Participatory Action Research to Improve Caregiver Education based on Cognitive Performance Test Results for Persons with Alzheimer's Disease or Mild Cognitive Impairments

Terriane Jones  
Nova Southeastern University

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Participatory Action Research to Improve Caregiver Education based on Cognitive Performance Test Results for Persons with Alzheimer’s disease or Mild Cognitive Impairments

by

Terrianne Jones

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Occupational Therapy Department
College of Allied Health and Nursing
Nova Southeastern University
Fort Lauderdale, Florida 33328

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Abstract

The aim of this study was to make changes to how occupational therapists in a transitional care unit setting provide education about Cognitive Performance Test (CPT) scores to caregivers of those patients with dementia or suspected dementia. Caregiver education for this population is important, as the incidence of persons living with Alzheimer’s disease and other dementias is expected to grow dramatically in the coming two decades. This study used a Participatory Action Research (PAR) approach to gather input from occupational therapists and caregivers of patients evaluated with the CPT. Interviews of caregivers indicated that they were unhappy with the education they received from therapists. Caregivers wanted a more collaborative relationship with therapists, and were sensitive to the experience of their loved one in occupational therapy in general, as well as to the approach to the education and the tone and language used to convey information about CPT scores. Therapists, with the caregiver input, worked together to develop education that reflected the needs of the caregivers, creating a new process, new tools and more opportunities for therapist- caregiver interactions. Interviews with a second group of caregivers who experienced the new education process revealed that they had a different, more positive experience overall with the new caregiver education process. This finding suggests that PAR as a methodology is well suited to facilitate changes to support development of client centered occupational therapy practice.
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Chapter 1: Introduction to the Study

One of every three seniors in the United States dies with a diagnosis of Alzheimer’s or another dementia (Tejada-Vera, 2013). Dementia is a neurocognitive disorder, defined as impairment in two or more cognitive domains that is accompanied by a loss of independence (American Psychiatric Association [APA], 2013). Although there are many causes of dementia, the most common form is Alzheimer’s disease. An estimated 5.2 million Americans had this form of dementia in 2013 and the incidence is expected to climb dramatically in the next decades, with an estimated 7.1 million persons affected by 2025 (Hebert, Weuve, Scherr, & Evans, 2013). Mild Cognitive Impairment (MCI), defined as emerging problems with memory, language, and thinking skills that are noticeable to family members and detectable on cognitive assessments (APA, 2013), is an established risk factor for Alzheimer’s disease. It is estimated that nearly half of those with MCI will go on to develop dementia within 3 or 4 years (Ganguli et al., 2011).

One of the symptoms experienced by persons with dementia is a progressive decline in the ability to perform everyday activities such as bathing, dressing, managing medicines, making meals, and other typical daily tasks. The term “functional decline” has been used in the literature to describe the deterioration of the skills necessary for physical self-care and independent daily living (Lowenstein & Mogosky, 1999). The management of functional decline in persons with Alzheimer’s disease falls primarily on their families, especially adult female children and to a lesser degree, spouses (Bouldin & Andresen, 2010). In the early stages of dementia, helping a person maintain safe performance of instrumental activities of daily living (IADL) such as driving and meal
preparation, etc., are typical concerns of caregivers (Schaber, 2010). In the later stages, caregivers often provide more hands on physical assistance for basic activities of daily living (ADL) such as bathing, toileting, and dressing (Au et al., 2009, p. 761). Eventually the caregiver assumes progressively more responsibility for all aspects of ADL and IADL as their loved one experiences significant functional decline.

Persons with Alzheimer’s or MCI who remain in a home setting are likely to be dependent on care provided by nonpaid, nonprofessional caregivers such as family members or close social contacts. This kind of care is referred to as informal care (Hurd, Martorell, Delavande, Mullen, & Langa, 2013). In 2013, more than 15 million persons in the United States were in the role of caregiver to someone with Alzheimer’s or another form of dementia (Alzheimer’s Association, 2014). The value of their unpaid work was estimated to be 220 billion dollars in 2013 (Hurd, et al., 2013).

Government assistance to help alleviate the burden of caregiving for a person with dementia has not been a priority in spending or policy decisions (Mannion, 2008). Services that are funded by the government under the Medicaid and Medicare programs are provided mainly in hospitals, skilled nursing, and long term care facilities. A limited amount of services are also provided in the home through home health services, though that care is episodic and usually connected to a coexisting medical event (Dartmouth Institute for Health Policy and Clinical Care, as cited by the Alzheimer’s Association, 2014). Respite care, adult day services and in home care are also available, but these services are not available to the same extent in every community, and when available, underutilized (Phillipson, Jones, & McGee, 2014).
As a result, most caregivers trying to support persons with dementia in the community are on their own when it comes to learning how to best care for a person with dementia and finding resources that they can access and/or afford to help them manage their loved one at home (Chenoweth & Spencer, 1986; DiZazzo-Miller, Pociask, & Samuel, 2013; Ducharme, Le Vesque, Lachance, Kergoat, & Coulombe, 2011; Gibson & Anderson, 2011; Harmell, Chattillion, Roepke, & Mausbach, 2011; Stirling et al., 2010; Takai, Takahashi, Iwamitsu, Oishi, & Miyaoka, 2011).

Without effective education and/or assistance, most caregivers will experience stress and burden related to being a caregiver, often resulting in negative effects on their own health and well-being as dementia progresses in their loved ones (Chiu et al., 2014; Diemling & Bass, 1986; Mittleman, Haley, Clay, & Roth, 2006; Pinquart & Sorenson, 2003; Romero-Moreno, Márquez-González, Mausbach, & Losada, 2012; Schulz & Martire, 2004). In addition to the stress of providing increasing physical assistance for ADL and IADL as the functional decline in the person with dementia continues, caregivers are also often “exposed to symptoms of depression, anger, agitation, and paranoia in their care recipients” (Mannion, 2008, p. 28). Although the literature clearly establishes these consequences of being a caregiver to a person with dementia, it also indicates that caregivers often do not use services that are available to them. For example, Brodaty, Thomson, Thompson, and Fine (2005) found that among Australian caregivers who reported feelings of stress and burden, the main reason for not using services was the perception that there was no need to do so, followed by a lack of awareness of services available.
In the United States, factors influencing use of services are often related to delays in obtaining a diagnosis of Alzheimer’s disease or MCI (Alzheimer’s Association, 2014). Bradford, Kunik, Schulz, Williams, and Singh (2009) found that the initial diagnosis of Alzheimer’s and MCI is often delayed significantly due to an assumption by primary care physicians that a formal diagnosis will harm more than it will help. Sometimes it is the person or family who interferes with obtaining the diagnosis. Boustani et al. (2006) found that almost half of all patients who meet the screening criteria for Alzheimer’s disease refuse further assessment to confirm that diagnosis, while Tang et al. (1996) found that family members waited as long as seven years after noticing cognitive symptoms before seeking medical care for their loved one. Vernooij-Dassen et al. (2005) concluded that the stigma of dementia contributes to the delay in obtaining a diagnosis.

Even when there is a diagnosis, Boustani et al. (2006) found that restricted health care options and limited financial resources also influence utilization of services by those with Alzheimer’s disease and MCI. However, once connected with resources, caregivers often will accept help. Miller & Butin (2000), in a study of an occupational therapy program that demonstrated that caregivers can be taught to better tailor the activities and environments of their loved ones, noted that “although caregivers come equipped with various skills in taking care of loved ones, they often seek ways in which to improve upon their management activities and coping skills” (p. 86). Education provided by professionals such as occupational therapists can help caregivers can learn strategies to help both themselves and their loved ones function more effectively (Schaber, 2010).
Occupational Therapy Assessment of Those with Alzheimer’s Disease or MCI

Access to professionals who can help caregivers is often encountered in the medical system when the person with dementia is being treated after a recent fall, for an illness, or for other reasons (Elsawy & Higgins, 2011). One example is occupational therapy.

Occupational therapy is a client-centered, evidence-based profession that is often ordered by the physician to provide interventions to and recommendations for families faced with dementia. The domain of occupational therapy is “achieving health, wellbeing, and participation in life through engagement in occupation” (American Occupational Therapy Association [AOTA], 2014, p. s4). Occupations are defined as “the everyday activities that people do as individuals, in families, and with communities to occupy time and build meaning and purpose to life. Occupations include things people need to do, want to do, and are expected to do” (World Federation of Occupational Therapists, 2012, para. 1).

Occupational therapists who work with older persons in hospitals, in transitional care units of skilled nursing facilities, in home health care, and in outpatient settings often assess the functional ability of persons with cognitive deficits to safely participate in daily occupations, and then make recommendations for necessary assistance and/or supervision, as well as for assistive devices for those persons upon their return home (Bonder & Dal Vello-Haas, 2009). Assessment of functional abilities can encompass physical performance of ADL as well cognitive skills necessary to carry out activities. There are a variety of tools available to occupational therapists for these purposes.
The Functional Independence Measure (FIM) is an example of a tool often used to objectively assess functioning by observation of task performance. Widely used and recognized in acute care settings such as hospitals or transitional care rehabilitation units in skilled nursing facilities, the FIM is an 18-item ordinal scale that allows trained clinicians of any medical or rehabilitative background to objectively rate performance of basic skills related to self-care, cognition, and functional mobility by observation alone. It can be used with any adult patient population (FIM, 2008).

Other assessments commonly used in less acute settings focus on performance of either basic ADL (related mainly to self-care) or IADL (higher level skills required for activities such as home maintenance, shopping, etc.). Examples of these assessments include the Kohlman Evaluation of Living Skills (Kohlman Thompson, 1992), a screening tool that involves asking persons to identify safety hazards from pictures, answer questions about how they would do given tasks, and perform selected simulated tasks. From this assessment the therapist rates the person as independent or needs assistance. Another tool is the Performance Assessment of Self Care Skills (Rogers, Holm, Chisholm, Raina, & Toto, 2008), an observation based tool that rates ADL and IADL performance in terms of quality, noting persons’ needs for assistance, their safety while engaged in the activity, and the adequacy of their performance.

Assessments that look exclusively at cognition are also utilized to determine if a person’s cognitive status may be impacting their function. The Folstein Mini-Mental State Exam, 2nd edition [MMSE-2] (Folstein & Folstein, 2010) is an example of a popular tool used in many care settings for the purpose of screening mental status and determining if further cognitive evaluation is warranted. The MMSE-2 standard version
(which replaced the original MMSE) is a 10-item test divided into sections that require verbal responses for questions related to orientation, memory, and attention. The second section requires reading and writing skills and assesses ability to name common objects, follow verbal and written commands, write a sentence, and copy a design. Cutoff scores are identified to indicate cognitive impairment. Although it is quick and easy to administer the test, and it has overall good reliability and validity for detecting moderate to advanced dementia, and improved validity for detecting mild dementia, the MMSE-2 does have several limitations (Folstein & Folstein, 2010).

The ability of the MMSE-2 to predict functional performance in daily living skills in adults with dementia remains undetermined. The original MMSE was found to be weak in this regard as well (Crizzle, Classen, Bedard, Laford, and Winter, 2012; Ozdemir, Birtane, Tabatabaei, Kokino, and Ekuklu, 2001). Other limitations of the MMSE-2 are that persons with low or high educational levels may have skewed results, though an extended version of the test, the MMSE-2:EV, aims to address the more educated persons with the addition of two new tasks called “Story Memory” and “Processing Speed." The main limitation of any version of the MMSE continues to be its status as a screening tool, and as such it cannot provide a diagnosis, nor should the information obtained via the tool be the basis for which an intervention plan is created (Anthony, LeResche, Niaz, Von Korff, & Folstein, 1982).

The Montreal Cognitive Assessment (MoCA) is another screening tool that is increasingly used to help detect cognitive impairment for persons with suspected dementia (Nasreddine et al, 2005). The MoCA is a paper and pencil assessment measuring visuospatial/executive, naming, memory (recall), attention, language,
abstraction, orientation domains. It is quick to administer (10 minutes), free, and easily accessed online in multiple languages. The MoCA has been found to be more sensitive than the MMSE in detecting cognitive impairment, though it does reflect an education bias, necessitating that scores be adjusted according to education level (Gagnon et al., 2013). Although the MoCA is continually researched (Costa, Reich, Fimm, Ketteler, Schulz, and Reetz, 2014; Goldstein, Ashley, Miller, Alexeeva, Zanders and King, 2014; Julayanont, Brousseau, Chertkow, Phillips and Nasreddine, 2014; and Lam, Middleton, Masellis, Stuss, Harry, Kiss, and Black, 2013), it remains a screening tool only, and does not predict degree of impairment or ability to function.

Another cognitive screen developed by and for occupational therapists is the Allen Cognitive Levels Leather Lacing Screen [ACLS] (Allen et al., 2007). It is based on the theory of cognitive disability developed by Claudia Allen (Allen, 1985). The ACLS is a standardized tool that screens for capacity for new learning by having the person attempt a series of increasingly complex leather lacing stitches. The score indicates degree of impairment on a 1-6 scale known as the Allen Cognitive Levels, where level 6 is considered normal cognitive functioning.

The original six levels have been revised to a 26-level decimal mode scale indicating a linear progression of change in cognitive domains such as attention span, language, and spatial awareness (Allen & Blue, 1998; Allen, Earhart & Blue, 1995). Although the ACLS is widely used by occupational therapists, it too is a screening tool and as such is not intended to be an adequate source of information from which a therapist might draw to provide caregiver education and make discharge planning recommendations.
A full cognitive assessment utilized by occupational therapists is the Cognitive Performance Test (CPT), which was also originally based on Allen’s theory of cognitive disability (Burns, Mortimor, & Merchak 1994). The CPT is a standardized, performance-based assessment instrument, designed for the objective evaluation of global function in Alzheimer’s disease. The CPT assesses the information processing required for seven separate functional tasks (DRESS, SHOP, TOAST, PHONE, WASH, MEDBOX, and TRAVEL). Clients are scored on each task, and then the total score is divided by the number of completed tasks for an average score.

Originally, the score was referred to as an Allen Cognitive Level, keeping it congruent with Allen’s scale developed under the theory of cognitive disability. However, with the ACLS score change to indicate 26 modes, the CPT score has been changed to Cognitive Functional score, because “while the CPT uses decimal mode scores for a sensitive assessment measure, scores represent an average performance or mean score but do not represent the 26 ‘modes of performance’” (Burns, 2013, p. 1). Burns (2013) states this was necessary “in light of the empirical evidence that CPT scores predict functional capacities that differ from the ACL, in particular at the higher end of the scale (i.e., Levels 4 and 5) where differences in cognitive domain processes are seen across individual clients with the same score” (p.1). According to Burns, the CPT score obtained is used by occupational therapists to:

Explain and predict the client’s capacity to function in various contexts and guide intervention plans, as well as to measure and track the severity of a cognitive-functional disability such as with Alzheimer’s disease. It examines cognitive integration with functioning in an environmental context; by incorporating
cognitive challenges within the complexity of an IADL context in order to evaluate higher levels of cognition in function and in particular rate executive control function, the group of cognitive processes that mediate goal-directed activity. (p. 1)

Understanding of the person’s cognitive processing as indicated by the CPT score allows the therapist to provide education to caregivers that can help them anticipate their loved ones’ needs for assistance, environmental changes, or modifications to activities.

**Statement of the Problem**

According to the Occupational Therapy Practice Framework (American Occupational Therapy Association [AOTA], 2014), the domain of occupational therapy, which includes individual client factors and performance skills in occupations; the context and environments in which occupations occur; and the performance patterns associated with occupations is “inextricably linked in a transactional relationship” (AOTA, 2014, p. 54) with the occupational therapy process. The occupational therapy process reflects:

- simultaneous attention to the client’s body functions and structures, skills, roles, habits and routines and context-combined with a focus on the client as an occupational being and the practitioners knowledge of the health and performance enhancing effects of occupational engagements-that outcomes such as occupational performance, role competence and participation in daily life are produced (AOTA, 2014, p. 54).

The occupational therapy process begins with development of an *occupational profile,* for which the therapist elicits information to better understand the person’s history,
interests, values, and needs in terms of performing daily occupations. The development of the occupational profile and the subsequent intervention plan is a collaborative process between therapist and clients, and may include the family and or others clients identify in their social environment. From this perspective, occupational therapists working with persons with MCI or Alzheimer’s disease are obligated to provide a comprehensive evaluation which includes the development of an occupational profile and analysis of occupational performance via assessments such as the CPT in order to create an intervention plan reflective of the full domain of occupational therapy and delivered in a collaborative manner between client, caregiver, and therapist. For clients with MCI or Alzheimer’s disease, a significant portion of the services offered by occupational therapy should focus on assessment of cognitive abilities, daily habits and routines, and the environment in which clients function, in order to create caregiver education that will ultimately support health and participation (Schaber, 2010).

Creating meaningful recommendations and caregiver education is problematic when the supporting assessment data are obtained using screening tools or other measures that only evaluate isolated task performance at best. Although many of the tools listed above purport to include assessment of cognitive skills, there is no consistency from tool to tool as to which aspect of cognition is measured. Reliance on screening tools alone may even result in missing subtle cognitive issues that impact safety and judgment in day-to-day activities. Tools that assess performance of basic self-care related tasks without consideration of context do not provide any information about how a person is likely to function in more complex daily activities such as meal preparation in their home environment. Further, scores on tools such as the FIM, though shown to predict the
number of hours of caregiving likely required after a stroke (Calmels, Ebermeyer, Bethoux, Gonard, & Fayolle-Minon, 2002), do not enjoy significant predictive validity for burden of care associated with persons with dementia (Glenny & Stolee, 2009).

Occupational therapists are often asked to predict the amount and type of assistance persons with Alzheimer’s disease or MCI might require to safely engage in ADL or IADL in their home environments. Bonder and Dal Vello-Haas, (2009) draws a distinction between occupational performance potential and actual occupational performance in those with dementia. From this perspective, assessments can be thought to examine occupational performance potential, or actual performance, or both. As it is not possible to directly observe and evaluate a client’s ability to perform in every activity and/or context that a typical day includes, therapists need tools that predict how a person’s cognitive processing skills influence the quality of their performance in daily occupations. Assessing cognitive abilities rather than the performance of specific ADL allows therapists to more accurately predict performance in non-observed tasks, and when combined with the other information about the client required to create a thorough occupational profile, can be used to create a customized caregiver education plan (Allen & Blue, 1998; Burns, 2013). For this reason, many occupational therapists have embraced the CPT.

Although it uses some commonly recognized activities, the CPT is a “cognitive-functional information processing measure that identifies patterns of occupational performance” (Burns, 2006, p.1). The intent of the CPT is to “measure working memory/executive function processing capabilities that underlie performance deficits” (Burns, 2006, p. 1). Levy and Burns (2005) state that the term working memory identifies
capacity to consciously focus attention, filter and inhibit stimuli/responses, divide 
attention, and think abstractly in the context of planning and executing higher level IADL 
activities.

In the upper Midwest region of the United States, the CPT has become very 
popular among therapists and physicians alike in hospital and transitional care 
rehabilitation facilities especially. It is often ordered by the physician by name and its 
results are used by the inter-professional team to make important recommendations to 
caregivers for supervision for persons with dementia or MCI. One pilot study of the use 
of the CPT in occupational therapy practice in Minnesota found that 70% of the therapists 
surveyed (N=67) reported using the CPT in their practice, and that therapists in 
transitional care units (TCU) of skilled nursing facilities reported using the tool most 
frequently (Jones, Gustafson, Lopes-Sarrao, & Skogen, 2009). Further, of those using the 
CPT, 89% did so for discharge planning and 87% also used it to help provide caregiver 
education (Jones et al., 2009). However, this pilot study revealed that only 36% of 
occupational therapists were providing individualized caregiver education based on the 
CPT, with the majority relying on report of the CPT score in writing on a standard form 
along with handouts describing an overview of each scoring level to relay the information 
(Jones et al., 2009). Although these handouts provide general information on 
characteristics of function associated with each score, they only minimally help a 
caregiver translate what the information might mean for their loved ones’ daily 
functioning. For example, a handout for CPT level 4.0 reads “Moderate functional 
decline; unable to complete complex daily tasks and difficulty with self-care tasks” (St. 
Therese Rehab, 2012, para. 2).
Test creator Teressa Burns has stated that it was never her intent that the CPT results alone would be the sole source of information for discharge planning and caregiver education. Rather, her vision is that therapists use the information generated from the CPT to supplement the information they obtain from observations of task performance as well as interviews with clients and caregivers to inform their clinical reasoning and create customized caregiver education (personal communication, February 25, 2011). However, in many settings where occupational therapists primarily use the CPT to assess cognition, caregiver education often consists of brief reports at short discharge planning meetings, where the CPT score and recommendations for discharge disposition (e.g., return home, go to an assisted living or obtain additional in-home services) are quickly presented along with a myriad of other information such as medication lists and follow up appointments with physicians (Jones et al., 2009). These meetings frequently happen within just a few days before discharge and are not always attended by the occupational therapist who made the recommendations, or by any occupational therapist for that matter (Jones et al., 2009). No research has been published regarding the best way to accomplish Burns’s vision for ideal caregiver education based on assessment of cognition using tools such as the CPT. Further, no study has been published of the experience and perceptions of being a caregiver who receives education about cognitive testing done by occupational therapy as part of the discharge planning process. The lack of both research and reflection of the voice of caregivers is problematic in light of the popularity of tools such as the CPT which are used as part of the occupational therapy process for the growing population of persons with dementia or MCI.
Purpose of study

The purposes of this study are to (1) gain an understanding of caregivers’ experiences with and perceptions of the process of receiving education from the occupational therapists at St. Therese Homes about their loved ones’ CPT score and the discharge recommendations provided by occupational therapists based on that score and (2) use the above understanding with the occupational therapists at St. Therese Homes to identify, create, and implement an improved process of providing caregiver education about CPT scores, so that it is truly individualized and client-centered.

Research Questions

In participatory action research, (PAR), there is no formal research question generated by a principal investigator of a given study. According to McNiff and Whitehead (2006), the beginning question in PAR is often a broader inquiry into the status of a current situation from the perspective of those functioning in the situation, for example, “Does what we are doing work?” For this study, the questions that are driving the inquiry are:

1. What do our clients (caregivers) think about the education they received from occupational therapy in a transitional care unit setting about the results of the CPT?
2. How can we better create and/ or more effectively deliver individualized and client-centered education for use with caregivers in a busy care system such as a TCU?

Definition of Variables

For purposes of this study, caregivers are defined as those non-paid persons who are the primary source of instrumental support to a person with dementia or mild cognitive impairment. Instrumental support is defined as providing practical assistance
(either physical or verbal) for the person with dementia or mild cognitive impairment so they can engage in activities of daily living (McColl, 1997). Examples of instrumental support in the context of this study would include things such as helping with meal preparation, setting up medicines, providing verbal cues to take medicine, etc.

*Individualized and client-centered education* is defined as that which is created specifically for the individual client, based on an occupational profile and results of the CPT.

**Rationale and Need for Study**

The expertise of an occupational therapist is built upon the knowledge of how engagement in occupation supports participation in context for persons of any age (AOTA, 2014). As the population in the United States continues to age and the prevalence of Alzheimer’s disease and MCI rises along with it, occupational therapists will be increasingly asked to make functional assessments of and recommendations for persons with cognitive decline in order to maximize their function. Currently just over a third of occupational therapy practitioners work primarily with persons aged 65 and older, mainly in the areas of home care, community based settings, and skilled nursing facilities (AOTA, 2010). In the first two settings, clients are likely to be in their own home environment, and are likely to return to their home environment after being treated in a skilled nursing facility. The home environment is where the majority of unpaid care takes place, and according to the Alzheimer’s Association (2013), the increasing numbers of persons with dementia, coupled with increasing health care costs, will only increase the demands for unpaid care, once a person is discharged home.
The American Occupational Therapy Association *Practice Guidelines for Adults with Alzheimer’s Disease and Related Disorders* (Schaber, 2010) endorses a family-centered-care model for occupational therapy intervention for this population. Family-centered-care is a concept that emerged from pediatrics and has expanded into the areas of HIV, cancer, and aging (Kovacs, Bellin, & Fauri, 2006). According to the Institute for Family-Centered Care (IPFCC):

Patient and family-centered care is an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families. It redefines the relationships in health care. Patient- and family-centered practitioners recognize the vital role that families play in ensuring the health and well-being of infants, children, adolescents, and family members of all ages. They acknowledge that emotional, social, and developmental supports are integral components of health care. They promote the health and well-being of individuals and families and restore dignity and control to them. Patient and family-centered care is an approach to health care that shapes policies, programs, facility design, and staff day-to-day interactions. It leads to better health outcomes and wiser allocation of resources, and greater patient and family satisfaction. (IPFCC, 2010, para. 1)

In the occupational therapy literature, Lawler and Mattingly (1998) write that a family-centered care approach considers not only the person in the context of their family, but also the needs of the caregivers who support them.

Schaber (2002) applied a family centered care model specifically to persons with Alzheimer’s disease and their families, and proposed that family-centered-care as a
model for therapeutic intervention should be considered in light of the nature of the disease and certain need for caregiver involvement. Occupational therapy interventions for persons with Alzheimer’s disease and MCI can help caregivers manage their loved ones (Schaber, 2010) and keep them optimally engaged and safe in home settings. Further, as a service profession that upholds client-centered approaches as a core value, it is imperative that therapists adhere to the four principles of the ethic of care as outlined by Tronto (1993): (1) recognizing and being attentive to others; (2) taking responsibility for action; (3) performing caring work competently; and (4) being responsive to the care receiver’s position or considering care from their perspective.

The CPT has gained popularity among therapists and physicians as an assessment tool for identifying a score that indicates how much assistance a person with Alzheimer’s disease or MCI might need to engage in daily activities; however, there has been no study of how caregivers who are given CPT scores perceive and utilize this information. In order to improve caregiver education, it is imperative that the occupational therapists responsible for developing the educational materials and approaches understand the experience of those on the receiving end. The goal of this study is to develop recommendations for a process and materials for caregiver education regarding the impact of cognition on occupational performance, as assessed by the CPT, at discharge from occupational therapy in a TCU setting that are reflective of the needs of the clients, the caregivers, and the therapists.

The results of this study will potentially inform occupational therapy practice for those utilizing the CPT as well as other cognitive assessments to inform caregiver education. This study will also give voice to the caregivers of those with Alzheimer’s
disease and MCI, a group that has not been well represented in occupational therapy literature. It is hoped that this study will demonstrate to occupational therapists a process for collaborative problem solving between professionals and those they serve that can be implemented in other settings. Finally, this study also has the potential to be a model of exemplary university-practice partnership using PAR methodology to solve real problems in the clinical setting.

Assumptions and Limitations of the Study

An assumption of this study is that occupational therapists, as members of a client-centered profession, are concerned with their clients’ (defined as both the caregivers and the persons with Alzheimer’s or MCI in this study) perceptions of and experience in the therapy relationship. Additionally, it is assumed that as members of an evidence-based profession, occupational therapists need to know if the services they provide produce outcomes desired by both the client and the therapist. Finally, it is an assumption of this study that there is room for significant improvement in the way caregiver education about CPT scores is provided in most settings. This assumption is based on anecdotal reports by many therapists and observations made by the test creator, Teressa Burns, OTR, who provides training and consultation on the use of the CPT to therapists all over the Midwest. According to Ms. Burns, the CPT information is not being presented in the individualized manner that she intended when she created the tool (personal communication, February 25, 2011). The main limitation of this study is its lack of generalizability to other populations or therapy delivery settings.
Chapter 2: Selected Review of the Literature

The number of persons with Alzheimer’s disease, other dementias, or MCI is large and anticipated to continue growing rapidly in coming years. Much information is published about cognition and cognitive decline, as well as about some of the needs of those who support persons with cognitive decline. There are established occupational therapy theoretical frameworks that support intervention for both the persons and their caregivers in this population, and many tools to choose from for the purpose of evaluating cognition to design appropriate interventions. In addition, education for the purpose of teaching caregivers to support persons with dementia that is delivered by occupational therapists must also reflect best practices in the areas of adult education and learning theory and health literacy. Finally, PAR is one method to study the impact of occupational therapy practices for this population with the intent of improving the experience for all involved.

Historical Overview of Relevant Theories and Research Literature on Topic

Dementia. Dementia is a broad term that describes symptoms that affect intellectual function, the most noticeable of which is memory loss. Other symptoms may include aphasia (difficulties with verbal language); apraxia (difficulties with motor planning); agnosia (difficulty recognizing objects and for what they are used); and executive function loss (impairments in the ability to plan, pay attention to, and efficiently engage in tasks). Changes caused by dementia are different than those caused by normal age related changes in the cognitive, motor, and sensory systems (APA, 2013). There are different types of dementia that are associated with specific diseases such as
Parkinson’s, Huntington’s, Acquired Immune Deficiency Syndrome, and heart disease, among others (Goetz, 2003). However, the most common and increasingly prevalent form of dementia is Alzheimer’s disease, which accounts for 73% of dementias in persons aged 70 or older (Plassman et al., 2007).

Alzheimer’s disease is a progressive and irreversible disease, named after German neurologist Alois Alzheimer (1864-1915), who first documented symptoms of the disease. Previously, persons presenting with symptoms were referred to as “senile” or having “organic brain syndrome” (Berrios, 1990). The etiology of Alzheimer’s disease remains unknown, but multiple theories abound. Theories proposing that environmental toxins, genetic mutations, autoimmune issues, and lifestyle, among other factors, are linked to the disease have not been conclusively proven (Abraham, 2005). The incidence of Alzheimer’s disease increases significantly with age (especially after eighty), and the disease is found all over the world (Brookmeyer, Ziegler-Graham, Johnson, & Arrighi, 2007).

Alzheimer’s disease is not definitively diagnosed until after death with an autopsy; however, the Alzheimer’s Association reports that skilled physicians can diagnose the disease with ninety percent accuracy with a combination of a medical exam, a detailed history of symptoms, use of imaging tests, laboratory tests to rule out physical issues, and neuropsychological tests (Alzheimer’s Association, 2013). Recently, Anoop, Singh, Jacob, & Maji (2010) have proposed that biomarkers found in the cerebrospinal fluid may expedite a more definitive diagnosis of Alzheimer’s disease, potentially even before cognitive decline is noticed; however, there are many obstacles to the clinical implementation of this approach to diagnosis.
Patients diagnosed at age 65 or earlier are classified as having younger onset disease, while those diagnosed older than age 65 are referred to as having late onset disease (Alzheimer’s Association, 2013). The progression of Alzheimer’s is slow yet unrelenting, moving through seven stages from normal functioning to severe cognitive decline, such that the person requires total assistance for nearly all aspects of daily activities (Alzheimer’s Association, 2013). Over the course of the disease, a person with Alzheimer’s will experience changes not only in cognitive functioning, but also in perceptual and motor skills (Abraham, 2005). These changes lead to functional deficits that influence not only the person with Alzheimer’s disease, but everyone around them as well, resulting in changes in roles and relationships among family members (Schaber, 2010).

There is no cure for Alzheimer’s disease. In recent years, there have been drugs approved specifically for the treatment of the symptoms of Alzheimer’s, but evidence that points to a significant improvement in functioning is minimal (Casey, Antimisiaris, & O’Brien, 2010). Instead, the focus of pharmacologic interventions has been on slowing the disease progression. The latest research finding on this front, a large scale clinical trial conducted over five years at 14 Veterans Administration hospitals, found that in patients with mild to moderate disease, vitamin E slowed down functional decline by 6.2 months as compared to a control group (Dysken, Sano, Asthana, Vertrees, Pallaki, Llorente, and Guarino, 2014). Although this is encouraging, disagreement remains in the medical community about when to utilize medicine in the course of treatment (Cummings, 2008). As such, non-pharmacological interventions remain a significant component of the management of Alzheimer’s disease. Interventions for caregiver
education, behavior management, and environmental modifications may all be utilized to help the person with Alzheimer’s disease maintain quality of life in any stage of the disease

Gitlin, Jacobs, and Earland, 2010; Rayner, O’Brien, & Shoenbachler, 2006).

**Issues of Caregiving for Persons with Dementia.** Caregivers have many needs, some of which have only recently begun to be recognized by the professionals who work with persons with dementia. Providing care for a person with dementia is different than providing to care to older persons in general or even to older persons with other chronic progressive diseases. For example, even between caregivers with comparable duration of caregiving, those providing care to a person with dementia spend significantly more weekly hours providing care (Ory, Hoffman, Yee, Tennstedt, & Schulz, 1999). And according to research conducted for the Alzheimer’s Association, they also provide significantly more physical assistance for ADL such as getting in and out of bed, managing incontinence and diapers, and feeding than do caregivers to older adults without dementia (National Alliance for Caregiving and AARP, 2009). In addition, Ory et al. (1999) found that caregivers to those with dementia help significantly more with IADL such as managing finances, preparing meals, and arranging for and supervising outside services and help.

This increased level of care has consequences to the caregivers’ lives as well. For example Ory et al. (1999) found that significantly more caregivers of those with dementia reported having to take less demanding jobs, turn down a promotion, retire early, or even give up work entirely to care for their loved one as compared to those providing care to persons without dementia.
The volume of literature available about caregiving for those with dementia continues to indicate that there are many other consequences to the health and wellbeing of the caregiver. Psychological stress and negative health consequences for caregivers of those with dementia have been well documented (Diemling & Bass, 1986; Pinquart & Sorenson, 2003; Schulz & Martire, 2004). These consequences of caregiving contribute to what is referred to as burden of care, defined by George and Gwyther as “the physical, psychological or emotional, social, and financial problems that can be experienced by family members caring for impaired older adults” (1986, p.253). Several studies have shown that burden of care can be predicted. Razani et al., (2007) found that for persons with mild dementia, caregiver burden can be predicted by the amount of assistance a person with dementia requires for activities of daily living, with assistance levels positively correlated to burden of care. Other studies have revealed that the prevalence of problem behaviors such as agitation and wandering are also predictive of increased burden of care (Aminzadeh, Byszewski, & Dalziel, 2006; Rosnes, Ulstein, & Engdahl, 2009; Savundranayagam, Montgomery, & Kosloski, 2011).

Literature exploring the needs of the caregiver from the perspective of the caregivers themselves is also prevalent. Turner & Street (1999), in a pilot study to assess caregivers’ needs, found that caregivers wanted not only information about dementia, but also specifically how to manage their loved ones’ memory loss and difficult behaviors, as well as how to manage risk. Borrayo, Goldwaser, Vуча-Haase, and Hepburn (2007) lead a qualitative study of the experience of Latino caregivers and found that feelings of being overwhelmed with caregiving responsibilities were common. Borrayo et al. also identified commonly used coping strategies utilized by caregivers such as changing
personal schedules and/or quitting paid employment to accommodate caregiving demands, verbally acquiescing to their loved one in order to avoid an argument, and seeking information about caregiving.

Lach & Chang (2007) employed a focus group design to study caregivers’ perspectives about managing the home safety of their loved one with dementia, identifying that the most frequently mentioned safety concerns were falling and driving. Although caregiver-driven home modifications and “supervision” (encompassing a broad range activities from “checking in on” to “taking over” of activities) were the most frequently cited approaches to managing the concerns, barriers to implementing safe care were also identified. In this study, the most frequently cited barriers by caregivers were lack of knowledge about what to do and when; lack of access to help, and resistance to change by the person with dementia, with caregivers noting that health professionals often would not address the problems they identified (Lach & Chang (2007).

Facilitators for improving home safety included getting information about identified problems and their management, professional advice to make changes, and support of professionals who are responsive to the caregivers’ concerns. Further noting the idea of health professionals as both help and hindrance was a study by Tomita et al. (2010), in which caregivers in the U.S. identified that the second most helpful support behind friends and family were health care professionals, and the second most unhelpful support, again behind family and friends, were health professionals.

Arai, Matsumoto, Ikeda, and Arai, (2007), in a study of Japanese caregivers, found that caregivers to those with early onset dementia perceived more difficulty in caregiving due to behavioral disturbances in their loved one than those who were
caregivers to person with late onset dementia. They theorized that the concerns identified with late onset dementia are often associated with aging in general, and that younger caregivers to those with early onset dementia may be insufficiently prepared to assume the role of caregiver. Yedidia and Tiedmann (2008) used focus groups to ask caregivers to describe their needs for professional help. Some of the identified needs were help communicating with professionals and with the person with dementia (to include managing behaviors).

Neufeld and Kushner (2009) studied male caregivers in Canada to learn their experience of non-supportive interactions in their role of caregiver to someone with dementia. Themes that emerged from this study were that many men experience a lack of orientation to the caregiver role and that they experience insufficient support in that role, and that they wanted access to a guide to assist them through the experience instead of learning as they go. Nichols et al (2009) identified that for caregivers of those with significant dementia, the most pressing concerns identified were a need for information about caregiver depression and coping skills, while caregivers to those with mild dementia identified managing their loved ones confusion and participation in activities such as driving to be most pressing. Robinson, Elder, Emden, Leah, Turner, and Vickers (2009) concluded from focus group discussions with caregivers in Australia that health professionals must listen empathically and provide information about dementia sooner rather than later.

Small, Geldart, and Gutman (2000) studied communication issues between caregiver and care receiver. They found that even in the case of mild dementia, almost half of the caregivers in the study reported that communication issues impaired their
loved ones ability to have a conversation, use the phone, use the bathroom, prepare a
meal, and plan an agenda. Rosa et al. (2010) in an Italian study of the needs of caregivers
of those with dementia found that in the area of education, 83% of the participants
reported a need to develop more effective caregiver to patient communication. A
significant number of participants also wanted more information on non-pharmacological
approaches to the management of cognitive disorders (71%) and behavioral disorders
(81%). Qazi, Spector, and Orrell (2010) found that while focus groups of caregivers
(both formal and informal) identified person-centered-care and engagement in
meaningful activity as important tools to help persons with dementia feel less anxious, in
clinical practice, the need for these approaches is often ignored and/or the anxiety treated
only pharmacologically.

Tottie (2010), who had a career in health and social services with older adults for
over 35 years, wrote from her own perspective in the caregiver role:

Carers [sic] need help to understand the diagnosis and the symptoms; the
treatments so that we can develop confidence in helping the person we care for
live well with dementia. For me, this meant supporting Dad to maintain his daily
and weekly routine of walking, gardening, and dancing, while I increased my
input around the house (p. 27).

Tottie goes on to write that she got no information from the memory clinic to support her
above stated needs, and that it was only after she independently found a specially trained
nurse who helped her develop the skills she needed that she felt she could support her
father at home.
Care transitions are another source of stress for caregivers. Byrne, Orange and Ward-Griffin (2011), in a qualitative study of the experience of taking a spouse home from a geriatric rehabilitation unit in British Columbia, found that caregivers went through a trajectory of experiences in the process of preparing for discharge, discharging, and adjusting to life back at home with their loved one that were far more complex than earlier literature revealed. One aspect of this trajectory is the concept of *reconciling*, a process in which the caregiver must adjust to new way of life with their spouse that is basically nonnegotiable (Byrne, Orange, & Ward-Griffin, 2011). In this study, many caregivers reported that they did not discuss any needs related to being able to care for their spouse while the person was in the rehabilitation unit. However, once their spouse had returned home, caregivers realized they were missing information on how to take care of their spouse, especially if there was a decline in function or an increase in depression in their spouse (Byrne et al, 2011).

There have been many studies of factors contributing to the transition to a nursing home. In a systemic review of 36 studies of predictors of nursing home placement among the elderly in developed countries, Luppa et al. (2010) concluded that findings suggested that predictors of nursing home placement are mainly based on underlying cognitive and/or functional impairment, and associated lack of support and assistance in daily living. In a larger systemic review of 80 studies examining nursing home placement specifically for those with dementia, Gaugler, Yu, Kirchbaum, and Wyman (2009) found that in addition to already established predictors of nursing home placement of severity of cognitive impairment and dependency in ADL, caregiver stress also likely plays a role in the decision to move a person with dementia to a nursing home.
Caregiver stress may result from the development of unmet needs in the person with dementia. Gaugler, Kane, Kane, & Newcomer (2005), in a longitudinal study over 18 months, followed 5,000 dementia patients and their caregivers from 8 different areas of the United States. Caregivers were asked to identify the ADL for which the person they provided care for required assistance, how much assistance they required, and whether or not the person with dementia was getting enough help for the given ADL. Any ADL for which the person with dementia required help yet was not receiving enough help was defined as an unmet need. Their multivariate analysis lead them to conclude that “dementia caregivers who reported more extensive unmet needs for care recipients’ ADL care were more likely to expedite nursing home placement” (p. 2103).

