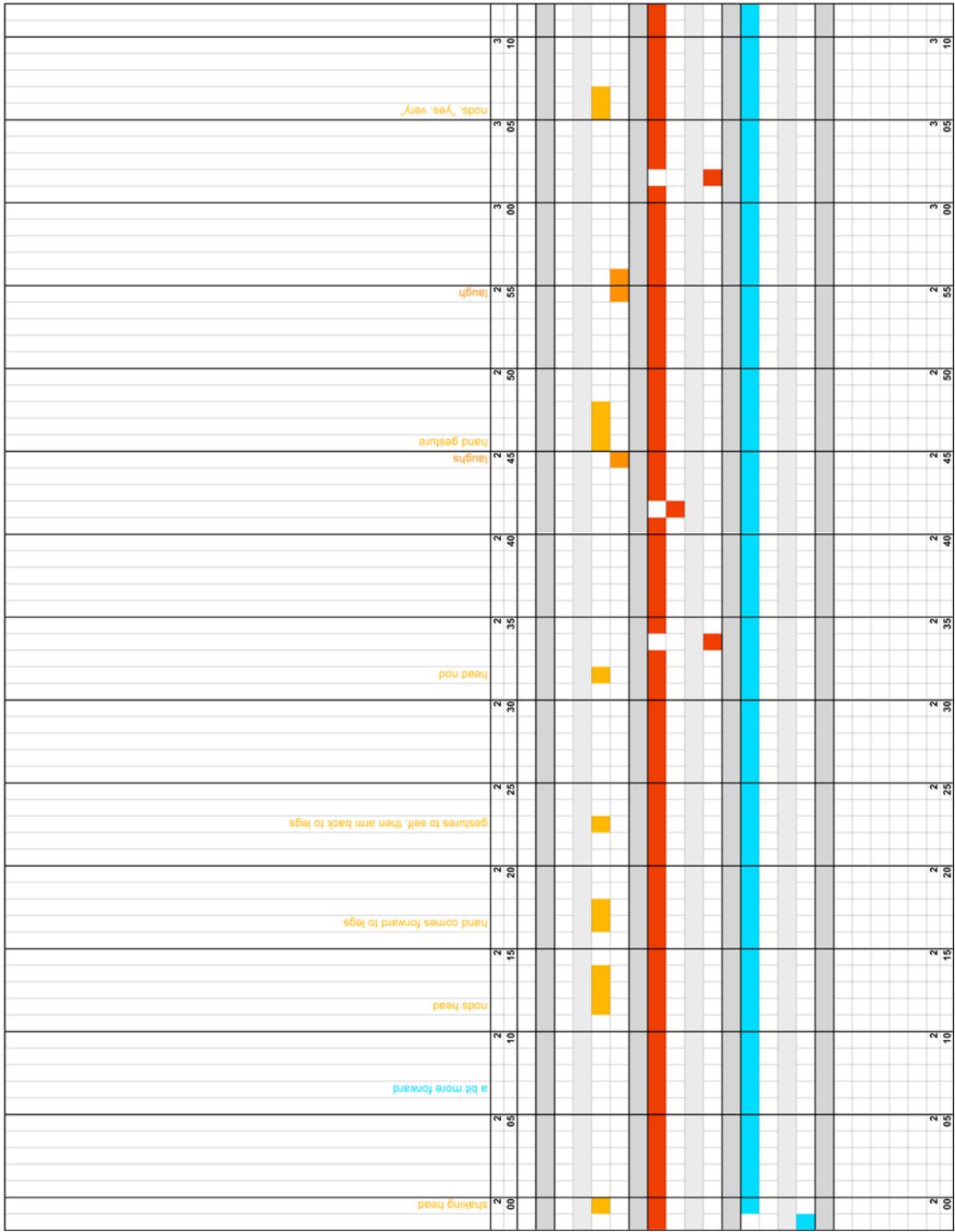
Red—Attention

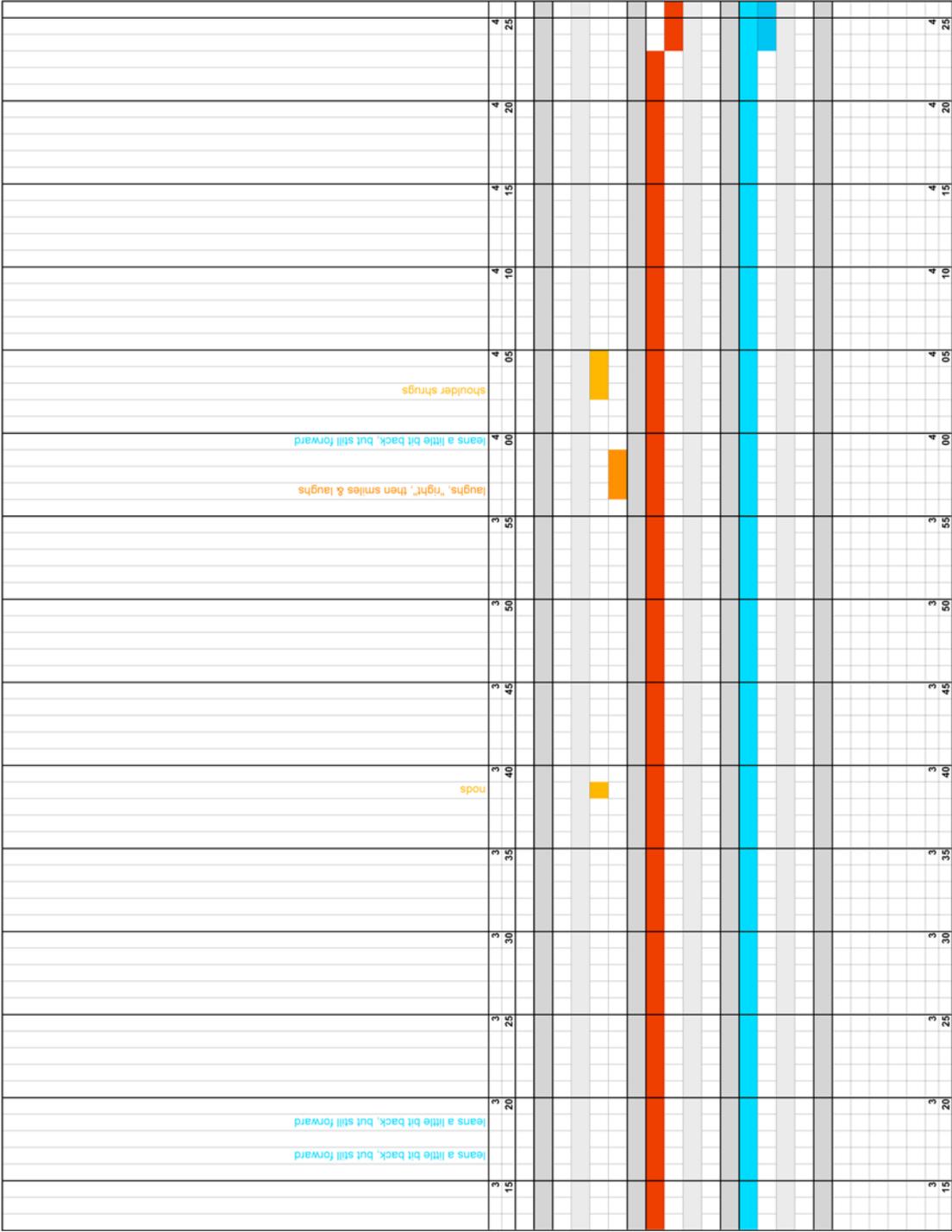
