Abstract
Assessing the Risk of IADL Tasks from the Perspective of Medically-at-risk Older Adults and their Caregivers
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The purpose of this study was to understand the impact of chronic disease on the functional ability of older adults by determining which instrumental activities of daily living (IADL) are most meaningful and may pose a safety hazard for the medically-at-risk older adult who plans to live independently. Data was collected through individual interviews with twelve older adults and their caregivers. The participants had to be recently discharged from a hospital due to their chronic disease that including heart disease, stroke, COPD, dementia, or diabetes. Data analysis indicates that the most important IADLs were driving, managing medication, cooking, and phone use. Participants reported all IADL tasks affected by chronic disease except managing finances and phone use. Qualitative results revealed discrepancy between the caregiver’s and participant’s perception of driving ability which leads to concerns for safety. It is also suggested there may be safety concerns with medication management. Further examination and research should compare older adults’ perception of functional performance and actual performance of IADL tasks.
Assessing the Risk of IADL Tasks from the Perspective of Medically-at-risk Older Adults and their Caregivers

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Chapter 1: Introduction

Summary of relevant literature

Research shows that as the human body ages, biological systems and structures begin to decline. For older adults, aging of the neurological, cardiovascular, and musculoskeletal systems impacts their ability to perform instrumental activities of daily living.

Specifically, studies have shown that neurological aging causes reduction in response speed as well as impairments to visual mechanisms which distorts control of movement and depth perception (Spirduso, Francis, & MacRae, 2005). Studies on the affect of the aging hippocampus structure of the brain exhibit a relation to memory loss (Naftali & Rodrigue, 2006; Zimmerman, Pan, Hetherington, Katz, Verghese, Buschke, Derby, & Lipton, 2008), both verbal memory and short term memory. Another affect of the aging brain is attention deficits (Whitbourne, 2005). Neurological decline causes memory loss and attention deficits which relate to ability to make decisions and efficiently complete tasks (Porter, April 2007; Whitbourne, 2005).

Along with neurological decline, aging affects the cardiovascular system. Thickening of the blood vessel walls produces higher blood pressure (Naftali & Rodrigue, 2006) and stresses the pumping mechanisms of the heart (Whitbourne, 2005). Thickening vessels and increasing stress on the heart muscle cause a decline in the amount of oxygen going out to the body which weakens performance capacity (Hollmann, Struder, Tagarakis, & Kin, 2007).

Musculoskeletal concerns also arise as the body ages. Muscles and bones begin to weaken (Freemont & Hoyland, 2007) decreasing mobility (Holstein, Due, Almind, & Avlund, 2007). Additionally reducing mobility is the diminishing capacity of knee

Aging is also associated with chronic illness such as heart disease, stroke, chronic obstructive pulmonary disease (COPD), diabetes, and dementia (Estes, 2007; Fraker, 2007). Along with regression of performance capacity related to normal aging, individuals with chronic illness have negative impacts on their daily tasks caused by their illness. Studying specific abilities that are impacted will enhance professional’s knowledge for prevention of disease and promotion of health in older adults (Holstein, Due, Almind, & Avlund, 2007).

**Definitions**

Tasks of daily living include activities of daily living (ADL) and instrumental activities of daily living (IADL). ADLs are the tasks of self-care and self-maintenance including hygiene, feeding, mobility, and dressing (American Occupational Therapy Association, 2008). Secondary to ADLs are IADLs which include money management, communication devices (telephone), traveling, shopping, meal preparation, and home management (Lawton & Brody, 1969; American Occupational Therapy Association, 2008).

**Statement of the problem**

Currently there are 35 million people over the age of 65 living in America and that number is expected to continue to rise (Wan, Sengupta, Velkoff, & DeBarros, 2005). As the older adult population rises, there will be increased need of the health care system to provide preventative care for at risk older adults. This will include assessments of IADL to determine if an older adult is safe to live independently or needs services such as
occupational therapy to decrease the risk of injury. There are many assessments available to test level of independence in the activities of daily living both simple and complex tasks. Some of these include the Canadian Occupational Performance Measure (COPM), Functional Independence Measure (FIM), Direct Assessment of Functional Abilities (DAFA), Caregiver Assessment of Function and Upset (CAFU), Assessment of Motor and Process Skills (AMPS), Extended Activities of Daily living (EADL), Instrumental Activity of Daily Living (IADL), and Performance Assessment of Self-Care Skills (Pass) (Gitlin, 2005; Letts & Bosch, 2005).

Some of the assessments are self report or caregiver report while others are observations of performance. There is likely no question that observation of performance is the best indicator of true performance, but with the shortened stays in hospitalizations, occupational therapists often have limited time with their clients. Therapists focus on basic ADLs and may not have time to assess the more complex instrumental activities of daily tasks such as driving and home management. The result may be that the client and caregiver are not prepared for managing the complex tasks of daily life and the client may be at risk for injury when attempting to perform some of these more complex activities. A further complication is that the medically-at-risk older adult may not have an accurate perception of their performance. The caregiver also may not have an accurate measure of safety upon discharge, but may recognize safety issues and potential problems once the client begins to function in their own environment.

The issue is that older adults have shortened hospital stays and occupational therapists have abbreviated therapy time to address all areas of occupation (Defrances, Hall, & Podgornik, 2005). Typically, basic ADLs are evaluated and addressed in therapy, but more complex ADLs may not be addressed (Defrances, Hall, & Podgornik,
The question remains whether the client is at risk for injury or dependency when they return to their home environment. What is needed is a screening tool or assessment that will accurately predict if there is safety risk and what level of risk exists. The first step in developing this tool is to determine what activities are perceived as important and meaning to the majority of older adults.

Since it is possible that the caregiver of the client will have a different view of the client’s ability, it is therefore necessary to survey both the client and their caregiver when assessing perception of function. Discovering which complex activities are most problematic and pose safety risks for older adults with chronic illnesses will allow therapists to amplify the effectiveness of their treatments and permit family members to make educated decisions for their aging parents and/or extended family.

**Significance of the study**

Daily activities become increasingly difficult for the aging adult to perform. When also impacted by a chronic illness such as heart disease, stroke, COPD, diabetes, and/or dementia, the complexity of daily tasks increases. The purpose of this study was to discover through survey/interview which specific tasks are harder to perform for older adults with chronic illnesses. The results will help develop a global assessment tool, the Functional Assessment of Safety Tool (FAST) which will evaluate the level of performance and safety risks of older adults in complex tasks. The expectation of the FAST is to help increase quality of life of older adults by determining which areas can be restored or modified through therapy and other related services.

**Limitations of the study**

One limitation of the study is that the researcher is a student who is new to research. To alleviate this, the researcher was trained on statistical methods used for this
research by taking a statistics class. Also the researcher worked under a highly qualified experienced researcher who agreed to mentor the new student through the research.

Another limitation is that the data gathered for analysis was self reported and therefore actual performance was not being tested. However, the goal of this study is not to develop the performance screening tool, but to identify which IADL tasks are seen as meaningful and important to clients, as well as to determine which are most affected by the identified medical conditions. This will help determine if there is risk for injury or nonperformance for each IADL task addressed.

A final limitation was that there is a limited area of subjects being used for this study and this could hinder data collection. Only one hospital Pitt County Memorial Hospital (PCMH) was used. To diminish this limitation, the researcher had four months to complete data collection and also had contact with members in the support groups for individuals who have had a stroke to use for this study. Using phone interviews when face to face interviews are not possible was an additional option to aide to data collection
CHAPTER 2: Literature Review

In America there are around 35 million people aged 65 or older and this number is expected to double over the next 25 years so that one in five Americans will be 65 or older (Wan, Sengupta, Velkoff, & DeBarros, 2005). Part of this increase is due to the high number of baby boomers (those born between 1945 and 1964) who are aging (Whitbourne, 2005). As the older adult population is rising the need for more research on the decline of cognitive and physical functions as they relate to daily tasks for older adults is essential.