**Summary.** Caregivers of those with dementia have unique needs, and the activities of caregiving impact not only the person with dementia, but the health and wellness of the caregiver as well. Caregivers want more than just information about the clinical features of dementia. They also want specific, individualized information to support their relationships with their loved ones, including practical strategies to improve communication, manage behaviors, and facilitate engagement in day to day activities. The literature also suggests that professionals who interact with the caregivers of people with Alzheimer’s disease or MCI are not always perceived as being helpful in the above endeavors. Finally, transitions to long term care can often be predicted by variables associated with the caregiver such as perception of unmet ADL needs in the person with dementia or stress related to the caregiving role.
**Occupational Therapy Theoretical Frameworks**

There are several theoretical models that support occupational therapy assessment of and intervention for persons with cognitive impairments. Most are framed from a cognitive rehabilitation perspective and are less useful for addressing the needs of those with Alzheimer’s disease or MCI, whose cognitive skills are not going to improve, but worsen over time. In this section, an overview of models pertinent to the population of concern in this study will be examined. Some are specific to cognition, while others reflect a more global view of the dynamic and interactive process of engagement in occupation, which incorporates all aspects of a client including cognitive skills.

**Model of Human Occupation.** The central concepts articulated by the Model of Human Occupation (MOHO) are motivation for occupation, routine patterning of occupational behavior, the nature of skilled performance, and the influence of environment on occupation (Kielhofner, 2008). The interplay of these influences directly shapes engagement in occupation and one’s personal state. A key assumption in MOHO is that personal causation or volition is an integral part of this interplay. MOHO also helps articulate how the influence of a person’s values, interests, and feelings may impact occupational outcomes. As applied to those with Alzheimer’s or MCI, this model supports that the desire of a person to engage in occupations, along with their habits, routines and environments within which they perform, contributes to the ability to self-organize (Kielhofner, 2008). As such, occupational therapists working with persons with Alzheimer’s or MCI and their caregivers may offer interventions that maintain engagement in desired occupations with supportive routines and environments.
Ecological Models.

**Person-Environment-Occupation Model.** Law et al. (1996) described the Person-Environment-Occupation Model (PEO), which proposes that functional abilities in humans reflect a complex interplay between the person, their environment, and the nature of the occupations themselves. As a transactional model, PEO recognizes that “the environment can be a positive or negative influence on occupational performance, enabling or constraining it, and is more readily changed than the person” (Rogers & Holm, 2009, p.483.) The PEO Model defines environment as encompassing cultural, socioeconomic, institutional, physical, and social domains (Law et al., 1996). From this perspective, it is appropriate that those interventions that address the environment (which is inclusive of the caregivers as part of the social environment in which the person functions), should be the focus of occupational therapy for persons with dementia.

Effective caregiver education has the potential to positively impact all aspects of the environment as outlined in the PEO Model. Caregivers make decisions that impact the environment within which their loved ones function, structuring the daily routine, and allocating resources to support their loved ones. In order to facilitate effective decisions, caregivers should be empowered with knowledge and skills to recognize the variables in the environment that they can alter (e.g., tasks, physical space, how they give cues) to support their loved one’s participation in desired occupations.

**Theoretical Framework of Ecology of Human Performance.** Dunn, Brown, and Youngstrom (2003) described the Theoretical Framework of Ecology of Human Performance (EHP), which assumes that it is impossible to understand the person without understanding the contexts in which they function. Further, not only do contexts
influence persons, but persons influence contexts; thus an individual’s performance is the reflection of a dynamic transaction between person and context. Beyond just physical context, EHP also recognizes the social, cultural, and temporal environments that together create a picture of human performance. From this perspective, choices made by the caregiver influence the contexts in which the person with dementia engages. These contextual variables then shape the responses, behaviors, and engagement of the person with dementia. In turn, the responses of the person with dementia influence the contexts in which the caregiver engages in caregiving and other occupations.

If not managed well by the caregiver, this dynamic transaction can lead to difficulties in relationships, poor health outcomes, and activity restrictions for both the caregiver and the person with dementia. This understanding of context as central to facilitating or inhibiting human performance also supports occupational therapy intervention to help caregivers understand how their interactions with their loved one influence participation, and to assist them to structure the environment around their loved one for optimal fit.

**Occupational Adaptation.** Schultz, (2009), described the Occupational Adaptation (OA) theory, which is also a useful framework for considering the occupations of the caregiver of a person with Alzheimer’s disease or MCI. Assumptions of this theory are that occupation is universal and that engagement in occupation, which requires adaptive responses from the individual, facilitates healthy participation in life (Schultz, 2009). Similar to MOHO, OA places an emphasis on the subjective experiences of engagement in occupation as the person adapts to a continuously changing environment. From this theoretical perspective, efficient and effective adaptation will
result in adaptive behaviors, and inefficient or ineffective adaptation will result in maladaptive behavior, the former facilitating health and the latter hindering it (Schultz, 2009).

From the OA perspective, occupational therapy interventions for those with Alzheimer’s disease or MCI can also focus on helping their caregivers adapt to the person’s changing abilities. This can be accomplished by teaching caregivers to adapt tasks, environments, and expectations for task performance, as well as by educating caregivers about the implications of failing to provide needed adaptations as their loved one’s behaviors fluctuate and their cognitive capacity diminishes.

**Occupational Therapy Models to Address Cognition Specifically.** There are several occupational therapy models that focus specifically on cognition. Many are oriented toward remediation of skills (Averbach & Katz, 2011; Polatajko, Mandich, & McEwen, 2011; Giles, 2010; Giles, 2011), which is not applicable for persons with dementia. Two that are applicable to persons with dementia are the Dynamic Interactional Model (Toglia, 2011) and the Cognitive Disabilities Model (Allen, Earhart, & Blue, 1992).

**Dynamic Interactional Model.** This model also is largely oriented toward increasing a person’s ability to generalize learning by viewing cognitive function from a systems perspective (versus from a component skills perspective). It is grounded in an occupation based approach to intervention, and there are some aspects of the model that can guide intervention for persons with dementia. Toglia (2011) recognizes that occupational performance is the dynamic interaction of aspects of the person, the context in which the person functions (physical, cultural), and the nature and familiarity of the
activity. Therefore, from a functional perspective for a person with dementia, one approach to improving occupational performance is to provide interventions aimed at adapting or modifying the activity and modifying the context (to include persons who provide cues and support, and objects used) rather than trying to remediate the cognitive skills of the person (Toglia, 2011).

The Cognitive Disabilities Model. This model emphasizes how information-processing skills influence occupational performance. Originally developed by occupational therapist Claudia Allen for use with persons with schizophrenia and then adapted for those with dementia, Allen brought together concepts from both developmental and information processing models (Bruce & Borg, 2002) to conceptually organize global cognitive processing skills. The Allen Cognitive Levels are on an ordinal scale, determined by evaluating the types of sensory information that can be processed and translated into task oriented behaviors. According to Allen, persons at full cognitive capacity (Level 6) are able to utilize abstract cues (e.g., symbols and ideas) to plan motor actions that result in the completion of complex tasks in an organized manner.

As persons experience cognitive decline, they increasingly rely on more concrete cues such as verbal directions and visual reminders and their motor responses become less efficient during task performance, until ultimately, at Level 1, persons are no longer able to act on any cues or use objects purposefully. Central to this theoretical framework is that understanding how cognition impacts motivation necessitates that therapists recognize the distinction between what a person with Alzheimer’s disease or MCI “will not” do versus “cannot” do (Bruce & Borg, 2002). According to Allen (1985), this fundamental understanding mandates that therapists look beyond what a person with
dementia might “say” to explain their own performance (e.g., “I don’t like to do that”) and further explore cognitive abilities though the lens of “doing,” which involves the processing of sensory and environmental cues to produce motor actions toward task completion.

With the knowledge of what types of cues a person is relying on to attempt completion of tasks, the therapist can predict how a person will perform other task oriented activities (Allen et al, 1992). The ACLS (Allen et al., 2007) was developed to determine at which Allen Level a person might be functioning. Allen further refined the Allen Cognitive Levels to include smaller modes of performance between each level, measured at .2 intervals. The CPT also emerged from the original Allen theory. Scores obtained via the CPT follow the original six-level ordinal scale developed by Allen with half level modes between each level (Burns, Mortimor, & Merchak, 1994), however the scores are now referred to as “CPT scores” instead of Allen Cognitive Levels (Burns, 2007).

**Summary.** The Cognitive Disabilities Model and the Dynamic Interactional Models, along with the theoretical frameworks of the MOHO, the PEO Model, the EHP Model, and the Theory of OA lay the groundwork for occupational therapy interventions that focus on the contexts in which persons with Alzheimer’s disease or MCI function. Contexts include not only physical environments, but also the cultural, personal, social, and temporal aspects of engagement in daily activities (AOTA, 2014). Caregivers, not only as people in the social environment of a person with dementia, but also as the orchestrators of compensatory and/or adaptive strategies to all the contexts in which the
person functions, have the potential to greatly impact the quality of engagement in occupation for people with Alzheimer’s disease or MCI.

**Cognitive Testing to Detect Dementia: Commonly Used Cognitive Assessments**

There are many tools available to help clinicians evaluate cognition and the functional implications of cognitive impairment. Many are screening tools only, while others attempt to assess specific cognitive processes. Most are readily available for use after self-directed training. Some require intensive training and certification in order to use the tool. When choosing a tool, occupational therapists must decide what constructs need to be evaluated and keep in mind other considerations such as the need for special training and/or standardized equipment, contextual requirements (e.g., for use in home versus clinical environments) and utility of the information the tool will yield in terms of supporting occupational therapy interventions (Schaber, 2010).

Because dementia is a syndrome, there is no particular diagnostic test that identifies with certainty a diagnosis of dementia in a living person (Nowrangi, Rao, & Lyketsos, 2011). Instead, physicians examine clinical features present in a person, most notably those related to cognition (Nowrangi et al, 2011). Persons who present with mild cognitive impairment but whose functional skills remain intact are candidates for formal neuropsychological testing which measures memory, attention, executive functions, processing speed, recall, and learning. A neuropsychological cognitive battery can determine if cognitive changes are related to normal aging or a possible dementia (Kelly & Petersen, 2007). Persons who are experiencing impaired functional skills may be subject to any number of the screening or assessment tools described below.
Screening Tools. Professionals who work with older adults often begin clinical assessment of cognition by screening mental status with tools such as the Folstein and Folstein (1975) Mini Mental State Exam (MMSE) and the more recently revised second version (MMSE-2). Both versions of the MMSE are a paper and pencil based assessment that evaluates orientation, registration, attention, calculation, recall, and ability to follow complex commands. It is easy to administer and enjoys wide use. Although it is the only short screening tool officially recommended by the American Academy of Neurology (2008), the original MMSE does not detect mild dementias and does not differentiate severity among more advanced dementias (Nowrangi et al, 2011). However, the MMSE-2 claims improved sensitivity to milder dementia (Folstein & Folstein, 2010). Teng and Chui (1987) created the Modified Mini Mental State (3MS) Examination in order to create a more sensitive measure that includes abstract thinking, delayed recall, and verbal fluency.

The Montreal Cognitive Assessment ([MoCA], Nasreddine et al., 2005) is another paper and pencil based cognitive screen that assesses short-term recall, visuospatial abilities, executive functions, phonemic fluency, verbal abstraction, attention, concentration, working memory, and orientation to time and place. It has been found to have good validity and is more sensitive to mild cognitive impairments than the MMSE (Hochstetler, 2013; Nasreddine et al., 2005).

Several versions of clock drawing tests have also been used to screen for changes in global cognition. Clock drawing tests are easy to administer and very quick to complete (Esther, Hagen, Sandilands, & Smith, 2004). Richardson and Glass (2002)
compared five versions of the clock drawing test and concluded that scores from all were significantly correlated with MMSE scores.

Another screening tool in use is the Mental Alteration Test ([MAT], Salib & McCartney, 2002), a shorter, verbal based, timed assessment where persons are asked to sequentially alternate between numbers and letters. The MAT has been shown to have high sensitivity for detecting impairments in cognition with results comparable to the MMSE, but can be administered more quickly, and to those who may struggle with the MMSE, MoCA, or clock drawing tests due to visual impairments or poor fine motor skills.

**Assessment Tools.** More thorough assessments of cognition include the Dementia Rating Scale -2 ([DRS-2], Mattis, Jurica, & Leitten, 1988). The DRS is a 36-task assessment that measures attention, initiation, construction, conceptualization, and memory. The DRS has shown to be significantly correlated with MMSE and can track cognitive changes over time. Another tool available, the Clinical Dementia Rating Scale ([CDR], Hughes, Berg, Danziger, Coben, & Martin, 1982) uses a semi-structured interview protocol administered to persons with dementia and their caregivers to rate memory, orientation, judgment, community affairs, home and hobbies and personal care. Santillan, Fritsch, and Geldmacher (2003) conducted a validation study of the CDR and concluded that it could reliably predict decline in persons with dementia.

**Task oriented assessments.** Beyond verbal or paper and pencil tasks, assessments of cognition that include evaluation of performance of activities of daily living (ADL) are also available. The Timed Instrumental Activities of Daily Living ([TIADL], Owsely, Sloane, McGwin, & Ball, 2002) uses 5 common tasks (finding a telephone number,
making change, reading the ingredients on a can of food, finding food items on a shelf and reading instructions on a medicine container) to assess a person’s ability to complete IADL in a timely manner. Owsley et al. (2002) found that while TIADL scores did not significantly correlate with memory or reasoning abilities, they were predictive of slower information processing speeds. Wadley, Okonkwo, Crowe, and Rosse-Meadows (2008) used the TIADL to compare those with known mild cognitive impairment (MCI) and a control group, finding that those with MCI performed all but the change-making task significantly slower than the control group, suggesting that decreased speed of performance alone in IADL might be an early indicator of impending dementia. The Direct Assessment of Functional Status for Independent Older Adults, Revised ([DAFS-R], McDougall, Becker, Vaughn, Aycee, & Delville, 2009) is a 55-item performance based test that evaluates communication abilities, financial skills, shopping skills, and medication skills. McDougall et al. (2009) found the DAFS-R to be as reliable and valid as the original DAFS (Lowenstein et al., 1989), yet better able to detect mild cognitive impairment due to the absence of a ceiling effect.

**Occupational Therapy Assessments of Cognition in Persons with Dementia**

There are also assessments created by occupational therapists to evaluate cognition, referred to in the profession as cognitive functional assessments (Schaber, 2010). The Large Allen Cognitive Levels Screening Tool-5 ([LACLS], Allen et al., 2007) is a screening tool that assesses working memory and new learning via a novel task, leather lacing. Persons are asked to either replicate or independently figure out an increasingly complex series of lacing stitches on a leather card. The large version is a
The ACLS has been found to have good reliability and validity. Newman (1987) found the ACLS to have strong test-retest reliability \( (r = .75, p < .0001, n = 22) \) and Howell (1993) found the ACLS to have strong interrater reliability \( (r = .91, p < .0001, n = 20) \). Mayer (1988) found the ACLS to be significantly correlated to the Weschler Adult Intelligence Scale tasks of Block Design and Object Assembly, \( (r = .729, p < .0001) \) and performance IQ \( (r = .55, p < .0003) \), which both measure adaptation and problem solving. Scores on the LACLS have been found to be significantly correlated to the original (Kehrberg, Kuskowski, Mortimer, & Shoberg, 1992). Scores are reported as an *Allen Cognitive Level* from one through six, with level one indicating severe impairment and level six indicating normal cognitive functioning. ACLS/LACLS scores can indicate the need for further evaluation (Allen, Earhardt, & Blue, 2002).

Although the use of leather lacing is appropriate for most people as a measure of new learning in an unfamiliar task, persons asked to attempt the test often resist and/or refuse because of the novelty of the task and its lack of obvious purpose. The ACLS/LACLS is relatively quick and easy to administer once a therapist is competent to do so, but due to potential issues with face validity, therapists must also be skilled in presenting the tool to patients such that they will cooperate and attempt the leather lacing task. Also, as a screening tool, it only indicates the need for further assessment. As such, recommendations to caregivers cannot be based exclusively on the results of the ACLS/LACLS.
The Lowenstein Occupational Therapy Cognitive Assessment–Geriatric (LOTCA-G; Elazar, Itzkovich, & Katz, 1996) was not originally created for use with those with Alzheimer’s disease or MCI but has since been validated for this population. Erez and Katz (2004) Compared MMSE scores and LOTCA-G scores in healthy elderly (n=30) and elderly with known dementia (n=43) and found that the LOTCA-G scores significantly differentiated those with mild dementia and moderate dementia as classified by the MMSE. Interrater reliability on the subtests ranges from .82 to .97 (Katz, Itzkovich, Avrtbuch, & Elazar, 1989). With its use of some simple goal-oriented tasks such as completing a puzzle, this tool fares somewhat better in the area of face validity than the ACLS/LACLS. However, like the ACLS/LACLS, the LOTCA-G also does not include observations of actual performance of occupations. This is problematic because engagement in occupations requires multiple simultaneous cognitive processes that are not captured in isolated test tasks structured to examine only one aspect of cognition at a time (Schaber, 2010). Evaluation of isolated component skills is not enough to allow the evaluator to make inferences about the whole of a person’s occupational performance (AOTA, 2014).

The Kitchen Task Assessment ([KTA], Baum, & Edwards, 1993) is an observation based assessment of initiation, organization, performance of steps, sequencing, judgment and safety and task completion in the context of a simple cooking task. The KTA has been demonstrated to be reliable and valid, and can provide information to caregivers about the level of support those with Alzheimer’s disease need to complete cooking tasks (Baum & Edwards, 1993). Interrater reliability for the total KTA score was found to be .853, and the separate test items (listed above) were highly
correlated to each other with lowest correlation coefficient at $r = .72$, $p < .001$ (Baum & Edwards, 1993). In addition, Baum and Edwards (1993) established construct validity of the KTA by favorable comparison of KTA scores to standard neuropsychological tests such as the Token Test Short Version (DeRenzi, Pieczuro, & Vignolo, 1968), Trail Making Test Part A (Armitage, 1946) and the Crossing Off test (Botwinick, & Storandt, 1973). The KTA provides useful information, but there is no information available to date about the ability of the KTA to predict needs for assistance in non-cooking tasks.

The process scale of the Assessment of Motor and Process Skills ([AMPS], Fischer, 1997) rates how persons select, interact with, and use tools and materials; carry out steps and actions; as well as problem solve when difficulties arise. The AMPS was standardized on an international sample of 148,158 people with and without disabling conditions and has been rigorously validated with many-facet Rasch analysis (Center for Innovative OT Solutions, 2014). It has been found to be useful for assisting the decision making about potential for living independently in the community (Kizony & Katz, 2002), and has been found valid for use with persons with Alzheimer’s Disease (Doble, Fisk, MacPherson, Fisher & Rockwood, 1997). However, a significant limitation of the AMPS is that it requires extensive training and certification, as well as proprietary scoring software.

The Performance Assessment of Self Care Skills ([PASS], Rogers et al., 2008) is another reliable and valid standardized tool that rates performance of ADL and IADL in terms of assistance needed, as well as noting safety and adequacy of the task performance. The PASS has good reliability with the percentage of agreement between raters on subtests ranging from 88% to 97%, and good test retest reliability, with subtest correlations ranging from $r = .2$ to $r = .97$ (Rogers et al, 2008). In addition, the PASS has
been validated in comparison to several other standardized functional assessments such as the Older Americans Resources and Services (OARS) Multidimensional Functional Assessment Questionnaire: Activities of Daily Living (Pfeiffer, 1975); the Comprehensive Assessment and Referral Evaluation (Gurland et al, 1977), and the Functional Assessment Questionnaire (Pfeffer, 1987). The PASS can be done in either a clinical or home setting, and utilizes familiar household objects and activities to complete the assessment. Scores on the PASS relay how much and of what kind of assistance a person requires for specific activities. Like other assessments, the information obtained from the PASS is only applicable to the activities assessed. The therapist is still left with the task of trying to predict how much assistance the person with Alzheimer’s disease or MCI might require in other, non-assessed activities.

**The Cognitive Performance Test**

The CPT is a standardized, performance-based assessment instrument, originally designed for the objective evaluation of global function in Alzheimer’s disease. Like the ACLS/LACLS, it is also based on the Cognitive Disabilities Model (Burns, 2006). The CPT helps the therapist assess the information processing required for 7 separate real life daily tasks that are representative of common ADL and IADL (*DRESS, SHOP, TOAST, PHONE, WASH, MEDBOX*, and *TRAVEL*), providing the clinician with information regarding a person’s ability to comprehend cues and to effectively problem solve while engaged in these tasks. Patients are scored on each task, and then the total score is divided by the number of tasks completed for an average score.

The CPT has been found to have good reliability and validity. An initial study
(N= 77) of the CPT (Burns et al, 1994) using Chronbach’s alpha found good internal consistency ($r = .84, p < .05$), inter rater reliability ($r = .91, p < .05$) and test retest reliability at 4 weeks ($r = .89, p < .05$). CPT scores were also significantly correlated with the MMSE ($r = .67, p < .001$) and the IADL caregiver rating scale ($r = .64, p < .001$) and were moderately correlated with the Physical Self Maintenance Scale ($r = .49, p < .01$).

Longitudinal testing of the CPT over 3 years (N=64) revealed significant decline in mean scores with disease progression. For the 64 patients followed for 1 year, a significant decline in mean CPT scores was found (paired $t = -9.1, p < .0001$). From the end of year 1 to the end of year 2, continued significant decline was noted ($n = 45$, paired $t = -6.8, p < .0001$), and in the group of patients followed for all three years of the study ($n = 26$), another significant decline was noted from year 2 to year 3 (paired $t = -2.8, p < .001$).

Predictive validity of the CPT was assessed by comparing CPT scores to risk of institutionalization during the 4 years of the study as measured by the Kaplan-Meier product-limit survival method (Kaplan & Meier, 1958). Patients in the study were divided into two groups: those with CPT scores above the median score at time of entry to the study (4.2), and those with CPT score that fell below median score at time of entry to the study. Using data about institutionalization and mortality available on all study participants, Burns et al. (1994) found those who scored below the median had a higher risk for institutionalization within the first 3 years of the 4 year study than those who scored above the median. They also found that there was a significant difference in survival between the above median group and the below the median group ($p = .003$, generalized Wilcoxon test). In contrast, comparison of patients similarly divided by
MMSE scores (above and below the mean MMSE score) found no significant difference in institutionalization rates between the two groups ($p = .353$, generalized Wilcoxon test).

Thralow and Reuter (1993) found that the CPT was significantly related to scores on the Self Care Performance Test ($r = .78, p < .05$), an observational tool used by nurses in long term care institutions to document the abilities of patients with dementia to perform self-care tasks. Bares (1998) in a retrospective study of 100 mild to moderately impaired Alzheimer’s patients evaluated in the Minneapolis VA Geriatric Research Education and Clinical Center found that CPT scores were significantly related to scores on several standardized neuropsychiatric assessments (Logic Memory 1 test, $r = .35, p < .001$; the Porteus Maze test, $r = .51, p < .001$; the Digits Forward Test, $r = .40, p < .001$; and the Grooved Pegs Test, $r = -.52, p < .001$. After controlling for comorbidities and other background variables, regression analysis of the variables predicting function as measured by the CPT revealed that measures involving psychomotor skills that require planning, sequencing and attention sub-skills were most significantly predictive of ability to carry out activities of daily living, while measures of memory and language were not (Bares, 1998).

Bar-Yosef, Weinblatt, and Katz (2000) conducted a reliability and validity study of the CPT in Israel. Studying both a control and a research group ($n= 30$ for each), they found good interrater reliability ($r = .98, p < .001$), and high internal consistency determined by alpha coefficient ($\alpha = .95, n=60$). Spearman Rho correlations between scores of individual subtests and the total CPT score demonstrated high correlation coefficients in the research group (range $r = .83$ to $r = .93$) and moderate to high
correlation coefficients in the control group (range $r = .39$ to $r = .84$). For validity testing, Bar-Yosef et al. (2000) compared subtests of the CPT to the Routine Task Inventory (RTI) II, a caregiver observation/interview scale providing descriptions of specific ADL and IADL behaviors associated with each of the six Allen Cognitive Levels. Correlations between the CPT and the RTI scored by therapists were high (control group $r = .91$, $p < .001$, research group $r = .96$, $p < .001$). When compared to caregiver scored RTI, the correlations were moderate (control group $r = .50$, $p < .001$, research group $r = .68$, $p < .001$). Supporting concurrent validity, Bar-Yosef et al. (2000) also found CPT scores to be significantly correlated with MMSE scores (control group $r = .88$, $p < .001$, research group $r = .76$, $p < .001$).

Jennings-Pikey (2001) in a validation study of the CPT ($N = 110$), studied relationships between selected neuropsychometrics (the Wechsler Adult Intelligence Scales, the Wechsler Memory Test, the MMSE, the Boston Naming Test and the Trail Making Test Part A) and the CPT. This study found significant correlations between the total CPT score and the MMSE ($r = .74$, $p < .01$); the Boston Naming Test ($r = .63$, $p < .01$), and the Trail Making Test Part A ($r = -.51$, $p < .01$). Jennings-Pikey also found a moderate correlation between total CPT score and the Global Assessment of Function ($r = .49$, $p < .01$), and found the CPT to be a strong measure of independent living skills, using Cronbach’s alpha ($r = .86$, $p < .05$). Jennings-Pikey concluded that “the validity of the CPT was supported to the extent that the test showed significant correlations with measures known to be sensitive to cognitive functioning in older adults” (2001, p. v) and that “the value of administering
the CPT lies in its ability to answer the question of competency to carry out independent living skills” (2001, p. v).

More recently, Douglas, Letts, Elva and Richardson (2012) evaluated the reliability, discriminant and concurrent validity of the CPT in a clinical study of older adults (N= 47) hospitalized in a geriatric rehabilitation unit. They found the moderate correlation between the CPT and the MMSE ($r= 0.47, p < .01$), the AMPS –Process scale ($r= 0.53, p < .01$), and to the ADL Burden of Care (FIM ($r= 0.32, p < .05$). They also found that age, sex, years of education, motor skills, or other co morbidities did not affect scores, concluding that the CPT is a reliable and valid measure of cognition for the population studied.

Though the literature around the psychometrics of the CPT is limited, what does exist suggests that use of the CPT can help therapists better understand the information processing of persons with Alzheimer’s disease or other dementias by observation and interpretation of performance of familiar daily activities through a common theoretical framework. This theoretical understanding, coupled with the therapists’ ability to analyze the motor and process skills required of a given activity, may assist therapists in predicting which daily activities in which a person with Alzheimer’s disease or MCI would likely struggle or perform in an unsafe manner. What the CPT does not provide is a score that is associated with a concrete list of activities that are able to be safely performed at each scoring level. Instead, it is best used as a measure to track changes in cognitive functional abilities over time and as a tool for therapists to analyze activities within its theoretical framework in order to suggest changes to how such activities might
be structured by caregivers to better accommodate the information processing skills of
the person with Alzheimer’s disease or MCI.

**Relevant Concepts**

In addition to the constructs of dementia, caregiving, and occupational therapy
assessment for persons with Alzheimer’s disease or MCI, there are several other relevant
concepts which must be recognized and incorporated into any occupational therapy
interventions created for caregivers.

**Principles of Adult Learning.** The term *andragogy* (Knowles, 1970) refers to
methods of teaching adults. Adult learners have a need to know not just the “what,” but
also the “why” and “how” of what they are being taught: they are self-directing, they
draw upon their previous experiences to make sense of new information, they are ready
to learn when the information is related to their own lives, they are oriented to learning
for the sake of problem solving, and their motivation is driven by the personal payoff that
will result from their learning (Knowles, Holton, & Swanson, 1998). In addition,
Knowles advocated that in order for adults to learn, a climate of collaboration and trust
must be present.

Jarvis (2004) articulated that adult learners require “practical knowledge,” a
concept he proposes that encompasses not only content and process knowledge, but also:
tacit knowledge; “everyday knowledge” (that which is gained from our senses);
attitudes, beliefs, values and emotions; as well as skills. Kolb (1984) identified a cycle
that operationalizes andragogy, referred to as the experiential learning cycle. Kolb
believes that “learning is the process whereby knowledge is created through the
transformation of experience” (1984, p. 38).
The four parts of the Kolb cycle are 1) concrete experience ("DO"), 2) reflective observation ("OBSERVE"), 3) abstract conceptualization ("THINK"), and 4) active experimentation ("PLAN"). In the first stage, concrete experience, the learner actively experiences an activity. The second stage, reflective observation, is when the learner is asked to reflect on the experience of the activity. The learner then moves on to abstract conceptualization, where they are making hypotheses about what they learned. Finally, in the fourth stage, active experimentation, the learner plans to apply what he or she has learned (Kolb, 1984).

This cycle is especially relevant to the caregivers of those with dementia, who as adult learners in the occupational therapy interventions they might receive, will likely be asked to learn new ways of helping or communicating with their loved one. Understanding on the part of the therapist of the need of adult learners to go thru the experiential learning cycle can ensure that the therapist builds opportunities for the caregiver learner to do, reflect, hypothesize about, and implement new strategies under the direction of the occupational therapist.

**Caregiver Education.** In light of the works of Knowles, Jarvis, and Kolb, caregiver education should reflect an interactive and collaborative approach to learning, centered on the caregiver’s needs and experiences. Professionals who work with persons with Alzheimer’s disease or MCI have attempted to meet the educational needs of their caregivers by offering a variety of interventions. Gallagher –Thompson and Coon (2007) completed an evidence-based review of 350 articles published between 1980 and 2005 that related to education to impact caregivers’ distress. They categorized approaches into
three categories: psychoeducational skill building, psychotherapy-counseling, and multicomponent approaches.

**Psychoeducational Approaches.** Psychoeducational approaches focus mainly on skill training for the caregiver to improve management of behaviors in their loved one with dementia, along with education to address potential issues of depression and anger in the caregiver (Coon & Evans, 2009). Gallagher-Thompsen et al. (2003) compared two groups of caregivers: those in a psychoeducational group, the Coping with Care Giving (CWC) program, and those in a community based support group. The psychoeducational group participated in a 10-week program where they learned skills to better appraise their care recipients behaviors, manage their own moods, and utilize strategies to help them relax in stressful situations, while the support group met weekly with no formal educational agenda. Their results indicated that the CWC group reported significant improvement in their own depressive symptoms and increased use of positive coping strategies when compared to the support group.

Chin and Lee (2011), in a randomized control trial in China, compared caregivers assigned to a comprehensive dementia family care program that included individual case management, weekly home visits, and tailored educational interventions for each caregiver, to those receiving routine care only (defined in this study as regular consultation meetings with the care recipient’s physician; referrals from social workers for community services, monthly lectures about dementia care, and social and recreation activities held at local dementia resource centers). Results from this study indicated that at 18 months post intervention, caregivers in the dementia family care program reported significantly greater improvements in their quality of life and burden of care, as well as
improvements in their loved ones’ symptoms, as compared to those who participated in the routine care activities. Morano and King (2010) conducted a pilot study of a psychoeducational approach to dementia education with African American caregivers and concluded that participant input into all aspects of the program was important in order to deliver an effective program.

**Psychotherapeutic Approaches.** Psychotherapeutic approaches are those that specifically emphasize interventions to reduce caregiver anxiety and depression (Coon & Evans 2009). Ackerman and Ostwald (2004) compared caregivers enrolled in a nine-week program based on cognitive behavioral therapy (CBT) interventions to reduce depression and anxiety to those on a waitlist (who served as a control group) for the program. They found that those in the CBT group demonstrated significantly less anxiety and depressive symptoms than those on the waitlist during the same nine-week period. Banningh, Kessels, Rikkert, Lanting, and Kraaimaat (2008), in a one group pretest posttest design study of CBT for caregivers and care recipients with mild cognitive decline, found that there was no significant improvement in mood or distress levels of either the caregivers or the care recipients. However, they did find that marital satisfaction and awareness of the issues around memory and behavioral problems did improve.

**Multicomponent Approaches.** Multicomponent approaches are those that incorporate two or more conceptually different approaches into a single intervention (Coon & Evans, 2009). Parker, Mills, and Abbey (2008), in a systemic review of literature of 40 articles (34 randomized control trial, three meta-analyses and three systematic reviews) of the effectiveness of interventions to support people with dementia
living in the community, concluded that interventions that were multifaceted and individualized were most effective, further recommending that only providing self-help materials be avoided. Their meta-analyses determined that the psychoeducational interventions demonstrated small but significant improvements in caregiver depression and burden. Although they were unable to use meta-analysis to assess multicomponent interventions due to the heterogeneity of the designs, they did report that 10 of 12 studies included in the review demonstrated significant outcomes in a variety of measures of well-being, depression, burden, and self-efficacy.

Examples of specific studies that fit the multicomponent approach include the Gitlin, Winter, Dennis, Hodgson, Huack (2010) Care of Persons with Dementia in their Environments (COPE) randomized control trial. This study compared caregivers who received up to 12 home visits or phone calls from health professionals who assessed the care recipients’ abilities, made recommendations for, and provided home safety training, task modification, and stress management to those who were randomized into a control group that received three telephone calls and educational materials. Results indicated that at 4 months, the COPE group had significantly better outcomes on a variety of measures of independence and engagement (care recipients), well-being and confidence (caregivers).

In an occupational therapy randomized control trial, Graf et al. (2007) compared a group of community dwelling seniors with dementia and their caregivers who received home occupational therapy to address safety, problem solving, supervision and cuing skills and activity adaptation for persons with dementia to a control group who did not receive occupational therapy services during the intervention period. This study found
that those who received the occupational therapy innervations (both care giver and care recipient) reported significantly better quality of life and health status. Caregivers also report significantly improved mood and sense of control. In another occupational therapy intervention study, Graf et al. (2006) used a qualitative approach to analyze a case study of a patient with dementia who had an informal caregiver living with him. At the end of a 10 week occupational therapy intervention program that focused on education and strategies to improve daily performance of activities and communication, the subject demonstrated improvements in his ability to perform daily activities and initiate activities, while his need for assistance decreased. His caregiver had improvements in the area of sense of competence and mastery of the situation.

The literature emerging about caregiver education seems to suggest that multifaceted, individualized approaches produce better outcomes in terms of the caregiving experience. Well-designed and delivered interventions can improve caregiver self-efficacy and mood, as well as decrease the perceived burden of care. These findings also support the recommendation of Parker, Mills, and Abby (2008) to avoid providing only written materials and recommendations to caregivers.

**Health Literacy and Caregiver Education**

*Health literacy* refers to “the degree to which an individual has the capacity to obtain, communicate, process, and understand basic health information and services to make appropriate health decisions” (U.S. Center for Disease Control, 2010, p. 3). Some have proposed an expanded definition of health literacy to also include the ability to effectively speak, listen, and write; to include having social skills, as well as the ability to use the internet and network with others (Nutbeam, 2008; Bernhardt, Brownfield, &
According to the National Assessment of Adult Literacy ([NAAL], 2003a), there are three types of literacy: prose, document, and quantitative.

Prose literacy refers to the ability to search, comprehend, and use continuous texts, for example, brochures, and instructional materials; document literacy refers to the ability to find and use non-continuous information, such as that found on a bus schedule or drug label. Quantitative literacy is the ability to perform quantitative tasks, (i.e., to identify and perform computations, either alone or sequentially, using numbers embedded in printed materials). Quantitative literacy enables a person to complete tasks such as balancing a checkbook or calculating a dosage of a medicine. All three types of literacy contribute to health literacy.

According to NAAL (2003a), approximately forty three percent of American adults (63 million persons) read at or below the eighth grade level, with thirty million reading at or below the fifth grade level. Educational level does not reliably indicate reading abilities. According to NAAL (2003b), up to fifteen percent of high school graduates read below a basic literacy level (eighth grade), while as many as forty nine percent of those adults with only a partial high school education read below the basic literacy level. In NAAL, health literacy was reported using four performance levels: Below Basic, Basic, Intermediate, and Proficient. The majority of adults (53 percent) had Intermediate health literacy. About 22 percent had Basic and 14 percent had Below Basic health literacy (Kutner, Greenburg, Jin, & Paulsen 2006).

Research shows that low health literacy is contributing to health disparities. As the Committee on Health Literacy of the Institute of Medicine wrote:
Health literacy is of concern to everyone involved in health promotion and protection, disease prevention and early screening, health care maintenance, and policy making. Health literacy skills are needed for dialogue and discussion, reading health information, interpreting charts, making decisions about participating in research studies, using medical tools for personal or family health care—such as a peak flow meter or thermometer—calculating timing or dosage of medicine, or voting on health or environment issues. (Institute of Medicine, 2004, p. 31)

Berkman et al., (2011) completed a systematic literature review of over two hundred studies examining health outcomes, health disparity, and/or health literacy and concluded that low health literacy is strongly connected to health disparities. Further, research also shows that people with low literacy skills are less likely to adhere to health instructions, and have longer hospitalizations, poorer prognoses, and higher morbidity and mortality rates than people who can read well (Chew, Bradley, & Boyko, 2004; Davis & Wolf, 2004; Wallace & Lennon, 2004).

This is of particular concern as research has also shown that more adults older than age sixty five are at risk for having low health literacy than those younger than 65 (White, Chen & Atchison, 2008), with the lowest performing older adults struggling with simple tasks such as following the directions on a medication label with two pieces of information (e.g., take in the evening on an empty stomach). According to the Alzheimer’s Association (2013), the average age of a caregiver to someone aged 65 or older with dementia is 63 years old, and caregiver ages are rising. This is important to keep in mind when caregiver education materials and process are developed for use with
this population. In order to create and deliver effective learning experiences to adults, especially older adults, information must be presented clearly and connected to their own experiences and level of health literacy. In addition, the use of multiple and diverse methods for providing education is necessary to achieve the best level of understanding by caregivers.

**Participatory Action Research**

Questions about how to improve practices and incorporate the voice of the recipients of interventions fit well within a qualitative approach to research. Qualitative approaches focus on understanding a given subject’s or group’s perceptions of experiences and processes in ways that cannot be captured in numbers and discreet variables. Qualitative methodologies are used often in social sciences and marketing in order to further understanding of human behavior (Denzin & Lincoln, 2005).

There are a number of methodologies available to guide qualitative research. Participatory Action Research (PAR) is an example of an approach to qualitative research. PAR is both a methodology and philosophy stemming out of critical social theory (McIntyre, 2008). Its focus is to empower those who are impacted by practices and processes to actively participate in the changing of such to meet their needs. In contrast to more top down research methodologies, PAR is a bottom up approach that starts with issues identified by ground-level groups who wish to seek change. This positions participants involved in PAR to be co-investigators as they go through the PAR process, and as a result, according to Israel, Schultz, Parker, & Becker (1998), researchers who engage in PAR must be “explicitly committed to conducting research
that will benefit the participants either through direct intervention or by using the results to inform action for change” (p. 175).

There is a growing body of literature about the benefits of the use of PAR in health care specifically to change practice. Lindeman et al. (2003) utilized PAR to empower residential care staff (e.g., nursing aides) in a nursing home in Australia to make changes that positively impacted the day to day lives of those in their care. Mitchell, Conlon, Armstrong, and Ryan (2005) found that they were able to use PAR to positively change nursing practices in a hospital in the United Kingdom around the safe physical handling of post stroke patients. Petersson, Springett, and Blomqvist (2009) used PAR to improve the discharge planning process among the medical team in an acute care hospital in Sweden. A 2014 study from Quebec, Canada, by Voyer et al. used a PAR process to work with the staff at a long term care facility in order to successfully implement and evaluate a new delirium prevention program.