Blue—Leaning

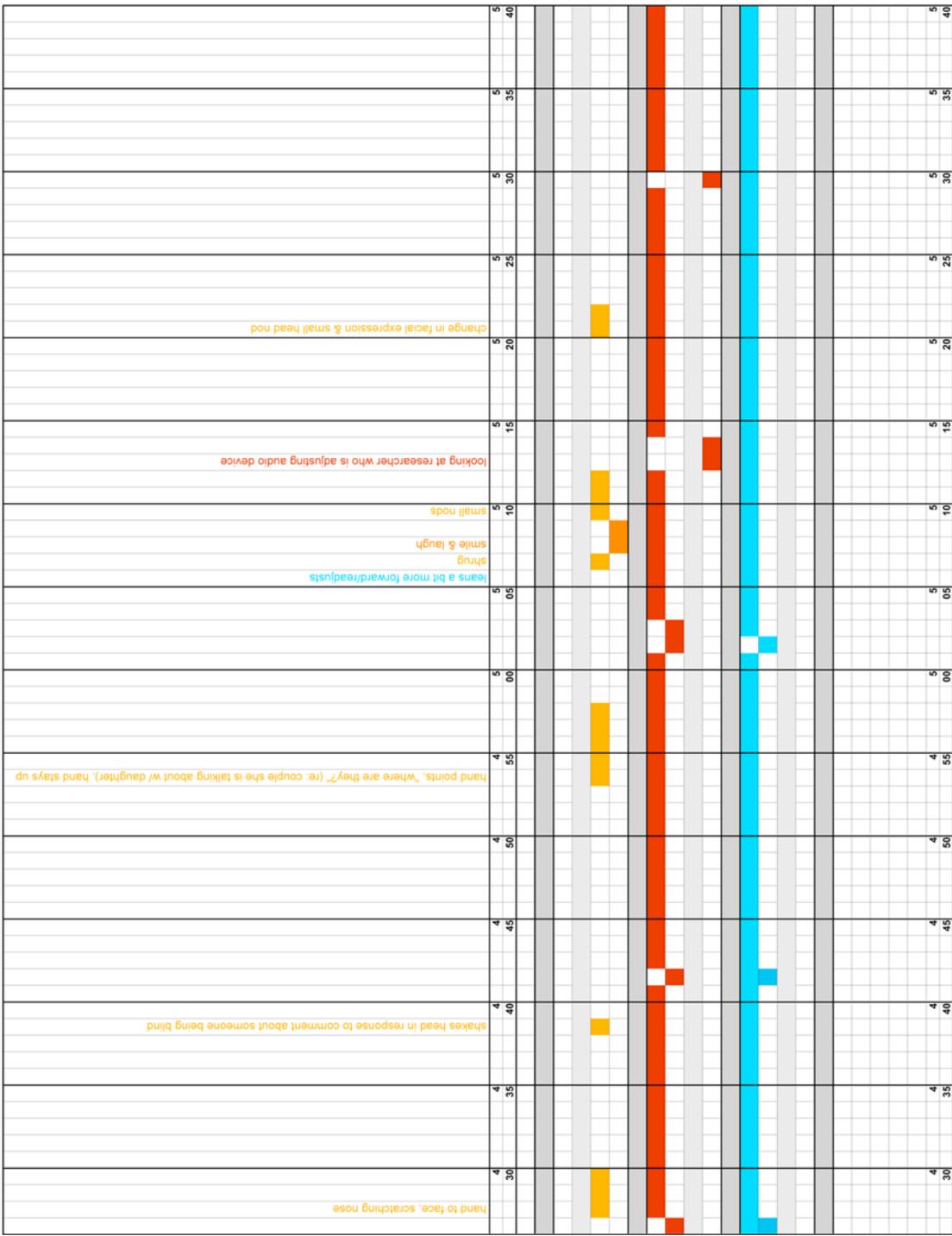
Green—Interaction with the stand