When studying aging, it is important to consider the variability of individual differences. People differ in their physical attributes, behaviors, and the rate of physiological change (Raz & Rodrigue, 2006; Spirduso, Francis, & MacRae, 2005). The result is that each individual will age slightly different from the next. Incongruity in the aging process can be attributed in part to choices and life (Whitbourne, 2005). Particularly heredity, diet, amount of exercise, and exposure to environment hazards (Morgan & Kunkel, 2007). Positive lifestyle choices such as maintaining a balanced diet and engaging in regular exercise will help promote health. Unfortunately, even if good choices are made accidents and diseases occur and can result in serious injury and/or decrease in function. Despite variability in the aging process, research and study focusing on function and performance related to aging will allow health professionals to gain the expertise needed to provide the best service for older adults (Spirduso, Francis, & MacRae, 2005). Such study should include the neurological system, musculoskeletal system, and cardiovascular system.
**Normal Aging**

**Neurological Systems.** Neurological studies are revealing that a decrease in the number of neurons (Jett, 2008), decrease in brain volume, and loss of frontal lobe function in older adults negatively influences memory, processing, sensory ability, response speed, and vision related to performance of activities of daily living (ADLs) (Surprenant & Neath, 2007). In such, as the brain ages areas of cognition relating to memory, attention, and executive function (Warren, 2006) begin to decline.

The link between neurological decline and loss of working memory is still unclear but a possible relationship between loss of cortico-subcortical connections and decline in working memory has been proposed (Raz & Rodrigue, 2006). Working memory is preservation of information for a short period of time, as needed when solving a problem, following instructions, or understanding language (Whitbourne, 2005). Examples of when working memory is needed are dialing a phone number, remembering ingredients and/or steps of a recipe when cooking, and engaging in a conversation. Newson and Kemps (2006) studied cognitive changes in older adults by conducting a questionnaire examining the function and decline of cognition and how this related to daily functioning. They found working memory to be the most affected cognitive function. Thus, they concluded that working memory was a key area to be addressed in the elderly (2006).

Some memory loss, such as verbal memory is specifically related to diminishing areas in the hippocampus (Raz & Rodrigue, 2006; Zimmerman et al., 2008). A study conducted by Zimmerman et al. (2008) used a cued list-learning verbal memory test with older adults who had no dementia. In this test, participants were presented with 16 objects to identify and then later were asked to recall the same objects. Those with a smaller hippocampus showed poorer recall than those with larger hippocampus volumes.
This finding supports the ability to predict verbal memory based on hippocampus size which can be used in the development of assessments for older adults (2008).

Attention is also an important aspect of cognition that is affected by age. Attention refers to the ability to focus on a task despite distractions (Tipton-Burton, McLaughlin, & Englander, 2006). To understand the decline of attention with age in regards to cognitive function, researchers have compared the differences in attention between young and older adults (Whitbourne, 2005). Gaeta, Friedman, Ritter, and Cheng (2001) tested attention in both adults both old and young. Tones were played in each ear and the study’s volunteers were instructed to attend to certain tones by pressing a button and to ignore other specific tones. It was concluded that the older adults were less able to discriminate between tones thus their level of attention was lower than that of younger adults. In a 2008 study by Fiorentino, cognition was evaluated and compared between young and elderly individuals. Attention was measured by having the participants identify an object on a computer that was in a busy background. The results of the study showed that the older participants performed inferior to the younger participants.

Along with memory and attention, another area of cognition affected by aging is executive function. Executive function is used in problem solving as the ability to create goals and plan steps to achieve desired outcomes (Glogoski, Milligan, & Wheatley, 2006). It is involved when making decisions, sequencing steps, and overseeing all cognitive processes, therefore it relies on effective operation of memory and attention.

Treitz, Heyder, and Daum (2007) examined executive function in young, middle aged, and older adults to see if there were changes during aging. Several tests were used to measure verbal fluency, reasoning, inhibition, task management, and multi-tasking. Results affirmed that after age 60, executive function begins to decline (2007).
Loss of executive function has been associated with regional atrophy of the brain. To investigate this relationship, Elderkin-Thompson, Ballmaier, Hellemann, Pham, and Kumar (2008) tested cognitive performance of 23 older adults compared to magnetic resonance imaging (MRI) of their frontal lobes. Cognitive performance was measured through several tests of verbal/nonverbal skills, memory, reasoning, word association, and response inhibition. When compared to the MRI the overall conclusion was that frontal lobe atrophy reflects levels of cognitive performance. Atrophy of the frontal lobe can be associated with lifestyle choices such as diet, exercise, and environmental factors (2008).

Another function of neurological and cognitive concern with aging is vision. Over time the lens thickens and hardens resulting in difficulty focusing on near objects; cataracts or clouding of the lens can also develop which causes vision to become blurred (Jett, 2008; Whitbourne, 2005). Haegerstrom-Portnoy (2005) assessed vision in older adults to determine the extent of visual decline with age and its impact on performance. The vision tests given to 900 older adults measured a variety of visual abilities including contrast, color, glare, and visual field. Findings indicated a gradual decline in all areas of vision with glare recovery being the most impaired visual function in those aged 85 and older (2005).

As research shows the areas of cognitive and neuronal capacities decline with age, research also shows how to improve and possibly delay such effects. Studies have revealed that engaging in cognitive training activities and mental activities can improve or delay cognitive decline.

To determine if working memory can be enhanced by engaging in memory training Carretti, Borella, and Beni (2007) tested the effects of memory training in both
younger and older adults. Testing included pretest/posttest evaluations on word list recall and training including using mental images to enhance word recall. Results concluded that working memory was enhanced by the training in both younger and older adults (2007). Another study conducted by Calero and Navarro (2007) focused on improving working memory with memory training program that used mnemonic strategies, and taught older adults how to use associated pairs and categorization for learning and recall. Finding presented positive correlations with the memory training program and improved working memory (Calero & Navarro, 2007).

Executive function which consists of reasoning and problem solving skills has been shown to enhance with training. Williams (2008) taught problem solving steps and strategies to older adults. The training was applied to phone lists, medication labeling and filling, and nutrition and healthy meal selection. Scores on posttest showed increase in reasoning and problem solving skills (2008). Gilhooly, Gilhooly, Phillips, Harvey, Murray, and Hanlon (2007) examined activity patterns of older adults compared to their cognitive performance. Participants who reported more engagement of mental activities such as reading, card games, chess, crosswords, writing, typing, listening to music, and sewing/knitting were found to have higher scores of cognitive assessments.

Improved cognition has also been attributed to physical activity. Physical activity consists of structured exercise, house/yard work, and recreation. When self reported level and amount of weekly physical activity is compared with performance on cognitive tests of intellect, inhibition, and memory a positive correlation is found (Bixby, Spalding, Haufler, Deeny, Mahlow, Zimmerman, Hatfield, 2007). Newson and Kemps (Jul-Sept 2006) used a self report activity inventory to measure the stimulation from physical and cognitive activities. The physical activities measured in were running, swimming, and
jogging. Finding showed that a lifestyle with engaged physical activities may protect against decline in cognition (Jul-Sep 2006). Buchman, Wilson, and Bennett (2008) further assessed the effect of physical activity on cognition using quantitative methods. Study participants wore an Actical which measured their physical activity level daily for an average of nine days. Nineteen cognitive tests were given to measure memory and executive functions. Results presented positive associations between physical activity and global cognition (2008).

*Musculoskeletal System.* Effects of aging not only produce declines in cognition but declines are seen in the musculoskeletal system as well. As the individual ages, physical changes occur in muscle tissue, bones become weaker and fragile, ligaments loose elasticity (Freemont & Hoyland, 2007), and joint function begins to weaken (Whitbourne, 2005).

Physiological changes in muscle are evidenced by decreased muscle mass and muscle fibers causing diminishing muscle strength. Decrease in muscle mass is known as sarcopenia (Whitbourne, 2005). Sarcopenia is partially induced by the death of muscle fibers which begins to occur after age 30 (Hollmann, Studer, Tagarakis, King, 2007). Loss of muscle mass leads to reduced muscle strength which can increase physical disability (Flynn, 2007).