There are a few studies emerging in the literature that involve occupational therapy specifically. In the Netherlands, Twilleert, Postema, Geertzen, Hemminga and Lettinga (2009) found that PAR improved rehabilitation practice among occupational and physical therapists providing prosthetic training to elderly amputees. Winpenny, Forsyth, Jones, Matheson, and Colley (2010) used PAR to successfully change to a more client-centered theoretical framework guiding the work of occupational therapists in a comprehensive mental health system in Britain. In 2011, Gauld, Smith & Kendall used a PAR framework to successfully change traditional clinic-based service provision for Australian Aboriginal people with head injuries into a model built on the principles of community based rehabilitation. In another study, Zakrajsek, Schuster, Guenther and
Lorenze (2013) brought together community-based older adult service providers and university researchers to explore older adult care transitions from a hospital stay to home with rehabilitative services. Their collaboration lead to the discovery that ensuring social support, fostering communication, and adjusting to home and planning for getting back into the community were the critical elements that needed to be in place for a successful transition. The above examples from diverse practice settings support that PAR has the potential to lead to changes that support client-centered practice and improved outcomes for the concerns to which the process is applied.

**Summary of the literature**

The increasing prevalence of Alzheimer’s disease and MCI means that the need for occupational therapists to provide caregiver education will remain an important aspect of practice with this population. The literature reveals that more than clinical factual knowledge about the disease process, caregivers want education that is directed toward supporting their ability to communicate with and connect to their loved one. They also want pragmatic help to make managing the functional activities of the person with dementia as least demanding as possible. When caregivers perceive that they are not meeting the needs of their loved one with dementia due to the increased demands of providing assistance, particularly for self-care ADL, the risk of the person they care for being placed in a long term care setting increases.

The occupational therapist can play an integral role in assisting caregivers to adopt approaches and strategies that can positively impact burden of care for caregivers. By finding ways for persons to continue to participate in their meaningful roles and occupations for as long as possible through their disease progression, occupational
therapists can provide a valuable service to both persons with dementia and their caregivers that will help meet caregiver needs for positive interactions and relationships with their loved one with dementia.

The many occupational therapy theoretical models that stress the interactions between person and environment and the resulting impact on occupational performance support therapy interventions that address the caregivers as an integral part of the environment in the life of a person with dementia. Education for caregivers, provided at different times and different places in the care continuum, will be a significant component of the occupational therapy intervention plan. Caregiver education for the purpose of supporting those with Alzheimer’s disease or MCI should begin with the use of reliable and valid assessments that will provide information to the therapist about a person’s abilities and potential concerns as related to their ability to engage in desired occupations.

Principles of adult learning theories should shape education directed at caregivers so that it is relevant to the caregiver, experiential in nature and meets the needs of the caregiver as they support their loved one with Alzheimer’s disease or MCI. The literature suggests that caregivers want pragmatic strategies that are tailored to the unique needs and circumstances of their loved one, and that a one dimensional or one size fits all approach is less effective for meeting caregiver needs than multicomponent, individualized education. Further, issues related to health literacy must be accounted for and addressed when providing caregiver education so that caregivers can effectively understand and utilize the information and strategies suggested by occupational therapists. Finally, the literature points to all of the above should be incorporated into the
occupational therapy process to optimally support caregivers, and is suggestive that a PAR approach might be an effective way to change practice to improve caregiver education about the meaning of CPT scores for this population served by occupational therapists.
Chapter 3: Methodology

Research Design and Methodology

The purpose of PAR carried out in a health care context is to improve practices of professionals for the ultimate goal of improving patient care (Williamson, Bellman, & Webster, 2011). More specifically, Koshy, Koshy, and Waterman (2011) identified that indications for PAR in health care are when “the participants are motivated by a common desire to improve an existing situation, or solve a problem in a local context” (p.74) and when “a group of colleagues feel there is a need for change in the existing level of services or in the quality of what is offered” (p. 74). As this was the situation with the occupational therapists at St. Therese, this study utilized a PAR approach that focused on empowering therapist stakeholders to:

- Improve their practice of providing caregiver education about CPT scores by reflecting on their own experiences.
- Hear the voice of caregiver stakeholders about their experiences of receiving education about CPT results from occupational therapy.
- Make changes incorporating both their own and the caregivers’ desires for change.
- Evaluate the impact of the changes made to the caregiver education experience for both themselves and the caregivers.

Rationale. PAR was selected for this study for several reasons. First, the nature of my relationship to St. Therese Homes (‘St. Therese’), the site where the study took place, is such that PAR is a natural fit. As both a faculty member at an academic
occupational therapy program and a member of St. Therese in the role of occupational therapist, I am a part of the larger department of therapists that have identified caregiver education about the results of cognitive testing with the CPT as an area of needed improvement. Further, as a trained researcher and consultant to the organization, I am looked to for leadership in endeavors involving programming and research.

McIntyre (2008) believes that PAR in an academic partnership such as described above can actually “shift perceptions of the academy as an exclusive place for thinking and theorizing to a site for collaborative experiences with local, national and global communities” (p.8). This is particularly important in the profession of occupational therapy, which historically struggled to generate evidence perceived to be directly relevant to occupational therapy practice when attempting to follow the evidence-based medicine model of research (Dubouloz, Egan, Vallerand, & Von Zweck, 1999).

Currently, recognition of the need for evidence has grown, but many practitioners are still ambivalent about its role in their work. Reagan, Bellin & Boniface (2008) in a qualitative study exploring the meanings attributed to evidence-based practice by occupational therapists discovered that although therapists strongly associated evidence-based practice with research, they found research to be only partially relevant to their interventions with individuals. Even more recently, Swedlove & Etcheverry (2012) found that experienced Canadian therapists preferred to rely more on their practice experience versus looking for and/or participating in the generation of evidence to inform their clinical reasoning.

PAR, which is increasingly recognized in occupational therapy as a method for “contributing knowledge that practitioners can readily use and that consumers will find
relevant to their needs” (Kielhofner, 2008, p. 7), can help the effort to more directly connect research to practice.

Second, although the therapists in the organization had identified an area of needed change, they had no idea how to go about creating it. One of the benefits of using PAR is that it has a defined set of processes, summarized here as look, think, act. 

Looking involves defining the research question and gathering data. Data gathering includes asking all of those involved (e.g., caregivers and therapists) to contribute to the understanding of the identified concern. In the thinking process, data is analyzed and interpreted by the group. Finally, in the act phase, the change is planned, implemented, and evaluated (Stringer & Genat, 2004). This process is cyclical and can be repeated as many times as the group desires. Its inclusivity ensures that the voices of both occupational therapy clients as well as practitioners are reflected in any changes to practice.

PAR in health care contexts is performed by collaborative teams of practitioners, and outside members are often brought in to help facilitate a PAR study. The inclusion of the experiences and views of the end user in health care PAR is a central feature, the extent to which varies depending on the nature of the problem driving the inquiry (Koshy et al., 2011). Further, PAR in health care is flexible enough to allow all participating to contribute according to their expertise (Marshall, & Rossman, 2010). These qualities of PAR fit the needs of the team at St. Therese, which recognized that the therapists would not have time or adequate training to conduct data collection; and that the voice of the end user must be heard as objectively as possible. Consideration of these factors lead to a study design that protected the identity of the caregivers who would be informing the
process, yet allowed them to participate in a manner that encouraged full expression of their experiences and desires for change around the problem addressed. Since I do not treat patients at the site of the study, this was accomplished by my taking on the role of facilitator for and between the two stakeholder groups.

**Specific Procedures.** In PAR, stakeholders are involved in the research process from the beginning (Herr & Anderson, 2005; Stringer, 2007; Taylor, Suarez-Balcazar, Foryth, & Kielhofner, 2006; White, Suchowierska, & Campbell, 2004). All are empowered to help identify the problem, as well as to determine how the data will be collected, analyzed, implemented, and disseminated. The role of a researcher in the context of this study was to be that of a facilitator rather than the leader. Stringer (2007) recommends against hierarchical titles that automatically imply that one stakeholder holds more power over the process than others.

In order to operationalize PAR for the purposes of this study, I proposed that the group use a modified version of Checkland’s (1981) “Soft Systems” theoretical framework to guide the process. Abad-Corpa et al. (2010) described the following steps based on Checkland (1981):

1. Assessment of the situation or practical problem and description of the problem
2. Identification of the systems involved
3. Desirable modeling of the systems involved
4. Comparison of the desirable model and the problematic situation
5. Establishment of a concept of what is desirable and what is possible
6. Implementation of the proposed activities and observations
7. Reflection about the proposed change
Steps 1 and 2 can be thought of as the looking activities; steps 3, 4, and 5 the thinking activities, and 6 and 7 the acting activities associated with PAR. Figure 1 illustrates the data collection and activities of each step.

Figure 1. Summary of activities at each step of Checkland’s Soft Systems Process.

**Checkland’s Soft Systems Process steps 1 and 2: Data collection and analysis.**

Because the therapists at St. Therese had long identified that they wanted to improve how they delivered education about CPT results to caregivers of their patients with dementia, it was natural to begin step one with the therapists. The larger occupational therapy department at St. Therese was convened at a regularly scheduled department meeting. At this meeting, the aim of the study was explained, along with the roles of the participants in the process (the facilitator, the therapists, and the caregivers). St. Therese occupational therapy management then asked the therapists to consider participation and noted that anyone who agreed to participate would have any activities associated with the study
built into their regular work activities. I negotiated this with the occupational therapy management in order to assure that therapists who might be interested in participating did not get deterred by the idea of their participation resulting in extra work. Those who were interested in participating were invited to attend another meeting later in the month, where the consent forms were presented, the study explained again in further detail, and the signed consents of six therapists who agreed to participate were obtained.

Once the group of therapist stakeholders was identified, there was some “pre-study” education that I initiated for the purpose of providing the therapists with a basic understanding of PAR, my role as a facilitator, and aspects of qualitative research that would apply to our study (e.g., analyzing interview transcripts). I felt this was an important step to begin with, because although therapists in a setting like St. Therese are quite accustomed to engaging in teamwork, they are not often engaged in a truly collaborative manner. Thomas, Sexton, & Helmreich, (2003) stated that the two concepts, though often used interchangeably, differ in that collaboration requires shared power and the reaching of a consensus, while teamwork does not.

Historically, when change occurred in the occupational therapy department at St. Therese, it was usually a reflection of a process that was more team focused versus collaborative. This was quite evident in my early conversations in the organization, when I would inquire about the history of a particular process or change, and often hear responses such as “so-and-so asked us to create it that way” or “we gave our ideas and then so-and-so decided how to proceed” (personal communications, 2012). Therapists were accustomed to being asked for their input on a proposed change, and were often delegated tasks associated with creating the change, but ultimately a decision of what the
change would look like and how it would impact day to day practice was determined by occupational therapy management.

Knowing the differences between teamwork and collaboration, along with my sense of the culture of St. Therese, I realized that I needed to be very explicit in preparing the therapists to function in a manner that might be out of their comfort zone. Thus, even though I had been using and defining the terms *participatory* and *facilitate* in every discussion about the project, I felt that it was imperative that I be very explicit with the therapists when describing what that might look like in my role. It was at this early pre-study meeting, and often again in the early stages of our work together, when I told them that I had no idea what the outcome of our work together would be in terms of a concrete product or process. “I don’t know” and “what does everyone think?” were my mantras in the early phases of the study.

The first official work of Checkland’s Soft Systems Process Step 1 began with a focus group of the six therapist stakeholders where the problem of how to improve caregiver education about CPT scores was explored. The discussion started with an open ended question of “what are your thoughts about how you work with caregivers to explain CPT scores?” From this, a conversation about the therapists’ thoughts, feelings, and perceptions of their current process and practices emerged. Just prior to this meeting, I engaged myself in a process of bracketing my own ideas and assumptions about what the therapists might say. *Bracketing* is a concept taken from phenomenology, and as I was interested in the lived experience of the therapists, it seemed appropriate. Bracketing is very important step to help researchers set aside preconceived ideas that might color perceptions about the meaning of what is being learned (Carpenter, 2007).
At this first 1.5-hour work session, I did not participate in the discussion, other than asking clarifying questions. Since this topic naturally lent itself to discussing the current systems that shaped current practices, I decided to let the initial work of Step 2 (identifying systems involved) also evolve from the conversation (to be revisited later). The entire discussion was recorded, and I took notes as the facilitator. I accomplished member checking via email, sending the notes out to the therapists for their review and corrections/ clarifications they identified.

From the recording and notes, I identified some possible themes about the current state of caregiver education about CPT scores at St. Therese and brought them back to the therapists for further discussion at the next working meeting. It was during that working meeting when the group came to consensus on what they identified as the current state of their practice in the area of caregiver education about CPT results, and what systems were in place that shaped their practice.

The next step at this meeting was a bracketing exercise lead by me to help the therapists identify their assumptions about what caregivers might think about the whole experience of learning about CPT scores from occupational therapy. I believed that this would be a critical step to complete prior to identifying what type of information the therapists might want to know from caregivers, and to avoid taking the therapists down a path of developing leading questions. I recall being a bit shocked during this bracketing exercise, as the therapists had some strong opinions and perceptions about caregiver motives behind their responses to information presented by occupational therapy. In fact, I had to later step back and reflect on my initial reactions to the therapists’ preconceived
ideas and assumptions in order to try to manage my potential bias about their ability to continue to reflexively engage in this collaborative research.

Once the group had completed the bracketing exercise and we discussed setting aside assumptions, we began brainstorming what type of information from caregivers might provide useful feedback to the group. The product of this session was the identification of caregiver demographic data to be collected, as well as a template to guide the interviews with caregivers.

The next phase of data collection for Step 1 of Checkland’s Soft Systems process, as adapted by Abad-Corpa et al. (2010), “assessment of the situation or practical problem and description of the problem,” was to learn about the experience of being a caregiver on the receiving end of the education about CPT scores from occupational therapy at St. Therese. Beginning in September 2012, caregivers were recruited for participation in the study. Originally, I had hoped to conduct larger focus groups and a few individual interviews; however, during the recruitment effort, only one caregiver agreed to come to a focus group. As there was no benefit for the caregivers to participate in a manner they did not wish to, it made sense that the only alternative was to go to the places the caregivers who wanted to participate would agree to meet. As a result, I conducted 12 individual interviews between October 2012 and March 2013 in individual homes and coffee shops as directed by the caregivers. The decision to conduct 12 interviews was based on Guest, Bunce, Johnson (2006), who found that 12 interviews are enough to reach saturation for less complex qualitative studies, and that meta-themes are often present after just 6 interviews.
All interviews were recorded on a computer using the Audacity recording program. Each audio file was then converted to a .aup file for use in Transana transcription software. Each recording was transcribed by me. Sections of the transcripts with details that could potentially be used to identify a patient were redacted. All transcripts were saved as Microsoft Word documents. In order to utilize a member check approach to ensure accuracy, each transcript was printed and mailed to the caregiver for review, along with a stamped and addressed return envelope.

At the conclusion of each interview, caregivers had been instructed that they would receive in the mail a copy of the transcript, de-identified and redacted as I saw necessary. They were instructed to make any changes they wished directly on the transcript itself, or to call me to discuss the changes, and then to return the transcript whether or not they wanted any changes. Written directions were included with the mailed copies as well. Caregivers were also asked at the end of the interview if they would be available to give feedback on any new process or practice the therapists might create in the future. Those who agreed to further participate in this manner had a notation made on their demographic questionnaire for easy reference later when their feedback would be solicited.

After all the interviews were transcribed, de-identified, and validated by each caregiver as described above, they were compiled into individual notebooks. This approach was chosen because the therapists did not have access to computers with any type of software for data management or analysis, such as NVivo. Software of this type is costly and most therapy clinics do not have any reason to invest in the expense when they are not regularly engaged in research activities.
In preparation for manual coding in the transcript notebooks, therapists were provided an overview of the data analysis process and the concept of coding as defined by Miles, Huberman, & Saldana (2014), who describes it as the identification of a “word or short phrase that symbolically assigns a summative, salient, essence capturing and/or evocative attribute for a portion of language-based data” (p.72). A short practice coding activity was conducted to ensure that all understood the concept prior to beginning their own coding. Finally, the therapists were lead through another bracketing type exercise to enhance their ability to objectively read the transcripts. Coding occurred in two distinct phases: First Cycle coding and Second Cycle coding. Miles, Huberman & Saldana (2014) describes First Cycle coding as the initial assignment of codes to chunks of qualitative data, with Second Cycle codes “resulting from the First Cycle codes themselves” (p. 73).

For the First Cycle coding, an In Vivo approach was employed. In Vivo coding means that words or phrases are identified verbatim from the words of the persons who generated the data. According to Miles, Huberman & Saldana (2014), this approach is a good fit for action research and very appropriate “for studies that prioritize and honor the participant’s voice” (p. 74). As Miles, Huberman & Saldana state that having multiple independent coders is one type of data triangulation technique that can be used to strengthen the validity of qualitative studies, the therapists were instructed to perform this first step of First Cycle coding individually. Each therapist was given highlighter pens and instructed to highlight on the actual transcripts the words, phrases or passages that they felt were conveying information about the experience of the caregivers. I also manually performed this first step of the First Cycle coding on the transcripts in the same
manner as the therapists. Therapists were given two weeks to complete this step, after
which a meeting was convened to bring their initial First Cycle coded transcripts together
for a large group analysis.

Because I did have access to NVivo 9 and wanted to use it to capture the final
outcome of our group First Cycle coding session, I uploaded all the uncoded transcripts
into the NVivo 9 program on a laptop computer in preparation for this meeting. When
the group convened, I again engaged the therapists in another bracketing exercise to help
the therapists adopt a reflexive mindset and set aside assumptions or conclusions they
may have inadvertently drawn based on their own First Cycle coding of the transcripts.
After the bracketing activity, the group together reviewed each individual page of all of
the individually coded transcripts.

Starting on line 1 of page 1 of transcript 1, each therapist in turn verbally
indicated what if any words or passages (what Miles, Huberman & Saldana (2014) refer
to as a ‘codable block of data’ ) they had coded with their highlighter pen. I reported my
codes last for each line. After we had each shared our selected words or passages for the
given line, we noted how many therapists had selected each word or passage. Since there
were a total of 7 raters including myself, the group decided that any words, phrases, or
passages that had been identified by less than 4 therapists should be discussed until
consensus was reached as to what words or passages to include so that sufficient
inter-coder agreement could be assured.

Most of the differences noted between the initial First Cycle blocks of data
identified by each therapist coder were related to how much of a passage to include in the
block versus identification of disparate words or blocks of data. Once inter-coder
agreement had been reached by consensus, I entered the selected initial First Cycle blocks of data on an electronic copy of each transcript in NVivo 9. At the end of the transcript, we went back to the beginning and reviewed the highlighted blocks of codable data to distill them to one, two or three words verbatim that we believed captured the essence of the passage and created In Vivo codes. Again, I noted the final In Vivo codes on the electronic copies of the transcripts in NVivo 9. A paper copy of the final In Vivo codes from each transcript was also created for the therapists’ later review, as they did not have access to NVivo 9. This process was repeated for all 12 transcripts. Along the way, one therapist functioning as a memo writer documented our collective analytic memos on notebook paper about several of the First Cycle In Vivo codes to capture our thinking at this stage of the analysis.

The next work session occurred one week later when we began Second Cycle coding together as a group, using *Pattern coding*. Miles, Huberman & Saldana (2014) describe Pattern coding as an approach that helps pull together separate units of information into more meaningful units of analysis. We began this cycle of coding by reviewing the work from the previous meeting, reviewing our analytic memos and confirming the First Cycle In Vivo codes through group discussion and consensus. After this review, we identified similarities and differences between all of the First Cycle In Vivo codes, and again through discussion and consensus, began to the process of sorting similar First Cycle In Vivo codes together. After we had combined similar First Cycle In Vivo codes, we chose a descriptive word or phrase that seemed to best capture the meaning of the codes represented in each new combination. The end result of this was a smaller number of new Second Cycle Pattern codes that distilled the feedback from
caregivers into several distinct themes that the group felt needed to be addressed in any proposed changes to the caregiver education process.

The demographic data from each caregiver was also compiled and analyzed at this meeting. As there was no identifying personal data was on the demographic surveys, each therapist was provided with copies of surveys completed by the 12 caregivers. I manually entered all of the demographic data from the paper surveys into a Microsoft Word document on my laptop and emailed the compiled results to the therapists for their review.

Finally, at the end of this meeting, the earlier identification of systems involved (Checkland’s Soft Systems Step 2) was revisited in preparation for the work of the next step. Reviewing our notes from the first working meeting, we reflected on our earlier thoughts about the systems in place that were contributing to the current practices for providing caregiver education about CPT scores, and through group discussion and consensus, refined our thoughts about the systems involved.

**Checkland’s Soft Systems Process steps 3 and 4: Data collection and analysis.**

Step 3, desirable modeling of the systems involved, and Step 4, comparison of the desirable model and the problematic situation, occurred next. At this meeting therapists were asked to consider their own experiences delivering education about CPT scores to caregivers, along with the themes that had been previously identified from the caregivers, to brainstorm and think big about envisioning a new process for caregiver education about CPT scores. I facilitated this discussion and took notes on large sheets of paper as the therapists spoke, hanging the sheets around the room so they could be seen at all times.
After a substantial number of ideas had been offered, each therapist walked around the room to each large sheet of notes and silently wrote on each sheet their new ideas, modifications to the ideas, questions about the ideas already expressed, and/or concerns about any of the ideas listed. This approach, a modification of the brain writing technique (Rohrbach, 1969) used to generate ideas, was chosen because it encourages more uniform participation from a group, gives voice to persons who may be less inclined to express ideas verbally, and has been shown to produce more high quality ideas in less time (Linsey & Blecker, 2011). After this exercise, we reconvened as a large group to review the therapist’s ideas from each large sheet and, through group discussion, came to consensus on which would be a part of ‘ideal world’ practice of delivering caregiver education about CPT results. After a break, the work of Step 4, comparing the ideal to current practice, began. As a large group, gaps between ideal practice and current practice were identified and discussed. This was a fruitful conversation to help move the group to the work of Step 5.

Checkland’s Soft Systems Process step 5: Data collection and analysis. Step 5 was where the reconciliation between the ideal and the possible was achieved. To help accomplish this objective, an occupational therapy manager who was not a part of the therapist stakeholder group was asked to attend. The manager, who was aware of the research project and problem being addressed, was there to discuss the feasibility of some of the ideas for ideal practice the therapists had identified. Her input helped the group understand the reasoning behind some internal processes, including which processes were open for change and which processes were non-negotiable. The end product of this meeting was a defined plan to revise both the process for communicating with caregivers
and the materials used to educate caregivers about the meaning of CPT scores. The goal was to integrate as many of the elements of “ideal practice” as possible that were also feasible within the constraints of St. Therese.

The process of creating and revising materials then took place over a one-month period. The therapist group revised written materials by assessing the readability levels of their current materials using a website that analyzed text using multiple tools (www.readabilityformulas.com), and then revising the materials to get the reading level as low as possible given the content. In addition, changes to formatting and layout were also made to improve the usability of the written materials. They also created a new online presentation for caregivers about the role of occupational therapy at St. Therese, which focused on why occupational therapists assess patients’ cognition and how they do so using the CPT. Finally, a standard process work flow outline for therapists detailing a new timeline for key communications with caregivers as well as the required components for interactions with caregivers was developed. The development and refinement of these various elements occurred in an iterative process, with therapist stakeholders taking the initiative to draft work, and then bring it to the larger group for review and revisions. Once agreement was reached, the group worked to package the process and materials in a way that allowed the caregivers to review and provide feedback and suggestions for change.

I called the caregivers who had agreed to provide feedback to confirm their continued interest in the project. I then mailed those who agreed a packet including step-by-step instructions for examining the materials as well as some specific and open ended questions for each aspect of the materials and proposed work flow process to elicit
their feedback. Caregivers were told that they could also make notes or comments anywhere on any of the materials as they reviewed them. Caregivers were provided with my phone and email contact information in case they had any questions as they reviewed the packet. Once their review was complete, caregivers were instructed to mail back their feedback along with the materials in a postage paid envelope provided for them. After the caregiver feedback was received, the therapists reconvened to review the comments and suggestions and make final adjustments to the new materials and proposed process.

*Checkland’s Soft Systems Process step 6: Data collection and analysis.*

Implementation of the proposed activities and observations (Step 6) occurred next with two of the six therapist stakeholders using the new process and materials, beginning in July 2013. The decision to only have two therapists rolling out the new process was determined by St. Therese occupational therapy management. I lobbied hard to have the entire group use the new process, but the occupational therapy management felt that it was important to not ask all of the therapists to change their practice until the project was complete and data about the impact of the new process and materials was obtained. The two therapists selected were both full time employees who used the CPT frequently and had the most opportunities to provide caregiver education. They were each asked to keep logs of patients who met the inclusion criteria and whose caregivers had been offered the new education materials and process. This list provided the pool from which the second round of caregivers were recruited to give feedback.

Interviews with the second group of caregivers who had received the new CPT caregiver education process began in August 2013 and concluded in October 2013. A total of eight caregivers were interviewed. Recruitment for potential caregiver
participants continued through February 2014 with no success. The slow recruitment of caregivers was the result of limiting the number of therapists implementing the new materials and process and the subsequent 1-month long medical leave of one of those therapists. I also believe that the record-breaking severe weather in Minnesota that started in November 2013 and lasted until April 2014 also may have negatively impacted recruitment of caregiver participants. Finally, because St. Therese occupational therapy management wished to expedite the conclusion of this study, they requested that the recruitment of caregivers end in February 2014.

Appreciating that Guest et al. (2006) found that even six interviews could yield some valuable information, the decision to stop with eight was made. Using the identical process as described above for the first round of caregiver interviews, the interviews were recorded, transcribed, validated, and analyzed by the therapists and me in preparation for the next step.

Checkland’s Soft Systems Process step 7: Data collection and analysis.

Reflection about the proposed change was the final step in the process. This step began with an interview of the two therapists who had delivered the new caregiver education process and materials. This interview was recorded, transcribed, and validated with a member check in the same manner detailed for caregiver interviews, though with no redacted information, because the two therapists agreed that they had no reason to keep their name separate from their feedback. Next, the six therapist stakeholders were reconvened in April 2014 to compare the data obtained from the second round of caregiver interviews to the data obtained from the first round of caregiver interviews, to reflect on the experience of the two therapists who implemented the new process and
materials, and to discuss the wider implications of the changes to the entire department. The final result from this meeting was a recommendation from the therapist group to St. Therese occupational therapy management for implementation of a new process and materials to be adopted by all therapists who provide caregiver education about CPT scores to caregivers.

**Strengths and Weaknesses of the Design.** The PAR process is client-centered and collaborative, a value that the occupational therapy profession upholds. As applied in the context of this study, PAR allowed the stakeholders to address a real world clinical practice problem in occupational therapy. More importantly, the outcomes of this PAR study made a positive change in the practice of occupational therapy at St. Therese. A potential weakness of PAR in any context is that it can get off track and lose focus if proceedings are not meticulously recorded and managed (McIntyre, 2008). In the context of health care settings, PAR is not well suited as a mechanism to mandate (versus create) change, nor is it effective when an organization has competing priorities resulting in lack of time and attention to the process (Koshy et al., 2011). However, when applied rigorously, in the right conditions and for the right motives, PAR is well suited as a methodology to create meaningful change in an organization.

**Threats and How They Were Addressed.** There are some agreed-upon principles for qualitative research that enhance the trustworthiness of the data. Trochim & Donnelly (2007) identify that threats to qualitative research can come from the study design and/or the participants. The use of the seven steps described above helped keep the process focused and minimized design threats. A necessary part of this process was to ensure that each of the steps was defined and operationalized so that all participants
had a shared understanding of definitions, terms, and constructs that were addressed in the study.

Potential threats arising from the participants were addressed by identifying inclusion and exclusion criteria that were explicit and reflected accurately the representation of persons and groups impacted by the problem driving the study. During data analysis, member checking was employed to ensure accuracy of the verbally obtained data, and a triangulation technique to analyze transcripts was used to ensure that multiple sets of eyes analyzed the data from caregivers before the larger group came to consensus on any possible meaning of the First Cycle In Vivo codes and the Second Cycle Pattern codes that emerged from the transcripts. Finally, each step of the Soft Systems process was informed by multiple data sources such as demographic information from questionnaires, notes from meetings of the therapists, and interview transcripts from both caregivers and therapists.

**Subjects (Participants)**

**Number.** There really are no subjects per se in PAR. As Winpenny et al. (2010) point out, “PAR is conducted with people as opposed to on people” (p. 508). Participants in this study were six staff occupational therapists and me, along with 20 caregivers of St. Therese patients with dementia or MCI who had been evaluated with the CPT during a transitional care unit stay at St. Therese during the past year.

The decision to involve six therapists reflected the willingness and availability of those therapists to participate. The decision to conduct 12 caregiver interviews in step 1 was made based on the findings of Guest et al (2006), who found that for less complex qualitative questions, data saturation was regularly found by the twelfth interview, and
that even in as few as six interviews, basic themes can be detected. The decision to conduct eight caregiver interviews in step 6 was one of pragmatics; with a significantly smaller pool of caregivers to recruit from for this set of interviews and desires of St. Therese occupational therapy management to conclude the study, the team decided that enough evaluation data from the caregiver perspective had been obtained to meet the needs of steps 6 and 7 of the process.

**Inclusion criteria.**

_Therapists._ Therapist participants were required to be registered occupational therapists who were regular employees of St. Therese Homes and who had met clinical competency requirements as assessed by the St. Therese occupational therapy clinical content evaluator to administer the Cognitive Performance Test. Therapist participants also had to be regularly administering the CPT and providing education about the test results to caregivers.

_Caregivers._ Caregivers for purposes of this study were those people who were identified from admission paperwork as the main contact for patients who were admitted to the St. Therese Transitional Care Unit. In compliance with the Health Insurance Portability and Accountability Act (HIPAA) requirements, the usual practice at admission to St. Therese is to ask the patient to identify the person(s) with whom the patient has given permission for the facility to share information. When recruitment for the study began, only patients who had identified a contact person for this purpose were considered.

In order to participate in this study, the caregiver must have either lived with the patient, or provided significant and frequent assistance, either in person or via other
methods such as ongoing coordination and management of other caregivers who provide assistance for ADL or IADL. The determination by the therapists to specify “significant and frequent assistance” reflected their desire to hear from the caregivers most closely involved with the day-to-day lives of their persons with cognitive issues, and for whom any education about cognition was likely to be helpful.

The person for whom the caregiver was providing assistance was required to have either a diagnosis or suspected diagnosis of MCI, dementia, or Alzheimer’s disease (per the physician), as the question of interest in this study pertained to caregivers for this population. Additionally, the person for whom the caregiver had cared must have been evaluated by an occupational therapist at St. Therese and completed a CPT assessment while in the TCU at St. Therese. The TCU stay with CPT testing must have been completed in a year prior to the start of the study, and the patient must have received a score of 5.0 or lower in order for their caregiver to be included.

The decision to identify the 5.0 CPT score as a cut off for inclusion was made because the test scoring guidelines indicate that patients scoring higher than 5.0 can often independently compensate for mild deficits in cognitive processing and generally require much less assistance from caregivers to manage their participation in ADL. Finally, caregivers were required to read and speak English and possess sufficient ability to describe how they provided assistance to the person for whom they provided care and verbalize understanding of the purpose of the study.

Determination of meeting the inclusion criteria was evaluated by answers to short questions asked by me as the team member making the calls to those who had responded to the recruitment letter. During the call, I inquired about the caregiver’s recall of their
loved one’s TCU stay at St. Therese, the types of assistance they were providing to the person, and their preliminary understanding of the purpose of the study as presented in the recruitment letter.

**Exclusion Criteria.** Therapists who were temporary contract employees were excluded from participation as their work schedules and tasks varied significantly from day to day, and their availability to participate could not be guaranteed. Certified occupational therapy assistants employed at St. Therese were also excluded regardless of their employment status as they do not administer the CPT nor provide the caregiver education. Caregivers who are not fluent in English were excluded, because the therapist participants were fluent only in English and therefore were not able to communicate in other languages. Further, the demographic characteristics of those served by St. Therese TCU reflected an overwhelmingly predominantly English-speaking population being served. Finally, the decision to exclude caregivers of patients who were at St. Therese TCU further out than one year prior to the current phase of the study was made to ensure quality of the data, as asking caregivers to accurately recall their experiences further out than a year seemed unrealistic.

**Characteristics.** Therapist participants were primarily bachelors prepared practitioners, with a range of experience from 2 years to more than 21 years in the field. On average, this group of therapists each administered about 4 CPTs in a typical week. See Appendix A for more demographic information of therapist participants.

Caregivers participated in one of two groups. The first group of 12 caregivers ranged in age from 54-90 years old, were primarily college educated, and had been functioning in a caregiver role for as little as one to three years to as many as 15 or more
years. The second group of eight caregivers ranged in age from 50-87 years old, were also primarily college educated, and had also been functioning in a caregiver role for as little as one to three years to as many as 15 or more years.

**Recruitment Procedure.** In PAR, the main stakeholder participants are not recruited per se, as the desire to study a problem and make change emerges from within the group that wishes to address the identified problem. In this study, therapists who had expressed interest in working to address caregiver education for the CPT were offered the opportunity to partner with me as a part of my dissertation study. With permission of the occupational therapy department management at St. Therese, PAR was presented as a methodology to study the problem identified at a routine occupational therapy department meeting. At a subsequent meeting, therapists who were interested in participating were given more information about the study, their potential role in the study, and their informed consent to participate was obtained (Appendix B).

Recruitment of caregiver participants occurred in two time frames. In the first, (step 1 of the process outlined), I was provided by St. Therese occupational therapy management a spreadsheet, dating back 12 months, of the names of patients with diagnosed or suspected cognitive issues as described above, and their CPT scores and their discharge date. From this list, I narrowed the pool down to those with a CPT score of 5.0 or lower.

From that pool, I went to the contact information page of the patients’ St. Therese TCU medical records to obtain contact information of the person identified as the primary caregiver. These persons were mailed a recruitment letter (Appendix C) along with a stamped return postcard enclosed to return if they were interested in learning more
about the study. Each post card was marked with a unique identifier code so that potential caregiver participants did not have to share any personal information on the post card. I cross referenced the code on the post cards that were returned to me with the list of persons to whom a recruitment letter had been sent so that I could determine who had responded to the recruitment letter. I then contacted potential caregiver participants via phone to discuss their interest in participating in the study, answer their questions, and to determine if they met the inclusion criteria.

If they expressed interest, could recall their loved one’s TCU stay, indicated that they were providing or managing enough caregiving activities to meaningfully participate in the study, and indicated a basic understanding of the study, the caregiver was invited to attend either a focus group and/or an individual interview. At the first meeting between each potential caregiver participant and me, the study was explained again and their informed consent obtained (Appendix D). Because only one caregiver participant expressed interest in attending a focus group, all meetings with caregiver participants took place as individual interviews. The location of each interview was negotiated with each caregiver. Half of the interviews took place in the caregiver’s own home, with the other half occurring in public venues such as coffee shops.

Recruitment of the second group of caregiver participants took place in a similar manner. A list of potential caregivers for this phase of the study, (step 6 of the process), was provided by the two therapists who provided the new caregiver education process (created in step 5). Both therapists maintained a list of those caregivers with whom they had interacted and who met the inclusion criteria described above. With names from this list, the same recruitment process described above was followed. Because the first group
of caregivers was individually interviewed, it was decided by the therapists that the second group of caregivers should be individually interviewed as well.

**Ethical Considerations**

This study was approved by St. Therese Homes on June 20, 2012 (Appendix E); the Institutional Review Board of Nova Southeastern University on July 12, 2012, approval number 07071203exp, with continuing approval granted on June 12, 2013 and again on June 12, 2014 (Appendix F). It was also approved by the University of Minnesota Internal Review Board on June 7, 2012, approval number 1205P14403, with continuing approval granted on May 13, 2013 and again on April 16, 2014 (Appendix G).

I conducted the recruitment for the study so as to leave the identity of the caregiver participants unknown to the therapist participants, a condition of the study requested by the management of St. Therese Homes. This approach ensured that both groups of participants could freely engage in their participation without fear of negative consequences based on any feedback they might have provided.

The confidentiality of all data gathered from caregiver participant interviews was maintained in several ways. The transcripts were de-identified prior to being provided to the therapists for analysis. Then, because occupational therapists often get to know significant personal information about their clients through the nature of the issues addressed by occupational therapy, all remarks made by caregivers that could be potentially identifying were removed from the transcripts, such as references to unusual characteristics, situations, and/or locations. Only I had access to the names of the caregiver participants. All electronic data files containing caregiver information (including recruitment lists, recordings of interviews, and transcripts of interviews) are
stored on an encrypted and password protected secure server at the University of Minnesota, accessible only by me. All paper copies of signed consent forms are maintained in a locked file cabinet, located in a locked office in a secured area of the University of Minnesota. I maintain all of this private information and will delete it three years from the conclusion of the study.

During the informed consent process, I explained the benefits and risks of participation to all potential participants. A benefit to those participating in the caregiver role was the opportunity to provide direct feedback about their experience receiving education about the meaning of their loved one’s CPT score from an occupational therapist at St. Therese. Benefits to the therapist participants were that they had an opportunity to provide feedback about and help shape changes to the processes they utilize as a part of their regular work duties.

Potential risks of participation in this study for the caregivers included the potential for feelings of frustration (e.g., wanting to provide feedback about services at St. Therese that were beyond the scope of this study), as well as the possibility of experiencing negative emotions associated with discussing the cognitive and functional status of their loved ones. I was knowledgeable of additional resources at St. Therese to direct participants with these needs to the appropriate assistance as needed.

Due to the nature of PAR and the role of the therapists in this study as co-collaborators, potential risk to therapist participants in this study was deemed to be minimal. Therapists were made aware that feedback in the transcripts from caregivers in the first set of interviews, even though actively sought out by the therapists, might be uncomfortable for therapists to learn. This concern was addressed by reiterating to the
therapists the value of PAR as a methodology to make changes to solve problems identified by themselves as well as the caregivers.

**Funding**

No external funding was obtained for this study.

**Setting**

This study took place in the Transitional Care Unit at St. Therese Homes Inc. in New Hope, MN. St. Therese is a not-for-profit senior living community that offers a full range of services to seniors including a Medicare-certified 36-bed transitional care rehabilitation unit that provides occupational, physical, and speech therapy.

**Instruments and Measures**

**Data type.** The data generated by this study was primarily qualitative in nature, obtained verbally through focus groups and interviews. A minimal amount of descriptive quantitative data was also obtained through checklists (e.g., demographic information of participants).

**Reliability and Validity.** Several steps were taken to ensure trustworthy data. As qualitative research is based on analysis of individuals’ subjective experiences, it is imperative that all stakeholders participating be credible (Stringer, 2007). In the context of this study, this meant that caregiver participants met inclusion criteria and desired to participate, were experienced in using the CPT and providing caregiver education based on its results, and had a desire to improve their approach to caregiver education at St. Therese. In addition, the therapist participants created the initial interview questions used to guide the caregiver interviews.
Interview data obtained from the caregiver participants was member-checked for accuracy by sending each caregiver a copy of their transcribed interview for their review and approval. After the caregiver transcripts were member-checked, they were de-identified and provided to the therapists for their analysis. Notes from the meetings of the therapists were compiled by me after each meeting and were provided via email for review and approval by the therapists prior to the next meeting. Any changes or clarifications identified by the therapists were added at those times.

**Equipment.** The Audacity Audio Computer Recording program was used to record interviews and proceedings of some group meetings. All interviews were recorded directly onto a laptop computer using the internal microphone on the computer. Transana Software was used to help with transcription of the audio files. NVivo 9 (QSR, n.d.) software was used to assist with organization of the data for analysis.