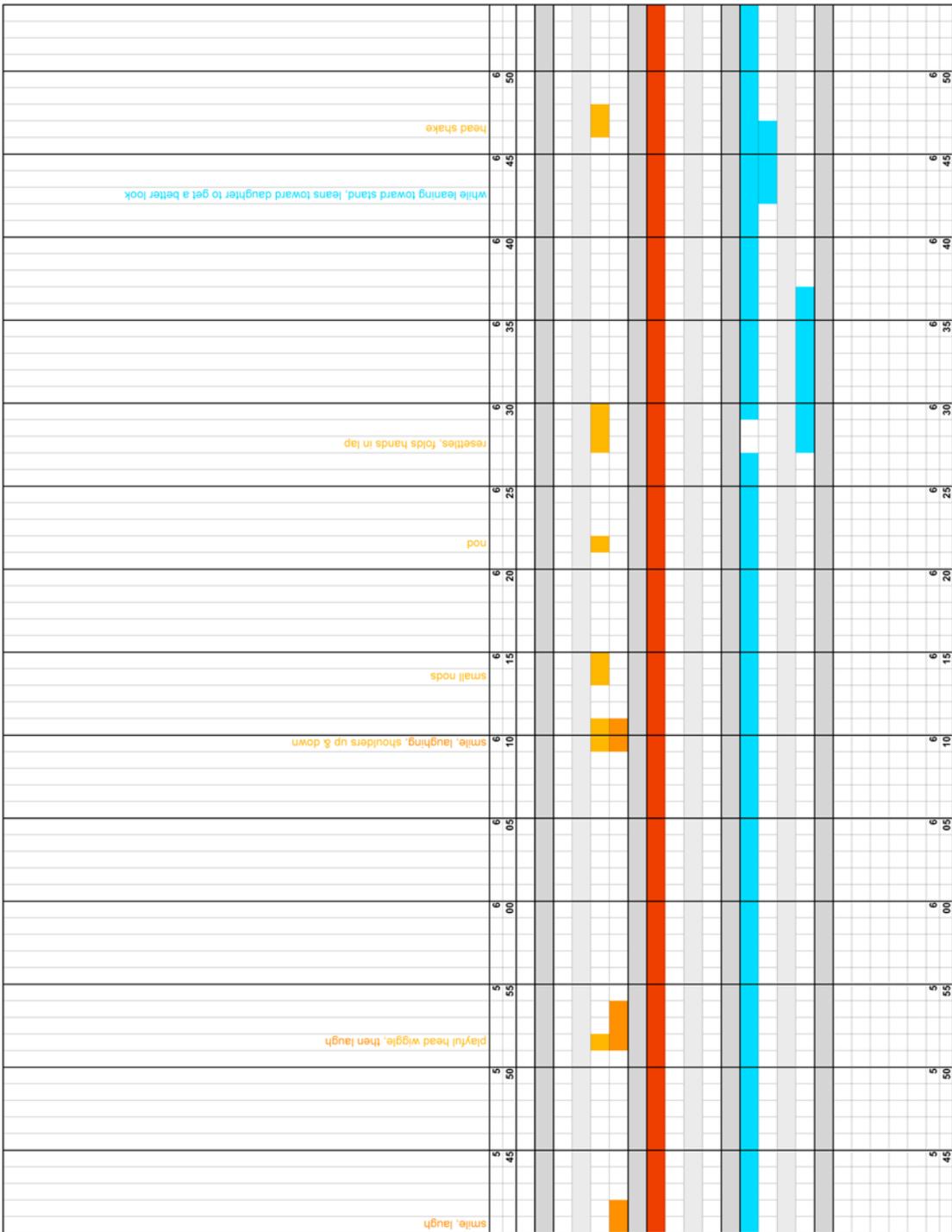
Rows filled in with light grey represent sub-categories that are not applicable.