Lee, Cheung, Qin, Tang, & Leung (2006) conducted a study to observe the differences in muscle fibers of the young and old. Muscle biopsies were taken from 65 participants aged 17-96. There were decreased Type II and Type IIA muscle fibers in the older adults. Type II and Type IIA muscle fibers are responsible for repetitive activities and fast movement. Findings suggest that muscle deterioration as related to balancing coordination results in increased risk for falls (2006).
Along with physiological changes in muscle, aging is associated with changes in bone structure. As with muscle, bone mass decreases with age (Jett, 2008). Alteration of bone structure in the aging process is caused by a decrease of renewal and absorption of calcium which increases the rate of bone destruction and risk for fracture (Whitbourne, 2005).

Related to the musculoskeletal system are joints, tendons, and ligaments. Joints which are at the junction of bones; tendons and ligaments are the connective tissue between the bones which allows movement (Jett, 2008). The function of joints begins to deteriorate with age as the tissues wear down and become less pliable thus reducing their flexibility (Whitbourne, 2005). Cartilage, the tissue between the joints, dries out with age resulting in pain and less movement (Jett, 2008).

Changes in joint function affect knee extension and flexion in aging adults. Akima et al. (2001) investigated muscle function and aging men and women by measuring peak torque of knee movement. Extension and flexion of the knee was found to decrease with age in both men and women (2001).

Musculoskeletal breakdown has been attributed to weakening of the endocrine system. The endocrine system ability to secrete hormones declines with age. Reduction of hormones such as growth hormone, insulin-like growth factor, estrogen, and testosterone affect the metabolic balance is muscle and bone (Freemont & Hoyland, 2007; Lytras & Tolis 2007; Whitbourne, 2005).

Just as with cognition, numerous studies have shown the positive effects of physical activity on the musculoskeletal system (Aagaard, Magnusson, Larsson, Kjaer, & Krstrup, 2007; Jett, 2008; Depp & Jeste, 2006; Flynn, 2007; Goodpaster, Chomentowski, Ward, Rossi, Glynn, Delmonico, Kritchevsky, Pahor, & Newman, 2008;
Benefits of exercise for older adults has been ascertained to be a low cost means to reduce fall risk, increase performance ability in activities of daily living (ADLs) (Flynn, 2007), and increase the maintenance of bone by making them stronger and healthier (Spirduso, Francis, & MacRae, 2005).

To determine if physical activity would enhance muscle strength, Goodpaster et al. (2008) gave sessions of physical activity interventions to 52 subjects aged 70 to 89. Physical activity interventions consisted of trainings focused on aerobic, strength, flexibility, and balance. Findings concluded that even the modest increase in physical activity prevented additional loss of muscle strength and fat accumulation (2008).

Capodaglio, Capodaglio Edda, Facioli, and Saibene (2007) measured the progress of a year-long training program on muscle function in 38 elder men and women. Participants attended a one hour exercise class twice a week consisting of warm up stretching, flexibility, and light aerobic exercises, then strength training on gym machines, and finally a cool-down stretch. Once a week participants performed a home exercise with Theraband and a 30 minute outdoor aerobic exercise. Effects of the study provide evidence that long-term physical activity programs increase coordination and muscle control thereby supporting promotion of physical activity in the elderly (2007).

Aagaard et al. (2007) compared subjects who had lifelong physical training with those who did not. The lifelong physical trainers had continued endurance and strength training in long/short distance running, sprinting, and cycling for 50 years. Muscle strength and muscle/fiber morphology was assessed in both the trained and untrained subjects. Those who had lifelong physical training had greater muscle fibers and muscle strength that those who had more sedentary lifestyle (2007).
Cardiovascular System. Cardiovascular decline is also associated with aging; in fact cardiovascular disease is the highest cause of death in older adults (Newman, Arnold, Naydeck, & Fried, 2003). Functioning of the cardiovascular system is required for maximum health and physical function enhancing the quality of life (Spirduso, Francis, & MacRae, 2005). The ability to perform physical tasks including walking, cleaning, and cooking are related to the function of the heart and venous system which maintains a balance in the body by delivering oxygen and nutrients to body cells as well as removing waste (Jett, 2008). Blood vessels begin to thicken with age which can lead to increased blood pressure (Spirduso, Francis, & MacRae, 2005). High blood pressure can produce negative effects on the brain (Raz & Rodrigue, 2006). Thickening also occurs on the cardiac muscle walls particularly the left ventricle deteriorating the pumping mechanism (Spirduso, Francis, & MacRae, 2005).

The decline in the amount of oxygen delivered through the blood and the amount of blood going out from the heart after each pump declines 10% per decade (Whitbourne, 2005). Oxygen deficits weaken performance ability in the areas of coordination, flexibility, strength, and endurance (Hollmann, Studer, Tagarakis, King, 2007). In general, the heart is able to provide ample function for everyday life even with the limitations caused by age; however it takes longer for the heart to adjust to the sudden demands of acceleration caused by strenuous task and deceleration after the task (Jett, 2008).

Exercise has been determined to have positive affects on the cardiovascular system (Flynn, 2007). Advantages of physical activity are shown by lowered blood pressure, decreased body fat, improved respiratory function, enhanced sleep, and less depression in subjects who exercise (Jett, 2008). Vatten, Nilsen, and Holmen (2006)
conducted a 16 year prospective study to see if physical activity was associated with decreased cardiovascular mortality. Participants were given questionnaires to determine frequency, duration, and intensity of their weekly physical activity. It was determined that those who reported more physical activity have less risk of cardiovascular death (2006).

Impact of Normal Aging in Tasks of Daily Living

Given that multiple systems of the body decline with age including the neurological, musculoskeletal, and cardiovascular systems, some limitations in performance of daily tasks are inevitable. Performance of daily tasks can be measured by assessments utilizing self report questionnaires, direct observation, or interviews of individuals and their caregivers (Holm & Foreman, 2006). Assessments that measure the level of independence in activities of daily living (ADLs) include the Assessment of Motor and Process Skills (AMPS) (Fisher, 2006), Canadian Occupational Performance Measure (COPM), Functional Independence Measure (FIM), Direct Assessment of Functional Abilities (DAFA), Caregiver Assessment of Function and Upset (CAFU), Assessment of Motor and Process Skills (AMPS), Extended Activities of Daily living (EADL), Instrumental Activity of Daily Living (IADL), and Performance Assessment of Self-Care Skills (Pass) (Gitlin, 2005; Letts & Bosch, 2005). Based on such ADL assessment scales, the majority of seniors under age 85 have few limitations in daily life activities of personal and home management; however those older than 85 require assistance with shopping, meal preparation, and mobility (Morgan & Kunkel, 2007). It is important for health care providers to understand how aging affects performance.

Ramifications of cognitive changes specifically changes in working memory, executive function, and vision, play a role in daily activities, driving, and leisure
activities (Whitbourne, 2005). Newson and Kemps found problems in working memory as the biggest hindrance of daily function (2006). As noted earlier, working memory stores information for a short period of time, and is needed when solving a problem, following instructions, or understanding language (Whitbourne, 2005). Therefore, as working memory declines, activities such as dialing a phone number, remembering ingredients and/or steps of a recipe, and engaging in a conversation may become difficult.

Cognitive decline in executive function also impacts daily tasks. As part of executive function, processing, decision making, and response speed are reduced. A study of performance ability across the lifespan found that processing skills begin to decline after age 55 (Hayase, Mosenteen, Thimmaiah, Zemke, Atler, & Fisher, 2004). Reduction in response speed impacts time to complete tasks such as dressing, grooming, cleaning, and driving (Spirduso, Francis, & MacRae, 2005). Craik and Bialystok (September 2006) found older adults between 60 and 80 could cognitively process instruction and complete simple tasks of cooking and setting the table similar to younger adults but spent more time setting the table. In another meal preparation study, Porter (April 2007) found specific processing issues related to food preparation for women 80 years and older. Specific issues related to processing and decision making were deciding what to fix, measuring ingredients, use of kitchen appliances/tools, and thoroughly cooking food (April 2007).