**Pilot Study**

No pilot study was conducted prior to this proposed study.

**Assumptions and Limitations of the Method**

Because the situation driving the inquiry was generated out of the day-to-day work experiences of the therapists, it was assumed that any potential solutions proposed would directly impact their patients and caregivers as well. Though therapists in the beginning had no concrete evidence from caregivers directly indicating that they wanted changes to the education they received, it was assumed that finding a way to hear what caregivers had to say would be valuable to the process of solving the problem, and that the approach to PAR utilized in this study would give adequate voice to the caregivers for this purpose. Further, it was assumed that PAR as a methodology would allow caregivers
to contribute in a meaningful way that would be flexible enough to allow them to give feedback in varying degrees of detail, without compromising the integrity of the process.

A limitation of PAR as utilized in this study was the extended duration of the study, which stretched 21 months. Implementation of the many steps of this approach in a busy clinical environment is always secondary to meeting the needs of the patients and maintaining the clinical business model, so coordinating times to do the work of the study took significant effort and time. Another limitation was that due to the desires of St. Therese occupational therapy management to keep caregiver participants anonymous, those who did agree to participate were not equal stakeholders, because they could not voice their concerns directly during face to face interactions with the therapist stakeholders. As such, they were not actively co-creating the proposed solution to the identified problem. Because there are few examples of PAR in clinical health care settings where patients and/or caregivers are equal stakeholders and participants in the process, the process followed was a “best-effort” attempt at maintaining the spirit of PAR while respecting the pragmatic concerns of a real world practice setting.

Summary

The goal of this study was to improve occupational therapy practice as it relates to caregiver education about CPT scores for persons with dementia through the use of a reflective and responsive approach to examining the experiences of those directly involved in caregiver education. PAR provided a framework from which a methodical and deliberate inquiry into the issue was made, so that a solution to the practical problem identified was achieved.
Chapter 4: Results

Each step of the process in this PAR study, which used a modified process based on Checkland’s Soft Systems, provided data for analysis that were analyzed to create the final outcome in this study. Caregivers and therapists both, at different times, contributed information that shaped subsequent steps and resulted in a process that appeared to be an improvement overall.

Results of Checkland’s Soft Systems Step 1: Review of the current process

The first step in assessing the situation and describing the problem began with a focus group discussion among the six therapists to review the current occupational therapy evaluation process in use at St. Therese. The therapists reported that the standard they strived to meet for all patients was to have the initial occupational therapy evaluation complete within 24 hours of admission, followed by a phone call made by the occupational therapist to the primary caregiver for the purpose of reporting the results of the evaluation and the plan of care for occupational therapy. Therapists reported that the phone call step of the process was not consistently performed by all the therapists, and not at all by weekend on-call therapists, with any attempted calls usually resulting in voicemail messages instructing caregivers to return the call to the occupational therapist.

Additionally, for persons with dementia or suspected dementia, the MD typically ordered the CPT to be completed within the first week of therapy. Upon completion of both the occupational therapy initial evaluation and the CPT, the evaluating therapist completed a written summary (for internal use) to provide information to the inter-professional team attending the care conference. This internal communication
shaped the recommendations for discharge presented to patients and their caregivers at the care conference. In addition to the recommendations presented verbally, a written handout that explained the specific CPT score for the patient was provided to caregivers at this care conference.

Team members at care conferences were the MD, social worker, nurse, case manager, and a therapy representative, usually an administrator with a therapy background. The role of the therapy representative was filled by a variety of people who did not usually work directly with the patients discussed at care conference. If families or caregivers had questions about the discharge recommendations or the handouts provided by occupational therapy, they were instructed to call the occupational therapist who evaluated the patient. Therapists did field many calls of this nature and reported spending significant time on the phone trying to explain the CPT results and the recommendations they made.

Prior to discharge, all patients were offered one home safety evaluation to be completed by an occupational therapist whose role was solely to perform these visits. For persons with dementia, a significant component of the home evaluation was to help caregivers make the environment safer to compensate for the patient’s cognitive deficits. If accepted by the patient and their caregiver, this home visit occurred after the discharge care conference, but just prior to discharge from the TCU.

**Therapists’ perceptions of the current process.** As the therapists reflected on this process and their perceptions of its efficacy for helping caregivers understand the meaning of CPT results, a more clear sense of the problem began to emerge. For example, therapists reported feelings of frustration when on follow-up phone calls after
care conferences, and often felt that their information and suggestions were challenged, downplayed, or dismissed by caregivers. One therapist reflected:

I hear all of us on the phone giving extensive recommendations to caregivers about the patient’s cognition and OT recommendations, but [the caregivers are] always finding a reason to invalidate what we are saying. They say things like “could it be the medication?” or “she doesn’t do those things at home anyway.”

(Therapist 3)

The outcome of this focus group was consensus that the themes listed in Table 1 best captured the current state of practice for caregiver education about CPT scores at St. Therese at the beginning of the study.

Table 1

Problems Identified by Therapists

- Disconnection from caregivers (linked especially to not being present at care conferences).
- Excessive effort for questionable outcomes (amount of time leaving messages and taking calls).
- Feeling “unheard” by caregivers when communicating important information about cognition.
- Not feeling respected as professionals who have many resources to offer patients and caregivers.

Note. N= 6 therapist participants.

Therapists’ perceptions about the reasons for caregiver’s responses to reported CPT scores. As part of the bracketing exercise in this step, therapists were asked to voice their assumptions and biases about what caregivers might be thinking, their motives, etc. when talking to the occupational therapist about their loved ones’ CPT scores. Table 2 lists the assumptions that emerged from this exercise.
Table 2
Assumptions of Therapists about the Caregivers’ Responses to Information about CPT Scores

Caregivers:
• Are not ready to listen.
• Don’t want to hear negative information about their loved ones.
• Are caught off guard when given information about their loved ones’ cognition.
• Often make excuses as to why their loved one scored as they did because they do not want to see their loved ones as cognitively impaired.
• Are afraid they might anger their loved ones with dementia if they make changes.
• Are unable to manage family dynamics that interfere with recommended changes to support their loved ones with dementia.
• Are often filtering suggestions for change through the lens of finances instead of what’s best for their loved ones.

Note. N= 6 therapist participants.

One therapist summed it up this way: “They need to be ready to listen, and some people just are not at that point. No matter what we offer in terms of information, if they are not ready to hear it, it won’t matter” (Therapist 1).

Information about caregivers desired by therapists. After setting aside the assumptions identified above, the therapists identified what sort of information might be useful from caregivers to improve the process for all, beginning with the identification of desired demographic data. Table 3 describes the demographic data identified for collection.
Table 3  
Demographic Data about Caregivers Desired by Therapists

- Age
- Gender
- Education Level
- Relationship to person with dementia
- Number of years in caregiving role
- Daily activities for which caregiver assistance is provided

*Note.* N= 6 therapist participants.

In order to obtain useful qualitative data from the caregivers, the therapists decided to write a broader opening question for all caregiver interviews, as well as a variety of possible follow up probe questions to be used. The opening question was, “What do you remember about getting any information regarding your mother’s (or father’s, or husband’s, etc.) cognition or thinking skills when she/he was at St. Therese?” Follow-up questions were related to their recall of the CPT, any communications they had with the occupational therapist, their reaction to the information presented by occupational therapy, the usefulness of any information they remembered getting verbally or in writing, their thoughts on the presentation of the information and the timing of such, and what their suggestions for improving the experience of learning about CPT scores from the occupational therapist would be.

**Caregiver feedback about their experience with education about CPT scores and recommendations from occupational therapy.** The initial pool of potential caregivers who met the inclusion criteria for the study was 125. Recruitment materials were mailed to this pool, with 16 responses received. Two sets of recruitment materials were returned due to changes of address with no forwarding information provided. The 16 respondents were contacted by phone for further explanation of the study and
confirmation of their meeting of the inclusion criteria. All 16 met the inclusion criteria for the study, and 12 agreed to participate. The four caregivers who elected not to participate cited time constraints or lack of interest in the study as the reason for declining to participate.

The 12 caregivers interviewed in this step of the study were all Caucasian, predominantly middle-aged females, with over half being daughters or spouses. This characteristic of the group fits with previously documented data showing that about 60% of caregiving for persons with dementia in the United States is performed by middle-aged daughters, wives, and other female family members (Brodaty & Donkin, 2009). The education level of this group of caregivers was quite high, with 75% having completed some college or graduate school. Half of the interviewees had been in the role of caregiver for 3 years or less. The most frequently identified caregiving activities were assisting with money management, followed by household activities (e.g., laundry, cleaning, maintenance), setting up medicines, and driving. Table 4 describes the demographic data of this group in detail.
### Table 4
Demographic Data from First Group of Caregiver Participants

<table>
<thead>
<tr>
<th>Caregiver</th>
<th>Age</th>
<th>Gender</th>
<th>Education Level</th>
<th>Relation to Patient</th>
<th>Years of Caregiving</th>
<th>Activities</th>
<th>CPT Score&lt;sup&gt;1&lt;/sup&gt;</th>
<th>Months since discharge&lt;sup&gt;2&lt;/sup&gt;</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>65</td>
<td>F</td>
<td>College</td>
<td>Daughter</td>
<td>15+</td>
<td>5, 6, 7, 8, 9</td>
<td>4.8</td>
<td>2</td>
</tr>
<tr>
<td>2</td>
<td>72</td>
<td>F</td>
<td>College</td>
<td>Spouse</td>
<td>4-7</td>
<td>1, 2, 3, 5, 6, 7, 8</td>
<td>5.0</td>
<td>6</td>
</tr>
<tr>
<td>3</td>
<td>73</td>
<td>M</td>
<td>Graduate degree</td>
<td>Son</td>
<td>0-3</td>
<td>7, 8</td>
<td>4.3</td>
<td>5</td>
</tr>
<tr>
<td>4</td>
<td>71</td>
<td>F</td>
<td>HS</td>
<td>D-in-law</td>
<td>0-3</td>
<td>7, 8</td>
<td>4.3</td>
<td>5</td>
</tr>
<tr>
<td>5</td>
<td>55</td>
<td>F</td>
<td>Graduate degree</td>
<td>Spouse</td>
<td>0-3</td>
<td>1, 2, 3, 7, 9</td>
<td>4.6</td>
<td>2</td>
</tr>
<tr>
<td>6</td>
<td>70</td>
<td>F</td>
<td>HS</td>
<td>Daughter</td>
<td>0-3</td>
<td>3, 5, 7, 8</td>
<td>4.2</td>
<td>4</td>
</tr>
<tr>
<td>7</td>
<td>90</td>
<td>M</td>
<td>College</td>
<td>Spouse</td>
<td>0-3</td>
<td>2, 3, 7, 8, 9</td>
<td>4.8</td>
<td>4</td>
</tr>
<tr>
<td>8</td>
<td>56</td>
<td>F</td>
<td>Graduate degree</td>
<td>Daughter</td>
<td>0-3</td>
<td>7, 8</td>
<td>4.8</td>
<td>3</td>
</tr>
<tr>
<td>9</td>
<td>58</td>
<td>F</td>
<td>College</td>
<td>Daughter</td>
<td>8-10</td>
<td>2, 3, 5, 6, 7, 8</td>
<td>4.9</td>
<td>3</td>
</tr>
<tr>
<td>10</td>
<td>63</td>
<td>F</td>
<td>Graduate degree</td>
<td>Partner</td>
<td>4-7</td>
<td>1, 2, 4, 5, 6, 7, 8</td>
<td>5.0</td>
<td>2</td>
</tr>
<tr>
<td>11</td>
<td>54</td>
<td>F</td>
<td>HS</td>
<td>Daughter</td>
<td>8-10</td>
<td>5, 6, 7, 8</td>
<td>4.8</td>
<td>3</td>
</tr>
<tr>
<td>12</td>
<td>61</td>
<td>F</td>
<td>College</td>
<td>Daughter</td>
<td>4-7</td>
<td>5, 6, 8</td>
<td>4.8</td>
<td>2</td>
</tr>
</tbody>
</table>

Note. HS = high school. D-in-law = daughter-in-law. Activities: 1=dressing, 2=bathing, 3=cooking, 4=feeding, 5=driving, 6=setting up medicine, 7=household activities, 8=managing money, 9= other.

1 Of patient being cared for.
2 Rounded to nearest month.

**Codes and Themes.** Results of the First Cycle In Vivo coding of the 12 transcripts were 220 separate codable blocks of text. Of the 220 codable blocks, there was agreement of at least 5 of 7 coders on 160 of them. The 60 blocks of text that had 4 or fewer coders identifying them were discussed as a group, and decisions to eliminate them, keep them, or combine them with an adjoining block of text were made by the group. This resulted in 170 blocks of text to which one or two verbatim words were assigned, creating the First Cycle In Vivo codes. The final First Cycle In Vivo codes
were then recorded in NVivo. Table 5 illustrates a sample of the First Cycle Coding process:

Table 5  
Sample of First Cycle In Vivo codes

<table>
<thead>
<tr>
<th>Passage with In-Vivo Selection in <em>italics</em></th>
<th>Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>“Well, she told me that because he lives alone and gets no help, he needed more help. I said “who told you he gets no help?” and she said “he did.” Well, he may not see all I do as “help,” but without it he couldn’t live alone where he is now. I said, well, <em>had anyone bothered to ask me I could have told you what he does</em>” (caregiver 12).</td>
<td>“Ask me”</td>
</tr>
<tr>
<td>“I would have liked to have a discussion with the people who were directly involved in her, I would have liked to take that hour of time, and had a conversation, with the team that was working with her” (caregiver 10).</td>
<td>“A discussion”</td>
</tr>
<tr>
<td>“You can’t ask ‘why is this happening’ if you don’t know what should be happening. We’ve never been in this situation before; we come in with zero background on things to ask” (caregiver 3).</td>
<td>“Can’t ask if you don’t know”</td>
</tr>
</tbody>
</table>

The resulting list of 170 in Vivo codes provided the starting point for the Second Cycle of Pattern coding. From this list, the group clustered similar In Vivo codes together and named the clusters to capture the essence of the content of the codes in the cluster, resulting in six Second Cycle Pattern codes. The six codes were *PERCEPTIONS OF OT* (41 In Vivo codes); *WHAT CAREGIVERS WANT* (43 In Vivo codes); *CAREGIVER AWARENESS OF PATIENT’S FEELINGS* (20 In Vivo codes); *COMMUNICATION CONCERNS* (36 In Vivo codes); *UTILITY OF THE CPT EDUCATION* (16 In Vivo codes), and *CAREGIVER ROLES* (14 codes In Vivo codes).

Table 6 shows a sample of the Second Cycle Coding process:
### Table 6
*Sample of First Cycle In Vivo Code Clusters That Formed Second Cycle Pattern Codes*

<table>
<thead>
<tr>
<th>Examples of Clustered First Cycle Codes</th>
<th>Assigned Second Cycle Pattern Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>“Doing a counting game”</td>
<td>PERCEPTIONS OF OT</td>
</tr>
<tr>
<td>“Counting buttons”</td>
<td></td>
</tr>
<tr>
<td>“Juvenile”</td>
<td></td>
</tr>
<tr>
<td>“Kiddy work”</td>
<td></td>
</tr>
<tr>
<td>“Kindergarten”</td>
<td></td>
</tr>
<tr>
<td>“Call”</td>
<td>WHAT CAREGIVERS WANT</td>
</tr>
<tr>
<td>“Conversation”</td>
<td></td>
</tr>
<tr>
<td>“Answer questions”</td>
<td></td>
</tr>
<tr>
<td>“Discussion”</td>
<td></td>
</tr>
<tr>
<td>“My opinion”</td>
<td></td>
</tr>
<tr>
<td>“Ask me”</td>
<td></td>
</tr>
<tr>
<td>“Afraid”</td>
<td>CAREGIVER AWARENESS</td>
</tr>
<tr>
<td>“Anxious”</td>
<td>OF PATIENT’S FEELINGS</td>
</tr>
<tr>
<td>“Frightening”</td>
<td></td>
</tr>
<tr>
<td>“Angry”</td>
<td></td>
</tr>
<tr>
<td>“Being scolded”</td>
<td></td>
</tr>
<tr>
<td>“Losing control”</td>
<td></td>
</tr>
<tr>
<td>“Covering their butts”</td>
<td>COMMUNICATION</td>
</tr>
<tr>
<td>“Didn’t explain”</td>
<td>CONCERNS</td>
</tr>
<tr>
<td>“Insisted”</td>
<td></td>
</tr>
<tr>
<td>“Terminology”</td>
<td></td>
</tr>
<tr>
<td>“The rules”</td>
<td></td>
</tr>
<tr>
<td>“No interpretation”</td>
<td>UTILITY OF THE CPT</td>
</tr>
<tr>
<td>“Not individualized”</td>
<td>EDUCATION</td>
</tr>
<tr>
<td>“Useless form letter”</td>
<td></td>
</tr>
<tr>
<td>“Family members know”</td>
<td>CAREGIVER ROLES</td>
</tr>
<tr>
<td>“Family members notice”</td>
<td></td>
</tr>
<tr>
<td>“Families see changes”</td>
<td></td>
</tr>
<tr>
<td>“I have knowledge”</td>
<td></td>
</tr>
</tbody>
</table>
The First Cycle In Vivo codes in each of the six Second Cycle Pattern Codes were again reviewed and reorganized within their Second Cycle codes. This was accomplished by clustering together conceptually similar In Vivo codes that made up each Second Cycle code into groups that seemed to represent a common theme. Review of our analytic memos, along with the corresponding original text in the transcripts, helped our understanding of the codes and the process of refining themes within them. This process resulted in 14 distinct themes.

Table 7
Themes emerging from the Second Cycle Pattern codes.

<table>
<thead>
<tr>
<th>Code</th>
<th>Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>PERCEPTIONS OF OT</strong></td>
<td>Positive Perceptions:</td>
</tr>
<tr>
<td></td>
<td>• Positive past experiences</td>
</tr>
<tr>
<td></td>
<td>• Trusted other</td>
</tr>
<tr>
<td></td>
<td>Negative Perceptions:</td>
</tr>
<tr>
<td></td>
<td>• No connection</td>
</tr>
<tr>
<td></td>
<td>• Demeaning therapy</td>
</tr>
<tr>
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<td>• Ineffective communication</td>
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<td>• Bad or minimal past experiences</td>
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<td><strong>WHAT CAREGIVERS WANT</strong></td>
<td>Directness</td>
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<td></td>
<td>Individualization</td>
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<td></td>
<td>Respect</td>
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<tr>
<td><strong>CAREGIVER AWARENESS OF PATIENT’S FEELINGS</strong></td>
<td>Desire for Autonomy</td>
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<td></td>
<td>Fear</td>
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<tr>
<td><strong>COMMUNICATION CONCERNS</strong></td>
<td>Tone</td>
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<td></td>
<td>Lack of caregiver voice</td>
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<td>Business as usual</td>
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<td><strong>CAREGIVER ROLES</strong></td>
<td>Knowing the patient best</td>
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<td>Acknowledging changes</td>
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The next paragraphs in this section describe in more detail the Second Cycle Codes and resulting themes in greater detail.

**PERCEPTIONS OF OT.** Forty-one First Cycle codes made up this Second Cycle code, with themes of ‘positive perceptions’ or ‘negative perceptions’ emerging. Within these two themes, subthemes were distilled from the original In Vivo codes within each theme that referenced interactions (or lack of) with the therapist, the nature of the therapy activities that caregivers either saw or heard about from the patient, and the effectiveness of communication with the therapist. Figure 2 is an overview of this code and themes.

![Figure 2. Themes within PERCEPTIONS OF OT.](image)

In the Positive Interaction theme, subthemes of a) Past positive experience and b) Trusted other emerged. One wife, a retired nurse who had a daughter who was a health care professional and was familiar with occupational therapy, felt that all of the information they received about her husband’s cognition was delivered professionally, was useful, and helped the family make decisions about enrolling him in an adult day
program. She felt that her daughter was especially helpful in enhancing her understanding of what her husband needed. She also reported that her own mother had previously had a great experience with an occupational therapist who specialized in low vision. Another caregiver reported knowing personally the occupational therapist who worked with her mother at St. Therese, and recalled frequent communications about her mother’s status. In addition, she also reported previous positive experiences with occupational therapists who had assessed her mother’s cognition, and as a result felt she had all the information she needed from occupational therapy to manage her mother’s current situation.

Subthemes with the *Negative Interaction* theme were (in order of most to fewer In Vivo codes within the theme a) *No connection*, b) *Demeaning therapy*, c) *Ineffective communication*, and d) *Bad or minimal past experiences*. Within the first subtheme of *No connection*, the illustrative words were mostly descriptive but general, e.g., “didn’t see the therapist.” In contrast, words used in the second subtheme *Demeaning therapy* were direct and pointed. Phrases such as “kindergarten work,” “kiddy work,” and the words “humiliated,” “insulted,” “juvenile,” and “stupid,” among others, gave a clear sense that many of the caregivers were aware that their loved ones felt demeaned in occupational therapy. One caregiver described her partner’s experience this way:

She is someone who had her masters from a prestigious college who, up until, and I said that to them at the care conference, up until she got sick, was reading 5, 6 books a week and the New Yorker and the newspaper every day and engaging in political conversation. So doing a counting game was terribly demeaning for her. (‘R,’ partner).
WHAT CAREGIVERS WANT. This code was comprised of 43 First Cycle In Vivo codes, all referring to desires expressed by the caregivers as they related to learning about CPT scores and understanding how the information was being used to make discharge recommendations for the patient. Three themes emerged in the code: Directness, Individualization, and Respect. Caregivers want direct communication with the occupational therapist, with recommendations that are specific and individualized and that demonstrate a respect for the patient’s desires. Figure 3 shows an overview of this code and themes.

![Diagram](image)

Figure 3. Themes within WHAT CAREGIVERS WANT.

The first theme in this code, Directness, was by far the strongest, with words such as ‘conversation,’ ‘discussion,’ and ‘ask’ appearing frequently. Many caregivers stated that they would have welcomed a call or invitation to come in to discuss their loved one, and that they wanted to be directly asked for their opinions. One caregiver said

They didn’t seek our initial advice on anything that I am aware of; they told us what they had planned. I thought it would have been nice if they had asked us a
little more up front, like “what do you guys see as a need, what do you guys see?”

(‘F,’ son)

Another caregiver offered this suggestion:

Maybe, possibly they could interview the caregiver or the prospective caregiver to ask: “What was this person like before this incident?” “What was she able to do?” “I don’t remember being asked that.” (‘C,’ daughter)

Another caregiver made this valuable observation about the professionals working with her father who seemed unaware of the impact of what they were pointing out about him really was to the family:

I guess I just think it’s important for them to understand that while it’s in their day-to-day lives to deal with deficits, especially in the elderly, it’s not our day-to-day life as a family, the changes we see are not. Understanding that and even asking us about that would help. (‘K,’ daughter)

The second theme in this code, Individualization, referred to recommendations that are specific and individualized, and was also illustrated by use of more specific terms among caregivers. Words like ‘tailored,’ ‘interpret,’ ‘understandable,’ and ‘team,’ as well as the concept of ‘problem solving’ were notable in this theme. One caregiver, who was expecting much more specific information than she was given about her father’s cognition, summed up the relevance of this theme:

I think the hardest part to assess is the cognitive. I can tell if he is not walking well and if we need to get him some help for that, but I have a hard time knowing for sure about cognition, and that’s something people get so offended about, especially if they suspect it for themselves. (‘K,’ daughter)
The final theme in this category, *Respect*, was reflected in the many references by caregivers to wanting to be respectful of the patient, maintaining as much independence and choice as possible for the patient, and letting the patient ultimately decide what changes in their life (as recommended by the therapists) would be acceptable.

**CAREGIVER AWARENESS OF PATIENT’S FEELINGS.** This code was comprised 20 First Cycle In Vivo codes that came from caregivers’ assessment of the patient’s feelings as they went through the process of having their cognition evaluated with the CPT and the impact of that test information on their discharge from St. Therese. Although this question was not asked directly during interviews, caregivers volunteered examples of how patients reacted during care conferences and/or reported their feelings about the whole process. Figure 4 shows an overview of this code and themes.

Figure 4. Themes within CAREGIVER AWARENESS OF PATIENT’S FEELINGS. Two themes, *Desire for autonomy* and *Fear* emerged from the many In Vivo codes about caregivers worrying about taking away their loved ones independence, and observing their loved ones’ fear that bad performance on the CPT would mean they could not go back home. Words such as ‘fear,’ ‘afraid,’ and ‘scared’ were used frequently. One caregiver stated about her mother’s CPT “She scored low in a couple of things and they
were concerned about that. But I understand my mom, and I know that she was so afraid that if she failed those tests they were going to keep her.” Remarks about autonomy used words like ‘control,’ ‘power,’ and ‘prisoner.’ The latter word was used by two different caregivers who were very cognizant that acting on some of the recommendations by the therapists would be perceived by the patients to be imprisonment in their own homes, and they wished to avoid eliciting these feelings in the patients. Once caregiver recalled the day she decided to just let her mother resume climbing the stairs to get back up to the bedroom she had slept in for 50 years:

Since this is anonymous I will confess that there were lights burned out upstairs, and that kept her downstairs for a while, and then I decided, because she said “I am a prisoner in my own home, I wanted to come home just to be home.” So I went around and changed light bulbs and that was at least a month ago and she has not slept upstairs once, BUT-she knows that she CAN. And (whispering as if telling a secret) she goes up there during the day—she’s got stuff she’s got to get—and she is very careful. She and I have discussed it, and I said, “Well-you’re xx years old, and I think that you sometimes need to call your own shots.” And I know the professionals are duty bound to tell you if they think you are doing something unsafe-if they don’t tell you they are in trouble. So anyway she’s been doing the stairs. (‘C,’ daughter)

Another caregiver proudly described how her mother took back control of her own personal care:

They told her someone should be giving her a bath...umm that she should do sponge baths and have somebody help her with a shower once a week...well she’s
not doing that. She’s a very neat clean person and she wants to do it her way, and more than once a week. And you know-she knows she has to be careful and she has learned the hard way, like a lot of us do. She is using one of those chairs where she can sit down and use the sprayer, so she can shower sitting down. So we told them I would help her, but actually she showers when she wants to, without me, and she has been doing just fine!

(‘P,’ daughter)

COMMUNICATION CONCERNS. Thirty-six First Cycle In Vivo codes comprised this code that reflected the many references made by caregivers to both the language used by therapists and others at the care conferences, as well the efficacy of the process of getting information about CPT scores and the meaning. Three themes of Tone, Lack of caregiver voice, and Business as usual stood out as caregivers discussed the communication from both the occupational therapist and the care conference team about the patient. Figure 5 presents an overview of this code and themes.
Figure 5. Themes within COMMUNICATION CONCERNS

In regard to language, many caregivers noted an authoritative tone in communications on phone, at the home safety visit and in care conferences when cognitive concerns were discussed. One caregiver said:

She called me on the phone, it was a phone conference, and she was trying to tell me what mom needed to do to get back home and it was things like “she’s going to HAVE to do this and she’s going to HAVE to do that” and whatever. (*P, daughter*)

Others commented on the use of “scare tactics” to push recommendations if they disagreed with the recommendations or asked questions about the CPT at the home safety visit or at a care conference. One caregiver, recalling the team’s concerns about her mother’s judgment of her own abilities said:

Well, she lives in a house and she has slept upstairs for 50 years, and up in her bedroom is her haven. And now they are telling us “it’s not safe,” “this isn’t safe,
“that’s not safe,” “you can’t go downstairs,” “you can’t go upstairs” and she says “they keep scaring me, they keep scaring me.” (‘C,’ daughter)

Another caregiver perceived this to be somewhat of a veiled threat:

When we sat around the table at the last time before she was discharged it was kind of like everybody voted, there were six of us there, and everybody voted to give her a chance, but they also said “well you might lose your room in the nursing home.”

(‘J,’ daughter)

One caregiver noted that though there was plenty of communication about what his mother was doing, he found the tone to lack sensitivity and empathy about the situation, and that it was not personal enough, saying “it was like ‘here’s what we’re doing to your furnace and you should know about it.” (‘F,’ son)

The theme Lack of caregiver voice was reflected by the many remarks caregivers made about feeling out of the loop in the process; of not even knowing what questions to ask, and of efforts by some to try to get what they thought would be relevant information to the therapist or the team, only to have it ignored. Some also noted feeling like they were not being heard at the care conference, and sensed that their questions were not welcome. One caregiver summed it up saying, “I have to say, I was not impressed with the involvement with myself or my brother in this process.” (‘K,’ daughter)

The Business as usual theme was evident from the many comments about the care conferences in particular feeling like well-oiled machines, with attempts by caregivers to ask questions perceived to be an unwelcome disruption to the process. Remarks about sensing there were ‘rules,’ that the people at the conference were only looking for a
certain score on the CPT to guide the discharge plan, the passive hand-off of large quantities of paper work to the caregiver with little time for discussion, and the perception of a ‘matter of fact’ approach to the entire care conference contributed to caregivers’ dissatisfaction. One caregiver made this comment about her experience at her father’s discharge care conference:

You know, I got the feeling from the way it was presented and the way it was written that this was covering their butts, not really meant to be useful for me, but a way to say “See, we told her this stuff here is our proof.” (‘R,’ partner)

**UTILITY OF THE CPT EDUCATION.** This code was comprised of 16 First Cycle In Vivo codes that all addressed caregivers’ feedback on their recall of learning about CPT scores and their participation in any education offered to them by the therapists. Themes in this category were a) *Minimal education* and b) *Uncertainty of meaning*. Figure 6 presents an overview of this code and themes.

![Themes within UTILITY OF THE CPT EDUCATION.](image)

*Figure 6. Themes within UTILITY OF THE CPT EDUCATION.*

Feedback in this code was strong. One caregiver, a professional teacher and educational administrator of a large public school system, recalling that he had no idea his mother was being tested, stated, “As a teacher, you know in the past few years that’s all we zero in on is tests, I would have been aware of it I think. I think I would have remembered it.” After retrieving the folder his mother took home from St. Therese and
finding the information sheet from occupational therapy about the CPT buried in the back of the folder, he stated:

If they thought it was something that they thought we should see or be highly aware of, I think they should have said (pulling out the sheet and holding it up) “This I want you people to be aware of, that we did this test,” and they did not. Because they could even have said “on this cognitive test she scored 4.3” and we would have said “what??” But to me this doesn’t make sense. I mean, don’t want to be too critical, but don’t give me a list of TV channels and this score that maybe has some real purpose for our lives, in the same pile. This is nuts! (’F,’ son)

Other caregivers made references to a ‘form letter’ feel to the written materials they received, which made them unsure of how much of it applied to their loved one, while others noted the lack of interpretation of the score for their benefit. One caregiver described a frustrating experience at the care conference, which was the first time she had heard of the CPT. Though she had expressed her concerns about her father’s failing cognition to the nurses when he was admitted to St. Therese, she heard nothing further until the discharge care conference. This was her experience trying to figure out what his CPT score meant:

And then she said he had a score of, I want to say 4. But she didn’t say of what-this is really critical-she said he had a score of 4. And I waited for her to say more, and she didn’t. So I said “4 out of how many?” and she said “oh-five.” And then I said, “Ok, what were the particular deficits?” You know, I’m trying, my dad was sitting there, I didn’t want to say “what were his cognitive deficits?”
right out. And she said, “Well, I don’t know.” I said, “Well it would be helpful to know that if he goes home to live by himself again” and she said “Well would it be helpful if I had the therapist call you?” and I said “That would be very helpful.” I never heard a word. I still to this day have no idea what the deficits were and why it was 4. (‘J,’ daughter)

References to the CPT score number not making sense and questioning whether or not the score actually meant anything were also noted in this category. Another caregiver, recalling hearing the CPT score for the first time with no discussion of its meaning, said

I don’t work in health care, but I do work with data, and I know that scores get interpreted, and that there are very few things when it comes to people where a score equals anything. I didn’t feel like there was any interpretation going on, about my father, and what this meant for him. (‘D,’ daughter)

**CAREGIVER ROLES.** The final code reflected 13 First Cycle In Vivo codes that referenced caregivers’ perceptions of what they knew about their loved one and how they could contribute to the team. Two themes of a) *Knowing the patient best* and b) *Acknowledging changes* emerged. Figure 7 below is an overview of this code and themes.
Half of the caregivers interviewed stated that they had seen some changes in their loved one’s cognition, yet stated they were not asked for their opinion by anyone on the team. There were many comments about caregivers knowing the patient’s habits and preferences, and feeling like that information could have helped the team if it could have been shared. For example:

Well, the therapist told me that because he lives alone and gets no help, he needed more help. I said “who told you he gets no help?”, and she said “he did.” Well, he may not see all I do as “help,” but without it he couldn’t live alone where he is now. I said, well, had anyone bothered to ask me I could have told you what s/he does. (‘J,’ daughter)

**Results of Checkland’s Soft Systems Step 2: Identification of the systems involved**

Data for this step was obtained through reflection and discussion between therapists in several early conversations, including the focus group in step 1. The therapists had many thoughts about the systemic contributors to the current situation for caregiver education at St. Therese, all of which were pragmatic in nature. There was no
indication of concerns about ethics or being pushed to practice in any particular manner by the management of St. Therese. Table 8 describes the consensus of the therapists regarding the systems therapist believed were impacting caregiver education at St. Therese.

Table 8

Systems Impacting Caregiver Education

- Tight evaluation deadlines (24 hour turn around)
- Care conference structure (who attends)
- Productivity expectations of therapists
- Expectation of cognitive testing and discharge recommendations by end of first week or sooner
- Use of on call therapy staff over weekends
- Heavy reliance on written information to deliver education about CPT scores and recommendations.

Note. N= 6 therapist participants.

Results of Checkland’s Soft Systems Step 3 and 4: Desirable modeling of the systems involved and comparison of the desirable model and the problematic situation

After analyzing the caregivers’ feedback, the therapists identified outcomes they desired from an improved caregiver education process. These outcomes were identified using a consensus process in a focus group setting. An assumption of the team was that addressing caregivers’ wishes, especially those for more contact and opportunities for conversations about patients, would lead to the outcomes desired by therapists. A strong theme in the therapist desired outcomes was the need by therapists to have their work of providing education about the CPT to patients and families be recognized as an effective and valuable service by those families. Table 9 lists these desired outcomes.
Table 9
Outcomes Desired of Caregiver Education by Therapists

- Patients and caregivers will understand occupational therapy at St. Therese in general, and the role of occupational therapy in assessing cognition at St. Therese.
- Caregivers will find the methods of education used by occupational therapy to be easy to understand.
- Caregivers will find value in the information about cognition presented by occupational therapy.
- Caregivers will see occupational therapy as an equal member of the professional team at St. Therese.
- Therapists will feel that the time they spend on caregiver education is a productive use of their time.

Note: N=6 therapist participants.

The therapists then brainstormed many ‘big ideas’ reflective of the feedback from caregivers as well as their own ideas to envision a desirable model of the systems and practices that would facilitate their desired outcomes. Table 10 outlines all of the elements of the ideal process desired by therapists.
Table 10

*Ideal Systems and Practices for Caregiver Education as Desired by Therapists*

1. Request admissions personnel to provide written education about occupational therapy and a tour of occupational therapy treatment area when patient is admitted to St. Therese TCU.

2. Utilize a short video presentation explaining occupational therapy that could be shown by admission personnel and also be put on the St. Therese website.

3. Require all OTs (regular employees as well as weekend staff) who complete evaluations to call the caregiver identified in the patient’s chart on evaluation day to ask for caregiver input and concerns. During this call:
   a. Occupational therapists will also request the caregiver’s email to provide further information as needed and also to send the link to the video presentation if not already seen.
   b. Occupational therapists will also invite caregivers to come in to observe cognitive testing and discuss results.

4. Ask MD to order cognitive testing further out into the TCU stay.

5. Have occupational therapists attend care conferences for patients assessed with the CPT and for whom a significant change in level of services upon return home is recommended, and/or if a change in discharge destination is recommended.

6. Create easier to read written hand-outs to supplement education provided face to face or via phone.

7. Have the occupational therapist who evaluated the patient and who administered the CPT perform the home safety evaluation.

*Note.* N=6 therapist participants.

The therapists then identified gaps between their desired model for caregiver education and their current practice. Though many of the proposed ideas were new ones never before suggested or attempted, the group agreed that the ideal practice would basically address three main areas: a) a need for more education about occupational therapy in general, b) improved written materials and use of other forms of communication (including verbal interactions), and c) a need for increased opportunities for direct caregiver contact with the therapist who is evaluating the patient with the CPT and making recommendations based on the CPT results.
Results of Checkland’s Soft Systems Step 5: Establishment of a concept of what is desirable and what is possible

Occupational therapy management met with the therapists to discuss which elements of the ideal systems and practices were open for change and which ones management determined were not feasible. Changes that were determined feasible were:

• Creation and utilization of a short video presentation explaining occupational therapy that could be shown by admission personnel and also be put on the St. Therese website.

• Requirement that all regular (non-weekend staff) OTs who complete evaluations call the patient’s caregiver identified from the chart on evaluation day to ask for caregiver input and concerns.

• Request for caregiver’s email to provide further information as needed and also to send the link to the video presentation if not already seen.

• Invitation by therapists to invite caregivers to come in to observe cognitive testing and discuss results.

• Creation of easier to read written materials to supplement education provided face to face or via phone.

Changes that were determined not to be feasible were:

• Request admissions personnel to provide written education about occupational therapy and a tour of occupational therapy treatment area when patient is admitted to St. Therese TCU. Management reported that patients and caregivers are already
overloaded with information and paperwork and that they did not want to add more work to the admissions staff.

- Require weekend staff to make calls to caregivers after the evaluation. It was determined that due to the fluctuating nature of weekend staff, training all to make calls would not be efficient. However, it was decided that regular staff who pick up a patient evaluated by a weekend therapist should make the call on Monday.

- Sending of education materials via email if caregiver agreed. Management worried that HIPAA could be violated if the email went to the wrong address, even if no patient identifiers are used on the materials sent.

- Ask MD to order cognitive testing further out into the TCU stay. Management reported that the MD had been approached with this request previously, and that he was firm in his desire to keep his current timeline for ordering the CPT in place as he felt the information provided to him was valuable in making discharge recommendations as soon as possible.

- Have occupational therapy attend care conferences for patients assessed with the CPT and for whom a significant change in level of services and/or a change in discharge destination is recommended. Management felt that productivity, staffing, and other logistical demands would not allow for multiple therapists to attend care conferences without significant disruption to the business model.

- Have the occupational therapist who evaluated the patient and who administered the CPT perform the home safety evaluation. Management determined that this was not possible due to the current staffing model.
After this conversation with management, the therapists reconciled their “ideal” with what was feasible. Keeping in mind the desired outcomes of an improved caregiver education process and the three main areas they wished to address, the therapists proposed the following process:

1. Patient admitted to St. Therese Rehab.

2. Occupational therapy evaluation completed within 24 hours.

3. Therapist calls the primary caregiver identified (no later than day 3 after admission) to start a conversation by saying (suggested script):

   • “Hello, my name is _____ and I am an occupational therapist at St. Therese Rehab. I have just completed an evaluation with ________________ and I would like to talk to you about what we would like to work on with ________________ while s/he is here.

   • I also want to find out any concerns you may have or things you want us to know about. I can also answer any questions you have about therapy.”

Therapists identified the key points to cover in the phone conversation:

• Ask for caregiver input about the patients prior level of functioning

• Ask about any worries or concerns the caregiver has for the patient

• Invite the identified caregiver to come in to see the patient in occupational therapy

• Share the link to the PowerPoint presentation with the caregiver (can ask for an email and email them the link).
• Be sure to let the caregiver know that another therapist may be the one working with the patient and provide the name and contact info of the other therapist to the caregiver.

4. If the caregiver is not reached by phone, the occupational therapist will leave the above as a message, adding “Please call me back at________________________.”

5. If a caregiver comes in to visit and observe therapy, invite them to watch the PowerPoint presentation if they have not already seen it.