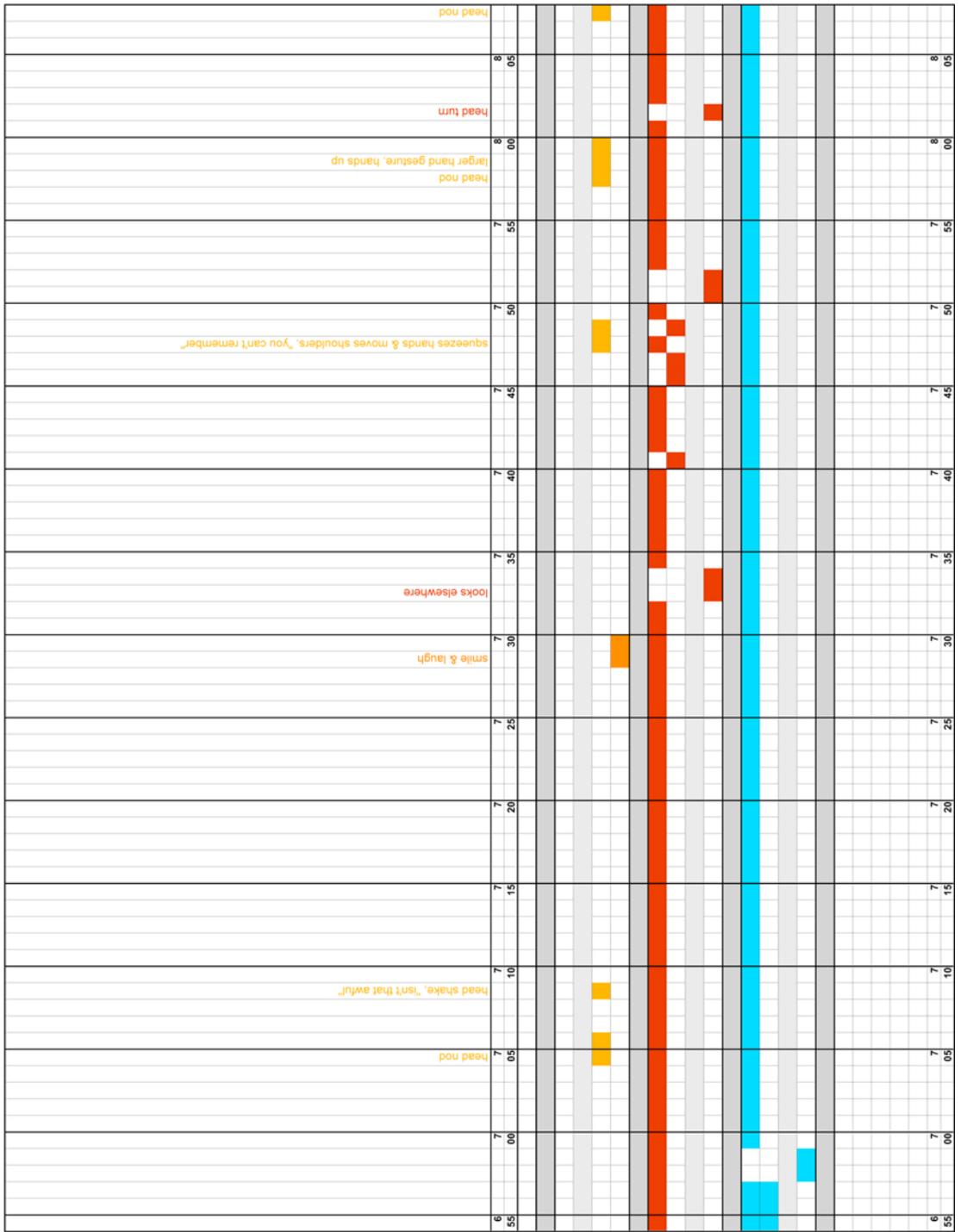


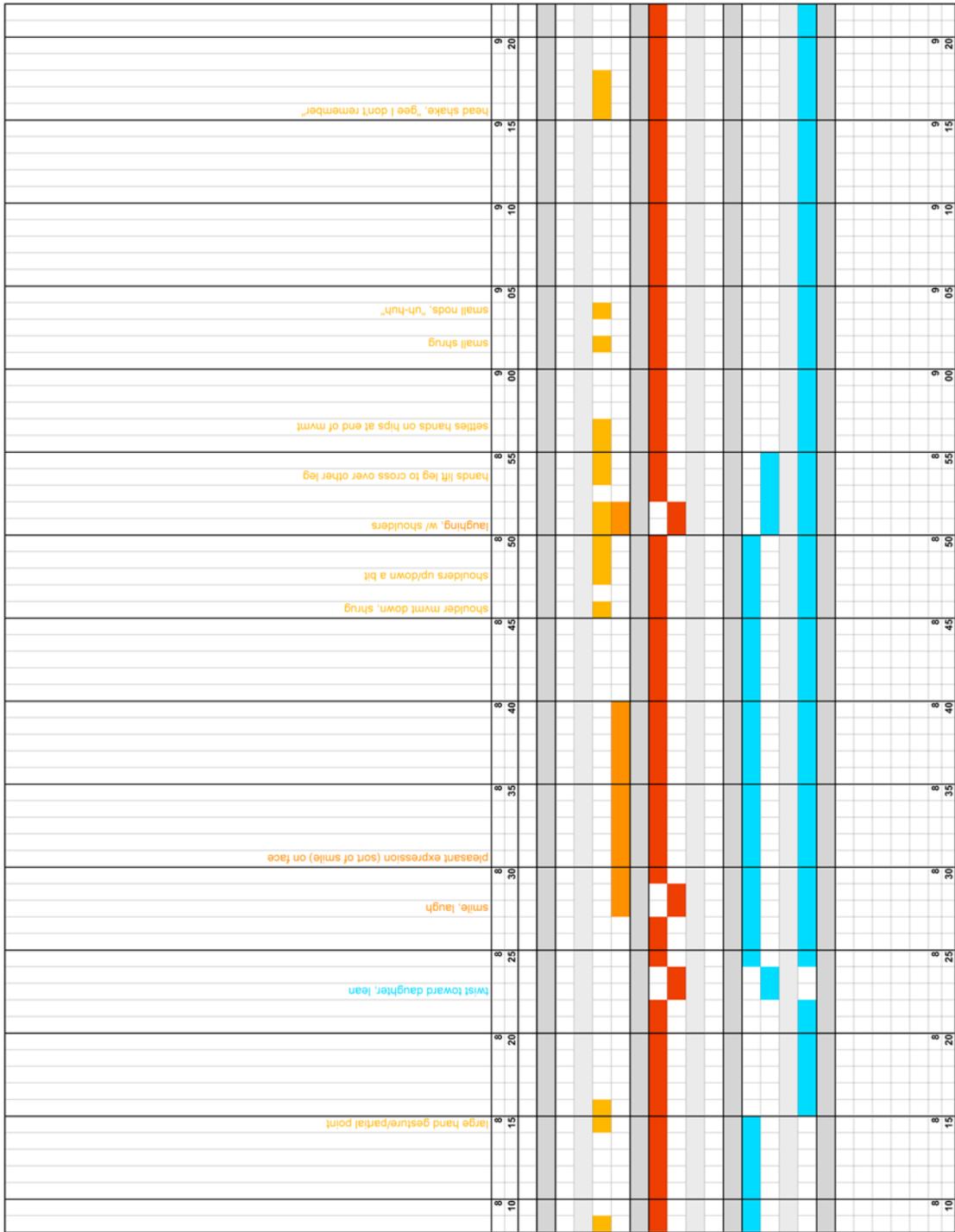


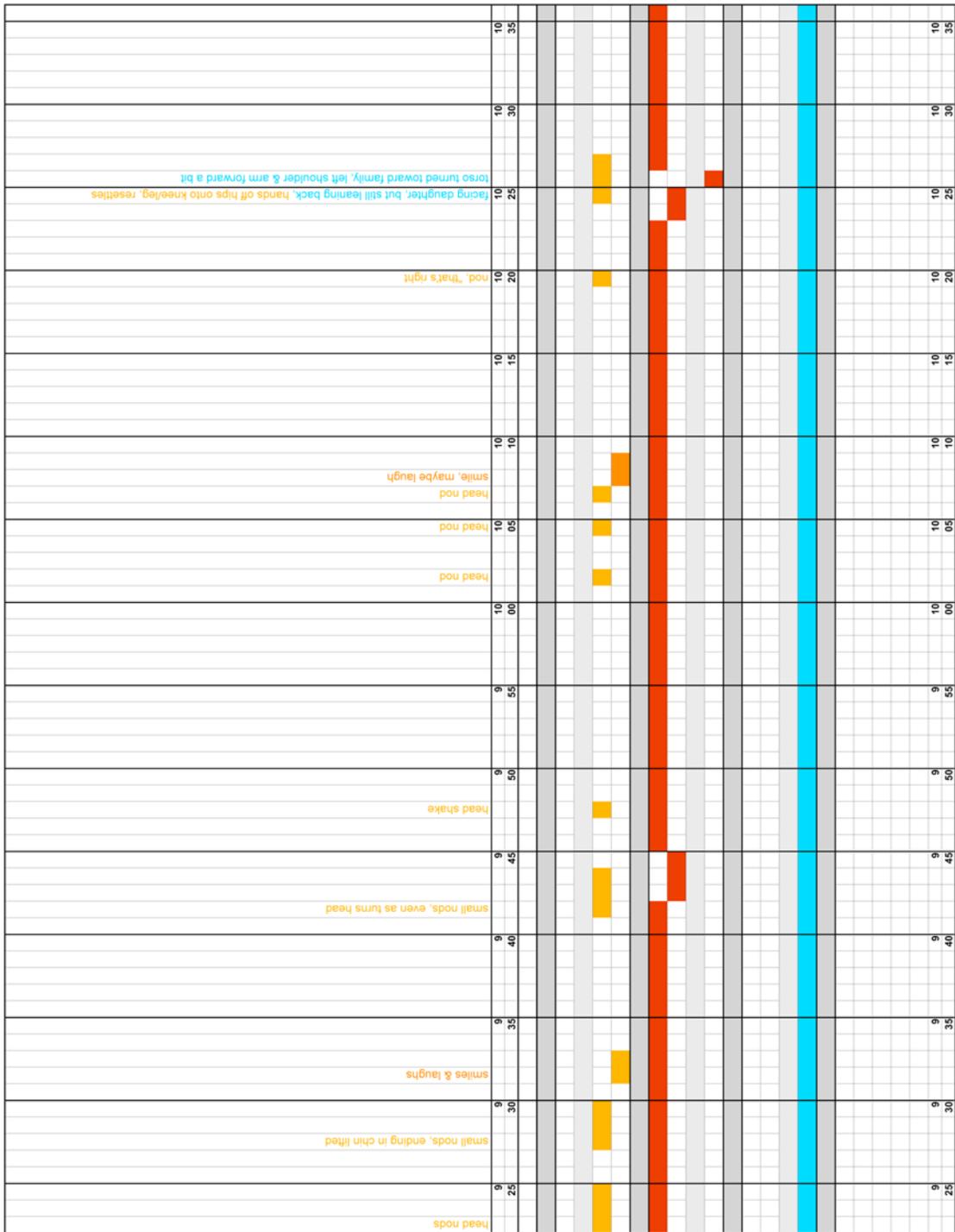


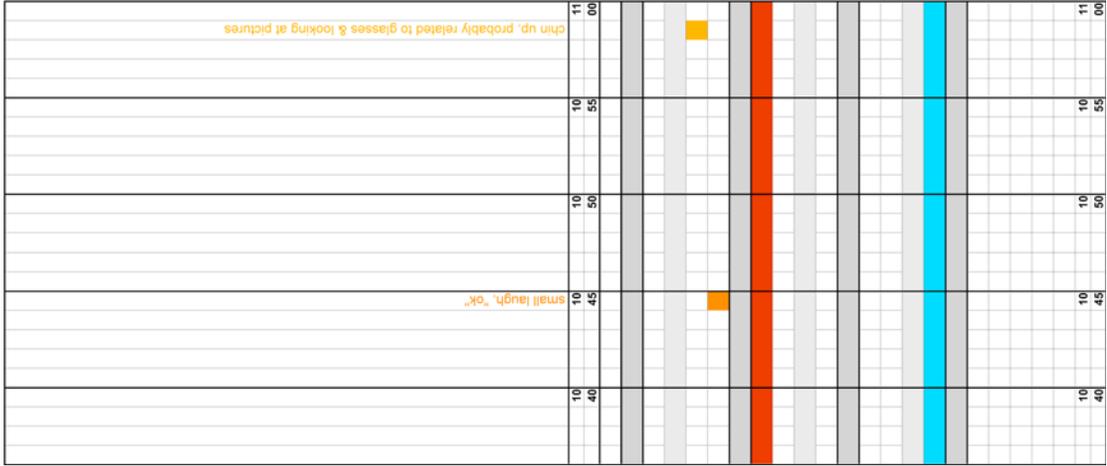








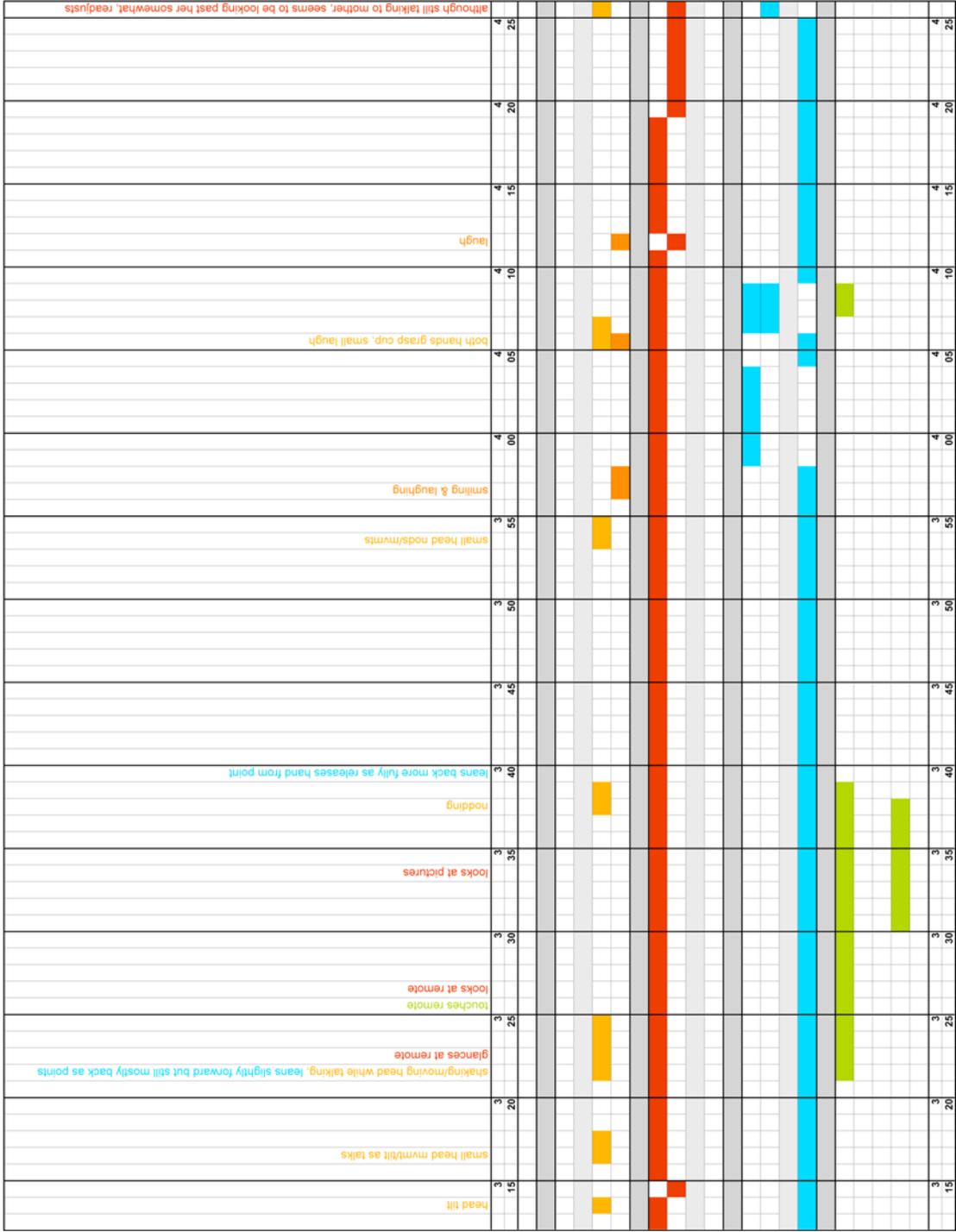


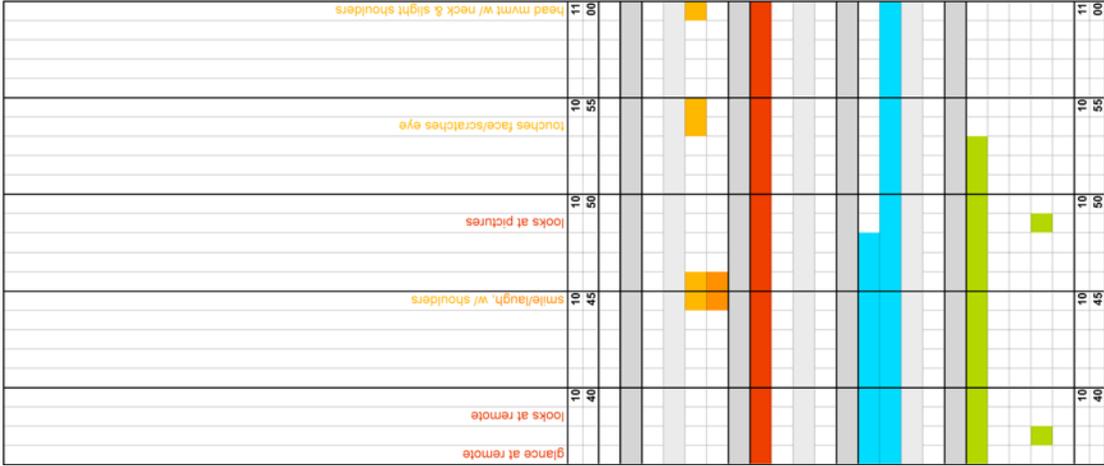


	0	05	10	15	20	25	30	35	40
Time (min)	0	05	10	15	20	25	30	35	40
(sec) 00									
Family A - Daughter:									
Touch/Gesture:									
Touching resident (initiated by family)									
Touching another family member - only if 2+ family members									
Touching/gesturing to self									
Smiling/laughing or other emotional indicators									
Attention/Line of Sight:									
Attention focused on pictures/stand									
Attention focused on resident									
Attention focused on another family member - only if 2+ family members									