As part of cognition, visual decline is related to activity performance. Visual changes present distorted information influencing movement control and depth perception (Spirduso, Francis, & MacRae, 2005). Haegerstrom-Portnoy (2005) reported disability glare to be the most affected visional decline. Additional visional impacts were found in reading, face recognition, and grocery shopping. Degeneration of movement
control, depth perception, and disability glare is a major hindrance in driving ability (2005).

As with cognitive decline, musculoskeletal decline impacts functional performance by affecting upper and lower extremity movement, motor responses, and posture which reduce functional ability and quality of life (Jett, 2008; Freemont & Hoyland, 2007). Upper extremity mobility and motor control is a prerequisite for daily life tasks such as bathing, driving, shopping, and participation in various social activities. Lee, Fradet, Ketcham, and Dounskaia (2007) inspected the impact of aging on upper extremity movement. Both young and elderly subjects were examined through a line drawing test where they were required to draw lines in different directions. The results showed a decrease in muscle force of the arms and indicated that arm movements were generally slower in older subjects (2007). Changes in the musculoskeletal properties of the hand may also contribute to functional loss. Grip strength declines after age 60 along with joint motion particularly flexion and muscle force; functional implications of the aging hand affect the fine motor tasks of manipulating buttons in dressing, holding a pen/pencil in writing letters and/or checks, and opening bottles of medicine (Carmeli, Patish, & Coleman, 2003).

Changes in mobility of the lower extremity are also observed during aging with decline beginning after age 51 (Hayase et al., 2004). Mobility can be functionally defined as the ability to walk, climb stairs, and get in/out out of a vehicle (bus, car) (Ayis, Gooberman-Hill, Bowling, & Ebrahim, 2006). Gregory & Fried (2003) report that of their 160 subjects, 66% had difficulties with mobility tasks including heavy housework, carrying and lifting 10 pounds, and walking upstairs. Measures of difficulty were rated
on a questionnaire, reasons for difficulty were identified as having to modify task, increased time to complete tasks, and pain associated with completing task (2003).

Another study on mobility by Holstein, Due, Almind, and Avlund (2007) described the change in functional mobility of adults over a period of eight years. Study participants complete questionnaires every four years (also a baseline measure at the start of the study) rating their health status and ability to complete tasks. Results revealed deterioration in mobility particularly in the older groups (80+). Tasks most affected were brisk walking, use of public transportation, shopping, and heavy household cleaning (2007). In Porter’s (April 2007) meal preparation study, specific mobility issues related to food preparation for women 80 years and older were endurance in standing and walking.

Researchers and health care providers should not only recognize the underlying physical and mental aspects of aging but should understand the psychosocial aspect of aging (Depp & Jeste, 2006). Older adults value independence, social contacts, and maintaining dignity (Touhy, 2008). Fear of falling and driving cessation present obstacles to valued activities and psychosocial health.

A component of psychosocial aspect in aging is fear of falling. Studies estimate that up to 60% of older adults report mild to severe fear of falling (van Haastregt, Zijlstra, van Rossum, van Eijk, & Kempen, 2008). In the United States, it was reported that around 5.8 million adults aged 65 and older had fallen at least once in the last three months (Centers for Disease Control and Prevention, 2008). According to the National Center for Injury Prevention and Control (2008) one in ten older adults have fall related injuries requiring medical attention, with falls accounting for 14,900 deaths among older adults in 2004 alone.
Etiology of falls can be contributed to musculoskeletal declines and environmental hazards in the home and community (Feldman & Chaudhury, 2008; Lytras & Tolis, 2007). Consequences due to fear of falling result in decreased confidence, reduced or avoidance of physical activities, social withdrawal, depression, and a diminished sense of quality of life (Scheffer, Schuurmans, van Dijk, van der Hooft, & de Rooij, 2008; Touhy, 2008).

Driving is another activity of importance to older adults. Age related changes associated with cognition including vision loss (Freeman, Munoz, Turano, West, 2005), executive function specifically problem solving and response speed (Spirduso, Francis, & MacRae, 2005); along with declines in mobility impact driving ability (Herriotts, 2005). Herriotts (2005) explored implications for car design and how to enhance driving ability for older adults. Questionnaires were sent to assess older adult’s view of car designs. Highlighted obstacles discussed were seating position, entry/exit, radio use, reversing/parking, and use of trunk. Most difficulty was reported with turning to see out windows when reversing and parking. One third had trouble entering and exiting the car, one sixth had difficulty putting things in the trunk and using the radio. Results indicate a mismatch of the needs of older adults and their car design (2005).

Driving is often seen as a symbol of independence therefore when it is threatened to be taken away anxiety and opposition may understandably arise. The inability to drive may cause depression along with isolation as older adults depend on driving to sustain their basic needs (Touhy, 2008). A qualitative study by Ralston, Bell, Monte, Rainey, Brayman, and Shotwell (2001) to explore the psychosocial impact for older adults who have given up the car keys noted that driving gives satisfaction in life and a sense of independence, control, and effectiveness. When adults no longer had the ability to drive,
they experienced a void and a loss of freedom (2001). This indicates the need for an accurate assessment tool to clearly define safe drivers from unsafe drivers and to ensure driving is not given up prematurely.

Difficulties performing daily tasks have been reported due to the aging neurological and musculoskeletal systems in some cases causing more dependence on others. Admitting need for assistance in daily life tasks is not always easy. Gregory and Fried (2003) examined why older adults decided they were having difficulty with certain tasks. Reasons for tasks being difficult were that they took more time to complete and the task required modifying to complete. Porter (May 2007) also found the tasks perceived as difficult were the ones that took more time and effort. Understanding the effects of aging and its impact on performance of daily tasks, gives professionals knowledge of human capacity for activity, therefore allowing them to establish suitable goals and provide optimal service (Hayase et al., 2004).

Chronic Disease

In addition to declines in performance seen with normal aspects of aging, ability to perform simple and complex tasks of daily living is hindered greatly by chronic disease. After age 50, the risk of chronic illness increases (Jett, 2008) which attributes to decline in function (Ayis, Gooberman-Hill, Bowling, & Ebrahim, 2006). The use of performance measures including self report, interviews, and observations of tasks as with normal aging can also exhibit the impact of chronic disease on functional performance. Chronic illness that can impact both cognition and mobility include heart disease, stroke, cardiac obstructive pulmonary disease (COPD), diabetes, and dementia (Fraker, 2007; Schultz-Krohn, Foti, & Glogoski, 2006).
Heart disease. The leading cause of death and disability in the United States is heart disease is (Jett, 2008, p 226; Radomski, 2008), affecting greater than one fourth of the population (Morewitz & Goldstein, 2007). Heart disease can be caused by blockage in the heart vessels, disease in the heart muscles, or structural irregularity of the heart (Radomski, 2008). The two major risk factors are high blood pressure and high blood cholesterol (Morewitz & Goldstein, 2007). Chronic conditions of heart disease include myocardial infarction (MI; i.e., heart attack), coronary artery disease, and congestive heart failure (CHF) when the heart is no longer capable of pumping effectively (Matthews, 2006).

Limitations to activity related to heart disease can be attributed to shortness of breath, swelling, fatigue, nausea, confusion, and impaired thinking (Eckert, 2007; Matthews, 2006). Oldridge and Stump’s (2004) survey of activity and older adults with and without heart disease concluded that those with heart disease had more limitations than those without heart disease. Limitation in activities of daily living included dressing, eating, and bathing; mobility limitations were climbing stairs, walking long distances, and pulling/pushing large objects (2004).

High blood pressure also known as hypertension (HTN) is a common occurrence in the elderly (Jett, 2008). It is estimated that in the United States 30% of older adults have high blood pressure (Morewitz & Goldstein, 2007). The incidence of high blood pressure particularly greater than 140/90 leads to an increased risk for MI and CHF (Jett, 2008; Huntley, 2008). When a MI takes place portions of the heart muscle die due to lack of oxygen (Matthews, 2006). Patients are placed on restrictions for at least six weeks to let the heart heal (Huntley, 2008; Matthews, 2006). If surgery is required major restrictions are given including avoidance of lifting, pushing, pulling objects 10 pounds
or more (Huntley, 2008). To lower the risk factors of additional cardiac problems patients are given recommendations to quit smoking, change their diet to lower cholesterol and blood pressure, maintain an exercise program, and reduce stress (Huntley, 2008).