6. After the cognitive testing is done, the occupational therapist will contact the designated caregiver to invite her or him in to discuss with the patient and occupational therapist the results of the CPT and the connections to discharge planning. The occupational therapist will prepare the following for the caregiver:

• A revised version of the *Occupational Therapy Cognitive Functional Levels* handout with the patient’s cognitive functional level highlighted.

• A copy of the revised ‘*Recommendations from Occupational Therapy*’ form that has been individualized for the patient.

• A copy of the appropriate *Geriatric Research and Education Clinical Center (GRECC) Caregiver Guide* (Appendix H) to be used if the occupational therapist thinks this level of detail is appropriate. This is a publication of the Minneapolis Veterans Administration Hospital, which houses the GRECC program and is where the CPT was created. It is a very detailed description of the various cognitive functional levels as assessed by the CPT.
Therapists identified that during the session with the patient and the caregiver, the occupational therapist will discuss the handouts and how the information might apply to the patients discharge plans, covering the following key points:

- A brief explanation of the CPT as a measure, if the caregiver has not seen the PowerPoint presentation.
- Individualized examples of how to apply the information to the patient
- Communication to the caregiver that they will not see the occupational therapist at the care conference, and that because of this, it is important to go over the information and recommendations beforehand.

The therapists decided that if a caregiver is unable to come in, the occupational therapist should arrange to mail the written information directly to the caregiver, and should let the caregiver know that he or she will not see the occupational therapist at the care conference, and that because of this, it is important to go over the information and recommendations before the care discharge conference. An offer to call in to the occupational therapist once the information is received by mail should be included in the mailing.

**Revisions of Materials.** The next step necessary was revision of the written materials. The therapists divided up the various forms created by occupational therapy at St. Therese to explain CPT scores, and used an open source online tool at Readability-score.com (readability-score.com) to evaluate the readability of the current handouts. Readability is defined as the level of ease or difficulty with which text material can be understood by a particular reader who is reading that text for a specific purpose (Pikulski, 2002). Each education handout was individually submitted to the tool, which then
calculated the Flesh Kinkaid Reading Ease score (Kincaid, Fishburne, Rogers, & Chissom, 1975) as well as a simplified measure of gobbledygook (SMOG) index score (McLaughlin, 1969). The Flesh Kinkaid Reading Ease score is an indication of comprehension difficulty when reading a passage of contemporary academic English, calculated by \((\text{total words/total sentences}) - (\text{total syllables/total words})\). The SMOG is a measure of readability that estimates the years of education (by grade level) needed to understand a piece of writing. The decision to use the Flesh Kinkaid Reading Ease and SMOG calculations was based on their wide recognition and established validity as tools for assessing readability. With this baseline information of the reading ease scores and SMOG scores, the therapists drafted revisions to their assigned documents. When all documents had been revised, one therapist took the responsibility for collectively formatting and editing all of the documents so they had the same format and voice. See Appendix I for the original versions of the materials and Appendix J for the revised versions of the materials.

Overall, reading ease improved in each document to a score of 45 or higher, which is recommended by some state and federal agencies as the minimum score for official documents and insurance policies (Florida State Senate, 2011; Si, L., & Callan, 2001). Grade level reading scores went down for each document as well. This was accomplished using many of the principles in the \textit{Simply Put} publication from the U.S. Centers for Disease Control (US CDC, 2010). In addition to changes to language, layout and formatting changes were also incorporated. The addition of more white space, the use of bullets, and the “chunking” of information were utilized to create less cluttered and easier to follow materials. Finally, the title of the \textit{Occupational Therapy Cognitive}
*Functional Scores* document was changed to *How Changes in Thinking Ability Affect Day-to-Day Living*, and the addition of a graphic depicting the occupational therapy process at St. Therese was added on the front page (Appendix K). See Table 11 for the side-by-side comparison of scores for each document.

Table 11
*Comparison of Readability Scores for Original Written Materials and Revised Written Materials*

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*Note.* *Higher scores indicate easier readability.*

Recognizing that the first three to four sentences of a written document may discourage a person from reading further if the material is too difficult, it was decided to also run the SMOG calculations for the first four sentences of each version of the cognitive level recommendation forms (which are the same on each form). The SMOG grade level for the first four sentences original version of the forms was 17.1, and went down to 4.1 in the revised forms.

**Creation of a video presentation.** The next step was to create a presentation that could explain occupational therapy at St. Therese, as well as the role of occupational
therapy in assessing cognition and providing recommendations for discharge. The therapists felt strongly that the presentation should include pictures, be narrated, and be fairly short. One therapist in the group took the lead on writing a script and drafting a PowerPoint presentation, with the larger group of therapists suggesting edits and revisions as the presentation took shape. The final product was a 17-slide narrated presentation lasting about 10 minutes that was housed on a publicly available server to which the written URL could be provided via mail or via a link could be sent in an email. See Appendix L for the slides and transcript of this presentation.

**Practice Considerations.** The feedback on the negative impressions of occupational therapy in general was an unexpected outcome of the first round of caregiver interviews, and presented a bigger problem that could potentially be a separate study. Although the scope of the question in this study was focused on improving caregiver education about CPT scores, therapists recognized that this aspect of the feedback could not be ignored and was a contributing factor to caregiver dissatisfaction with their experiences of receiving education about CPT scores from the occupational therapists. As there are no “cookbook” or standard approaches to most occupational therapy interventions, coupled with the fact that most intervention selection is done by the individual therapist treating the patient, the group decided to make a concerted effort to encourage all therapists to choose interventions that were based more in occupation. It was hoped that implementing the new process as outlined above would yield more personal information about the patients that would then allow therapists to make the interventions more meaningful to the patients.
Caregiver Feedback on the New Materials and Process. Six of the original 12 caregivers interviewed agreed to participate in the review of the new materials and workflow process for caregiver education about CPT scores. Each of these caregivers was sent a packet containing the summary of the findings from the first group of interviews, as well as step-by-step instructions for examining the materials as well as some specific and open-ended questions on each aspect of the materials and proposed workflow process to elicit their feedback. Caregivers were told that they could also make notes or comments anywhere on any of the materials as they reviewed them. Caregivers were provided with my phone and email contact information in case they had any questions as they reviewed the packet. Once their review was complete, caregivers were instructed to mail their feedback to me, along with the materials in a postage-paid envelope provided for them. Overall, their feedback was positive with only minor suggestions for change or increased emphasis on particular aspects of the materials or process. This feedback resulted mainly in changes to the language therapists were to use during communication with the caregivers. Caregiver responses to each aspect of the process are noted in Table 12.
Table 12  
*Caregiver Feedback to Proposed Caregiver Education Materials and Process*

<table>
<thead>
<tr>
<th>Aspect</th>
<th>Feedback</th>
</tr>
</thead>
<tbody>
<tr>
<td>Phone call within 3 days of admission</td>
<td>Positively received by 6/6 reviewers. Comments: Cautioned against it sounding too “scripted”; suggested stronger emphasis on getting link to presentation to caregivers ASAP via this call.</td>
</tr>
<tr>
<td>Video presentation</td>
<td>Positively received by 6/6 reviewers. Comments: Suggested fewer words on the screen that describe occupational therapy education; strongly suggested finding ways to let patients and caregivers see the video at admission or prior to phone call from occupational therapy.</td>
</tr>
<tr>
<td>Invitation to come to therapy to observe therapy and cognitive testing, and/or to discuss results.</td>
<td>Positively received by 6/6 reviewers. Comments: Thought that having this opportunity to meet prior to discharge care conference would be very helpful.</td>
</tr>
<tr>
<td>Written Materials: <em>How Changes in Thinking Affect Day to Day Living (formerly OT Cognitive Functional Scores)</em></td>
<td>Graphic overview appreciated by 3/6 reviewers. Comments: Perceived it to be easy to understand and helpful (3/6 reviewers). Other 3/6 reviewers made no comment on this aspect.</td>
</tr>
<tr>
<td>Recommendations from OT forms</td>
<td>Liked that it was personalized to the patient, 6/6 reviewers. Comments: suggested circling or other highlighting of specific strategies pertinent to the patient on the back side of the form.</td>
</tr>
<tr>
<td>In person discussion of the CPT results and handouts</td>
<td>Strong support for this idea by 6/6 reviewers. Comments: emphasized wanting to be asked their opinions, hopes and fears for their loved one. Strong support for focusing the communication with occupational therapy at this meeting on letting them know that even though the occupational therapist will not be at the discharge meeting, that the occupational therapist genuinely cares about what happens to the patient.</td>
</tr>
</tbody>
</table>
Mailing of information and recommendations if caregiver unable to come in. Less support for this option (2/6 reviewers); others wanted a phone call instead (4/6 reviewers). Comments: Use as a ‘last resort,’ and that a phone call to discuss the information is preferable to getting it in the mail. If by mail, they want the information prior to the discharge care conference.

General feedback

In the open-ended section, 5/6 reviewers offered feedback. Comments: Desire to hear the specific name of the therapist mentioned at the care conference, versus referring to them as “the therapist” when recommendations are reported (2/6 reviewers). Strongly suggested that care conference staff be cognizant of tone and language to avoid ‘dictating’ at the care conference (2/6 reviewers). Comments that overall process is an improvement (5/6 reviewers).

Note. N=6.

Results of Checkland’s Soft Systems Step 6: Implementation of the proposed activities and observations

The next step was to begin using the new materials and implementing the process outlined. Two therapists adopted the new process and documented the names and contact information of their patients and their caregivers who met inclusion criteria and who were offered the new process. This pool of 31 caregivers was sent the same recruitment materials as described for the first round of caregiver interviews, and the same recruitment procedures were followed. A total of 10 postcards were returned and those caregivers were contacted to continue the recruitment process. Eight of the caregivers met the inclusion criteria and agreed to participate in an interview. One person did not meet the criteria as she was confused and could not articulate understanding of the project, and had no recall of her husband’s recent TCU stay. The other caregiver did not return a phone call to further explore her participation in the study.
Comparison of the second group of caregivers to the first group of caregivers revealed that the second group was a bit older, was providing more assistance for basic self-care activities than did the first group of caregivers, and was interviewed sooner to the actual discharge date of their loved one than the first group. Similarities between the two groups were that the second group was still overwhelmingly female (83.3% in group 1 and 87.5% in group 2), with half also having a college or higher level of education, and half having also been in the caregiving role for 0-3 years. Overall, the therapists were satisfied that this second group of caregivers was similar enough to the first group of caregivers to provide feedback on the new CPT education process. The therapists also believed that the fact that the second group was not as far removed from the discharge date as many of the first group of caregivers were was advantageous for data collection that relied on recall. Table 13 describes the demographic characteristics of the second group.
Table 13
Demographic Data from Second Group of Caregiver Participants

<table>
<thead>
<tr>
<th>Caregiver</th>
<th>Age</th>
<th>Gender</th>
<th>Education Level</th>
<th>Relation to Patient</th>
<th>Years of caregiving</th>
<th>Activities</th>
<th>CPT Score ¹</th>
<th>Months since discharge²</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>59</td>
<td>F</td>
<td>Graduate degree</td>
<td>Daughter</td>
<td>0-3</td>
<td>2, 5, 6, 7, 8</td>
<td>5.0</td>
<td>1</td>
</tr>
<tr>
<td>2</td>
<td>84</td>
<td>F</td>
<td>HS</td>
<td>Spouse</td>
<td>4-7</td>
<td>1, 2, 3, 5, 6, 7, 8</td>
<td>5.0</td>
<td>1</td>
</tr>
<tr>
<td>3</td>
<td>87</td>
<td>F</td>
<td>HS</td>
<td>Spouse</td>
<td>15+</td>
<td>1, 2, 3, 5, 6, 7, 8</td>
<td>4.5</td>
<td>1</td>
</tr>
<tr>
<td>4</td>
<td>77</td>
<td>F</td>
<td>HS</td>
<td>Sister</td>
<td>0-3</td>
<td>5, 6, 7, 8</td>
<td>4.7</td>
<td>2</td>
</tr>
<tr>
<td>5</td>
<td>78</td>
<td>M</td>
<td>College</td>
<td>Brother</td>
<td>0-3</td>
<td>5, 6, 7, 8</td>
<td>4.6</td>
<td>2</td>
</tr>
<tr>
<td>6</td>
<td>50</td>
<td>F</td>
<td>College</td>
<td>Niece</td>
<td>8-10</td>
<td>2, 5, 7</td>
<td>4.7</td>
<td>2</td>
</tr>
<tr>
<td>7</td>
<td>65</td>
<td>F</td>
<td>College</td>
<td>Daughter</td>
<td>0-3</td>
<td>1, 2, 3, 5, 6, 7, 8</td>
<td>4.8</td>
<td>2</td>
</tr>
<tr>
<td>8</td>
<td>65</td>
<td>F</td>
<td>Graduate degree</td>
<td>Daughter</td>
<td>4-7</td>
<td>6, 8</td>
<td>4.1</td>
<td>2</td>
</tr>
</tbody>
</table>

Note. HS = High school. D-in-law = Daughter-in-law. Activities: 1=Dressing, 2=Bathing, 3=Cooking, 4=Feeding, 5=Driving, 6=Setting up medicine, 7=Household activities 8=Managing money, 9=Other.

¹ Of patient being cared for.
² Rounded to nearest month.

Transcripts for the second round of caregiver interviews were analyzed using the same process employed with the first group of caregiver interview transcripts. Results of the First Cycle coding of these transcripts revealed 104 codable blocks of text. Of the 104 codable blocks, there was agreement by at least 5 of 7 coders on 60 of the blocks. The 44 blocks that had 4 or fewer coders identifying them were discussed as a group, and decisions to eliminate them, keep them, or extend them to an adjoining block of text were made by the group. This resulted in 65 codable blocks of text to which one or two word verbatim words were assigned, comprising the First Cycle In Vivo codes. The final First Cycle In Vivo codes were then recorded in NVivo.

The resulting list of 65 First Cycle In Vivo codes provided the starting point for the Second Cycle of Pattern coding. From this list, the group clustered similar In Vivo
codes together and coded the clusters to capture the essence of the content of the In Vivo codes in the given cluster. This resulted in three Second Cycle Pattern codes:

*Interactions; CPT Education and Overall Impressions.* See Table 14 for a sample of the Second Cycle Coding process for the second round of caregiver interview transcripts:

Table 14
Sample of First Cycle In Vivo Code Clusters for Second Cycle Pattern Codes for Caregiver Group 2

<table>
<thead>
<tr>
<th>Examples of Clustered First Cycle In Vivo Codes</th>
<th>Assigned Second Cycle Pattern Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>“Got a call”</td>
<td>INTERACTIONS</td>
</tr>
<tr>
<td>“Sat there”</td>
<td></td>
</tr>
<tr>
<td>“Right on it”</td>
<td></td>
</tr>
<tr>
<td>“Felt respectful”</td>
<td></td>
</tr>
<tr>
<td>“Had an answer”</td>
<td></td>
</tr>
<tr>
<td>“She asked us”</td>
<td></td>
</tr>
<tr>
<td>“I remember the OT”</td>
<td></td>
</tr>
<tr>
<td>“Good at her assessment”</td>
<td></td>
</tr>
<tr>
<td>“Got that ahead of time”</td>
<td>CPT EDUCATION</td>
</tr>
<tr>
<td>“Very clear”</td>
<td></td>
</tr>
<tr>
<td>“Marked on that sheet”</td>
<td></td>
</tr>
<tr>
<td>“I read it”</td>
<td></td>
</tr>
<tr>
<td>“I started doing”</td>
<td></td>
</tr>
<tr>
<td>“A lot of new information”</td>
<td></td>
</tr>
<tr>
<td>“Wonderful”</td>
<td>OVERALL</td>
</tr>
<tr>
<td>“Great”</td>
<td>IMPRESSIONS</td>
</tr>
<tr>
<td>“Impressed”</td>
<td></td>
</tr>
<tr>
<td>“Appreciated”</td>
<td></td>
</tr>
</tbody>
</table>

The First Cycle In Vivo codes within each of the three Second Cycle Pattern Codes were then again reviewed and reorganized within their Second Cycle codes. This was accomplished by clustering together conceptually similar In Vivo codes that made up each Second Cycle code into groups that seemed to represent a common idea or theme. Review as needed of our analytic memos, along with the corresponding original text in
the transcripts, helped our understanding of the codes and the process of refining themes within them. This process resulted in six distinct themes. Table 15 lists the themes that emerged from the Second Cycle Pattern Codes for Caregiver Group 2.

Table 15
Themes within Second Cycle Pattern Codes for Caregiver Group 2.

<table>
<thead>
<tr>
<th>Code</th>
<th>Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>INTERACTIONS</td>
<td>Feeling Heard</td>
</tr>
<tr>
<td></td>
<td>Understanding OT</td>
</tr>
<tr>
<td></td>
<td>Leadership</td>
</tr>
<tr>
<td>CPT EDUCATION</td>
<td>Utility</td>
</tr>
<tr>
<td></td>
<td>Value</td>
</tr>
<tr>
<td>OVERALL IMPRESSIONS</td>
<td>Positive Impression of the Profession</td>
</tr>
</tbody>
</table>

Figure 8 illustrates these themes.

Figure 8. Codes and themes within Second Cycle Pattern Codes for Caregiver Group 2.

**Interactions.** Twenty-seven First Cycle In Vivo codes comprised this code and reflected many references to recalling and evaluating the quality of various encounters with the therapist who provided the CPT education. The three themes emerging from this category were a) *Feeling heard*, b) *Understanding OT*, and c) *Leadership*. The strongest
of these themes was *Feeling heard*, which was made up of references to listening, asking, and being in the same space with the occupational therapist. Words that indicated the tone of conversations such as ‘respectful’ and others that indicated caregivers felt welcomed by therapists to ask questions were prevalent.

One caregiver, who sat in on several sessions of occupational therapy that included both cognitive testing and other therapy activities stated, “Anytime I felt like I had a concern or a question, she talked to me, and she had an answer for me.” (*D,* daughter) Another caregiver recalled being pleasantly surprised at the number of phone calls she received:

I didn’t know they would be calling me, which was a nice benefit. But I don’t recall ever hearing that they would be calling me with updates, so that would have been good to know at the beginning. I just wish there was a bit more of a routine to it. (*C,* niece)

One caregiver in particular commented on the tone of the conversation with the therapist, noting:

They were not at all condescending. It was like “these are the facts as we see it,” and actually, they were confirming what we felt. (*D,* brother)

The absence of occupational therapy at the care conferences was mentioned to a lesser degree by this group of caregivers, and the tone of the remarks was very different from that of the first group. One caregiver noticed that while it was just one person reporting about therapy, it was helpful to meet with the occupational therapist prior to the care conference. Some caregivers reported meeting with the occupational therapist immediately after the care conference, which they felt helped to make the discharge
recommendations make sense. One caregiver, who declined the invitation to come in and meet with the occupational therapist prior to the care conference because she felt her own professional background in a health care field would help her understand the recommendations, admitted that once at the care conference, she wished she had met with the occupational therapist.

*Understanding OT* was reflected in the In Vivo codes indicating that the caregiver understood why the occupational therapist was assessing cognition, and that it made sense to the caregiver that it was occupational therapy who would discuss the implications of the CPT with them. Many of these particular references came from watching the video. All caregivers (N=8) were offered the opportunity to watch the video; one declined as she felt she knew already the role of occupational therapy due to her profession, and three others did watch the video. The remaining four caregivers cited lack of time (n=2), or no recall of being offered the video (n=2) as the reasons that they did not watch the video. From those who had seen the video, all of the comments were positive. One caregiver said:

> I thought it was good, because no one knows OT, or what that means. I thought it was helpful to make me think ‘what are the tasks it takes to manage’? (*’D,’ daughter*)

Another commented:

> I think it was a very good idea, because a lot of people, when it’s their first time going into a situation like that, they don’t even know what therapy is and they don’t know what it can do…it gave me an idea of what they were trying to do, and how they were doing it. (*’I,’ spouse*)
A third caregiver recalled:

I remember that on the first or second day that mom was in OT, the therapist, she gave me something to go see about what OT was, because what’s confusing to me is the difference between OT and PT. I don’t remember a lot about it right now, but I remember at the time feeling like “oh, there’s a huge difference” and I see what she is talking about, it’s a lot of cognition stuff, which I did not realize at all. I thought it was more like working with your hands or doing hobbies. (‘A,’ daughter)

This caregiver also felt that the new understanding of occupational therapy helped her appreciate the cognitive testing she observed:

I didn’t have the right definition of OT, but once I knew, I saw that what they were doing was very appropriate, and I remember thinking, oh good, they’re going to catch a lot of stuff”. (‘A,’ daughter)

The Leadership theme emerged from In Vivo codes about wanting the care conferences to feel more coordinated in terms of addressing all of their other concerns about the patients, and wanting a ‘go to’ person instead of several individuals. The one caregiver from this second group who felt that her experience at St. Therese was negative said, “I just kept waiting for them to take the lead” when discussing her desires to move her father out of St. Therese to a different level of care because he had plateaued on his therapy goals and was discharged from therapy. (‘B,’ daughter)

**CPT education.** This code was comprised of 27 First cycle In Vivo codes that reflected many references to recalling receiving and/or participating in specific aspects of
the CPT education (e.g., invitations to come in; the written materials). Within this code, two themes emerged: Utility and Value.

Within the theme of Utility, recall of the written materials was particularly strong, with 6 of the 8 caregivers distinctly recalling the materials, and 3 of the 6 still in possession of them. Most of the caregivers remembered that there was information highlighted on the Recommendations from OT form, and recalled the therapist discussing the highlighted information with them. One caregiver, who appreciated the conversation that came during the review of the recommendations with the occupational therapist, recalled this about the form:

She [the occupational therapist] highlighted this sheet, and went over it with me in the OT room…and I could tell her not to focus on the stuff I would be doing for my mom, but to focus on decision-making and safety. (‘A,’ daughter)

The theme of Value was represented by codes indicating that caregivers found the information to be of value in terms of helping them make changes to caregiving activities or drawing their attention to potential needs of their loved one that they had not yet considered. One caregiver, a spouse, recalled that the recommendations form was helpful for her to communicate to her son, who also provided some assistance to his father, what type of help he required. She said “I started doing some of the things they marked on the sheet. I showed my son the sheet, and my son is now helping too with money.” (‘I,’ spouse). One more caregiver remembered that “Some of the things were checked off, like they were very critical or highly recommended, and we paid attention.” (‘F,’ spouse). Yet another caregiver stated that at a sit-down session with the occupational therapist, the therapist “did an excellent job of explaining what they were
doing” ('C,’ niece) as they reviewed the written materials. Other caregivers used the words ‘wonderful’ and ‘helpful’ when discussing the recommendations as presented on the education materials.

**Overall Impressions.** Eleven First Cycle In Vivo codes made up this code that captured caregivers’ overall feelings about their experience learning about the patients’ CPT scores from occupational therapy and the resulting recommendations. Within this code, the theme of *Positive impression of the profession* emerged. Words like ‘impressed,’ ‘appreciated,’ and ‘great’ came up multiple times in the interviews.

Comments from caregivers about the overall experience with occupational therapy were largely positive, such as this one:

She had good care, and I really felt like it was a good transition back to her apartment, and I would say that it was largely due to OT more than nursing. It was a great experience. (‘D,’ daughter)

One caregiver, however, did note that although she felt that she was knowledgeable about the role of OT and appreciated that what she got from occupational therapy services was exactly what she needed as a caregiver, her mother, while enjoying the interaction with the therapists, had a different take on the experience with occupational therapy:

Every day that she stayed, the whole process at St. Therese became a “test.” And if she didn’t pass the tests, she wasn’t going home; that was her thinking. So she got more anxious every day, and nobody picked up on that, until the coming home visit, when she came home to show her house…she thought she wasn’t ever coming home if she did not pass that test. Had I known that I would have talked to her quite a bit differently about the whole thing. (‘A,’ daughter)
This was the only reference in all eight interviews of a caregiver reporting that the patient was fearful and anxious, a theme that was much stronger in the first round of caregiver interviews. Related to this, another difference noted between the first round interviews and this caregiver in the second round was that this caregiver was not blaming the therapists for her mother’s fear and anxiety. Rather, this caregiver felt that she, knowing about and appreciating the role of occupational therapy, was the one who should have addressed the situation differently. Finally, one caregiver, reflecting on her interactions with occupational therapy stated that had she not had this positive experience at St. Therese with occupational therapy:

I would have challenged some of the results a little bit more. I would have asked “how did you get this?” That care conference, you know, the results from OT and PT were what I wanted to know, and it was really important to me. It was going to be her future, what we were going to do with her. (‘D.’ daughter)

There was one caregiver who reported a largely negative experience with her father’s stay at St. Therese. Though she did recall meeting with the occupational therapist to go over the cognitive testing, she had very little recall of any other details of the experience as it related to occupational therapy.

In summary, the themes derived from this round of interviews were generally more positive, even absent participation in all steps for the new caregiver education process. Table 16 summarizes the extent of caregiver participation in each step.
Table 16

*Caregiver Recall of the Steps of the New Education Process*

<table>
<thead>
<tr>
<th>Step of Process</th>
<th>Number of caregivers who recalled participation in the step*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Contact with occupational therapy during initial evaluation by phone or in person</td>
<td>4</td>
</tr>
<tr>
<td>Invitation to watch video</td>
<td>6</td>
</tr>
<tr>
<td>Actual watching of the video</td>
<td>3</td>
</tr>
<tr>
<td>Invitation to come in during occupational therapy</td>
<td>5</td>
</tr>
<tr>
<td>Received written education materials from occupational therapy</td>
<td>6</td>
</tr>
<tr>
<td>Met with occupational therapy to discuss test score and written handouts</td>
<td>4</td>
</tr>
</tbody>
</table>

*Note.* N=8.

*All caregivers were offered each step.*

**Observations by the therapists implementing the new process.** The two therapists utilizing the new process reported an overall positive experience with caregivers. They felt positive about the increased amount of contact they had with caregivers, though they noted that it did not come without a lot of effort, as described by one of the therapists:

> You know a lot of times we really have to make it work and it doesn’t always work in this setting because of the timing of when we need to get it done before the care conference because they’re waiting for it. We don’t always have time to get together with the family. So it’s hard sometimes, but when I was able to work it out, I liked it.

Both therapists also reported perceptions of improved communication with caregivers. One said:
I feel like using this process I was better able to say, and learn how to say, “these are some of the things I am seeing, can you tell me more about what you are seeing?” and I think that in itself gave them the ability to talk with me more.

The other commented:

Having that video definitely enhanced my ability to talk about things, because I can say “this video can probably say it a lot better than I can, so please watch it.”

In regard to their absence at the care conferences, both therapists reported consistent efforts at alerting caregivers to their absence and making arrangements to meet with caregivers prior to the care conference:

I really tried up front to warn my families that I am not going to be there, because they do miss us, they probably expect us. And I think of the people I worked with for this process, 80% I was able to meet with.

The therapists’ assessment of the revised written materials were mixed, especially as used when meeting with the caregivers. One remarked:

I guess I would say that as I was talking to people, I couldn’t say with any accuracy whether I felt they made a difference or not in the conversation. There were maybe one or two that I do recall throughout the process that would go home to their other family members and say “here is what they are saying at St. Therese,” but I experienced that before too.

When giving the recommendations, I tried to follow the handout, and have it highlighted ahead of time, and it didn’t work very well for me to look and talk at the same time. So a lot of times I would just summarize the information based on
what I was seeing, and the CPT score, and I would then say at the end “and
everything we’ve just talked about is written on here and highlighted.”

Therapists also noted changes in how their presentation of education was received by
caregivers when using the new process. One commented:

I felt that I got a little more respect for what I was saying, they still didn’t maybe
agree with it, but I felt like they respected my opinion as a professional, whereas I
don’t know that I experienced that as many times before.

The other found that:

There is a trust level that develops when we sit down and educate, but also when
we listen to how they feel about what they see. Just having that interchange is so
important.

The therapists attributed this new respect to the increased level of communication and
efforts to ask caregiver opinion about their loved needs:

I think it was because we took the time to talk to them and ask them questions
about what they wanted and what they saw as a viable outcome. It also helped
them to see that it is not ‘my opinion,’ but that it is based on a battery of
assessments and tasks, and it gave validity to help them understand that we are
not just seeing that their mother is confused, but we have specific data to say
“and these are the things she is having trouble with.”

Finally, the therapists concluded that the increased efforts on their part, though
worthwhile from their perspective, also required time that was a struggle in their current
system. One noted:
I was able to definitely talk to a lot more people. Conversely, my stress level and my amount of work and trying to do things throughout my day also increased. This definitely made more challenges to our job. If we had a 90% productivity expectation there is no way this would happen. You leave messages and get calls back and it doesn’t always happen when the patient is sitting right there, so you can’t bill for it.

Similarly, the other reported:

It’s just that within the current expectations of our free time, and then being able to call everybody, and work that out, and then half the time it doesn’t work into treatment time, and trying to…the communication piece and the time it can take, it’s pretty challenging to fit it in within the days you need to. You’re leaving messages and not hearing back, and trying to keep track of 6 people, stuff like that. I would try to set appointments with my people for the morning a couple of hours before the care conference, and try to fit in and change my schedule sometimes to see if they could come in before the conference, since they are coming in anyway.

Results of Checkland’s Soft Systems Step 7: Reflection about the proposed change

The larger group of therapists met to reflect on the caregiver feedback, the experiences of the two therapists who used the new caregiver education process, and the observations of those not using the new process. This group commented on observing caregivers watch the video in the occupational therapy clinic, and hearing many anecdotal remarks about how informative the caregivers thought it was. This was one
part of the process that was most strongly recommended by the larger therapist group to
be continued, even by those who were not using the video for their patients’ caregivers.

The two therapists using the new process reported to the group that they noticed
that everybody seemed to be making the initial calls to caregivers during the evaluation, a
step in the old process that had always been encouraged but seldom done. The other
therapists confirmed that not only were they increasingly performing this step, but that
most had also changed the type of interaction they were having with caregivers from that
of reporting information from the evaluation to one of asking for input from the
caregivers. This lead to further admissions by the other therapists that they too were
trying to invite caregivers in to therapy more frequently, with one admitting that she too
was trying to meet with caregivers prior to care conferences as well even though she was
not technically required to do so. When asked why they think this occurred, one therapist
said, “Well, it’s hard to continue doing the usual thing when we knew what the caregivers
told us about what they wanted.”

Other benefits identified by the therapists were a greater sense of professionalism
and satisfaction with the education process aspect of their practice, though these new
perceptions did surprise one therapist:

At first, in the back of my mind, a little part of me I felt like we were giving up
part of our job by asking the caregivers to give us input during the evaluation, and
I was unsure of how I felt about asking them to come in and meet with us. Yet
now, after doing this, I feel the exact opposite; giving the caregivers more say in
the process has made me feel more professional and I really enjoy the
communication with caregivers.
One benefit that therapists did not identify but that was reported by the occupational therapy manager was that the MD and others in care conferences had noticed that these meetings were running smoother, and that the person representing therapy was not spending nearly as much time trying to explain the recommendations from occupational therapy or deferring caregiver questions back to the occupational therapist.

**Decisions of St. Therese regarding the new caregiver education process.** The therapists felt strongly that the time required to coordinate the contact and meetings with caregivers was too great to spend on every patient for whom cognitive testing was ordered. They suggested identifying a “triage” system where the patients for whom they were recommending significantly more help or an entirely different discharge setting (e.g., going from independent living to assistive living) might be prioritized in terms of pursuing face to face caregiver education. However, occupational therapy management rejected this idea, and reminded the therapists that it was their aim to support best practice, and as such they wanted all patients who required caregiver education about cognition to be treated the same. To that end, occupational therapy management suggested that the therapy support staff person take over the calling for scheduling the face-to-face meetings for education prior to care conferences. They reasoned that this staff person was calling to arrange the care conferences anyway, so could easily add on this element to the schedule as well. In addition, this staff person has access to the therapists’ schedules and can easily add the agreed upon meeting with the caregiver onto the schedule and rearrange other patients as necessary to accommodate the face-to-face sessions with the caregiver.
All the therapists have to do is let the caregiver know during the evaluation call or voice message that the caregiver will receive a call from a scheduler to request a time to come in to talk with occupational therapy. The therapists were pleased with this solution, and agreed that, freed from playing phone tag and juggling schedules, they could continue to offer all patients the opportunity to come in to meet with occupational therapy. Occupational therapy management also agreed to keep all other elements of the new process, including the revised written materials, and suggested a plan for a professional production of the video that could also be used as a part of the marketing plans for the TCU.
Chapter Five: Discussion and Interpretation

The purposes of this study were (1) to gain an understanding of caregivers’ experiences with and perceptions of the process of receiving education from the occupational therapists at St. Therese homes about their loved ones’ CPT scores and the discharge recommendations provided by occupational therapists based on that score, and (2) to use the above understanding with the occupational therapists at St. Therese Homes to identify, create, and implement an improved process of providing caregiver education about CPT scores, so that it is truly individualized and client-centered. As demonstrated in chapter four, PAR as a methodology, guided by the use of Abad-Corpa’s et al. (2010) modified “Soft Systems” theoretical framework (Checkland, 1981), was an effective methodology to accomplish these goals. The step-by-step approach was utilized to assess the situation, gather and analyze data, make changes and try them out, and then assess the impact of the changes reflected a collaborative process among the therapist participants and between therapist and caregiver participants. This approach allowed each group to contribute according to their ability and scope of knowledge while working within the organizational constraints of St. Therese Homes.

Participants in both groups reflected the larger groups from which they were recruited. The therapist group was all female, which is consistent with a profession that is 92% female (AOTA, 2010), and represented a broad range in the number of years in practice. Both caregiver groups were also predominantly female, which fits with the literature describing that 65% of caregivers for this population are female (Bouldin & Anderson, 2010). All members of both groups were Caucasian, which is not unexpected
in Minnesota where 86% of the population is solely Caucasian (United States Census Bureau, 2014). The educational level of the caregiver groups was also representative of the educational levels in Minnesota, where 70% of the adult population has some college or higher level of education (Minnesota Office of Higher Education, 2014).

From a logistical perspective, the use of PAR as a methodology in a TCU presented some challenges. First, as in any health care settings, the business of treating patients was the top priority. As a result, trying to find times to meet with the therapists was difficult, even when the meetings times were preplanned well ahead of time. If the patient census was high, meetings not related to patient care were the first things canceled. This happened frequently, especially during the time frame when the first steps of the process were scheduled to occur. During the data analysis phases, I had to be especially firm in protecting enough time to allow the group to analyze the caregiver transcripts together. This was a delicate negotiation complicated by the fact that although this study was of great interest to St. Therese Homes, it was still a dissertation study. Had they paid a consultant to come in and direct this research study, they might have had a more vested interest in keeping a timely schedule, and might have been less questioning of the need for the amounts of time required to complete many of the steps of the process.

Finally, because of the St. Therese Homes mandate that therapists and caregivers not participate directly with each other (driven by HIPAA considerations), some of the essence of pure PAR methodology was lost.

Although in an ideal world it would have been wonderful to have the caregivers working directly with the therapists to co-create solutions, realities of the context in which the study occurred dictated otherwise. However, the work of the therapists as
significant stake holders who were actively creating a solution to a problem they had identified around their own practices did employ the principles of PAR to the fullest. In the end, the therapists were satisfied with the outcomes they achieved as identified by caregiver feedback and their own subjective observations. What follows is my own individual analysis of the underlying reasons why the data collected revealed what it did. My analysis will be shared with the therapists in a structured conversation to minimize potential feelings of judgment by me toward them and so that the concerns identified below might be addressed further by the group.

Discussion and Interpretation of Steps 1 and 2

Conflicting Perspectives. It was clear from the desires expressed by therapists in the beginning of this study that their initial motivation for making changes was driven by their perceptions of a lack of respect from caregivers. Their own assessment of the situation was that they had a unique contribution to make toward patient care because of their use of the CPT and ability to provide its results and recommendations to the caregivers. The main outcome they initially desired from this study was that their contributions in this regard be recognized and valued by the caregiver.

Prior to analyzing the caregiver feedback, the therapists’ perceptions of why they were not getting the respect they wanted focused mainly on finding fault with the caregivers. Although they did acknowledge that their logistical process for providing education about the CPT (e.g., absence from care conferences) and tools used (e.g., handouts) had room for improvement, these were the only factors in which they believed they had a role as part of the problem. Their assumptions about the reasons why caregivers were not happily and respectfully accepting the information they received
from occupational therapy about CPT scores did not reflect any other considerations of what the therapists were or were not doing in the process.

Feedback from the first round of caregiver interviews did not at all substantiate the assumptions of the therapists. It did however reflect what the literature clearly states about caregivers to those with dementia perceiving that health professionals are not very helpful (Tomita et al, 2010) and often do not address the problems they have identified (Lach & Chang, 2007). Caregiver feedback also reflected the findings of Turner & Street (1999), who reported that caregivers wanted not only information about dementia, but also specifically how to manage risk. The caregiver comments about recognizing risk, which appreciated the patients’ established habits and routines and the will to respect their autonomy in maintaining them, clearly reflected a desire to have information and recommendations that were not framed exclusively from the perspective of elimination of all risk. Rather, caregivers made it clear they wanted more collaborative relationships with the therapists, starting with an explicit invitation by the therapists to the caregivers to share their own perspectives as managers of that patient. Caregivers wanted more than just communication about assessment results; they wanted conversations about how to minimize risk yet still support participation in meaningful occupations by the patient. Therapists were somewhat surprised by these findings.

Lack of Client–Centered Care. There are a few different popular terms at present that at first glance all seem to refer to the same concepts of individualized care (e.g. patient- centered care, client-centered care, person-focused care). The term ‘patient–centered care’ comes out of the medical model. The Institute of Medicine (2011) defined patient-centered care as a philosophy of respect, responsiveness, and
attention to individual patient preferences, needs, and values to guide clinical decisions. This philosophy extends to the patient’s families and caregivers as well. Although this concept has been widely implemented in the years since the Institute of Medicine report that elevated it was published, what it looks like in theory versus what it look like in practice varies greatly. Epstein & Street (2011), provided this assessment:

Confusion about what patient-centered care really means, however, can produce efforts that are superficial and unconvincing. In the name of patient-centeredness, hospitals have been adopting models used by boutique hotels with greeters, greenery, and gadgetry. Although such amenities might enhance the patient’s experience, they do not necessarily achieve the goals of patient-centered care. Calls for patient-centered care have often emphasized the implementation of infrastructural changes. These changes, such as electronic health records and advanced access scheduling, may be necessary to move medical care into the 21st century, but they should not be conflated with achieving patient-centered care. Simply implementing an electronic health record in itself is not patient-centered unless it strengthens the patient-clinician relationship, promotes communication about things that matter, helps patients know more about their health, and facilitates their involvement in their own care. (p. 102)

Epstein and Street emphasize that patient-centered care is necessary at all levels in an organization, from the individual employee to the departments and the organization as a whole. Starfield (2011) however argues that the problem inherent in a patient-centered care philosophy, at least at the provider level, is that it is grounded in a diagnosis instead of the totality of the person’s experiences. Starfield suggests that ‘person-focused care’ is
a better model because its lens is not directed at one diagnosis and an encounter by
encounter perspective. Instead, person–focused care is oriented toward understanding
persons over time by accumulating knowledge of their comorbidities and other life
variables.

Within the profession of occupational therapy, those served by therapists are
referred to as clients (AOTA, 2014). Clients are persons, groups (which includes families
and caregivers) and populations (AOTA, 2014), and occupational therapists have been
charged to provide client-centered care. Though other professions also use the term
client-centered care, and in much of the literature the term is used interchangeably with
that of patient-centered care, I believe that in the profession of occupational therapy,
client-centered care is actually more closely aligned with person-focused care.
Therefore, in the rest of this section when I refer to client-centered care, I am using the
term to imply person–focused versus patient-centered occupational therapy practices.
However, I will continue to use the word ‘patient’ to distinguish the care recipients of
occupational therapy as that is what they are referred to at St. Therese which is an
inpatient setting.