Attention focused elsewhere									
Posture/Orientation of Body:									
Leaning towards pictures/stand									
Leaning towards resident									
Leaning towards another family member - only if 2+ family members									
Leaning back in seat									
Interaction w/ stand/pictures:									
Pointing at/touching screen									
Pulling the stand/screen closer									
Pushing the stand/screen farther									
Turning the stand									
Tilting the screen									
Time (min)	0	05	10	15	20	25	30	35	40
(sec) 00									
reading body, cup switching hands									
readjusts body-uncrosses, recrosses legs, angles body more toward mother									
recrosses legs as readjusts posture									
sips drink									
settles									
holds cup w/ both hands									
few glances down									
leans in a little more towards mother									
settling, fidgeting w/ cup & napkin									
settling, readjusting body & legs									
looks down as takes off shoe/readjusts									









APPENDIX G

The following is a table documenting attention for all participants. The values for each category represent percentages of the total time of the video recording of the visit.

Attention/Line of Sight Percentage of total time (video)	Family A		Family B				Family C		Family D					
	Resident	Daughter	Resident	Son	Great-grandson	Great-granddaughter	Resident	Son	Daughter-in-law	Resident (wife)	Resident (husband)	Son	Granddaughter	Daughter-in-law
Focused on pictures/stand	91.857	75.572	63.186	34.023	5.2205	38.614	86.193	69.76	79.709	87.792	75.438	45.623	59.387	0
Focused on resident (only if 2+ residents, i.e. husband/wife)		20.818		11.971	2.7903	4.1404		26.104	15.763	4.2315	3.9883	48.589	5.7879	0
Focused on family (only if 2+ family members)	4.3321		23.582				10.872			3.1615	15.856			
Focused elsewhere	3.8151	4.2519	7.8308	3.2403	6.9307	12.781	4.2202	2.4595	3.6333	4.572	5.3502	8.6576	16.245	0
Blocked	0	0	0	0	0	0	0	0	0	2.3346	0	1.3619	2.1401	0
No fill (i.e. couldn't tell)	0	0.2407	6.0306	41.584	81.908	37.714	0	0	0.1956	0	3.0642	0	19.115	100
Total	100	100.88	100.63	100.09	101.08	100.72	101.29	108.41	105.45	102.09	103.7	109.29	112.01	100
Key:		N/A												
		Residents												
		Family Members												

APPENDIX H

The following is a table documenting leaning and posture for all participants. The values for each category represent percentages of the total time of the video recording of the visit.