Congestive heart failure is another form of heart disease. CHF is described as the inability of the heart to affectively pump blood to the body (Huntley, 2008). This causes inadequate blood flow to the organs and tissues of the body resulting in a lack of oxygen for sufficient function (Bennett, Save, & Shaw, 2005; Huntley, 2008). Studies of congestive heart failure have revealed an association with additional cognitive impairments beyond that of normal aging such as memory, concentration, attention, and executive functioning (Almeida & Tamai, 2001; Bennett, Save, & Shaw, 2005; Lavery, Bilt, Chang, Saxton, & Ganguli, 2007). On a battery of cognitive tests those with CHF scored significantly lower on cognitive functioning and attention tasks than those without CHF (Almeida & Tamai, 2001). Another cognitive study of older adults with CHF and those without reported that those with CHF scored lower on tasks requiring working memory and higher order processing which is needed to follow their complex treatment constraints (Lavery, Bilt, Chang, Saxton, & Ganguli, 2007).

Symptoms of CHF such as shortness of breath and fatigue restrict musculoskeletal mobility in performance of daily tasks such as walking, house work, and yard work (van den Bergemons, Bussmann, Balk, Keijzer-Oster, & Stam, 2001). In a study of performance among individuals with CHF, shortness of breath and fatigue were found to be the main predictors in activity modification (Seo, Roberts, Fann, Pina, & Dolansky, 2008). Mobility tasks that were modified most were short distance running, long distance running, and hiking (2008). Another study on mobility limitations with CHF by Gure,
Kabeto, Blaum, and Langa (2008) was conducted in a cross-sectional design based on a survey of disability related to CHF. Specific variables investigated were ability to perform ADLs and IADLs. Study results showed respondents with CHF had more impairment in both ADLs and IADLs. Major limitations were found in walking and grocery shopping (2008).

*Stroke.* Stroke is third cause of death in the US, affecting 700,000 each year as well as the leading cause of long-term disability; with chance of occurrence doubling after age 55 (Gillen, 2006). Stroke or cerebrovascular accident (CVA) is an injury in the brain’s vascular system often caused by a blocked or ruptured blood vessel that disrupts the flow of blood thereby disrupting the oxygen supply causing brain tissue to die(Gillen, 2006; Jamison & Orchanian, 2007; Woodson, 2008).

The most common impairment of a CVA is hemiplegia or paralysis of the limbs, trunk, and occasionally the face and mouth (Jamison & Orchanian, 2007). Both cognition and mobility can be impaired due to CVA presenting obstacles in vision, sensation, communication, and motor planning, (Jamison & Orchanian, 2007; Woodson, 2008).

Areas of cognition often impaired by a stroke are process skills, attention, sequencing, orientation, problem solving, and learning skills (Jamison & Orchanian, 2007) which affect performance in activities of daily living (Mercier, Audet, Hebert, Rochette, & Dubois, 2001). Particular impairment can be seen in health and financial management, safety procedures, and meal preparation. Zinn, Bosworth, Moenign and Swartzwelder (2007) examined the relationship of executive function impairment and post stroke older adults. Participants completed an activity questionnaire to determine their level of independence in activities of daily living. Intelligence quotients were
measured and executive function was measured on tests of memory, initiation, mental flexibility, self-monitoring, and abstract thinking. Stroke survivors had lower scores in working memory, cognitive flexibility, and processing speed than non-stroke participants (2007). In a large cohort study conducted by Pohjasvaara, Jokinen, Ylikoski, Kalska, Mantyla, Kaste, and Erkinjuntti (2007) which focused on the effect of brain lesions associated with stroke found that the greater the lesion, the greater the impairment of complex tasks, memory, and executive function. Complex tasks impaired were use of the telephone, shopping, meal preparation, management of home/finances/medication, and transportation (2007). In a quality of life study of stroke survivors, it was found that those who had even mild difficulties in cognition were limited in their ability to plan and develop life goals to achieve higher satisfaction in life (Haacke, Althaus, Spottke, Siebert, Back, & Dodel, 2006).

Musculoskeletal deficits impacting mobility are significant for the ability to perform activities of daily living (Mercier, Audet, Hebert, Rochette, & Dubois, 2001). Increased muscle tone known as spasticity is a common occurrence after stroke (Gillen, 2006). Spasticity can impair performance of daily tasks; however it was determined by Sommerfeld, Eek, Svensson, Homqvist, and Arbin (2004) that even stroke survivors without spasticity after 3 months had major motor and activity problems. Tested activities were grasping, pinching, and walking, along with ADLs (2004).

Upper extremity function is critical for independence in daily life. Lai, Studenski, Duncan, and Perera (2002) discuss the implications of hand and upper extremity impairment after stroke. Disability post-stroke involvement of upper extremity affects grasp, holding objects, and manipulating objects. Older adults with history of stroke scored lower on hand functioning compared to those with no stroke history (2002). To
determine impact of one to three years post stroke van de Port, Kwakkel, van Wijk, and Lindeman (2006) assessed mobility, cognition, and social support of stroke survivors living in their homes. Results showed that one fifth of stroke victims have significant deterioration in their mobility (2006). Changes in muscle tone and postural control after CVA make movements awkward and impact balance and mobility (Gillen, 2006; Jamison & Orchanian, 2007). Functional deficits of balance and mobility can impair feeding, dressing, oral care, transfers, and meal preparation (Gillen, 2006).

**COPD.** Chronic obstructive pulmonary disease (COPD) is an obstruction of airflow in the lungs affecting the exchange of gas and functional capacity (Eckert, 2007). The US Department of Health & Human Services (2004) stated that COPD is the fourth leading cause of death in the United States, with more than 15 million diagnosed (Matthews, 2006). COPD can include emphysema, peripheral airway disease, and chronic bronchitis (Huntley, 2008; Matthews, 2006). Symptoms include shortness of breath, fatigue, sputum production, confusion, impaired judgment, and depression (Huntley, 2008; Matthews, 2006). COPD can cause impairment to cognitive and musculoskeletal function. Results of a survey on the quality of life with COPD by the American Lung Association revealed limitations in work, physical exertion, social activities, sleeping, and family activities (Hillegass & Sadowsky, 2001).

Individuals with COPD can have limitations in cognition due to respiratory insufficiency and hypoxemia. Hypoxemia or low blood oxygen levels causes oxygen supply to the brain to decrease which can weaken cognitive function (Ortapamuk & Naldoken, 2006). Liesker, Postma, Beukema, ten Hacken, van der Molen, Riemersma, van Zomeren, and Kerstjens (2004) compared cognition of healthy adults and those with COPD by performance on a battery of cognitive tests. Older adults with COPD were
found to have impairments in memory, mental flexibility, and processing (2004). To determine if complications to cognitive impairment can affect independence in daily tasks Antonelli-Incalzi, Marra, Giordano, Calcagni, Cappa, Basso, Pagliari, and Fusco (2003) rated the level of dependence of rehab patients with COPD. It was found that patients were dependent on help from others in at least one daily task with medication management to be the most affected task (2003).

Musculoskeletal weakness and inactivity are related to COPD. Because fatigue and shortness of breath accompany mobility, tasks those with COPD tend to adapt sedentary lifestyles which in turn can cause muscles to become weak from disuse (Kapella, Larson, Patel, Covey, & Berry, 2006; Tkac, Man, & Sin, 2008). Sandlan, Singh, Curcio, Jones, and Morgan (2005) reported findings of an activity questionnaire that individuals with COPD participated in only half the amount of daily activities of healthy individuals. Pitta, Troosters, Spruit, Probst, Decramer, and Gosselink, (2005) used an activity monitor to measure physical activity. Results showed that individuals with COPD spent more time sitting and lying down than walking or standing (2005). Garrod, Bestall, Paul, Wedzicha, and Jones (2000) used an activity questionnaire to assess the degree of dependence. More than half of the participants with COPD reported dependence in self care activities of dressing and bathing. Forty two percent required help with sweeping and cleaning the floor. Fifty three percent reported help needed with washing window curtains (2000).