There are many occupational therapy theoretical models that are built upon
concepts of client-centered care that also support person-focused care. In particular, the
ecological models of Person-Environment-Occupation, The Ecology of Human
Performance, and Occupational Adaptation all emphasize the interactional relationship
between the person, the occupation, and the influence of both the contexts and
environments in which occupations occur. In relation to both patient-centered and
person-focused care, these models highlight personal performance patterns and aspects of
context and environment that speak directly to personal preferences, needs, and values. They recognize that environments are much broader than just a physical place, and that the actions of the persons supporting individuals are one of many changeable elements of the environment that can ultimately inhibit or support engagement in occupation. Further, if therapists are not practicing from an occupational therapy model that supports full exploration of the role of the family and significant other caregivers, it is difficult to truly operate under a Family-Centered Care Model to support the caregivers and families of those with dementia.

Although St. Therese Homes had implemented many of the infrastructure changes to support patient-centered care as discussed by Epstein and Street (2011) above, the occupational therapists at St. Therese were not successfully integrating the professions core values of client centered care into the larger organizations philosophy of patient-centered care. It appears that the St. Therese therapists were evaluating patients largely through a patient-centered diagnostic driven lens and applying a narrow definition of environment when exploring that part of patients’ contexts. This narrower lens led them to place more emphasis during initial evaluations on identifying non-human elements in the patient’s home environment like architecture (e.g., number of stairs) and tools (e.g., grab bars) than on elements of the patient’s social environment, in which caregivers are often central figures. Although diagnosis, features of the physical environment and tools used are very important elements of a patient’s environment that need to be considered, limiting exploration of the role of the other persons involved in the social environment to basic questions like “does anyone help you?” does not help the therapist understand the potential “behind the scenes” occupational orchestration that is being provided by
caregivers. When this aspect of environment is not fully appreciated by the therapist, it is likely that the recommendations generated will feel out of sync to the caregiver. This was quite clearly the case at St. Therese, where the standard process at evaluation time was to gather all assessment data from therapy assessments and from patient report exclusively, and then dictate it back to the caregiver in a one-way discussion.

Although the therapists genuinely perceived their evaluation to be comprehensive, and likely considered their efforts to educate caregivers to be client-centered, the responses from the caregivers suggested otherwise. Caregiver feedback about not being asked for their input and not feeling like they were a part of a collaborative decision making process clearly reflected this discrepancy. Although patient self-reports, observations of performance, and use of standardized evaluations are all central features of therapy evaluations, they do not always paint an accurate picture for populations who rely on others to plan, orchestrate, and assist with aspects of their occupations. This is especially true in an inpatient setting such as St. Therese, where personal performance patterns and less tangible contextual and environmental variables are unlikely to be naturally expressed. The only way an occupational therapy evaluation can capture a more accurate picture of what the concerns with engagement in occupation outside of the inpatient setting might be is to have the therapist make a point to collaborate with caregivers. This in turn has the potential to also impact the receptivity of patients and their caregivers to taking advantage of the home safety evaluations offered to persons about to discharge from St. Therese back to the community. These visits could also be another touch point in the collaborative relationship between caregivers and therapists.
**Caregivers as guardians of quality of life.** One of the assumptions made by therapists suggested that caregivers were in denial about patients’ cognition, and as such were not open to the information being present by the therapists. However, the caregiver data did not show this to be true. None of the feedback from the first group of caregivers indicated that they were totally unaware of changes in patients’ cognition, and in fact, most acknowledged that they did see changes. Yet instead of framing the changes from a deficit perspective, most caregivers articulated that the patients were still capable of participating in occupations with support in spite of cognitive changes. Further, the first group of caregivers made it clear that while they knew that some of the occupations in which the patients engaged posed potential risk, their desire to respect the autonomy and dignity of the patient was stronger than the need to eliminate all risk. In fact, several caregivers seemed quite proud that their loved one had in fact returned to valued habits, routines, and occupations in spite of strong recommendations against doing so from therapists. Further, at the time of the interviews with this group of caregivers, none reported adverse events in patients related to disregarding discharge recommendations. This is significant as the timeframe between patient discharge and caregiver interviews in this group ranged from two to six months, providing plenty of time for possible negative consequences of disregarding therapy recommendations to occur.

These findings support what is well documented about maintaining dignity as a part of the quality of life for persons with dementia. Quality of Life (QOL) was first described the World Health Organization (WHO) in the 1980s (WHO, 2014). It is a multidimensional concept that recognizes the many objective factors and subjective perceptions that contribute to a person’s state of wellbeing. The concept has been further
expanded to Health Related Quality of Life (HRQOL), which emphasizes the physical and mental/emotional aspects of life that impact health (U.S. CDC, 2014).

Dignity as an integral part of both QOL and HRQOL for persons with dementia has been examined from two perspectives. The first is from the lens of the person with dementia and their own feelings about how they are being treated, and the second is from the perspective of the caregiver, whose actions toward the person with dementia confer dignity (Kane et al, 2003). To best support good HRQOL, the relationships between persons with dementia and their caregivers should simultaneously support these two aspects of dignity.

Persons with dementia, who by nature of the disease process are experiencing the loss of abilities that support the occupations and relationships that define them, want to feel respected as the whole persons they know themselves to be. Caregivers, often experiencing what has been referred to as anticipatory grief (Meuser & Marwit, 2001) as they watch the person with dementia slip further and further away, want to support the person’s identity and life roles for as long as possible. There was clearly evidence of this dynamic occurring in the patients for whom caregivers were interviewed, and it was not limited to just those who were providing the most significant amounts of care. Although caregivers were each in varying places on the caregiving continuum in terms of the level of support they were providing at the time of the interview, most made references to their awareness of the feelings of the patients and their own desire to not mandate changes that might diminish their dignity. This substantiates the finding of a lack of collaboration between therapists and caregivers, who were often put in the position of having to weigh
the recommendations for OT against their own assessment of their loved one’s abilities and desires, in order to support their loved one’s autonomy and dignity.

**Question of credibility.** One unexpected finding in the data collected from the first group of caregivers was the negative perception about occupational therapy that caregivers possessed based largely on what their loved ones reported doing in therapy. The many reports by caregivers of the remarks the patients made about occupational therapy mostly referenced both daily interventions in the clinic as well as the CPT assessment process. Words used such as ‘kindergarten work,’ ‘juvenile,’ and ‘kiddy work’ clearly indicated that patients felt that at least some of their occupational therapy was childlike, and other words such as ‘humiliated’ ‘insulted’ and ‘stupid’ were also strong indicators of their negative perceptions.

Therapy activities in use at St. Therese at the time that would lend themselves to this perception by patients were sorting buttons, stacking cones, playing simple card games such as Concentration that were viewed by patients as an enjoyable leisure activity and other activities not based in occupations. At best, these therapy interventions could be described as “preparatory tasks,” described in the OT Practice Framework, 3rd edition (AOTA, 2014) as:

> Actions selected and provided to the client to target specific client factors or performance skills. Tasks involve active participation of the client and sometimes comprise engagements that use various materials to simulate activities or components of occupations. Preparatory tasks themselves may not hold inherent meaning, relevance, or perceived utility as stand-alone entities. (p. s30)
The OT Practice Framework states that preparatory tasks are not to constitute an entire treatment session, and when possible, should reflect elements of components of occupations that are relevant and meaningful to the patient.

This was not the case at St. Therese at the time. Instead, therapists relied heavily on the same repertoire of preparatory tasks that were used with the many patients who were being treated in the OT clinic versus in their rooms, where therapists could offer interventions that were more grounded in occupation (e.g., completing morning self-care and dressing). Unfortunately, I have observed from my own work experiences that patients in inpatient settings do not always understand that participating in self-care ADL can be a therapeutic activity when performed under the direction and supervision of an occupational therapist. In a setting where nurses and aides otherwise provide assistance for nearly all aspects of ADL, what resonates with patients as “therapy” is what they do in the therapy clinic. This was quite evident in the caregiver comments as there were no references to any of the therapy activities occurring outside of the therapy clinic.

In regard to the remarks about the process of being evaluated with the CPT, many comments from caregivers noted that the patient was very afraid of “failing” the test and not being able to go home. In light of the previous discussion about dignity as an aspect of QOL, negative perceptions about why a person is being asked to complete a test or participate in therapy activities that do not seem relevant and age appropriate are more than just unpleasant to the patient; they undermine that patient’s dignity as a person. Further, therapists are not likely comprehending the magnitude of the impact of feelings of fear and failure on a patient’s dignity, nor the fact that patients, even those with memory deficits, communicate their feelings about this to their families and caregivers.
It was evident in this study that caregivers, as guardians of the patients’ QOL, paid attention to this information.

When therapists fail to recognize this potentially strong dynamic and utilize therapeutic activities that elicit the sorts of reactions described by the caregivers in this study, it sets the stage for dissonance in both the caregiver and the therapist. On the part of caregivers, occupational therapy services, though designated as professional, may not be perceived to be valuable. This perception, in combination with the fact that many patients and caregivers know very little about occupational therapy in the first place, contributes to a lack of professional credibility. Why would any caregiver, whose only knowledge of occupational therapy comes from watching or hearing about their loved one describe demeaning therapy activities, take seriously any recommendations from the therapist? What evidence do therapists provide that demonstrates they are qualified to not only assess cognitive skills, but to make sometimes life altering recommendations? Further exacerbating the lack of credibility is that therapists do not apply the available theoretical models such as PEOP to guide their practice, resulting in limited knowledge of the person for whom they are making potentially significant recommendations. It is only natural then that caregivers would question how therapists came to their conclusions about a person’s life outside of St. Therese when they have no evidence that the therapist considered much about the individual’s personal context and social environment.

Therapists, whose identities are that of a professional with a title and credentials, experience dissonance when they do not get the positive reaction to the services they provide or the information they offer. This is interpreted by the therapists as a lack of respect from patients and caregivers. This is likely the result of therapists operating from
an “expert” model rather than a truly patient-centered care model. In the expert model, the professional dispenses care and recommendations to the patient in a relatively one-way relationship. Recipients of care are expected to honor the expertise of the professional and accept the information, even if they have no intention of acting on it. Therapists expecting patients and caregivers to recognize the value of their contributions simply because they possess a professional title and use professional tools and assessments (e.g., the CPT) risk misplacing blame on patients and caregivers for the dissonance instead of examining their own practice.

Communication Issues. Another finding from the first set of caregiver interviews was that caregivers especially noticed the tone of communications. Comments about therapists and others on the team strongly emphasizing recommendations with a dictatorial tone were frequent. Other references to tone in communications reflected some caregiver’s perceptions that the therapists and the team were sometimes just going through the motion of transferring information versus truly having a conversation about its meaning for the patient. The particularly strong comment from the caregiver who reported that he felt like he was getting an update on a furnace repair instead of his mother perfectly captured this issue. Others noted that they detected an element of trying to scare the patient or caregiver into accepting the recommendations by strongly emphasizing worst possible scenarios as outcomes, which was not appreciated by either patients or caregivers.

Although therapists did not realize they were using tone and tactics that were negatively received, it is not surprising that they did so. When a therapist has concerns about a patient’s potential to be unsafe after they leave therapy, they are responsible for
communicating them to the patient and caregiver. However, if they are not getting the response to the information that they want from caregivers especially, therapists may subconsciously fall back into a more authoritative approach in order to feel like they have communicated their concerns sufficiently. Lack of a culture of truly patient-centered care likely facilitates this practice. Unfortunately, an authoritative tone, coupled with poor credibility, only further exacerbates the gap between what caregivers and therapists want and receive from each other.

**Systems Barriers.** Therapists’ assessment of the systems in place at St. Therese Homes that helped create the situation at the beginning of the study revealed those to be fairly consistent within the industry of transitional rehabilitation. Productivity expectations, which are actually a bit lower at St. Therese than in similar transitional care rehabilitation settings in the area, were the only exception. Only one of the variables identified, heavy reliance on written material to deliver caregiver education about CPT scores, was actually under the control of the therapists themselves. This fact may in part explain why the therapists did not assess themselves as having as large a role as they actually did have in terms of contributing to the caregivers’ dissatisfaction.

**Discussion and Interpretation of Steps 3, 4, and 5**

Envisioning an ideal process, comparing the current process to an ideal, and then ultimately reconciling the two to come up with a new process that was feasible at St. Therese Homes was one of the more challenging parts of this study. Work in these steps required that therapists step out of their current thinking about their work processes and materials to create a starting place from which to start making substantive changes to their caregiver education process. Although these steps were enjoyable, the last step was
more difficult to navigate as it involved ultimate approval from the management at St. Therese Homes.

**Processes.** The therapists, though initially somewhat surprised by the caregiver feedback in Step 1, did not discount it. This was reflected in their work in Step 3, when they identified their desired outcomes for a new process. In contrast to their earlier desire for respect from caregivers, the outcomes they imagined at this stage of the study clearly reflected the feedback expressed by caregivers. The emphasis in the new outcomes changed from a focus on the therapists needs to one in which the perceptions of the caregiver were the primary concern. Outcomes of increasing understanding of the profession, improved ease of understanding of the information, and perception of value of the information all reflected this shift in thinking. Although the therapists did not let go completely of the desire to have outcomes that were more reflective of their own needs, the two that they did choose (being seen as an equal member of the team, feeling like the education process was a productive use of their time) were likely to occur if the other caregiver oriented outcomes were achieved.

The ideal process that was originally conceived for caregiver education about CPT scores also reflected the incorporation of caregiver feedback, especially as it related to opportunities for communication between therapists and caregivers. Evidence of this was found in the multiple strategies proposed by the therapists to reach out to caregivers via phone, email and in person, and at key times. More importantly, the emphasis on reporting information to caregivers was switched to one of soliciting information from caregivers as key informants on the lives of the patients. Responding to the need of caregivers to have more conversations with the therapists lead to the explicit invitation to
caregivers to come in to observe occupational therapy and sit down face to face with the therapist to discuss the patient’s needs. Finally, remaining convinced that their participation in the care conference was critical to meeting the desired outcomes of the study, therapists designed the ideal process with this element as the central feature. Analysis of the gaps between the ideal and the current process distilled down to three things missing: 1) education about OT for patient and caregivers, 2) high quality communication of information (to include written and verbal communication) and 3) direct caregiver contact. These were the main points that therapists agreed must be addressed in whatever process was ultimately decided upon.

At the point in the study where the work was to reconcile the ideal process with one that was feasible at St. Therese Homes, discussions about competing needs between the therapists and management emerged. Therapists, now fully committed to strengthening their relationships with caregivers, wanted a process that involved not only themselves, but also the weekend therapy staff. Further, they requested not only that they participate in care conferences, but that they also get to follow their individual patients into their homes for the home safety evaluation.

The management, however, felt that both of these requests were not feasible because they would disrupt the business model. In particular, they explained that care conferences took a lot of time and were not billable if the patient wasn’t in attendance (which happened in about 50% of the conferences), and that the variability in the length of the care conferences would make it difficult to manage therapist’s individual productivity. In regard to the home safety evaluations, management cited the same concerns about productivity, and felt it was more efficient to have one therapist conduct
all of the home safety evaluations versus having individual therapists trying to work them into the schedules. Since the position for a therapist who performed home safety evaluations became open at the conclusion of the study, management agreed that whoever was hired into the position would be trained in the new caregiver education process and made aware of the results of the study so that the collaborative relationship begun at St. Therese would be carried into the home safety visit.

Although it did not seem so at first, this firm stance by management was likely a positive development. It forced the therapists to look more deeply at what they could change, namely their own person to person interactions and their tools. This lead to the creation of guidelines and suggested scripts for starting conversations with caregivers over the phone and in person for the purpose of both sharing evaluation information and getting more personal information about the patients in order to make more meaningful recommendations. Conversations then flowed to consideration of the timing of these communications for optimal impact.

Therapists identified key times during a patient’s stay (early during the OT evaluation, prior to cognitive testing, after cognitive testing, and before or after care conferences) to reach out to caregivers. The contacts at evaluation and those adjacent to care conference time were identified by the therapists as priority touch points. They agreed that they would manage their own schedules to accomplish these contacts. This was especially necessary to take advantage of the opportunities to meet with caregivers face to face that coincided with the caregiver coming in for a care conference anyway. Therapists proposed that they scheduled time with caregivers directly to sit face to face either just prior to the care conference (ideally) or immediately afterward to discuss the
occupational therapy recommendations. The therapists recognized that coordinating schedules with caregivers for this purpose had the potential to increase their work, but felt strongly enough about the potential value of this interaction that they were willing to try to make it work.

**Materials.** Therapists had identified that they relied heavily on their written materials in the current caregiver education process. This makes sense in a system where therapists have limited contact with caregivers and yet are expected to document that they have provided recommendations that address potential safety concerns post discharge. This is a common practice among therapists in the local area (Jones et al, 2009), and reflective of national trends that have been well documented over the past two decades that indicate an overwhelming amount of health information is presented in writing to patients and caregivers (U.S. Department of Health and Human Services, 2010).

The original caregiver education materials for the CPT scores were assessed to be largely written at a 10th grade reading level or higher, with reading ease scores well below the recommended score of 45 or higher (Si & Callan, 2001). They were not written in plain language, and were visually very crowded in an attempt to keep information to one sheet. In addition, there was information explaining the standardized nature of the CPT as a test, with no explanation of what “standardized” meant. In light of earlier discussions of therapists’ desires to be respected as professionals, it appears that the original materials attempted to serve a dual purpose of providing information to caregivers and elevating the status of occupational therapists as the professional who administered the test and made the recommendations. Neither purpose was being realized.
Revising the written materials was not an easy task. It proved impossible for our group, with relatively little expertise in this area and a limited amount of time to make the changes, to modify the original versions to get the overall reading levels down to the recommended 5th grade reading level as assessed by the SMOG calculator. Use of an expert in this area would likely have produced better results. However, the introductory paragraph on the materials that explained how occupational therapists decide which recommendations to make for a patient was reduced from a grade level of 17.1 on the original versions to 4.1 on the revised forms. Therapists were satisfied that this more dense section of information right up front was now written at a low enough grade level to not lose the average reader, and they hoped that the additional changes of more plain language, more white space, use of bullets and other easier to read formatting changes would improve the overall use experience. In addition, in response to caregiver feedback about not even knowing the name of the therapist making the recommendations for the patient, a large space for the therapist’s name and contact information was moved more prominently to the top of the forms. A second (back) side of the form was also added for examples of activities with which the patient might need help, with space for the therapist to write in additional personalized information.

The goal was to create a form that would facilitate a conversation between therapist and caregiver, but that could be understood by caregivers in the absence of a meeting with the therapist. Caregiver reviewers liked the changes and suggested that therapists consider circling or otherwise highlighting the examples on the back side to make it even more personalized for the patient. Therapists incorporated this suggestion.
The other handout revised was an overview of all of the cognitive functional levels. The same types of changes as described above were also made to this document, and a graphic was added as well to the front of the document to explain how cognitive testing fit into the rest of the therapy program. The therapists thought adding a graphic would break up the text and meet the needs of those with visual learning styles. With this change, the SMOG grade level for this form went down from 11.5 to 8.2, and the reading ease went up from 33 to 58. Half of the caregiver reviewers thought the graphic was helpful, and the other half had no comment.

The idea for a presentation came from recognizing the need to use multiple approaches (in person, in writing, visual and auditory) to convey information. The video presentation (an automated narrated PowerPoint loaded to a server for online access) was an entirely new creation. The goal of the presentation was to give an overview of the profession of occupational therapy, so that caregivers could better understand why occupational therapists were the ones making the types of recommendations they do. The content did cover assessment of thinking skills, but this was not the exclusive focus of the presentation. In particular, therapists also included information about the academic preparation of occupational therapy practitioners. The first draft of this slide included excessive detail about continuing education requirements and licensure; upon review the therapists did recognize that they were slipping into an old thinking pattern of trying to convince the audience of their credibility and cut most of it out. Feedback from the caregivers was overwhelmingly positive, and they suggested showing it to patients and caregivers at the earliest possible convenience.
**Discussion and Interpretation of Step 6**

Implementation of the new caregiver education process and materials did not roll out as neatly as desired. This was largely due to the decision by management to limit the roll out to two therapists instead of letting all six begin to use the new process and materials. Their reason for limiting the trial of the new process was that they did not want to introduce wide scale change until they knew it would be positively received. This meant that most of the department was functioning under the status quo, while only the two selected were allowed to implement the new process and materials. This aspect of the study seemed incongruent with the inclusive principles of PAR. As all of the therapists had worked together to co-create the changes they wanted to see, those who had to continue in the old process were unhappy that they did not get to participate in the changes from which the assessment of the success of the study would be judged. In the end, many confessed that they began using the new process and materials anyway, because they felt conflicted about using the old approach and materials when they knew from caregiver feedback it was not meeting the needs of caregivers. This disregard of the directive of management signaled a shift in therapists’ attitudes to that of a more client-centered orientation than they had previously.

**Caregiver Feedback.** As hoped, the caregiver feedback from the second group was overall much more positive than that of the first group. Differences between the first caregiver group and the second caregiver group who had the benefit of the piloted new CPT caregiver education process can be distilled down to positive changes in relationships, tone of communications, and utility of the information presented. Whereas the first group indicated they often didn’t know who the therapist was and felt like no one
ever asked them for their insights about the patient, the second group conveyed a very different experience. Their comments about frequent contact with therapists, feeling welcomed in therapy sessions, and having their input respected by the therapists demonstrated this turn around in the caregiver-therapist relationship.

One other notable change between the two groups that supports that therapist’s efforts to establish relationships with the caregivers was successful was the decline in references to noticing the absence of the therapist at care conferences. The first caregiver group reported strong negative opinions about the absence, however the second group did not. Although several caregivers made remarks about realizing the occupational therapist was not present at that meeting, they reported no perception of this being problematic. This was likely due to the efforts of the therapists to meet with caregivers right before or right after the care conference.

References to communication from the second group were actually glowing at times, with words like “wonderful” and “excellent” coming through in their descriptions. Differences in the tone of communications noted between the two groups were striking. Whereas the first group recalled an authoritative tone and use of words that seemed intended to scare both the patient and caregiver into agreeing with the recommendations, the second group made no mention at all of negative tone or use of scare tactics. Interestingly, the one reference in the second group to anything even close to that of the first group came when one caregiver noted that her mother was anxious about passing the test (CPT) and fearful of not being able to return home. This feedback by the patient to the caregiver was interpreted by the caregiver to be her own fault for not helping explain what was going on to her mother, rather than a reflection of something the therapist said.
to the patient. Though clearly the therapist should have noticed and addressed the anxiety of the patient, it appears that empowering the caregiver with knowledge of the occupational therapy process and supporting her participation in the process lead the caregiver to take some of the responsibility for managing her mother’s outcomes as well.

Utility of the information about CPT scores as presented by the occupational therapists was also perceived to be better in the second group of caregivers. This outcome, while anticipated with the improved readability and usability of the written materials and the development of the video presentation, was also likely influenced by the increased emphasis on therapists both personalizing the recommendations as well as presenting them verbally in face-to-face meetings. This practice reflects what the literature has established about both adult education and health education needing to be relevant to the person (in this context, relevant to caregiver as related to their support of the patient) and presented in multiple formats (in writing, visually, and verbally).

In total, the changes made by the therapists to their verbal communications and interactions with caregivers, along with the improved written handouts and development of the video presentation, collectively represented best practices in adult education. The use of multicomponent approaches, employing a variety of strategies that allow the caregiver to apply the information they are learning to their own relationship with the person for whom they provide care proved effective in this study.

Another difference between the two groups that supports the positive outcomes of this study were the lack of negative comments about occupational therapy activities reported by the second group of caregivers. Though this could have been a result of the small sample size of the second group of caregivers (N=8), the fact that it was such a
strong theme in the also relatively small sample of the second group of caregivers (N=12) suggests that the lack of comments in group two was an indicator of a positive change. The biggest factor likely contributing to this change was the informal strategy by the therapists to try to reduce the use of preparatory therapy activities in favor of more occupation-based interventions.

The other difference between the two caregiver groups that supports that the positive outcomes of this study was evidence of a phenomenon documented in the psychology literature relating to the timing of the caregiver interviews. The interviews of the first group of caregivers occurred an average of 3.1 months past the discharge date of the patient, while the second group of caregivers who experienced the piloted new education process occurred closer to the patient’s discharge at an average of 1.6 months. Even though the first group was further removed for the experience, they still had strong feelings (mostly negative) about their experiences. Time did not appear to diminish their dissatisfaction. This phenomenon of recalling negative experiences longer than more positive experiences is well documented in the psychology literature (Brown & Kulik, 1977; LaBar & Cabeza, 2006; Mather & Carstensen, 2005; McGaugh, 2004). Researchers believe that when persons attach emotions to experiences, the memories of the experience are stronger.

This phenomenon may explain why the first caregiver group had explicit recall of interactions and situations associated with occupational therapy at St. Therese Homes, even though they were interviewed nearly twice as far out from those interactions as compared to the second group of caregivers. Second, it might explain why the second group of caregivers, though they had less recall of specific incidences, had more positive
comments about their overall experiences with CPT education with the occupational therapists. It is possible that having no egregious experiences with occupational therapy (either themselves or as reported by the patients) that triggered their need to protect the patients dignity left them with less specific memories and yet an overall positive impression of their experience with occupational therapy at St. Therese.

**Therapist’s observations of the changes.** The two therapists who officially piloted the new CPT caregiver education were overall pleased with the new process and their efforts, and noted that they did feel more respected as professionals. They attributed this to being able to sit down with caregivers and have conversations about patient needs and caregiver desired outcomes, as well as to having the video in particular to prepare caregivers for these conversations. Although the video did help with caregivers understanding of occupational therapy, it was more likely that the relationship the therapists created with the caregivers was what contributed the most to leaving therapists feeling like their input was valued. This is because the video, though valuable, was still a one-way, non-personalized communication to caregivers that did not actively involve the therapists. Because they could offer recommendations that were reflective of caregiver concerns, therapists had something of value to bring to the conversation.

Another factor possibly influencing the perception of value was the one-to-one meeting with caregivers just prior to care conferences. The therapists reported going to great lengths to both alert caregivers to the fact that they would not be at the care conference and to arranging their schedules to make the one-to-one meetings happen. Although initially the therapists’ perspective was that they needed to be around the table with the other professionals to be recognized as such, the reality might actually be that
having client-centered information important enough to warrant an individual meeting actually elevates the perception of the professional value of occupational therapy by the caregivers.

**Discussion and Interpretation of Step 7**

Reflection on the piloted CPT caregiver education process by the entire group of therapists revealed shifts in thinking that supported the positive outcomes of this study. Some therapists were initially a bit nervous about the idea of involving the caregivers more, and believed that it was their job to be the one with the information about the patient (i.e., to practice from an expert model). However, after their own anecdotal observations of the improved quality of the interactions the two pilot therapists were having with caregivers, the other therapists found that it was difficult to continue to practice as they had been. This explains why the other therapists basically ignored the directive from management to continue with the status quo. Further, it also illustrates that therapists were willing to take responsibility for their own practice, which is an attribute of being a professional (Jackson, 2010). Fortunately the nature of this study, along with the fact that the materials and processes were not experimental, was such that the integrity of the study was not at risk by the actions of these therapists. Further, management also recognized that the therapists were only trying to promote best practice, and as such there were no ramifications of their actions.

The therapists’ recommendations to continue the new CPT caregiver education process based on the outcomes of this study were met with acceptance by the management. The surprise “late finding” of management reporting that care conferences were going more quickly and smoothly undoubtedly influenced their decision to offer up
a resource to assist with the scheduling of the one-to-one meetings so that therapist productivity would not be compromised. Although the overall productivity of the two therapists piloting the new CPT caregiver education process did not suffer, it did come at some cost to the department as the two therapists reported spending the time normally allocated to other activities such as program development making phone calls and trying to arrange meetings.

**Summary**

The purposes of this study were met using a PAR process that brought to light perspectives from both therapists and caregivers for the goal of improving the process of education about CPT scores for caregivers. Through analysis of caregiver feedback and expressed desires, therapists were able to re-imagine an education process and materials that better reflected a patient and family centered approach to education and that was feasible in a busy transitional care rehabilitation unit. Therapists’ desires to feel valued and respected as professionals, the initial driver of the study, were realized only when they let go of these goals and moved away from an expert model of practice to a more collaborative model of practice that engaged caregivers in conversations about patients. In turn, caregivers appreciated the more collaborative approach and saw occupational therapy as a valuable professional service that made a positive impact on the lives of patients.

**Implications for OT practice**

Mary Reilly (1962), in her 1961 Eleanor Clark Slagle Lecture over a half century ago astutely pointed out that the profession of occupational therapy could be one of the
greatest ideas of the 20th century, but only if it could demonstrate what vital need it served:

Therefore, to any group which aspires to be a profession, there is placed before it a clear-cut mandate. This mandate says that if we wish to exist as a profession we must identify the vital need of man which we serve and the manner in which we serve it. (p. 85)

Over 50 years later, this study presents several implications for occupational therapy practice that relate to Mary Reilly’s assertions. First and foremost, this study confirms that seeking out the voice of therapy recipients, to include families and caregivers, and then acting on their input, is critical to creating truly client-centered occupational therapy services. Assumptions about what our patients and their families need can be biased by our values and lead to erroneous conclusions. As the population of persons with Alzheimer’s disease and other dementias continues to increase, the “vital need” of our society to cope with and manage the impact of these conditions is an increasingly strong one. Bringing patients and caregivers, as the experts on their own needs and stakeholders of the therapy process, into a collaborative conversation to shape occupational therapy interventions is critical to ensuring that the profession remains relevant and of perceived benefit to its clients. As Mary Reilly further stated that “Society requires of us a much sharper focus on its needs” (1962, p. 85). That claim is just as true if not more so today.

This study also points to the need for occupational therapists to reset their professional lens toward activity and participation level outcomes as the main focus of occupational therapy interventions in any practice setting. The World Health Organization’s International Classification of Functioning, Disability, and Health (ICF)
defines that activity and participation refer to functional abilities, and are not dictated by a person’s body functions and structures (WHO, 2014). The Occupational Therapy Practice Framework is congruent with the ICF, and also articulates that the end result of the occupational therapy process should be engagement in occupation.

In contrast, many therapists, especially those in medical settings, can easily get side tracked assessing and treating body structures and/or functions under the assumption that improving those will automatically equate to improved function. In this mindset, therapists treating persons with dementia are often focused on the assessment of cognitive skills and the provision of safety recommendations reflective of cognitive status and do not give equal time to working with families and caregivers to figure out how to support the person in valued occupations once outside of the treatment setting. This was the case at St. Therese Homes. Caregivers in this study clearly focused on keeping their loved ones engaged, and were less concerned with knowing the detailed explanation of cognitive deficits (body functions) as measured by the CPT.

Third, this study also reiterates the need for occupational therapists to pay attention to the theoretical frameworks and models that are applicable to the populations they treat. When practice does not reflect use of a guiding framework that is appropriate for the population, there is a risk that significant variables in the equation for engagement in occupation for the person treated will be missed or underappreciated. Several of the ecological models mentioned earlier (PEOP, Occupational Adaptation, the Ecology of Human Performance) are appropriate for guiding the development of the occupational profile, and make explicit the need to explore the role of others in a person’s various contexts. Failure to work from a guiding theoretical framework can lead to therapy
recommendations that may not be useful out of the context of the treatment setting. This was the experience of many of the caregivers in the first group who reported ignoring the recommendations made by the occupational therapist once the patient had returned home, or who reported having no more direction for supporting their loved one than they had before occupational therapy intervention.

In addition to these implications, this study also illustrated that having a professional credential and using standardized tools does not alone confer professional credibility and perceptions of value. In addition, therapists must orchestrate the other aspects of their practice so that patients and caregivers see the relevance of therapy interventions to their daily lives. Failure to do so diminishes the trust of patients and caregivers that the therapist really understands their needs and desired goals. Further, therapists need to appreciate that asking patients to do therapy activities that do not make sense or feel demeaning significantly devalues occupational therapy and does not help portray the profession as a valuable part of the health care system. In an era when consumers are directing more of their own health care spending (Buntin et al, 2006), the profession cannot afford to alienate anyone who might take negative impressions of one experience with occupational therapy, be it their own or that of their loved ones, and assume that all occupational therapy is not worth the time it takes or the money it might cost.

Another implication for practice derived from this study is the importance of consideration of language and tone in communications with both patients and caregivers. Even if all of the other considerations described above are addressed, failure to communicate in a respectful tone and with supportive language will diminish any value
of the content relayed. As this study demonstrated, language and tone have the potential to evoke strong emotions, and in turn can leave patient and caregiver with long lasting negative impressions that they will remember longer than might be suspected.

This study also demonstrated that it is necessary to make changes to practice that work within existing systems. Wishing for other circumstances or a return to another era of time does not show the profession to be flexible and willing to actively co-create solutions to day to day problems in current clinical practice. In the absence of active problem solving, acquiescing to less than desirable practices in the name of maintaining the status quo only puts the profession at risk of having its practices dictated by others. A proactive approach to problem solving, even if at first it seems to reveal more barriers, can yield creative ideas not previously considered that are capable of bringing about desired changes.

Finally, the conclusions of this study also have implications for the clinical education of occupational therapy students. Many professional habits develop beginning in fieldwork, and students are looking to their clinical educators as role models. If students are taught OT theory and the OT process from a client centered perspective in school, but do not see these same practices in the clinical world, it is likely that they will be at risk for developing many of the same habits the St. Therese therapists possessed at the beginning of this study. To that end, students have to be empowered with not only with didactic knowledge of best practices, but also with action strategies to move practice forward in ways within systems and the politics of interpersonal relationships in the workplace so that suggestions for change are not perceived to be threatening. The profession would be well served if it had accreditation standards addressing competencies
to facilitate organizational change that could be assessed in Level II fieldwork experiences.

**Implications for further research**

Outcomes of this PAR study lead to further potential research questions such as:

1. What is the impact of therapy interventions on patients’ perceptions of the value of occupational therapy? And
2. Is PAR an effective methodology for the purpose of changing practice in occupational therapy?

This study also demonstrates that PAR as a methodology in occupational therapy research has the potential to contribute valuable understanding of the persons and processes involved in potentially any aspect of occupational therapy. Further development of PAR as a methodology in occupational therapy should also focus on bringing therapists, patients, and caregivers together as equals in the collaborative process.

**Limitations**

This study was conducted over an extended length of time, with a small group of therapists and small groups of caregivers, in a practice setting that though not unique, presented its own challenges to conducting research. The therapist participants were not trained researchers, and data analysis, though done methodically and collaboratively following a prescribed process, was performed under time constraints and was potentially subject to bias of the therapists. Further, the role of caregivers as participants in this study was limited by constraints imposed by the site of the study and the requirements of
HIPAA. Therefore the results obtained in this PAR study cannot be generalized to other settings or other populations.

Recommendations

The results of this study have been presented to the management of St. Therese Homes. Having now successfully implemented a change in one particular aspect of practice using the PAR methodology, it is recommended that St. Therese Homes develop a formal process by which to obtain patient and caregiver feedback about occupational therapy practice in their setting, and strive for one that brings therapists and persons impacted by occupational therapy practices directly together.


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Appendix A

Demographic information about therapist participants.

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<tr>
<th>Participant</th>
<th>Entry Level OT degree:</th>
<th>Years in practice:</th>
<th>Years at St. Therese:</th>
<th>Number of CPTs administered weekly</th>
<th>Training to administer CPT:</th>
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<td>1</td>
<td>B.S.</td>
<td>21+</td>
<td>7.5</td>
<td>8</td>
<td>Level II FW with CPT creator Teressa Burns</td>
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<td>2.5</td>
<td>2</td>
<td>Learned it on Level II FW</td>
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Appendix B

Informed Consent: Therapist Participants

Therapist Consent Form for Participation in the Research Study Entitled
Participatory Action Research to Improve Caregiver Education for
Persons with Alzheimer’s Disease and Mild Cognitive Impairment based
on the use of the Cognitive Performance Test (CPT)

Funding Source: None.

IRB protocol #06071203

Principal investigator
Terrianne Jones, MA, OTR/L
3043 Benjamin St NE
Minneapolis, MN 55418
612-626-3252

Co-investigator
Catherine Peirce, Ph D.
3200 So. University Drive
Davie, Florida 33314
954-262-1223

For questions/concerns about your research rights, contact:
Human Research Oversight Board (Institutional Review Board)
Nova Southeastern University
(954)262-5369/Toll Free:866-499-0790
IRB@nsu.nova.edu

Site Information
St. Therese Homes, Inc.
8000 Bass Lake Rd
New Hope, MN 55428

What is this study about?
You are invited to be in a research study of how caregivers to persons with dementia feel about the education they received about their loved ones cognitive abilities, from testing done at Saint Therese Home Transitional Care Unit, New Hope, MN.

Why are you asking me?
You were selected as a possible participant because you are an occupational therapist employed by St. Therese Homes, Inc. who administers the Cognitive Performance Test.

Initials:______ Date:_______
What will I be doing if I agree to be in the study?
If you agree to be in this study, we would ask you to do the following things:
1. Complete a short demographic questionnaire.
2. Participate in 4-5 focus groups that will last approximately one hour and will be audio recorded for note taking purposes.
3. Be available for occasional follow up phone calls or emails to clarify notes from the focus groups.
4. Work with the primary investigator to help create a draft caregiver education protocol and materials that have incorporated your feedback as well as caregiver subjects feedback.
5. Work with the primary investigator to devise an evaluation plan to evaluate the new protocol.

Is there any audio or video recording?
This research will involve audio recording of focus groups via a digital voice recorder. This audio recording will be available to be heard by the researcher, the IRB, Saint Therese Homes Inc. and Dr. Catherine Peirce, dissertation committee chair. The recording will be transcribed by the primary investigator, Terrianne Jones, and will be kept securely on a password protected secure server at the University of Minnesota. The recording will be kept for 36 months after the end of the study and destroyed by permanent deletion after that time. Because your voice will be potentially identifiable by anyone who hears the recording, your confidentiality for things you say on the recording cannot be guaranteed although the researcher will try to limit access to the tape as described in this paragraph. At the time of transcription, all names will be coded for your privacy so that when focus group or interview data is shared with the caregiver subjects participating in the study, no information can be linked to you.

What are the dangers to me?
The study poses minimal risk to you. You may occasionally be asked to read or reflect on the work of the group during the course of your regular work day. In addition, there is the potential for loss of confidentiality as the information you share in a focus group will be heard by others in the focus group, in addition to the researcher. To minimize this risk, at the beginning of each focus group, the researcher will discuss with the group participants the importance of not disclosing group discussions outside of the focus group.

You may contact the IRB at the numbers indicated above with questions as to your research rights. You may also contact Terrianne Jones or Dr. Catherine Peirce at the phone numbers listed above if you have any questions or concerns about the research, your research rights, or have a research-related injury.

Initials:_______ Date:_______  
Page 2 of 4
If you have any questions or concerns regarding the study and would like to talk to someone other than the researcher(s), you are encouraged to contact the Fairview Research Helpline at telephone number 612-672-7692 or toll free at 866-508-6961. You may also contact this office in writing or in person at University of Minnesota Medical Center, Fairview Riverside Campus, 2200 Riverside Avenue, Minneapolis, MN 55454.

Are there any benefits to me for taking part in this research study?  
There is no direct benefit to subjects who participate in this study.

Will I get paid for being in the study? Will it cost me anything?  
There are no costs to you or payments made for participating in this study.

How will you keep my information private?  
All information obtained in this study is strictly confidential unless disclosure is required. Your answers to questionnaires, focus groups and interviews will not have information that could be linked back to you. In any sort of report we might publish, we will not include any information that will make it possible to identify you. Research records will be stored securely and only researchers will have access to the records. Study data will be encrypted according to current University policy for protection of confidentiality. Audio tapes will be transcribed, then deleted 36 months after the end of the study. The IRB, regulatory agencies or Dr. Peirce may review the research records.