Posture/Orientation of Body Percentage of total time (video)	Family A		Family B			Family C		Family D						
	Resident	Daughter	Resident	Son	Great-grandson	Great-granddaughter	Resident	Son	Daughter-in-law	Resident (wife)	Resident (husband)	Son	Granddaughter	Daughter-in-law
Leaning toward pictures/stand	32.812	10.79	16.472	15.662	14.761	9.541	7.8256	50.252	24.818	43.434	15.272	94.261	63.716	0
Leaning toward resident		77.818		1.7102	0	1.3501		73.086	73.728			4.1829	3.4047	0
Leaning toward another resident (only if 2+ residents, i.e. husband/wife)										3.2588	24.757			
Leaning toward family	3.0485		12.331				0.6708			0	1.0214			
Leaning toward another family member (only if 2+ family members)				11.251	88.569	72.637		0	0.2236			41.877	0.535	0
Leaning back in seat	71.4	42.479	71.197	70.207	10.891	52.385	92.174	8.2169	74.847	53.405	82.15	5.2043	33.512	0
Blocked	0	0	0	0	0	0	0	0	0	2.286	0	0.1946	2.1401	0
No fill (i.e. couldn't tell)	0	0	0	4.2304	1.1701	0.8101	0	0	0	0	1.2646	0	0.5837	100
Total	107.26	131.09	100	103.06	115.39	136.72	100.67	131.55	173.62	102.38	124.46	145.72	103.89	100
Other (i.e. standing)	0	0	0	0	82.178	10.981	0	0	0	0	0	0.3404	0	0
Key:														
		N/A												
		Residents												
		Family Members												

APPENDIX I

The following is a table documenting physical interaction with the stand for all participants. The values for each category represent percentages of the total time of the video recording of the visit.

Interaction with the Stand Percentage of total time (video)	Family A		Family B			Family C		Family D						
	Resident	Daughter	Resident	Son	Great-grandson	Great-granddaughter	Resident	Son	Daughter-in-law	Resident (wife)	Resident (husband)	Son	Granddaughter	Daughter-in-law
Pointing to and/or touching screen/stand	0.72202	35.1785	6.3006	16.2916	8.55086	5.31053	2.79486	82.2806	4.13639	2.91829	1.21595	38.9105	43.3366	0.14591
Pulling the stand/screen closer	0	0	0	0.09001	0	0	0	0.22359	0	0	0.04864	0	0	0
Pushing the stand/screen farther	0	0	0	0	0	0	0	0.02795	0	0	0	0	0	0
Turning the stand	0	4.33213	0	1.26013	0.18002	1.26013	0.08385	5.39407	0.02795	0.09728	0	2.91829	1.94553	0
Tilting the screen	0	0	0	0.36004	0	0	0	0	0	0	0	0.04864	0	0
Total	0.72202	39.5106	6.3006	18.0018	8.73088	6.57066	2.87871	87.9262	4.16434	3.01557	1.26459	41.8774	45.2821	0.14591
Key:														
	Residents													
Family Members														

APPENDIX J

The following is a table documenting emotion indicators of smiling/laughing for all participants. The values for each category represent percentages of the total time of the video recording of the visit.

Smiling/Laughing Percentage of total time (video)	Family A		Family B				Family C			Family D				
	Resident	Daughter	Resident	Son	Great-grandson	Great-granddaughter	Resident	Son	Daughter-in-law	Resident (wife)	Resident (husband)	Son	Granddaughter	Daughter-in-law
Smiling/laughing or other emotion indicators	6.69876	8.1428	12.7813	1.80018	0	0.45005	1.9005	2.09614	6.28843	33.9981	2.82101	17.072	4.42607	8.21984
	Key:													
	Residents							Family Members						

APPENDIX K

The following is a table documenting touch and gesture for all participants. The values for each category represent percentages of the total time of the video recording of the visit.

Touch/Gesture Percentage of total time (video)	Family A		Family B			Family C			Family D					
	Resident	Daughter	Resident	Son	Great-grandson	Great-granddaughter	Resident	Son	Daughter-in-law	Resident (wife)	Resident (husband)	Son	Granddaughter	Daughter-in-law
Touching/gesturing to self Touching family (initiated by resident)	27.5973	21.7409	15.6616	8.73087	25.7426	29.1629	14.5333	14.142	11.9899	12.4514	17.1206	10.5058	28.2588	22.9572
Touching resident (initiated by family)	0		1.08011				0			0	0			
Touching another family member (only if 2+ family members)		0.08022		0	0	0.54005		0	0.08385			2.86965	0	0
Touching another resident (only if 2+ residents)				19.2619	24.2124	30.243		0	0			0.19455	0.09728	0
Total	27.5973	21.8211	16.7417	27.9928	49.955	59.946	14.5333	14.142	12.0738	17.4125	28.4533	13.57	28.3561	22.9572
Key:	N/A													
	Residents													
	Family Members													

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