Diabetes. Diabetes Mellitus (DM) is a disorder of glucose metabolism (Jett, 2008). Each year in the US 800,000 people develop diabetes (Powers, 2001) affecting more than 18.3% of adults over the age of 60 (Jett, 2008). Symptoms of diabetes can include fatigue, frequent urination, increased thirst, weight loss, blurred vision, frequent
infections, and slower healing (Whitbourne, 2005). Because glucose metabolism is needed to create energy for the body diabetes weakens ambulation, manipulation, and grip strength producing difficulties in dressing, grooming, and functional mobility (Estes, 2007).

Diabetes has been associated with cognitive deficits. To assess implication of diabetes on the brain Gold, Dziobek, Sweat, Tirsi, Rogers, Bruehl, Tsui, Richardson, Javier, and Convit (2007) compared MRI images of adults with and without diabetes. Images revealed those with diabetes had atrophy in the hippocampal region of the brain which is associated with memory (2007). Grodstein, Wilson, Chen, and Manson (2001) conducted a large telephone study of cognition in older adult women living in the community. Cognitive areas assessed included orientation, registration, immediate verbal memory, and attention. Those with a diagnosis of diabetes had lower scores on all cognitive areas measured (2001). Arvanitakis, Wilson, Li, Aggarwal, and Bennett (2006) examined cognitive function in older adults with and without diabetes. Cognitive function measured was episodic memory, semantic memory, working memory, perceptual speed, and visuospatial ability. Lower scores were found in semantic memory and perceptual speed of those with diabetes (2006).

To determine if cognitive impairment is related to performance of daily activities Sinclair, Griling, and Bayer (2000) investigated the performance of older adults with diabetes compared healthy adults. Activities of daily living measured were eating, bathing, grooming, dressing, toileting, transfers, home management, and mobility. Cognitive areas tested included orientation, attention, memory, comprehension, and planning. Finding stated for older adults with diabetes there was increased cognitive dysfunction and increased dependency in daily tasks. Significant deficits were found in
self care and self management of illness (2000). Overall studies found cognitive decline in the areas of memory and perception which is needed to perform self care tasks such as managing medication and nutrition. Control of diet, strict monitoring of blood glucose levels and management of medication is critical for treatment of DM (Whitbourne, 2005). Recommendations for assistance with cognitive decline are to use pillboxes with auditory alarms and education for older adults in the form of oral instructions along with written handouts (Haas, 2007).

Vision impairment is related to diabetes as older adults with DM are at risk for developing diabetic retinopathy (Morewitz & Golstein, 2007). Diabetic retinopathy is bleeding from the retina which can cause vision loss (Quintana, 2008). In the United States it is estimated that 1 in every 12 persons with diabetes has diabetic retinopathy, with diabetic retinopathy being the 3rd leading cause of blindness (Touhy, 2008). Park, Dziobek, Sweat, Tirsi, Rogers, Bruehl, Tsui, Richardson, Javier, and Convit (2006) reported impaired vision was twice more prevalent in subjects with diabetes.

Musculoskeletal complications in older adults with diabetes are due in part to neuropathy, feet problems, and decreased muscle strength. Older adults with diabetes are at greater risk for neuropathy which causes numbness, pain, and weakness in the extremities (Morewitz & Golstein, 2007). Problems affecting the feet are decreased blood flow, burning, hypersensitivity, numbness, infections, and slow healing wounds (Jett, 2008).

Studies have shown muscle strength decreasing in older adults with diabetes. To evaluate muscle strength Anderson, Nielsen, Mogensen, and Jakobsen (2004) tested older adults with diabetes compared to those without. It was establish that muscle strength is lower in the ankles and knees of those with diabetes (2004). Park et al. (2006) evaluated
muscle strength in the upper and lower extremity of older adults with diabetes. A dynamometer was used to measure strength in the hands and knees. Compared to older adults without diabetes those with a positive diagnosis had less muscle strength in both the upper and lower extremities (2006).

Functional implications of the musculoskeletal deficits due to diabetes can limit independence of older adults. Gregg, Beckles, Williamson, Leveille, Langlois, Engelgau, Narayan, 2000) assessed physical disability through a questionnaire addressing physical functioning as walking 1/4 th a mile, climbing 10 steps, and doing housework. Self reported disability in each functional area was higher in those with diabetes (2000). Maty, Fried, Volpato, Williamson, Brancati, and Blaum (2004) identified the tasks of walking and heavy housework to be the most difficult for older women with diabetes. More than 50% of women with diabetes reported difficulty in these areas (2004).

Dementia. Dementia is a progressive dysfunction of cognition resulting in restriction of daily activities (Janssen-Pharmaceutica, 2008; Whitbourne, 2005). A common type of dementia is Alzheimer’s disease (AD) with memory loss being the most prominent symptom (Fraker, 2007). The National Institute on Aging (2003) predicts that by the year 2050, 14 million older adults will have AD in the US. Other forms of dementia are vascular dementia which is caused by strokes, frontal lobe dementia (FTD), Picks disease, and dementia from Parkinson’s disease (Whitbourne, 2005).

Dementia impairs memory, language, visuospatial abilities, and executive functioning (Fraker, 2007). Clinical features include loss of speech ability, loss of ability to perform purposeful movement, inability to recognize familiar faces and objects, and disturbance of executive function (Touhy, 2008). Implications of dementia affect ability to perform daily tasks, complex conversations, maneuvering in familiar settings, and
keeping up with financial duties. Dementia is a progressive disease, defined in terms of levels or stages which are mild, moderate, and severe or early, middle, late (Fraker, 2007). Functioning becomes increasingly challenging at each level.

Wicklund, Johnson, Rademaker, Weitner, and Weintraub (2007) examined functional ability of individuals with AD and FTD in the mild stages of impairment. Caregivers were interviewed on the individual’s independence in self-care, household care, employment, recreation, shopping, money, travel, and communication. Both AD and FTD had the greatest impairment activities of employment, recreation, shopping, money, travel, and communication (2007). In another study, Liu, Chan, Chu, Ng, Chu, Hui, Yuen, and Fisher (2007) explored the performance of activities of daily living in older adults with dementia through direct observation of process and motor tasks. Measures of both process and motor skills were below that of healthy adults. Assistance was required in the activities of shopping and managing finances (2007).

Digression of functional ability continues further ending in full dependency in performance of ADLs including bathing, dressing, mobility, toileting, and eating (Fraker, 2007). In most cases, restriction of daily activities is so great that long term care, as in a skilled nursing facility, is needed (Janssen-Pharmaceutica, 2008).

Summary

Research shows that as the human body ages, biological systems and structures begin to decline. Neurological aging brings a decline in memory, attention, vision, and executive function. Musculoskeletal aging affects the body by weakening of the muscles and bones, diminishing capacity of knee flexion and extension, and decreased joint function. Affects of the aging cardiovascular system are thickening of the blood vessel walls producing higher blood pressure and stressing the pumping mechanisms of the
heart. Thickening vessels and increasing stress on the heart muscle causes a decline in the amount of oxygen going out to the body which weakens performance capacity. When comparing the performance of older adults to younger adults, it is clear that these biological changes impact the older adults’ performance of tasks. In addition to normal aging, chronic illnesses including heart disease, stroke, COPD, diabetes, and dementia can further decrease performance ability by impacting both cognition and mobility.

Performance ability in older adults has been measured by self reports, interviews, and observations. Meaningfulness of specific daily activities and compensation however have not been measured by these assessments. To better understand areas not measured by current assessment tools, there is a need to examine from the older adult's perspective, which meaningful tasks have become difficult to perform and propose safety risks. Specifically instrumental activities of daily living (IADL) because of their complexity should be addressed. Examples of IADLs are cooking, driving, home management, financial management, and medication management (American Occupational Therapy Association, 2008). The purpose of this study was to further the understanding of the impact of chronic disease on functional ability in older adults by determining which IADL tasks are most meaningful and which may pose a safety hazard for medically-at-risk older adults who plan to live independently.