What if I do not want to participate or I want to leave the study?  
Participation in this study is voluntary. Your decision whether or not to participate will not affect your current or future relations with the St. Therese Homes Inc. If you decide to participate, you are free to not answer any question or withdraw at any time without affecting this relationship. If you choose to withdraw, any information collected from you before the date you leave the study will be kept in the research records for 36 months from the conclusion of the study and may be used as part of the research.

Other Considerations:  
If the researchers learn anything which might change your mind about being involved, you will be told of this information.

Initials: ______ Date:_______
Voluntary Consent by Participant:
By signing, you indicate that

- This study has been explained to you
- You have read this document or it has been read to you
- Your questions about this research study have been answered
- You have been told that you may ask the researchers any study related questions in the future
- You have been told that you may ask Institutional Review Board (IRB) personnel questions about your study rights
- You are entitled to a copy of this form after you have read and signed it

You voluntarily agree to participate in the study entitled Participatory Action Research to Improve Caregiver Education for Persons with Alzheimer’s Disease and Mild Cognitive Impairment based on the use of the Cognitive Performance Test (CPT)

Participant’s Signature: ___________________________ Date: __________
Participant’s Name: ______________________________ Date: __________
Investigator’s Signature: __________________________ Date: __________

Initials: _____ Date: _______
Appendix C

Caregiver Recruitment Letter

Dear __________,

My name is Terrianne Jones. I am a doctoral student in the Occupational Therapy Department at Nova Southeastern University. I am also an instructor of Occupational Therapy at the University of Minnesota and an occupational therapist at St. Therese Homes. I am conducting a research study as part of the requirements of my doctorate degree in occupational therapy and I would like to invite you to participate. This study is not funded or sponsored by any agency.

I am studying how caregivers such as yourself feel about how the discharge information/education from occupational therapy was provided to you at your loved ones’ discharge meeting at St. Therese. You were selected to participate because your loved one received occupational therapy services at St. Therese and because your loved one was evaluated with the Cognitive Performance Test to help the therapists make discharge recommendations.

In particular, I am interested in hearing your opinions and suggestions for how the occupational therapists might improve the education they give to caregivers. Though there is no direct benefit to you for participating in this study, your participation will provide St. Therese with valuable information about what is important to caregivers so that we can improve our services for future patients and caregivers at St. Therese.

If you decide to participate, you may be asked to complete a paper survey, participate in a small focus group with other caregivers, and /or participate in an individual interview. The study will last several months, requiring approximately 1-2 hours of your time in total.

Your participation in this study is confidential. Study information will be kept in a secure location at the University of Minnesota. The results of this study will be presented and published but your identity will not be revealed.

If you have any questions that I may answer before you begin the study please contact me at 612-626-3252. **If you would like to participate, please return the enclosed stamped response card provided.** I may also call you in the next few weeks to see whether you are willing to participate.

Sincerely,

Terrianne Jones, MA, OTR/L
516 Delaware St SE
Minneapolis MN 55455
jone1727@umn.edu
Appendix D

Informed Consent: Caregiver Participants

Funding Source: None.

IRB protocol #

Principal investigator Co-investigator
Terrianne Jones, MA, OTR/L Catherine Peirce, Ph D.
3043 Benjamin St NE 3200 So. University Drive
Minneapolis, MN 55418 Davie, Florida 33314
612-626-3252 954-262-1223

For questions/concerns about your research rights, contact:
Human Research Oversight Board (Institutional Review Board)
Nova Southeastern University
(954)262-5369/Toll Free:866-499-0790
IRB@nsu.nova.edu

Site Information
St. Therese Homes, Inc.
8000 Bass Lake Rd
New Hope, MN 55428

What is this study about?
You are invited to be in a research study of how caregivers to persons with dementia feel about the education they received about their loved ones cognitive abilities, from testing done at St. Therese Home Transitional Care Unit.

Why are you asking me?
You were selected as a possible participant because your loved one was a patient at St. Therese in the Transitional Care Unit in the past year, and received cognitive testing performed by occupational therapy staff. There will be approximately 20 participants in this study.

Initials:______ Date:_______
What will I be doing if I agree to be in the study?
If you agree to be in this study, we would ask you to do the following things:
6. Complete a short demographic questionnaire.
7. Participate in one small focus group with other caregivers that will last approximately one hour and will be audio recorded for note taking purposes. In the focus group you will be asked questions about your experience getting information about your loved ones abilities at discharge from St. Therese. Your comments will be used to make changes to how the occupational therapists provide caregiver education at St. Therese.
8. If you elect to, you may participate in a personal interview of approximately one hour that will be audio recorded for note taking purposes, scheduled at your convenience at a time separate from the above focus group.
9. Be available for occasional follow up phone calls to clarify notes from either the focus group or interview if necessary.
10. Read the new plan for providing caregiver education at St. Therese that has incorporated your feedback, so that you can tell us your opinion about the new materials and give further feedback.

Is there any audio or video recording?
This research will involve audio recording of focus groups and interviews. This audio recording will be available to be heard only by the researcher, Terrianne Jones. The recording will be transcribed by Terrianne Jones in a private and secure area to guard your privacy. The recording will be kept securely on a password protected, secure server at the researchers university (University of Minnesota). The recording will be kept for 36 months and permanently deleted after that time. At the time of transcription, all names will be coded for your privacy so that when focus group or interview data is shared with the St. Therese therapists participating in the study, no information can be linked to you.

What are the dangers to me?
The study poses minimal risk to you. You may experience feeling of sadness discussing your loved ones dementia or cognitive decline.

Are there any benefits to me for taking part in this research study?
There is no direct benefit to subjects who participate in this study.

Initials: _______ Date: _______
Will I get paid for being in the study? Will it cost me anything?
There are no costs to you or payments made for participating in this study.

How will you keep my information private?
All information obtained in this study is strictly confidential unless disclosure is required. Your answers to questionnaires, focus groups and interviews will not have information that could be linked back to you. In any sort of report we might publish, we will not include any information that will make it possible to identify you. Research records will be stored securely and only researchers will have access to the records. Study data will be encrypted according to current University policy for protection of confidentiality. Audio tapes will be transcribed, then deleted 36 months after the end of the study. The IRB, regulatory agencies or Dr. Peirce may review the research records.

What if I do not want to participate or I want to leave the study?
Participation in this study is voluntary. Your decision whether or not to participate will not affect your current or future relations with the St. Therese Home. If you decide to participate, you are free to not answer any question or withdraw at any time without affecting this relationship. If you choose to withdraw, any information collected from you before the date you leave the study will be kept in the research records for 36 months from the conclusion of the study and may be used as part of the research.

Other Considerations:
If the researchers learn anything which might change your mind about being involved, you will be told of this information.
Voluntary Consent by Participant:
By signing, you indicate that
- This study has been explained to you
- You have read this document or it has been read to you
- Your questions about this research study have been answered
- You have been told that you may ask the researchers any study related questions in the future
- You have been told that you may ask Institutional Review Board (IRB) personnel questions about your study rights
- You are entitled to a copy of this form after you have read and signed it
You voluntarily agree to participate in the study entitled Participatory Action Research to Improve Caregiver Education for Persons with Alzheimer’s Disease and Mild Cognitive Impairment based on the use of the Cognitive Performance Test (CPT)

If you have any questions or concerns regarding the study and would like to talk to someone other than the researcher(s), you are encouraged to contact the Fairview Research Helpline at telephone number 612-672-7692 or toll free at 866-508-6961. You may also contact this office in writing or in person at University of Minnesota Medical Center, Fairview Riverside Campus, 2200 Riverside Avenue, Minneapolis, MN 55454.

Participant’s Signature: ____________________________ Date: __________
Participant’s Name: ____________________________ Date: __________
Investigator’s Signature: ____________________________ Date: __________

Initials: _____ Date: _______
Appendix E
Letter of Cooperation

Saint Therese

Letter of Cooperation - Consent for Research at Saint Therese Homes, Inc.

Participatory Action Research to Improve Caregiver Education for Persons with Alzheimer's disease or Mild Cognitive Impairment based on the use of the Cognitive Performance Test

Principal Investigator:
Terriane Jones, MA, OTR/L
3043 Benjamin St NE
Minneapolis, MN 55418

This letter is to confirm permission for the principle investigator named above to engage in the above proposed study after approval by the Institutional Review Boards of both University of Minnesota and Nova SE University have been obtained.

What is the study about?
This purpose of this study is to identify how helpful the caregiver education being provided by occupational therapists at Saint Therese is for caregivers of those with dementia. This study will get input from the caregivers of those who have received cognitive testing from the occupational therapy department at Saint Therese New Hope, as well as from the therapists who administer to testing. The goal is to create a new and improved process for creating and delivering caregiver education from the occupational therapy department that is valuable to caregivers of those with dementia.

Why is the study being conducted at Saint Therese?
Saint Therese serves many older adults with dementia and cognitive decline who are admitted to the transitional care unit for short term rehabilitation. Cognitive testing by occupational therapy is routinely ordered for these patients, and the occupational therapists provide feedback to the family and the care team about cognitive assessment results and recommendations for caregivers. The therapists at Saint Therese desire to evaluate their process and strategies of creating and delivering caregiver education for this population, and wish to work with the principle investigator to address this aspect of their practice.

What role will the organization have in this research?
Saint Therese will provide access to a pool of potential subjects for recruitment of caregiver subjects by the PI from the medical records, as well as providing the therapist subjects for this study. Saint Therese agrees to allow the PI to access patient medical records to identify potential caregiver subjects for recruitment.

<table>
<thead>
<tr>
<th>Saint Therese of Oxrow Lake</th>
<th>5200 Oak Grove Parkway</th>
<th>Brooklyn Park, MN 55443</th>
<th>763.493.7020</th>
</tr>
</thead>
<tbody>
<tr>
<td>Saint Therese of New Hope</td>
<td>8000 Bass Lake Road</td>
<td>New Hope, MN 55428</td>
<td>763.531.5000</td>
</tr>
<tr>
<td>Saint Therese of St. Odilia</td>
<td>3500 Vincia Avenue</td>
<td>Shoreview, MN 55126</td>
<td>651.842.6780</td>
</tr>
<tr>
<td>Saint Therese Foundation</td>
<td>8000 Bass Lake Road</td>
<td>New Hope, MN 55428</td>
<td>763.531.5000</td>
</tr>
</tbody>
</table>

www.theresenmn.org
Appendix F

Nova SE University IRB Approval

MEMORANDUM

To: Tertianne Jones, MA, OTR/L
HPD—College of Health Care Sciences

From: Ana I. Fins, Ph.D.
Chair, Institutional Review Board

Date: July 12, 2012

Re: Participatory Action Research to Improve Caregiver Education for Persons with Alzheimer’s Disease and Mild Cognitive Impairment Based on the Use of the Cognitive Performance Test (CPT) - Research Protocol No. 06071203Exp.

I have reviewed the revisions to the above-referenced research protocol by an expedited procedure. On behalf of the Institutional Review Board of Nova Southeastern University, Participatory Action Research to Improve Caregiver Education for Persons with Alzheimer’s Disease and Mild Cognitive Impairment Based on the Use of the Cognitive Performance Test (CPT) is approved in keeping with expedited review categories #6 and #7. Your study is approved on July 12, 2012 and is approved until July 11, 2013. You are required to submit for continuing review by June 11, 2013. As principal investigator, you must adhere to the following requirements:

1) CONSENT: You must use the stamped (dated consent forms) attached when consenting subjects. The consent forms must indicate the approval and its date. The forms must be administered in such a manner that they are clearly understood by the subjects. The subjects must be given a copy of the signed consent document, and a copy must be placed with the subjects’ confidential chart/file.

2) ADVERSE EVENTS/UNANTICIPATED PROBLEMS: The principal investigator is required to notify the IRB chair of any adverse reactions that may develop as a result of this study. Approval may be withdrawn if the problem is serious.

3) AMENDMENTS: Any changes in the study (e.g., procedures, consent forms, investigators, etc.) must be approved by the IRB prior to implementation.

4) CONTINUING REVIEWS: A continuing review (progress report) must be submitted by the continuing review date noted above. Please see the IRB web site for continuing review information.

5) FINAL REPORT: You are required to notify the IRB Office within 30 days of the conclusion of the research that the study has ended via the IRB Closing Report form.


Cc: Dr. M. Samuel Cheng
Dr. Cathy Peirce
Ms. Jennifer Dillon
Novo Southeastern University

MEMORANDUM

To: Irizarie Jones, MA, CTR/L
    EPO – College of Health Care Sciences

From: David Thomas, M.D., J.D., 45s for D1
    Chair, Institutional Review Board

Date: June 13, 2013

Re: Participatory Action Research to Improve Caregiver Education for Person with Alzheimer’s Disease and Mild Cognitive Impairment based on the Use of the Cognitive Performance Test (CPT) - Research Protocol No. 09071207(P).

I have reviewed the above-referenced research protocol by an expedited procedure. On behalf of the Institutional Review Board of Nova Southeastern University, Participatory Action Research to Improve Caregiver Education for Person with Alzheimer’s Disease and Mild Cognitive Impairment based on the Use of the Cognitive Performance Test (CPT) is approved. Your study is approved on June 12, 2013 and is approved until June 11, 2014. You are required to submit for continuing review by May 11, 2014. As principal investigator, you must adhere to the following requirements:

1) CONSENT: You must use the stamped (dated consent forms) attached when consenting subjects. The consent forms must indicate the approval and its date. The forms must be administered in such a manner that they are clearly understood by the subjects. The subjects must be given a copy of the signed consent document, and a copy must be placed with the subjects’ confidential chart file.

2) ADVERSE EVENTS/UNEXPECTED PROBLEMS: The principal investigator is required to notify the IRB chair of any adverse reactions that may develop as a result of the study. Approval may be withdrawn if the problem is serious.

3) AMENDMENTS: Any changes in the study (e.g., procedures, consent forms, investigators, etc.) must be approved by the IRB prior to implementation.

4) CONTINUING REVIEW: A continuing review report must be submitted by the continuing review date noted above. Please see the IRB web site for continuing review information.

5) Final Report: You are required to notify the IRB Office within 30 days of the conclusion of the research that the study has ended via the IRB Closing Report form.


Cc: Dr. M. Samuel Chang
    Dr. Cathy Petrus
    Ms. Jennifer Dillon

Institutional Review Board
200 College Drive – Fort Lauderdale, FL 33314-7796
(954) 561-3888 • Fax (954) 262-5360 • E-mail: IRB@novasc.edu • Web site: www.nova.edu/irb
MEMORANDUM

To:    Veronica Jones, M.A., OTR/L  
HFD – College of Health Care Sciences

From:  David Thomas, M.D., J.D.  
Chair, Institutional Review Board

Date:  May 15, 2014

Re:    Participatory Action Research to Improve Caregiver Education for Persons with Alzheimer’s Disease and Mild Cognitive Impairment Based on the Use of the Cognitive Performance Test (CPT)—NSU IRB Protocol No. 06071203

I have reviewed the above-referenced research protocol in keeping with Continuing Review requirements by an expedited procedure. On behalf of the Institutional Review Board of Nova Southeastern University, Participatory Action Research to Improve Caregiver Education for Persons with Alzheimer’s Disease and Mild Cognitive Impairment Based on the Use of the Cognitive Performance Test (CPT) is approved. Yearly study is approved on May 15, 2014 and is approved until May 14, 2015. You are required to submit for continuing review by April 14, 2015. As principal investigator, you must adhere to the following requirements:

1)     ADVERSE EVENTS/UNANTICIPATED PROBLEMS: The principal investigator is required to notify the IRB chair of any adverse reactions that may develop as a result of this study. Approval may be withdrawn if the problem is serious.

2)     AMENDMENTS: Any changes in the study (e.g., procedures, new recruitment, investigators, etc.) must be approved by the IRB prior to implementation.

3)     CONTINUING REVIEWS: A continuing review (progress report) must be submitted by the continuing review date noted above. Please see the IRB website for continuing review information.

4)     FINAL REPORT: You are required to notify the IRB office within 30 days of the conclusion of the research that the study has ended via the IRB closing report form.


CC:     Dr. M. Samuel Chang  
Dr. Conley Pierce  
Ms. Jennifer Dillon
Appendix G

University of Minnesota IRB Approval

UNIVERSITY OF MINNESOTA
Twin Cities Campus

Human Research Protection Program
Office of the Vice President for Research
2528 Mayo Memorial Building
420 Delaware Street S.E.
MMC 520
Minneapolis, MN 55455
Phone: 612-626-5143
Fax: 612-626-9243
E-mail: irb@umn.edu or irb@umn.edu
Website: http://research.f.umn.edu/irb/appendix/

07/02/2012

Terrianne T Jones
Allied Health - OT, Ctr
MMC 368 Mayo
420 Delaware St SE
Minneapolis, MN 55455

RE: "Participatory Action Research to Improve Caregiver Education for Persons with Alzheimer's Disease and Mild Cognitive Impairments based on the use of the Cognitive Performance Test (CPT)
IRB Code Number: 1205P14403"

Dear Terrianne Jones:

The Institutional Review Board (IRB) received your response to its stipulations. Since this information satisfies the federal criteria for approval at 45CFR46.111 and the requirements set by the IRB, final approval for the project is noted in our files. Upon receipt of this letter, you may begin your research.

IRB approval of this study includes the caregiver consent form and therapist consent form, both received June 26, 2012.

The IRB would like to stress that subjects who go through the consent process are considered enrolled participants and are counted toward the total number of subjects, even if they have no further participation in the study. Please keep this in mind when calculating the number of subjects you request. This study is currently approved for 30 subjects. If you desire an increase in the number of approved subjects, you will need to make a formal request to the IRB.

For your records and for grant certification purposes, the approval date for the referenced project is June 7, 2012 and the Assurance of Compliance number is FWA0000312 (Fairview Health Systems Research FWA0000325, Gillette Children's Specialty Healthcare FWA00004003). Research projects are subject to continuing review and renewal; approval will expire one year from that date. You will receive a report form two months before the expiration date. If you would like us to send certification of approval to a funding agency, please tell us the name and address of your contact person at the agency.

Page 1
Gophermail: Message Display

Printed:

Mon 10 June 2013, 13:07:34 (CDT)

Subject: 1205S14403 - PJ Jones - IRB - APVD Continuing Review
From: irb@umn.edu
Date: Thu, 16 May 2013 23:16:24 -0500 (CDT)
To: jone1727@umn.edu

Section 2:
TO : jone1727@umn.edu, cpeirce@g Nova.edu,

The IRB: Human Subjects Committee renewed its approval of the referenced study listed below:

Study Number: 1205S14403
Principal Investigator: Terrianne Jones
Expiration Date: 05/14/2014
Approval Date: 05/15/2013

Title(s):
Participatory Action Research to Improve Caregiver Education for Persons with Alzheimer's Disease and Mild Cognitive Impairments based on the use of the Cognitive Performance Test (CPT)

This e-mail confirmation is your official University of Minnesota HRPP notification of continuing review approval. You will not receive a hard copy or letter. This secure electronic notification between password protected authentications has been deemed by the University of Minnesota to constitute a legal signature.

You may go to the View Completed section of http://eresearch.umn.edu/ to view or print your continuing review submission.

For grant certification purposes you will need this date and the Assurance of Compliance number, which is FWA00000312 (Fairview Health Systems Research FWA00000325, Gillette Childrens Specialty Healthcare FWA00004053). Approval will expire one year from that date. You will receive a report form two months before the expiration date.

file://H:\Dissertation\IRB materials and approvals\U of MIRB Continuing approval UM... 10/24/2014
In the event that you submitted a consent document with the continuing review form, it has also been reviewed and approved. If you provided a summary of subjects' experience to include non-UPITSO events, these are hereby acknowledged.

As Principal Investigator of this project, you are required by federal regulations to inform the IRB of any proposed changes in your research that will affect human subjects. Changes should not be initiated until written IRB approval is received. Unanticipated problems and adverse events should be reported to the IRB as they occur. Results of inspections by any external regulatory agency (i.e. FDA) must be reported immediately to the IRB. Research projects are subject to continuing review.

If you have any questions, please call the IRB office at (612) 626-5654.

The IRB wishes you continuing success with your research.
The IRB: Human Subjects Committee renewed its approval of the referenced study listed below:

**Study Number:** 1205S14403

**Principal Investigator:** Terrianne Jones

**Expiration Date:** 04/15/2015

**Approval Date:** 04/16/2014

**Title(s):**
Participatory Action Research to Improve Caregiver Education for Persons with Alzheimer’s Disease and Mild Cognitive Impairments based on the use of the Cognitive Performance Test (CPT)

This e-mail confirmation is your official University of Minnesota HRPP notification of continuing review approval. You will not receive a hard copy or letter. This secure electronic notification between password protected authentications has been deemed by the University of Minnesota to constitute a legal signature.

You may go to the View Completed section of [http://eresearch.umn.edu/](http://eresearch.umn.edu/) to view or print your continuing review submission.

For grant certification purposes you will need this date and the Assurance of Compliance number, which is FWA00000312 (Fairview Health Systems Research FWA00000325, Gillette Childrens Specialty Healthcare FWA00004003). Approval will expire one year from that date. You will receive a report form two months before the expiration date.

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If you have any questions, please call the IRB office at (612) 626-5654.

The IRB wishes you continuing success with your research.
Appendix H

GRECC Caregiver Educational Materials

Dementia Care Clinic
MPLS VA Medical Center

CAREGIVING GUIDANCE

FUNCTIONAL LEVEL 4.5

UNDERSTANDING CHANGES IN THE IMPAIRED PERSON.

During early dementia the person is able to make use of long-time coping measures to continue to manage most activities of daily living. This usually entails relinquishing complicated tasks and establishing familiar routines. These coping measures may serve the person well for some time. But as thinking abilities decline, coping becomes more difficult; the person continues by using very rigid familiar routines for carrying out daily activities. The person will not usually be receptive to changes because s/he cannot comprehend something different or plan and initiate new endeavors. The struggle to manage such things as finances, shopping, preparing appropriate meals, understanding medications, or remembering appointments begin to produce anxiety and may be performed inconsistently.

At level 4.5 the person cannot manage all aspects of living without mistakes and errors. When both memory and abstract thinking are declining, the person loses the ability to cope or “figure out” how to solve problems. This lack of control leaves the person feeling dependent or “at the mercy of others.” People react to frustration in different ways. Some become cautious and hesitant and withdraw or seek advice and assistance from others. A person in a loving, trusting relationship may be able to rely on others and even express awareness and appreciation.

Other persons may deny problems and begin to act impulsively, refusing direction or help. With impaired ability in reasoning and judgment, the person is unable to plan or consider consequences. It is often hard for family members to know whether the person is “covering up” or has lost insight. The person may or may not be aware of the changes, but by level 4.5 the ability to objectively evaluate situations is lost. Though the person may be adamant about what s/he wants to do, the determination is based on what he wants to do at the time, not on logical reasoning or consideration of the pros and cons of the choices or consequences of the actions in question.

CAREGIVER ROLE AND COPING.

When the person can no longer cope with the changes independently without anxiety and errors, the role of the caregiver becomes increasingly important. During level 5, both the impaired person and the caregiver are adjusting to the disease. The relationship remains mostly reciprocal.
The person participates in learning about the disease, making plans for the future and continuing to do all s/he can. The caregiver’s role has been mostly one of support and reassurance.

By level 4.5, when there are errors in both judgment and actions, someone must begin to monitor the person’s abilities and intervene when the person can no longer perform safely. Though the approaches need to continue to be supportive and reassuring, the caregiver is assuming responsibility for decisions without the participation of the impaired person. In fact, hard decisions often must be made when the person is adamantly against a decision and cannot be made to understand.

**Goals/tasks of Level 4.5 Caregiving.**

- maintain the reassuring, supportive relationship.
- learn to objectively identify what the person can and cannot do.
- monitor for inconsistency and supervise for safety.
- assume the responsibility of being a caregiver.
- balance the caregiving role with caring for one’s self.

Accepting the responsibility and assuming the role of caregiver is a process! It doesn’t happen overnight! Caregivers have to learn and adjust to the changes. Most important, they need to be tolerant of the mistakes they make and proud of their progress.

Caregiving during level 4.5 is usually a difficult period of adjustment for most families. It is a time of uncertainty and ambivalence. There are definite signs of problems, so the caregiver worries. But the person performs well and seems perfectly normal at other times. Families may still be reluctant to believe the diagnosis or to actually make changes until they have to. This stress will build as they wait for a crisis to occur. Caregivers usually want to continue with the same relationship they’ve always had with the person--spouse and friend or mother-child. It is hard to let go of the mutual sharing and begin to take sole responsibility without the other’s help. The caregiver will undoubtedly make mistakes and take risks during this struggle. Caregivers feel great pressure to do what the person wants. It is very hard to restrict and take over things the person wants to continue doing. We don’t want to take away their freedom or injure self esteem. The caregiver may not want to take on the tasks, themselves. When a person can no longer drive, someone else must do all the driving. This is restricting the person’s independence, most likely injuring self esteem, causing anger, and putting a burden on someone else. Angry episodes directed at the family are often seen as purposeful. The natural tendency to explain things, reason and argue with the person is very difficult to break. Even when it is known that the person no longer is able to reason, we still try to make them understand.

This is the time when caregivers are trying to understand the disease and the changes in the person they love. It is our belief that caregivers who see this as a challenge can learn to take very good care of the person, can continue to have a loving relationship, and can gain great satisfaction in the job they’re doing. **The first step in level 4.5 caregiving is accepting the fact that the person can no longer be independent. The caregiver must muster the strength to take control--to make decisions, take over responsibilities, to learn to get help from others.** In order to do this the caregiver has to let go of the reciprocal part of the relationship with the
person. The person can no longer be asked to make the decisions about such things as financial investments, planning for moves or detailed trips or purchases.

However, at the same time the caregiver is taking control, the impaired person is losing control. This has severe impact on the person’s emotional stability. The losses suffered as the person becomes dependent on others cause decreased self esteem, insecurity, and feelings of uselessness. These can lead to anxiety, fearfulness, anger, or depression. Thus the caregiver has to develop strategies to meet these needs as well. **This involves balancing the control with increased support and reassurance--subtle ways to maintain self-esteem**, to help the person feel good about what s/he can still do. The strategies for caregiving in this program aim toward this goal.

When caregivers resolve to give good care they learn to be creative in finding ways to take over stressful or hazardous activities in ways that preserve the person’s sense of worth and protect the person from fear and anxiety. The strategies during level 4.5 can help maintain the sense of normalcy for both the impaired individual and the family. Togetherness can be a way to strengthen relationships within the family. Doing activities together provides socialization and allows the caregiver to slip in subtle assistance that the person will not even be aware of.

**Caregiving at level 4.5 should include special effort to involve other people in the person’s life.** Family members and friends need to be taught by the caregiver how to help the person. Day care and other community programs should be used so the person continues to be comfortable with other people. It is crucial for the caregiver’s health that others stay involved in the care. As the caregiver takes on the role of caregiver for a person with dementia it is important to make special effort to take care of him/herself.

The person functioning at level 4.5 has significant difficulty with organizing complex activities. Family members need to provide daily structure, assistance and reminders. Simple changes in the environment, in approach, and in expectations for performance can help the person to continue to be involved and successful with many activities. Most families want the person to continue to do as much as possible to maintain their normal relationships and routines. However, families are often worried about the person’s competence and safety, as concrete evidence of unsafe behavior or poor decisions often occur at this level. When the impaired person denies problems and refuses help, the family can benefit from counseling to help them cope and to subtly take over the situation.

The strategies and approaches used to compensate for the cognitive decline allow the person to continue to function and avoid behavioral problems. Family members must continue to look objectively at the changes in the person. Misunderstanding the changes can be traumatic for all. Anger or impulsive behavior may be assumed to be purposeful rather than a result of the disease. As a caregiver, it is natural to react with anger and impatience. This can easily lead to confrontational exchanges, suspiciousness and mistrust between the person and the caregiver or other members of the family.

During level 4.5 the major goal of caregiving is to provide safety and structure from day-to-day. The person becomes increasingly dependent on others to initiate and organize activities. Feelings
of trust and the security that comes with routine, structured activities are very important to a person who is confused and aware of losing control. Behavior problems increase whenever the person is confused, stressed, or angry. Ignoring the persons needs for structure can lead to out of control behaviors.

**LEVEL 4.5 PATIENT CHANGES.**

**Characteristics of Thinking.**

Mild to moderate functional decline; significant deficits in abstract thinking abilities; increased difficulty with solving problems and with considering consequences. Abstract thought processes including memory, judgment, reasoning and planning ahead show obvious impairment. Persons have significant difficulty with reading, writing and calculating. Complex daily tasks are performed with obvious difficulty or error. Basic daily tasks such as dressing may begin to show some change or decline. Hazardous activities may need to be monitored for safe performance or restricted to ensure safety. Self-centered behavior or the inability to consider the needs of others is common as the person loses sight of the larger picture.

**Orientation.**

Awareness of time and place is inconsistent at level 4.5. Some persons remain well oriented while others remain oriented in familiar settings but get confused when moved to a new location, when on vacation, or when they start a new program such as Adult Day Care. For these persons, repetition of the program or time spent in the new setting can increase the person’s grasp of the situation. Although familiarity and comfort level generally will increase with time and repetition, the person may never fully understand where they are or why they are there. For example, the person who attends a day program but considers her/himself to be the volunteer. Some persons at this level are able to follow time; more often caregivers are needed to provide reminders and to help the person to follow daily schedules. The person may obsess about time and where they are going or where they need to be; this may be a sign that more structure, subtle direction and activity are needed.

**Language and Communication.**

More noticeable changes in language abilities are typically seen at level 4.5. The person may repeat the same stories over and over, or ask the same questions repeatedly. The questions asked may reflect confusion about time or the sequence of activities for the day as in asking repeatedly ‘where are we going’ or ‘what time do we leave’. Word-finding difficulties may be evident or more pronounced. The ability to engage in reciprocal conversation diminishes as conversation may be difficult to follow or remember unless related to familiar topics such as major past life events. Comprehension or understanding of what is said is usually good at level 4.5.

**Emotional and Behavioral Changes.**
Obvious changes in behavior often begin at level 4.5. Understanding the deficits described above can help caregivers realize how the impaired thinking impacts the person’s thinking. Every person will also have emotional responses to the changes taking place in his thinking. The emotional reactions may be similar to the person’s prior way of coping with problems, or they may seem to be very different from behaviors of the past. It is important for families to consider thoughtfully, both the cognitive and emotional factors related to the behavior changes they’re worried about. Only then can they decide how best to help the person with the changes.

Common emotional responses.

**Depression** is a common reaction to awareness of cognitive impairment and the loss of abilities and life roles such as driving.

**Withdrawal** can be used as a means of protection from inability to perform an activity or follow conversation. The person may give up things that are frustrating or withdraw from people or situations that are stressful.

**Anxiety** may be evident as attempts to carry out usual activities become more difficult. The person may worry or become overly concerned or obsess about situations they can no longer understand.

**Agitation**, frustration and anger may erupt at the inability to comprehend and interact as before. Irritability is common and often directed toward family members.

**Denial** can take various forms, from humor to belligerence. The person may appear to cover up difficulties. It may be hard for the family to know how aware the person is of their deficits. Some seem to lose insight into their problems quite early in the course of the disease.

**Impulsivity** or ‘not thinking ahead’ can cause mild disruption or even danger. Impaired judgment coupled with agitation and denial often lead to determined behaviors without thought to consequences.

**GENERAL GUIDELINES FOR CARE.**

Use of simple written notes, daily checklists and calendars may or may not be helpful. Monitor the person’s ability to use these with consistency and discontinue written reminders if there is confusion or rejection. Expect more time to be needed for most activities. Keep extra pairs of glasses, keys available. Try to express reassurance and acceptance.

Recognize that at level 4.5, trying to reason with the individual may no longer be effective. It is important to avoid long explanations that include abstract concepts. When the person cannot understand issues anger and agitation often escalate.

Watch for signs of frustration and anxiety that may indicate that a task is too complicated for the person to understand. Break the task down into more manageable, separate steps and monitor completion of the task. Work together on the task. By beginning to do tasks and activities together, you can give subtle guidance and allow the person to feel a sense of accomplishment without experiencing the frustration he/she might if trying to struggle with the task alone. During level 4, it becomes necessary to take over responsibility for many complex tasks - without drawing attention to the fact. Replace complex activities with simple, routine tasks.
Limit the need for the individual to do activities requiring a reliance on reading, planning, writing, or calculating. Suggest other jobs that need to be done - e.g., yard work or repetitive housework tasks such as vacuuming, dishes, sweeping or raking. Point out safety procedures and monitor work if necessary.

Maintaining social contacts and involvement with others remains an important goal for care during level 4.5. Families can let friends know how they can help by continuing to include the person in their usual activities such as golf, cards, fishing, going out for lunch or coffee. It is helpful to ask friends to lower their expectations for performance, and to provide reassurance and acceptance of the change in performance. Some persons with dementia will continue to enjoy their usual activities even though their abilities have declined. For others, not being able to do as well causes frustration and the person may not want to continue with a particular activity. Less demanding activities need to be substituted and family and friends can help by providing supervision and transportation as well. Programs such as Adult Day Care can offer the structure and routine that should be established early in the course of the disease.

Encourage involvement in the community. Encourage friends to continue social contacts. If transportation is an issue, (e.g., to and from a daily program), it is advisable to begin using community-based transportation services at this stage. At later stages of thinking impairment, it is more difficult for the person to adapt to changes in routine.

As some activities begin to cause frustration, be prepared with a list of replacement activities (e.g., gardening, reviewing photos from a favorite vacation, grooming the pet). Encourage relatives to initiate outings on a regular basis - restaurants, tours, special events (home and garden shows, sports).

**ACTIVITY MANAGEMENT.**

**Independence and Basic Care.**

Independent Living is possible at level 4.5 but requires much support from caregivers. The demands of the setting must be evaluated including the activities that need to be done and any potential hazards. There will be a decline in ability to perform everyday activities that require abstract thinking, planning and solving problems - e.g., managing money, shopping, meal planning and preparation, home maintenance, medication management and driving. Errors can be disruptive, costly or even dangerous. Caregivers are needed to do these activities for or with the person at this level of function. As a result, many persons choose to move to an assisted living facility where services and supervision can be added as needed. Adjusting to a new environment is much easier at this point than it will be later when thinking is more impaired. Regardless of whether the person lives alone, in assisted living or with family, it is important to maintain the usual arrangement of the home or establish a structured and simplified arrangement of personal belongings. Sometime during level 4, the person’s ability to follow schedules or to know when to do things shows impairment. Provide reminders for where things are or make thing more visible. Provide reminders for when to do tasks that the person does not initiate (i.e. showering, change dirty clothes). Begin to simplify any parts of basic self-care activities that show decline; for example, limit the amount of clothing in the closet if the person has trouble
making appropriate selections, or hang entire outfits together on one hanger, or lay clothes out for the next day. Keep all supplies for a task such as grooming together, in easy to see places.

**Travel and Ambulation.**

**Driving and options for travel in the community** need to be looked at early in the course of the disease in order to prevent problems later on. Frequent driving errors made by persons with dementia include becoming lost, driving too slow or too fast, and failure to follow directional signs as in running a red light or going the wrong way on a one way street. These problems can be potentially dangerous to the impaired driver, their passengers, other motorists and pedestrians. Sometimes the person will be unable to see that they are presenting a safety risk and will refuse to stop driving. In those situations, the family or health care professionals must become involved. Well meaning family members often feel bad about making the person stop driving. They may incur the wrath of their family member, or they may have a vested interest in the person continuing to drive if they rely on them for transportation. Sometimes your physician or other health care professional may be willing to talk to the impaired person about driving. Some who no longer have a valid license may insist upon driving. In those instances, families must take action. To avoid the person’s anger toward family members, help may be sought from health care providers, the state department of transportation or local police departments. Families may notify the state of the person’s diagnosis and ask that the person be retested for ability to drive. To prepare for the time when the person can no longer drive, other transportation must be available to replace this loss. Family members can gradually begin to do more of the driving. Community resources need to be investigated. When formal resources are limited or inconvenient, planning ahead for shopping and appointments and enlisting the help of neighbors or agencies may be needed.

**Finances and Shopping.**

**Managing finances** including keeping track of income, paying bills, writing checks or doing other banking activities often becomes difficult early in the course of the disease. These activities involve complex thinking skills. They involve reading, writing and calculating, and also the ability to make decisions and to use good judgment. Family may be unaware of the difficulty with money management or decisions made to spend money until something happens or there is a crisis. Money management activities need to be simplified and restricted. For example, paying bills together or limiting the bills that the person must deal with routinely to a few, and supervising or restricting credit and investments. For many persons functioning at level 4.5, managing finances is too complex and is done by others.

Legal and financial planning is necessary when a family receives a diagnosis of dementia. Early planning will permit the person to have their estate managed in a manner consistent with their wishes. To plan and sign legal documents one must be competent. Competence is a legal term which basically means that the person has the capacity to make decisions for him or herself. A person who is competent may sign a power-of-attorney, a document that authorizes another person to make decisions for them. This power is given to someone by completing a form called
statutory short form power-of-attorney. The powers given under the power-of-attorney can be broad or limited. When it is broad, it can include taking care of banking transactions, family matters, insurance transactions, litigation and other business matters. It is limited when the person indicates only a few of these matters to be managed. Some states permit a durable power-of-attorney, which remains in effect after the impaired person becomes incompetent. It is recommended that all persons have a will. This document specifies how the person’s assets will be distributed upon his/her death. It has no impact on the individual’s assets while he/she is alive. The will-maker must name an executor, who will be responsible for distribution of the estate according to the will’s terms.

Some persons may prefer to execute a living trust. A trust describes certain property, such as cash accounts or real estate, and names a trustee to manage these and a beneficiary who will receive benefits from it. The trust will specify how its funds are to be spent and distributed when the creator of the trust dies. A trust is well suited for persons with sizable estates.

A payee is someone who can receive and use an impaired person’s benefits in their best interest. It is useful when a person can no longer manage benefits. Agencies such as Veteran’s Affairs, Social Security and Medicare issue benefits and can appoint payees.

It is advisable to discuss these legal and financial matters with an attorney. It is best to seek out an expert in elder law, an attorney who is skilled in legal matters of interest to seniors. Elder law attorneys can assist with tax and estate planning, preparing advanced directives and understanding the complexities of Medicare, Medicaid and other public programs.

**Shopping** involves not only handling money, but also making decisions about what to buy and remembering the items. It also involves getting to and from the store. All of these activities are complex. Therefore, problems can occur in any of these areas. Some of the difficulties that reflect poor judgment and memory include buying things that aren’t needed such as subscribing to over 200 magazines or using credit cards and home shopping programs for frivolous of repetitive purchases. Caregivers are needed to help with and closely supervise shopping activities.

**Food Preparation and Eating.**

**Preparing meals** can be complicated at level 4.5 as the person has difficulty with planning, remembering the steps and timing the preparation of several items for a meal. It’s common to hear of persons who live alone relying on simple or the same meals or a narrow choice of convenience foods. The ability to prepare meals and good nutrition should be monitored and assisted or taken over. Having meals prepared or delivered by others is an option. Having the person participate in meal preparation with family or others is a good way to establish some routine activity. Persons who function at this level have a lot of ability to follow direction for visual, straight-forward tasks such as chopping, peeling, mixing, setting the table or washing dishes. Even persons who have never cooked may enjoy being involved in daily kitchen activities.

**Medication Management.**
Medication management should be monitored at level 4.5. Caregivers are needed to monitor the use of medications, or to set them up as in using a pill box with labels, or if living with the person, may need to provide daily reminders. Sometimes persons will have trouble understanding the effects of their medications and may decide to not take their pills or to take more than what was prescribed. The role of the caregiver is to monitor how medications are handled and to provide the necessary structure and assistance.

Telephone Use.