Data was collected through interviewing older adults who have been recently hospitalized and their caregiver. The results not only further the understanding of the impact of chronic disease on functional ability in older adult, but also can be used in the development of assessment tools for use in older adult populations. Specific research questions include:

1. Which IADL tasks are the most meaningful to older adults?
2. Which IADL tasks are most affected by chronic disease?

3. How do the perceptions of meaningfulness and performance capability differ between older adults and their caregivers?
Chapter 3: Methodology

Design

The purpose of this study was to further the understanding of the impact of chronic disease on functional ability in older adults by determining which IADL tasks are most meaningful and which may pose a safety hazard for medically-at-risk older adults who plan to live independently. Specific research questions include:

4. Which IADL tasks are the most meaningful to older adults?
5. Which IADL tasks are most affected by chronic disease?
6. How do the perceptions of meaningfulness and performance capability differ between older adults and their caregivers?

In order to answer these questions, this study was designed to be a mixed design for the purpose of examining how medical conditions in older adults affect functional performance. An interview format was used that included objective scales in order to measure the participant’s and their caregiver’s perceptions of the meaningfulness and performance of selected instrumental IADLs. Open ended questions were used to expand on the participant’s and their caregiver’s perspective on how their health condition is affecting their ability to carry out tasks of daily living.

Participants

Two groups of study participants were used for this study. The inclusion criteria for the first group consisted of an age requirement of 60 years or older, recent hospitalization in the last six months due to a chronic illness (heart disease, stroke, COPD, diabetes, or dementia), and an expectation to return to his or her own home and participate in complex IADLs.
The first group was paired with a second group of study participants who were identified as their main caregiver. The caregivers could be a spouse, family member, friend, or neighbor that lives with the participant or close by. Other inclusion criteria for both study groups were that the participant must live within a 50 mile radius from the research center and speak English.

Twenty four participants fit the inclusion criteria and agreed to the interview. Of the participants in the first group six were men and six were women, average age was 71.7 (SD= 68.5, range- 61-87). Hospital stays occurred between August and December 2008 and the average LOS was 23.2 days. None were reported to live alone. See table 1 for demographics on ethnicity and education. See table 2 for frequency of chronic disease.

In the second group of twelve caregivers four were men and eight were women, the average age was 53.1 (SD 13, range 32-68). See table 1 for demographics for education and ethnicity. See table 3 for caregiver relationship and amount of contact with the older adult.

Instrumentation

Participants completed a survey which was created by the researcher on Snap surveys US (1987-2006). Snap surveys is a survey design program that includes many styles for survey questions containing options for multiple choice and open ended questions.

The survey of IADL tasks utilized both closed and open ending questions concerning eleven IADL tasks including shopping for groceries, planning a meal, cooking, driving, planning a trip, community participation, home management, yard work, financial management, medication management, and phone use. These IADLs
were gathered in part through revision of the occupational therapy practice framework (American Occupational Therapy Association, 2008) and through discussion with experts in the field as well as through the pilot studies.

Closed ended questions included a rating scale that determined how important IADLs were to the participant, which activities had been affected by their health condition, and how much those activities had been affected. Open ended questions composed a second section, these questions asked participants to state specific difficulties they were experiencing with each task and how they are addressing those difficulties. Demographics were gathered at the end including age, gender, education, and race. Researcher used the survey as an interview; however, if the caregiver was unable to attend therapy sessions, the survey was sent home to be completed and brought back at a later date. A sample survey for the first group of study participants entitled Participant Activity Survey can be found in Appendix A. A sample survey for the second group of study participants entitled Activity Survey for Caregivers can be found in Appendix B.

It is critical that a design tool solicits the best information from clients with identified medical conditions. However, since it is known that clients with some disabilities (in particular dementia) may not perceive their disabilities realistically, it was also deemed essential to get objective information from the primary caregiver. Thus, caregivers of the older adult participants were also interviewed or surveyed to determine which tasks they perceived their family member to have difficulty with and how he/she is compensating for those tasks.

A standardized evaluation was not used for this study and therefore no validity or reliability is established. The survey was developed by reviewing the literature on primary diagnoses for older adults, studies of performance evaluations, and techniques to
gather information. The researcher also met with three occupational therapists with expertise in older adults to gather information to format and seek the needed information. The list of questions were drafted and reviewed by the three content experts as well as the specific IADLS that would be addressed.

As part of the review and revision of the survey tools, the study’s tool was piloted with two older adults one who has been hospitalized in 2007 and one with beginning signs of dementia (i.e.: memory loss). A caregiver was also given the survey to complete. These pilot studies determined that the survey questions and format were understandable and appropriate for older adults and their caregivers.

Procedure

The study was submitted to the Institutional Review Board (IRB) for approval in October 2008. In October 2008, the researcher met with occupational therapists in the outpatient rehabilitation and day rehab program at PCMH in Greenville, NC to explain the study and participant criteria in order to obtain their cooperation to use patients from their rehab programs. Therapists were instructed to notify researcher via email when they had patients who met the inclusion criteria for participation in the study. The researcher scheduled times to collect data either before or after the participant’s therapy sessions. At the scheduled time and place, researcher met with the participants (both the older adult and the caregiver) to further explain the study and to ensure the information and answers gathered will be kept confidential. Both participants then signed a consent form which is found in Appendix C. Interviews took no more than twenty minutes to complete and were conducted in a closed room in the outpatient center and the day rehabilitation center. The closed room ensured that participant confidentiality was reserved.
The researcher conducted each interview separately (one with the participant and one with the caregiver). A few of the caregivers were unable to meet with researcher and filled the survey out at their own convenience. Both the participant and the caregiver were instructed to skip the questions on tasks that did not pertain to the participant or that were not meaningful to the participant.

All completed surveys and consent forms were stored in a locked cabinet to protect the subject’s privacy. Once all surveys/interviews were completed, the data gathered was put into Excel and SPSS and were analyzed by the researcher in the Occupational Department at the Allied Health Science Building of East Carolina University.

Data Analysis

Data from the surveys was organized on the computer in Excel and then imported into SPSS for quantitative analysis using both parametric and nonparametric statistics. Descriptive statistics were calculated for each scaled question. Table 4 shows the mean and standard deviation of meaningfulness, previous level of function, and current level of function for older adults. Table 5 shows the mean and standard deviation of the caregiver’s perception of the older adult’s meaningfulness, previous level of function, and current level of function.

A paired sample t-test was computed to examine the significance of perception of change in level of function from the older adults and caregiver’s point of view. A paired sample t-test was also used to compare the older adult and caregiver scores for meaningfulness, previous level of function, and current level of function.

Qualitative analysis was used to analyze answers to the open ended questions from both surveys. Open ended questions were summarized for each participant pair.
Each IADL task was also summarized for meaningfulness, specific difficulties, and compensation.
CHAPTER 4: RESULTS

The tasks that were most important to the participants were driving and managing medication, ten out of twelve participants stated that these tasks were meaningful. The least important was planning a trip, only three participants stated that planning a trip was important. See table 6 and 7 and graph 1.

The most important IADLs for the participant as perceived by caregivers were managing finances and driving. The least meaningful IADL was planning a trip. See graph 2. A paired sample t-test was computed to examine significance difference between the participants and their caregiver for meaningfulness. Nine IADLs had no significant difference for meaningfulness. There was a significant difference in planning a trip ($t= -2.17, p< .04$) and managing finances ($t= 2.42, p<.03$). See table 8 for scores. See graph 3 for mean scores of participants and caregivers IADL meaningfulness.

A paired sample t-test was computed to examine significance difference between the participant’s perception of previous level of function and current level of function. Ten IADLs had a significant difference in previous level of function and current level of function. There was no significant difference in phone use ($t= 1.00, p< 0.35$). See table 9 for scores.