Phoning abilities usually change by level 4.5. The person may do well with familiar or posted numbers but may have difficulty with getting new numbers, dialing long distance, or anything out of the ordinary. Persons functioning here may be less interested in talking on the phone if they are fearful of having difficulty remembering things, conversing, or taking a message. On the other hand, persons may be less aware of, or not bothered by their deficits and may use the phone often. It is common to hear of persons at this level making repetitive calls. Frequent calls to a family member or others may be an indicator that the person requires more structure to their day. Frequent calls for help or assistance also reflects the person’s inability to solve problems or to figure things out on their own. Providing assistance with making non-routine calls may be necessary. Encouraging family and friends to make regular phone calls, especially if the person lives alone or is home alone may also be helpful.

Work and Leisure.

Competitive employment is usually no longer possible at level 4.5. However, the individual can continue to function productively in a structured work setting (a sheltered work program) or in home-based work projects that are not to complex. Task supplies need to be set-up for the person and assistance given to get the person started. Hazardous equipment often needs to be restricted or closely supervised.

Laundry, housekeeping and yard work activities should be monitored and supervised if there is concern for safety. Persons who have operated their laundry machines and are used to doing the wash may be able to continue with this into level 4. However, difficulty can be expected with even familiar machines at some point in level 4; if new machines need to be learned or where the laundry is done changes the person may never learn the new procedures. Operating hazardous equipment such as power tools, lawn and snow blowers may be risky, especially if the person is impulsive or expected to maintain and repair the equipment without help. Repetitive house and yard work such as vacuuming, dusting, raking, sweeping and folding can give the person some routine, purposeful activities that are safe and within their range of abilities. Many persons with early dementia who have never done these activities start these for some routine in their daily life. Caregivers may need to help by getting out supplies and helping the person to get started.

Leisure - There may be less interest in typical activities such as watching television, reading or playing cards due to difficulty retaining what is seen or read, or difficulty planning game strategies. Group activities may become frustrating as the individual loses the ability to keep up with the interplay of conversation. As some activities begin to cause frustration, be prepared with
a list of replacement activities (e.g., gardening, reviewing photos from a favorite vacation, grooming the pet). Encourage relatives to initiate outings on a regular basis - restaurants, tours, special events (home and garden shows, sports). An exercise group or a routine at home can be helpful in maintaining fitness and may be a good activity to do with others! Encourage continuing with any sports that do not cause frustration. Family and friends can help by lowering their expectations for performance.
Appendix I

Original Forms

Occupational Therapy Cognitive-Functional Levels

Occupational therapists assess an individual's cognitive abilities for daily living, or the cognitive-functional level, through administration of the Cognitive Performance Test® (CPT), a standardized, performance-based assessment instrument. The CPT uses common daily activities (toast, phone, shop, wash, mailbox, dress, travel) for which the information processing requirements are varied to assess the average performance level across several tasks. The levels are based on a scale of 5.6 to 1. CPT 5.6 typically indicates normal abilities and each decreasing level indicates more functional impairment. CPT levels can predict the individual's ability to perform daily activities, appropriate assistance and supervision needs, and also guides recommendations for the appropriate living setting. CPT scores should be rounded down, not up, to determine the appropriate CPT level description below.

- **CPT Level 5.6: Normal function** – the person can use complex information to carry out daily activities with accuracy and safety. Written information, numbers, symbols, ideas and hypothetical thoughts involving cause and effect concepts are well understood. Activities involving reading, writing, calculating and planning ahead are done with ease. Problems are anticipated, errors are avoided, and consequences of actions are considered.

- **CPT Level 5.0: Mild functional decline, start of difficulty with complex tasks** - Shows start of decline in memory, keeping track of details, decision-making, planning, insight, and organization. Can learn new information.

<table>
<thead>
<tr>
<th>Monitor and/or partial assist</th>
<th>Considerations</th>
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</thead>
<tbody>
<tr>
<td>Managing medications and health care</td>
<td>Meal planning and preparation</td>
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<tr>
<td></td>
<td>- Medication box and written medication guide</td>
</tr>
<tr>
<td></td>
<td>- Cook familiar meals or microwave meals; automatic stove shut-off, if appropriate</td>
</tr>
<tr>
<td></td>
<td>- Institute health care directives</td>
</tr>
<tr>
<td>Managing finances</td>
<td>Shopping</td>
</tr>
<tr>
<td></td>
<td>- Automatic bill pay</td>
</tr>
<tr>
<td></td>
<td>- Together pay bills and shop</td>
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<tr>
<td></td>
<td>- Institute power of attorney</td>
</tr>
<tr>
<td>Driving</td>
<td>Managing calendar/schedule</td>
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<td></td>
<td>- Driving evaluation</td>
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<tr>
<td></td>
<td>- Use of calendars and reminder notes</td>
</tr>
</tbody>
</table>

- **Live alone with weekly safety check**

- **CPT Level 4.5: Mild to moderate functional decline; significant difficulty with completion of complex daily tasks and start of difficulty with self-care tasks** - May show decreased quality or initiation of self-cares (for example, shaving less). Shows significant decline with memory, judgment, and planning. Person may not be aware of his own deficits and may be able to verbally speak better than they can actually perform. Can learn new information with repetition, but learning may not generalize to a different setting, and typically shows inconsistent follow through.

<table>
<thead>
<tr>
<th>Full assist</th>
<th>Monitoring and/or partial assist</th>
<th>Considerations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Managing medications, health care, and finances</td>
<td>Monitoring safety and planning/initiating tasks</td>
<td>- Automated pill dispenser or caregiver administration</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Institute power of attorney</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Health care directives</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Lifeline</td>
</tr>
<tr>
<td>Transportation and shopping</td>
<td>Frequency of laundering and cleaning</td>
<td>- Metro mobility, facility van, family transport</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Remove soiled clothes from closet</td>
</tr>
<tr>
<td>Meal planning</td>
<td>Simple meal preparation (microwave, hot plate, cold items)</td>
<td>- Meals on Wheels, facility dining, microwave use</td>
</tr>
<tr>
<td>Stove or oven use</td>
<td>Frequency and quality of showers</td>
<td>- Reminders of bathing days</td>
</tr>
<tr>
<td>Managing calendar/schedule</td>
<td></td>
<td>- Weekly dry-erase calendar kept up by family or staff</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Labels and reminder notes</td>
</tr>
</tbody>
</table>

- **Live alone with daily assistance – i.e. Senior apartment, assisted living, home with daily checks**

- **CPT Level 4.0: Moderate functional decline; unable to complete complex daily tasks and difficulty with self-care tasks** - Shows decreased initiation and completion of self-cares (for example, re-wearing clothes). Shows significant

April 2012
Occupational Therapy Cognitive Report

Date: ___________________________  Client Name: ___________________________
Physician: ______________________  DOB: _________________________________

Occupational therapists assess an individual’s thinking abilities for daily living, or the cognitive-functional level, through administration of the Cognitive Performance Test® (CPT). The CPT is a standardized, performance-based assessment that uses common daily activities (such as making toast and using the phone) for which the difficulty and decision-making requirements are varied to allow assessment of thinking abilities. Scores for each subtask activity are averaged into a final score based on a scale of 5.6 to 1. CPT 5.6 typically indicates normal abilities and each decreasing level indicates more functional impairment. CPT levels can predict what types of tasks the individual may need help with; when a caregiver should offer supervision and help; and also guides recommendations by occupational therapy for the appropriate living setting.

CPT Score: __________  Date Completed: __________________________

* A typical description of deficits and assistance areas at this level:
CPT Levels 2 and 1: Late stage dementia. Severe functional decline; poor use of familiar objects.
Does not recognize objects or know what to do with them. The person needs to be totally cared for by others. May respond to touch, movement, and sound. Total assistance for self-cares; and 24 hour supervision or Hospice care.

* Individualized concerns and recommendations for this client:
___________________________________________________________
___________________________________________________________
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___________________________________________________________
___________________________________________________________

Therapist: ___________________________  Phone Number: __________________________

April 2012
Occupational Therapy Cognitive Report

Date: __________________________  Client Name: __________________________
Physician: ______________________  DOB: ________________________________

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CPT Score: ______________  Date Completed: __________________________

A typical description of deficits and assistance areas at this level:

CPT Level 3.0: Moderate to severe functional decline; unable to complete self-care tasks without assistance.
Can handle and use objects, but is unaware of task goals or outcomes. Caregivers are needed to give direction throughout task and set supplies in front of the person. The person may need verbal cues, demonstration, and hand over hand assist. Use short, direct commands, such as “Put on your shirt.” Routine and structure is important. Resisting care may occur as the person is confused about the world around them. Conversation is typically tangential and may not make sense or seem relevant to the situation. Cannot learn new information. Not oriented to time (month, day of week) or place they are at.

| Full assist |  |
|-------------|  |
| Managing medications, finances, shopping, schedule | Tolleting, hygiene, and managing incontinence; every 2 hour schedule |
| Transportation, meals, laundry, cleaning | Safe walking and transfers |
| Monitoring safety and carrying out tasks | All steps of eating and drinking; monitor for swallowing difficulty |
| Dressing, grooming, hygiene, showers |  |
| 24 hour supervision - i.e. memory care, skilled nursing facility, or home caregiver 24 hours |  |

Individualized concerns and recommendations for this client:

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

Therapist: __________________________  Phone Number: __________________________

April 2012
Occupational Therapy Cognitive Report

Date: ____________________  Client Name: ____________________
Physician: ____________________  DOB: ____________________

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CPT Score: __________  Date Completed: ________________

☆ A typical description of deficits and assistance areas at this level:

CPT Level 3.5: Moderate functional decline; unable to complete complex daily tasks, significant difficulty with self-care tasks – Shows significant decline with self-cares and needs set-up, demonstration, and step by step assist. Shows inability to complete complex tasks and needs prompting and cues to complete even simple tasks. Language may show decline, such as less spontaneous speech, or incomplete sentences. Attention span is limited. Routine and structure is important. Cannot learn new information. Not oriented to time (month, day of week) or place they are at.

<table>
<thead>
<tr>
<th>Full assist</th>
<th>Partial assist</th>
</tr>
</thead>
<tbody>
<tr>
<td>Managing medications, finances, shopping, schedule</td>
<td>Tolieting (remembering to flush, complete hygiene, wash hands)</td>
</tr>
<tr>
<td>Transportation, meals, laundry, cleaning</td>
<td>Feeding (finger foods, present few items at a time)</td>
</tr>
<tr>
<td>Monitoring safety and carrying out tasks</td>
<td>Safe walking and transfers</td>
</tr>
<tr>
<td>Dressing, grooming, hygiene, showers</td>
<td></td>
</tr>
<tr>
<td>24 hour supervision - i.e. memory care, skilled nursing facility, or home caregiver 24 hours</td>
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</table>

☆ Individualized concerns and recommendations for this client:

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Occupational Therapy Cognitive Report

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CPT Score: __________  Date Completed: __________

☆ A typical description of deficits and assistance areas at this level:
CPT Level 4.0: Moderate functional decline; unable to complete complex daily tasks and difficulty with self-care tasks - Shows decreased initiation and completion of self-cares (for example, re-wearing clothes). Shows significant decline with memory and an inability to plan, reason, and maintain own safety. New learning ability is limited. Become unaware of time (ex. month, day of week) and place they are at.

<table>
<thead>
<tr>
<th>Full assist</th>
<th>Partial assist</th>
<th>Considerations</th>
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<tbody>
<tr>
<td>Managing medications and finances</td>
<td>Remembering all steps and set-up of supplies for dressing, grooming, hygiene</td>
<td>Institute power of attorney, if not already done</td>
</tr>
<tr>
<td>Transportation and shopping</td>
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<tr>
<td>Meals, laundry, cleaning</td>
<td>Frequency of laundering or changing clothes</td>
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<tr>
<td>Monitoring safety and planning/Initiating tasks</td>
<td>Frequency and quality of showers</td>
<td>-Structured living environment -Keep a routine</td>
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<tr>
<td>Managing calendar/schedule</td>
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</table>

Live with someone, may be able to alone parts of the day – i.e. memory care, living with family member

** 24 hour supervision is recommended to ensure safety**

☆ Individualized concerns and recommendations for this client:

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CPT Score: __________ Date Completed: ______________

★ Typical description of deficits and assistance areas at this level:

CPT Level 4.5: Mild to moderate functional decline; significant difficulty with completion of complex daily tasks and start of difficulty with self-care tasks - May show decreased quality or initiation of self-cares (for example, shaving less). Shows significant decline with memory, judgment, and planning. Person may not be aware of his own deficits and may be able to verbally speak better than they can actually perform. Can learn new information with repetition, but learning may not generalize to a different setting, and typically shows inconsistent follow through.

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<th>Considerations</th>
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</table>
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- Institute power of attorney and health care directives  
- Lifeline |
| Transportation and shopping         | Frequency of laundering and cleaning | - Metro mobility, facility van, family transport  
- Remove soiled clothes from closet |
| Meal planning                        | Simple meal preparation (microwave, hot plate, cold items)  
Frequency and quality of showers     | - Meals on Wheels, facility dining, microwave use  
- Reminders of bathing days |
| Managing calendar/schedule          |                                 | - Weekly dry-erase calendar kept up by family or staff  
- Labels and reminder notes |

★ Individualized concerns and recommendations for this client:

________________________________________________________________________________________

Therapist: __________________________ Phone Number: __________________________

April 2012
Occupational Therapy Cognitive Report

Date: ____________________________  Client Name: ____________________________
Physician: ________________________  DOB: _________________________________

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CPT Score: _______________  Date Completed: ____________________________

A typical description of deficits and assistance areas at this level:

CPT Level 5.0: Mild functional decline, start of difficulty with complex tasks - Shows start of decline in memory, keeping track of details, decision-making, planning, insight, and organization. Can learn new information.

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<td>Managing medications and health care</td>
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<td>- Medication box and written medication guide</td>
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<td>- Driving evaluation</td>
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<tr>
<td>- Use of calendars and reminder notes</td>
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<tr>
<td>Live alone with weekly safety check</td>
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</table>

Individualized concerns and recommendations for this client:

__________________________________________________________
__________________________________________________________
__________________________________________________________

Therapist: ____________________________  Phone Number: ____________________________

April 2012
Appendix J

Revised Forms

Recommendations from Occupational Therapy

CPT Score: _______/5.6          Date Completed: __________________________

This report was written by: ________________________________________________

If you have any questions about any of the concerns or recommendations I’ve made please contact me at:

Phone: __________________ email: _________________________________________

Occupational Therapists assess person’s abilities to do daily things such as to taking care of themselves; taking medicines; getting food for meals; paying bills; getting in and out of the home; and many other typical daily activities.

Occupational Therapists do this by:

- Asking the person about their typical day and what they need to be able to do when they go home
- Watching persons do activities in therapy that are similar to what they might do at home
- Using tests that give the therapist information about the persons thinking skills.

Therapists take all of this information about the person to create a therapy program that prepares the person to leave Saint Therese Rehab. They also use this information to give information to families and caregivers about how much help a person might need when they leave to return home or go to a new place to live such as assisted living. Based on the occupational therapy evaluation and testing, the following amount of help is recommended:

At this level, persons do not recognize objects (such as eating utensils, a tooth brush, etc.) or know what to do with them. The person needs to be totally cared for by others under 24 hour supervision or in Hospice care. The person may respond to touch, movement, and sound.

Other: ___________________________________________________________________

________________________________________________________________________
Recommendations from Occupational Therapy

CPT Score:__________/5.6 Date Completed:__________________

This report was written by: ____________________________________________

If you have any questions about any of the concerns or recommendations I’ve made please contact me at:

Phone: ___________________ email: ________________________________

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• Asking the person about their typical day and what they need to be able to do when they go home

• Watching persons do activities in therapy that are similar to what they might do at home

• Using tests that give the therapist information about the persons thinking skills.

Therapists take all of this information about the person to create a therapy program that prepares the person to leave Saint Therese Rehab. They also use this information to give information to families and caregivers about how much help a person might need when they leave to return home or go to a new place to live such as assisted living.

Based on the occupational therapy evaluation and testing, the amount of assistance recommended for _____________ is highlighted on the other side.
<table>
<thead>
<tr>
<th>This person will need TOTAL HELP from others with:</th>
<th>Recommendations that apply to ___________ are highlighted below:</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Living situation</td>
<td>- This person must have 24 hour supervision – e.g. in memory care, skilled nursing facility, or at home with 24 hour care</td>
</tr>
<tr>
<td>• Managing medications, finances, shopping, following a schedule</td>
<td>- Others must perform these activities</td>
</tr>
<tr>
<td>• Monitoring safety and carrying out tasks</td>
<td>- The person will need others to direct their daily activities and tell them when it is meal time, when to take medicine, etc.</td>
</tr>
<tr>
<td></td>
<td>- Will need others to watch for safety concerns and avoid problems</td>
</tr>
<tr>
<td>• Feeding</td>
<td>- The person will require help with all steps of eating and drinking</td>
</tr>
<tr>
<td></td>
<td>- Monitor for swallowing difficulty</td>
</tr>
<tr>
<td>• Self care: dressing, bathing, grooming</td>
<td>- Set out clothing and physically help dress the person</td>
</tr>
<tr>
<td></td>
<td>- Set out grooming and hygiene supplies, physically help perform grooming activities</td>
</tr>
<tr>
<td></td>
<td>- Prepare bathroom and the person for showering and assist with getting in and out of the tub/shower, cleaning, drying off.</td>
</tr>
<tr>
<td>• Toileting</td>
<td>- Assist the person to use the bathroom every two hours</td>
</tr>
<tr>
<td></td>
<td>- May need to use incontinence products; will have to help the person get them on and change them as needed.</td>
</tr>
</tbody>
</table>

Other: ___________________________________________
Recommendations from Occupational Therapy

CPT Score: __________/5.6  Date Completed: ________________

This report was written by: _______________________________________________________________________

If you have any questions about any of the concerns or recommendations I’ve made please contact me at:

Phone: __________________ email: ________________________________

Occupational Therapists assess person’s abilities to do daily things such as to taking care of themselves; taking medicines; getting food for meals; paying bills; getting in and out of the home; and many other typical daily activities.

Occupational Therapists do this by:

- Asking the person about their typical day and what they need to be able to do when they go home
- Watching persons do activities in therapy that are similar to what they might do at home
- Using tests that give the therapist information about the persons thinking skills.

Therapists take all of this information about the person to create a therapy program that prepares the person to leave Saint Therese Rehab. They also use this information to give information to families and caregivers about how much help a person might need when they leave to return home or go to a new place to live such as assisted living.

Based on the occupational therapy evaluation and testing, the amount of assistance recommended for ______________ is highlighted on the other side.
<table>
<thead>
<tr>
<th>This person may need TOTAL HELP from others with:</th>
<th>Recommendations that apply to _____________ are highlighted below:</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Living situation</td>
<td>- This person must have 24 hour supervision – e.g. in memory care, skilled nursing facility, or at home with 24 hour care</td>
</tr>
<tr>
<td>- Managing medications, finances, shopping.</td>
<td>- Others must perform these activities</td>
</tr>
<tr>
<td>- Following a schedule, carrying out tasks, noticing safety concerns</td>
<td>- The person will need others to direct their daily activities and tell them when it is meal time, when to take medicine, etc.</td>
</tr>
<tr>
<td>- Will need others to watch for safety concerns and avert problems</td>
<td></td>
</tr>
<tr>
<td>- Self care: dressing, bathing, grooming</td>
<td>- Set out clothing and physically help the person get started and/or dress the person</td>
</tr>
<tr>
<td>- Set out grooming and hygiene supplies, physically help the person get started and/or perform the task for the person (e.g. tooth brushing)</td>
<td></td>
</tr>
<tr>
<td>This person will need SOME HELP from others with:</td>
<td>Things that family and caregivers can do:</td>
</tr>
<tr>
<td>- Feeding</td>
<td>- Give the person finger foods</td>
</tr>
<tr>
<td>- Present few items at a time</td>
<td></td>
</tr>
<tr>
<td>- Walking and getting around</td>
<td>- Remind person to use their walker if applicable</td>
</tr>
<tr>
<td>- Assist with walking on uneven surfaces outside, going over thresholds</td>
<td></td>
</tr>
<tr>
<td>- Keep the environment clutter free with wide pathways</td>
<td></td>
</tr>
<tr>
<td>- Toileting</td>
<td>- Supervise this activity by monitoring how long the person is in the bathroom and offering assistance if needed</td>
</tr>
<tr>
<td></td>
<td>- Remind the person to complete hygiene, flush the toilet, wash their hands.</td>
</tr>
</tbody>
</table>

Other:________________________________________________________________________
________________________________________________________________________

3.5
Recommendations from Occupational Therapy

CPT Score: _________/5.6 Date Completed: ________________

This report was written by: ____________________________________________

If you have any questions about any of the concerns or recommendations I’ve made please contact me at:

Phone: ______________________ email: ________________________________

Occupational Therapists assess person’s abilities to do daily things such as taking care of themselves; taking medicines; getting food for meals; paying bills; getting in and out of the home; and many other typical daily activities.

Occupational Therapists do this by:

- Asking the person about their typical day and what they need to be able to do when they go home
- Watching persons do activities in therapy that are similar to what they might do at home
- Using tests that give the therapist information about the persons thinking skills.

Therapists take all of this information about the person to create a therapy program that prepares the person to leave Saint Therese Rehab. They also use this information to give information to families and caregivers about how much help a person might need when they leave to return home or go to a new place to live such as assisted living.

Based on the occupational therapy evaluation and testing, the amount of assistance recommended for _____________ is highlighted on the other side.

4.0
### Recommendations that apply to __________ are highlighted below:

<table>
<thead>
<tr>
<th>This person will need HELP FROM OTHERS with:</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Living situation</strong></td>
<td>Move the person to an environment that can provide 24 hour supervision for safety OR</td>
</tr>
<tr>
<td>-</td>
<td>Have the person live with someone who can provide 24 hour sup.</td>
</tr>
<tr>
<td>-</td>
<td>Consider memory care for those who may be able to be left alone for parts of the day</td>
</tr>
<tr>
<td><strong>Keeping medicines organized and/or taking them correctly</strong></td>
<td>-Have another person give out the pills at the right time</td>
</tr>
<tr>
<td><strong>Making complex health care decisions</strong></td>
<td>-Fill out a health care advance directive</td>
</tr>
<tr>
<td><strong>Managing money, shopping</strong></td>
<td>-Have a power of attorney in place</td>
</tr>
<tr>
<td>-</td>
<td>Have a trusted family pay the bills</td>
</tr>
<tr>
<td>-</td>
<td>Have family bring in groceries and supplies</td>
</tr>
<tr>
<td>-</td>
<td>Always escort the person on shopping trips and tightly oversee financial transactions</td>
</tr>
<tr>
<td><strong>Household chores and Laundry may not do frequently enough</strong></td>
<td>-Hire housekeeping help</td>
</tr>
<tr>
<td>-</td>
<td>Have someone else do the persons laundry</td>
</tr>
<tr>
<td>-</td>
<td>Have someone else assist with laundry and housework and direct the person to help as able</td>
</tr>
<tr>
<td><strong>Transportation</strong></td>
<td>-Persons at this level should not be driving.</td>
</tr>
<tr>
<td>-</td>
<td>Provide rides to appointments or shopping</td>
</tr>
<tr>
<td><strong>Using appliances and power tools</strong></td>
<td>-Persons at this level should not use power tools.</td>
</tr>
<tr>
<td>-</td>
<td>Help the person use appliances, but unplug them when no one is around to help them.</td>
</tr>
<tr>
<td><strong>Cooking-may leave stove on, may not eat a balanced diet</strong></td>
<td>-Sign the person up for Meals on Wheels</td>
</tr>
<tr>
<td>-</td>
<td>Arrange for person to eat more meals in community dining room if in assisted living</td>
</tr>
<tr>
<td>-</td>
<td>Supervise meals to ensure adequate diet</td>
</tr>
<tr>
<td><strong>Planning and starting activities; paying attention to safety: may forget to do daily activities, may not recognize safety concerns.</strong></td>
<td>-Keep a structured routine and environment for person</td>
</tr>
<tr>
<td>-</td>
<td>Provide 24 hour supervision</td>
</tr>
<tr>
<td><strong>Managing a schedule</strong></td>
<td>-Persons at this level will not be able to mange their own schedule, appointments etc.</td>
</tr>
<tr>
<td>-</td>
<td>Others will have to tell the person when its time to go and assist with getting ready for appointments in a timely manner</td>
</tr>
<tr>
<td><strong>Self Care-dressing, bathing, grooming and hygiene: May not change clothes daily, may not bathe unless told do so</strong></td>
<td>-Hire a home health aide to come in several times a week to assist with bathing</td>
</tr>
<tr>
<td>-</td>
<td>Have a trusted family member assist with bathing if possible</td>
</tr>
<tr>
<td>-</td>
<td>Set out supplies such as clothing, tooth brush etc. and direct the person to perform to dress, etc.</td>
</tr>
</tbody>
</table>

**Other:**
Recommendations from Occupational Therapy

CPT Score: __________/5.6  Date Completed: _________________

This report was written by: ____________________________________________

If you have any questions about any of the concerns or recommendations I’ve made please contact me at:

Phone: _______________ email: _________________________________

Occupational Therapists assess person’s abilities to do daily things such as to taking care of themselves; taking medicines; getting food for meals; paying bills; getting in and out of the home; and many other typical daily activities.

Occupational Therapists do this by:

- Asking the person about their typical day and what they need to be able to do when they go home
- Watching persons do activities in therapy that are similar to what they might do at home
- Using tests such as the Cognitive Performance Test that give the therapist information about the persons thinking skills.

Therapists take all of this information about the person to create a therapy program that prepares the person to leave Saint Therese Rehab. They also use this information to give information to families and caregivers about how much help a person might need when they leave to return home or go to a new place to live such as assisted living.

Based on the occupational therapy evaluation and testing, the amount of assistance recommended for ________________ is highlighted on the other side.
### This person may need SOME HELP from others with:

<table>
<thead>
<tr>
<th>Activity</th>
<th>Recommendations that apply to ____________ are highlighted below:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Living alone</td>
<td>Arrange for or provide daily assistance and monitoring, e.g., a senior apartment, assisted living, home with daily checks.</td>
</tr>
<tr>
<td>Keeping medicines organized and/or taking them correctly</td>
<td>Use an automatic pill dispenser to give out the medicines; have another person give out the pills at the right time.</td>
</tr>
<tr>
<td>Making complex health care decisions</td>
<td>Fill out a health care advance directive.</td>
</tr>
<tr>
<td>Managing money, shopping</td>
<td>Have a power of attorney in place; have a trusted family member oversee bill paying and go with for shopping trips.</td>
</tr>
<tr>
<td>Transportation</td>
<td>Provide rides to appointments or shopping; use buses/vans for small living in an assisted living facility; sign up for metro mobility.</td>
</tr>
<tr>
<td>Using appliances and power tools</td>
<td>Hire help or have family mow lawn and remove snow. Move power tools out of sight and provide supervision and help when used.</td>
</tr>
<tr>
<td>Cooking—may leave stove on, may not eat a balanced diet</td>
<td>Sign up for Meals on Wheels; arrange for person to eat more meals in community dining room if in assisted living; purchase easy to prepare, one step foods that can be heated in a use microwave instead of stove.</td>
</tr>
</tbody>
</table>

### This person will need someone to WATCH OVER:

<table>
<thead>
<tr>
<th>Activity</th>
<th>Things that family and caregivers can do:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Planning and starting activities: may have problems remembering when to do things</td>
<td>Leave notes and reminders on dry erase boards</td>
</tr>
<tr>
<td></td>
<td>Put labels and reminder notes on items</td>
</tr>
<tr>
<td>Doing laundry—may not wash clothing as much as should, may put dirty clothes away with clean</td>
<td>Have someone come in weekly to help with laundry by taking dirty clothes to be washed, carrying loads up and down steps, helping the person to put clean clothes away</td>
</tr>
<tr>
<td>Self care—may not bathe or shower enough</td>
<td>Use written reminders for showers; have a family member come over weekly to set up showers and be available to help if needed; hire home health aides to help with showers</td>
</tr>
</tbody>
</table>

**Other:**

---

4.5
Recommendations from Occupational Therapy

CPT Score: __________/5.6  Date Completed: ________________

This report was written by: ________________________________________________

If you have any questions about any of the concerns or recommendations I’ve made please contact me at:

Phone: ______________________ email: ________________________________

Occupational Therapists assess person’s abilities to do daily things such as to taking care of themselves; taking medicines; getting food for meals; paying bills; getting in and out of the home; and many other typical daily activities.

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Based on the occupational therapy evaluation and testing, the amount of assistance recommended for _______________ is highlighted on the other side.

5.0
Appendix K

Form: How changes in thinking ability affect day to day living

One of the ways occupational therapists help a person get ready to leave rehabilitation at Saint Therese is by evaluating how the person thinks. They are specially trained to do this using a test called the Cognitive Performance Test (CPT). The test involves having persons do several common tasks such as making a phone call or setting up medicines. During the test, the occupational therapist is looking for clues about how much help the person needs when they come across a problem, and what type of help they need to solve the problem.

Below is an overview of how the CPT fits into the OT evaluation process:

For an introduction to what the CPT score means, see reverse.
The CPT gives a score from 1-5.6 called a cognitive functional level. Below is an introduction to each level. Further information about how your friend or family member scored and specific recommendations for them will be provided to you by the occupational therapist.

**Level 5.6 - Normal functioning.** At this level, the person can use complex information to carry out daily activities safely and accurately. For example, they can learn to do things differently such as using a walker or remember to take a new medication correctly without assistance.

**Level 5.0 - Mild decline: start of difficulty with complex tasks.** At this level, problems with memory, judgment, reasoning and planning ahead are seen. For example, the person may make mistakes in their checkbook or struggle to take a new medicine that requires different dosages at different times of the day. However, the person can learn to do things differently with repetition and reminders.

**Level 4.5: Mild to moderate decline: significant difficulty with completion of complex daily tasks and start of difficulty with self-care tasks.** At this level, the person may struggle with reading, writing and calculating. For example, though the person may remember to take their medicine, they may not be able to follow the directions on a pill bottle correctly, even though they can read the label. It is possible for the person to learn new information or other ways to do things, but they cannot repeat what they’ve learned in a different setting or situation. 24 hour supervision is recommended.

**Level 4.0: Moderate functional decline: unable to complete complex daily tasks and difficulty with self-care tasks.** At this level memory, judgment, reasoning and planning ahead are very impaired in the person. For example, the person may not remember at all to take their medicine, even with verbal or written reminders. The person’s ability to learn new information or other ways to do things is limited. 24 hour supervision is recommended.

**Level 3.5: Moderate functional decline; unable to complete complex daily tasks, significant difficulty with self-care tasks.** At this level the person will need more prompting and cues from caregivers to start and complete even simple tasks such as getting dressed. The person cannot learn new information. 24 hour supervision is recommended.

**Level 3.0: Moderate to severe functional decline; unable to complete self-care tasks without assistance.** At this level the person can hold and use objects for tasks, (e.g. a wash cloth) but is unaware of the goal of the task (e.g. washing the same spot over and over instead of washing the entire body part). The person cannot learn new information. 24 hour supervision is recommended.

**Levels 2 and 1: Severe functional decline.** At these levels, the person does not recognize objects or know what to do with them. The person needs to be totally cared for by others. They may respond to touch, movement, and sound. They require total assistance for self-cares and 24 hour supervision or Hospice care.
Appendix L
Presentation slides

Welcome to Saint Therese!

Figure L1: Presentation slide 1.
Narration:
Welcome to Saint Therese! We’re glad you’ve chosen us to help with your needs.
Figure L2: Presentation slide 2.

Narration:

The purpose of this short presentation is to orient you to what occupational therapy is, how it can help your family member or loved one, and what you might expect during their course of occupational therapy, or OT, treatment at Saint Therese.
To begin, we’ll give you some background. Occupational therapists have a master’s degree, and occupational therapy assistants have an associate’s degree.

Both levels of therapists are licensed to practice by the State of MN Dept of Health and must renew their license on an annual basis through meeting practice and continuing education requirements.

The occupational therapy plan of treatment is ordered and approved through the physician. This may be the house physician and not necessarily the person’s regular physician.
Occupation refers to everything that people do during the course of everyday life. Occupational therapy helps individuals when their ability to do everyday tasks is interrupted due to illness, a surgery, a fall, or other issues. Everyday tasks that could be affected include getting dressed; Cooking; Attending to needs in the bathroom, like using the toilet and shower; Shopping; Cleaning; Driving; Getting around the room; and managing medications.
In order to regain or improve the ability to do everyday tasks, occupational therapy may work on many skills that are needed in order to successfully complete a task. For instance,

- the strength to reach, stand, and lift objects;
- balance to be able to safely reach into the refrigerator;
- Endurance or stamina, to be able to make breakfast without becoming exhausted;
- Thinking skills, to be able to remember and figure steps out in order to make a meal;
- Coordination – of the arms and hands to be able to pick up objects and use them;

Improvement can occur in many of these skill areas during occupational therapy, but sometimes there is a limit to what the person regains or there is a permanent condition present that permanently limits one of these component skill areas.
When a skill area remains limited

- Adapt the Task
- Adapt the Environment
- Adaptive Equipment
- Caregiver Education
- Recommend Services or Alternate Living Situation

**Figure L6:** Presentation slide 6.

Narration:

When a skill area, such as balance, thinking skills, or vision, remains limited, the focus of occupational therapy moves from trying to improve the skill area to making adaptations or changes to compensate for losses in that area. The occupational therapist, with the patient/family input, may:

- Adapt the task, for example using a chair in the shower to improve safety when the person’s balance is not good
- Adapt the Environment – for example, recommending a grab rail or marking a stove dial that cannot be easily read
- Recommend Adaptive equipment – for example, a reacher to pick things up, a walker basket, a magnifying glass
- Educate the Caregivers – for example, ways to decrease the risk of falls or education about the person’s thinking skills and how it impacts the person’s abilities and safety at home
- Recommending services or alternate living situation – for example, meals on wheels, a bath aide, adult day service program, or possible home care, assisted living, memory care, or long-term care facility.
Narration:

All departments have special focuses for patients staying in the transitional care unit. For instance, the nursing department focuses on things like medications and vital signs. The physical therapy department has a special focus on walking. In occupational therapy, the focus is the ability of the person to do everyday tasks, with a special focus on the thinking abilities for everyday tasks. Thinking abilities include memory, knowing the next steps, and being aware of potential safety issues.

Why is it important to look at this?

- As we age, we are more likely to have memory difficulties.
- After age 85, the risk reaches nearly 50 percent.
- Other types of dementia are more likely, as well.
- Older adults can be vulnerable in many ways. They may have many medical diagnosis and may be physically frail.
Why the focus on thinking abilities?

- Guides the decision making of the care teams
- Strategies can be put into place to help a person
- Families can gain a better understanding

Figure L8: Presentation slide 8.
Narration:

Knowing about any memory issues that are present can help the care team to look at the patient's full situation, to help with knowing the patient's challenges and how to meet them, so that the person is safe.

Physicians and the interdisciplinary team work with our occupational therapy department to understand the thinking abilities of the person, which can help guide the care center team in decision making regarding discharge planning.

When there is difficulty with thinking skills and doing everyday tasks, occupational therapists can work with that patient and/or caregivers to develop adaptations or strategies that can help aide memory, communication, and completion of everyday skills. Occupational therapists can help families understand more about memory loss and ways to meet these challenges.
How thinking abilities are assessed

- Formal methods
  - Researched tests for evaluating a person’s thinking skills for everyday tasks.
    - Cognitive Performance Test (CPT)

- Informal methods
  - Gathering information from the patient and family
  - Observing the person doing actual activities.

Figure L9: Presentation slide 9.

Narration:

The occupational therapy department assesses thinking skills through a combination of formal and informal methods. The formal method includes giving OT tests that were researched and developed specifically for evaluating a person’s thinking skills for everyday tasks. The primary test used is called the Cognitive Performance Test or CPT. We will tell you more about it in a minute.

The informal method includes gathering information from the patient and family about how the person has been functioning at home. It also includes observing the person while doing actual activities that the person might do at home. This will include how the person learns new things; responds when the unexpected happens; recognizes and fixes errors when they arise; and their overall safety.
The CPT was developed by an occupational therapist to determine how a person is functioning now. It also can be given over time, to detect any changes that might be occurring. There is research to support the use of this CPT. The CPT looks at how a person thinks through and performs common daily tasks. Depending on how the person performs, the test can predict how much help the person might need with daily tasks, including the type of help and how often it is needed. Last, the CPT can help figure out what the strong points are for the person which can then be used to create strategies to help compensate for loss in thinking skills. For example, the person who has trouble following spoken directions but can follow written directions, might benefit from the use of reminder notes.
How does the CPT measure how a person thinks through a task?

All daily tasks have multiple steps. In order to do a task successfully, the person needs to take what they have at hand and figure out how to proceed. They need to know what to do first, second, third, etc. – even in a different environment than they are used to. They need to be able to recognize if something goes wrong and then know how to fix it. They need to make good decisions throughout the process. If a person has difficulties with any of these steps, he or she might need help to be successful. This could be needing a verbal reminder, a written note, or an item handed to the person.
Cognitive Performance Test (CPT)

- 6 Tasks
  - Making toast
  - Setting up new medications
  - Dressing for particular weather conditions
  - Washing their hands
  - Calling for the price of paint
  - Shopping for a pair of gloves

Figure L12: Presentation slide 12.

Narration:

There are 6 tasks that are presented, each with very specific instructions and items to use, per the outline of the test. Whenever the person needs more help or a different set-up to do the task, their score is lowered, per the CPT process that the OT carefully follows. Each task receives a score. Then the 6 scores are averaged together to give a final CPT score. The OT’s are not just seeing what the outcome is of each task, but rather they are determining what the general pattern of ability is throughout all of the 6 tasks, such as:

- Can they do tasks without help?
- Do they need some set-up of items first?
- Do they need some verbal cues or more visual cues?
- Do they need tasks simplified, so that they only have 1 or 2 steps to do?

Note, that if the person no longer does 1 or more of these tasks, it will still be a part of the CPT. It remains a fair assessment to see what steps of the task are difficult for the person.
The CPT score gives information about how much help a person is currently needing to figure out and complete tasks. It also gives guidelines about what level of assistance the person might need in order to function at their best and be safe. This guide is a reference to what the score means. You will receive reference guides, such as this to help with explaining the meaning of the CPT score.

CPT scores can be influenced by medication side effects, refusals to participate, if the person is not taking it seriously, and other difficulties like vision or hearing loss. The therapist will note if these are factors in the testing. A CPT can be re-tested during a stay in the transitional care unit, as needed.
The typical course of occupational therapy at Saint Therese looks like this:

- An initial occupational therapy evaluation is completed, to see how the person is currently doing. This will include asking the patient about a typical day for them at home and what they need to be able to do when they leave Saint Therese.

- Together, the patient and therapist develop a therapy plan and set goals, to help prepare the person to leave Saint Therese Rehab.

- The OT will communicate with the patient’s primary contact to tell them about the plan and ask them for additional information.

- Treatments to address the goal areas will be completed and, in most cases, will include a CPT to assess the person’s thinking skills.

- An OT update, including the person’s abilities and thinking skills, will be provided to the primary contact through phone calls, emails, and/or at care conferences.

- For some patients, a visit will be scheduled by our home visit occupational therapist.

- Follow-up communication or training with the caregivers will occur, as needed.

Also use info to give info to families and caregivers about how much help person might need to return home or new place such as assisted living.
The patient is our number one priority; family or other caregivers are extensions of this. We invite you to think of us all as partners. We welcome your questions or any feedback or comments you have. If you feel you do not understand something or are wondering how the person is doing, please ask – or better yet, come in to an OT session with your loved one!

Together we can help patients achieve their maximal potential, while staying safe in their environment!
Figure L16: Presentation slide 16.

Narration:

To contact any of the OTs in the department, please call.

OT sessions are generally held between the hours of 6:30am until 3:30pm; times and days will vary.

Learn more about Saint Therese at our website www.sttheresemn.org
Figure L17: Presentation slide 17.
Narration:
Thank you for your time and interest in learning about the occupational therapy department of Saint Therese!