A paired sample t-test was computed to examine significance difference between the caregiver’s perception of the participant’s previous level of function and current level of function. Ten IADLs had a significant difference in previous level of function and current level of function. There was no significant difference in managing finances ($t= 1.86, p< 0.10$). See table 10 for scores.

A paired sample t-test was computed to examine significance difference between the participant and their caregiver for previous level of function. There was no difference
for nine IADLs. There was a significant difference for managing medication \((t= -3.23, p< .001)\) and phone use \((t= -4.58, p< .001)\). See table 11 for scores.

A paired sample t-test was computed to examine significance difference between the participant and their caregiver perception of current level of function. There was no difference for any of the IADLs. See table 12 for scores.

For each IADL, the objective of the open ended questions was to gather the specific difficulties related to each task from the participant and the caregiver. Open ended questions were not given to the IADLs that were not meaningful or important to the participants.

Shopping for groceries: Six participants and nine caregivers stated that shopping for groceries was meaningful and important. Specific cognitive/perceptual difficulties related to shopping for groceries are understanding prices, mental processing, focusing, vision, disagreeable, and fear of the judgment of others. Specific musculoskeletal difficulties for shopping for groceries are mobility, grabbing and lifting with left hand, reaching, standing, weakness, inability to drive, fatigue, carrying bags, and getting in/out of the car. Overall the greatest barriers reported by the majority of the participants were vision and mobility.

Participants reported compensating by either not going or attempting to do some shopping with help from caregivers. One caregiver reported the participant uses a power wheel chair to go to the grocery store. Caregivers also stated they do the shopping but encourage the participant to come to the store with them. The previous level of function reported by both the participant and the caregiver was independent.

Planning a meal: Seven participants and seven caregivers stated that planning a meal was meaningful and important. Specific cognitive/perceptual difficulties were
speech, organizing thoughts, and decreased short term memory. Musculoskeletal difficulties reported were balance and standing. Only one participant and two caregivers stated specific difficulties related to this task.

Participants and caregivers reported the participant had not attempted planning a meal and that the caregivers do all the planning. The previous level of function reported by both the participant and the caregiver was independent.

Cooking: Eight participants and seven caregivers stated that cooking was meaningful and important. Specific cognitive/perceptual difficulties with cooking include vision. Specific musculoskeletal difficulties include standing, balance, lifting, mobility in the kitchen, reaching in cabinets, opening jars, putting food in the oven, and stirring at the stove. Overall the greatest barriers reported by the majority of the participants were decreased mobility and using a non-dominant upper extremity.

Participants reported they compensate for cooking by attempting some cooking, using the microwave to cook frozen dinners, or giving directions to family members to cook meals. Caregivers report that participants can still do some cooking. One caregiver stated the participant helped make a pies and another stated the participant rolled out cookie dough. Caregivers help compensate by pushing them to do simple cooking tasks like make coffee or measure out ingredients for a recipe, or having the participant instruct the caregiver how to make a dish. The previous level of function reported by both the participant and the caregiver was independent.

Driving: Ten participants and ten caregivers stated that driving was meaningful and important. Specific cognitive/perceptual and musculoskeletal difficulties for driving given by the participant and caregiver were dizziness, decreased peripheral vision, weakness in the lower extremities, poor reaction time, paralysis of left hand, arthritis in
leg, loss of sensation in feet, loss of coordination and balance, and entering/exiting vehicle. Overall the greatest barriers reported by the majority of the participants were decreased coordination of the lower extremity and decreased vision.

All of the caregivers stated that the participants were not currently driving. Two of the participants reported they were still able to drive, one of which reported driving some short distances. The other had their license taken away as reported by their caregiver. This caregiver also stated that the older adult understood why they were not able to drive. The previous level of function reported by both the participant and the caregiver was independent.

Planning a trip: Three participants and eight caregivers stated that planning a trip was meaningful and important. Specific cognitive/perceptual difficulties are frustration with not being able to independently drive to desired destination. Caregivers stated that participants could plan a trip but then if they got sick they wouldn’t be able to go. Musculoskeletal difficulties include weakness on right side, taking longer to complete tasks, inability to use the computer, lack of coordination with fine motor activities, sitting for extended periods of time, and fatigue.

Participants reported compensating by taking fewer trips. Caregivers reported that participants are not planning trips because they cannot carry out the plans and they don’t like to rely on others to take them. The previous level of function reported by both the participant and the caregiver was independent.

Community Participation: Seven participants and seven caregivers stated that community participation was meaningful and important. Specific cognitive/perceptual difficulties included feeling embarrassed to be seen with disabilities in public, depression, self esteem issues, and trouble sleeping. Musculoskeletal difficulties include fatigue,
taking a long time to get ready to go, standing, walking long distances, depending on others for transportation and ADLs, holding silverware, paralysis, and entering/exiting vehicle. Overall the greatest barriers reported by the majority of the participants were decreased mobility and lowered self-esteem.

Participants reported compensating by staying at home, doing home exercises, or using a walker. Caregivers report they try to encourage the participant to go out and they assist them when they do go out. The previous level of function reported by both the participant and the caregiver was independent.

Home Management: Seven participants and seven caregivers stated that home management was meaningful and important. Specific cognitive/perceptual difficulties were dizziness with standing tasks. Specific musculoskeletal difficulties were decreased balance, fatigue, paralysis, decreased mobility, weakness, and decreased coordination of hands. Overall the greatest barriers reported by the majority of the participants were decreased balance, decreased coordination of the upper extremity due to paralysis, and fatigue.

Participants reported compensating by trying to do some simple chores (wiping), taking their time to complete tasks even though it takes longer, or having a caregiver do the tasks. The caregivers reported the participants attempting simple tasks such as some wiping or folding dish towels and wash cloths. The caregivers stated they did the heavy house work. The previous level of function reported by both the participant and the caregiver was independent.

Yard work: Seven participants and eight caregivers stated that yard work was meaningful and important. Specific cognitive/perceptual difficulties and musculoskeletal
difficulties included decreased standing balance, fatigue, and paralysis of upper extremity.

Participants reported compensating by attempting some raking, sweeping and tending a garden in a wheelchair, or having a family member or contractor do the yard work. One caregiver reported the participant used a riding lawn mower instead of a push mower to cut grass. The previous level of function reported by both the participant and the caregiver was independent.

Managing Finances: Seven participants and ten caregivers stated that managing finances was meaningful and important. Specific cognitive/perceptual difficulties were decreased short term memory. Musculoskeletal difficulties reported were decreased fine motor coordination, and decreased mobility. Participants reported compensating by paying bills over the phone or having a family member take care of this task.

Caregivers report they take care of managing finances although two stated the participant instructed them on when their bills were due. The previous level of function reported by both the participant and the caregiver was independent except for one which stated the family cared for the finances.

Managing Medication: Nine participants and ten caregivers stated that managing medication was meaningful and important. Specific cognitive/perceptual difficulties were decreased comprehension. Specific musculoskeletal difficulties were decreased fine motor coordination. It was reported by the caregivers that the participant had a lack of desire to take medicines, lack of understanding dose requirements, opening the bottles and/or pill case, and picking up the prescriptions from the store. Four of the nine participants stated they had trouble opening pill bottles.
Compensation for managing medication includes use of pill boxes, ordering prescriptions over the phone, and caregivers sorting meds. The previous level of function reported by both the participant and the caregiver was independent.

Phone Use: Eight participants and ten caregivers stated that phone use was meaningful and important. Specific cognitive/perceptual difficulties with using the phone involve decreased speech and decreased vision. Musculoskeletal difficulties decreased fine motor coordination and decreased coordination of the upper extremity.

Participants and caregivers reported that the participants were still able to use the phone by compensating with their non-dominant upper extremity or by having the caregiver dial numbers and then hand phone to participant. The previous level of function reported by both the participant and the caregiver was independent.
CHAPTER 5: DISCUSSION

Although a small sample, this pilot study offers evidence that driving is the most meaningful activity to older adults. Similar to older adults in other driving studies, the participants in the study indicated that driving contributed to their sense of independence (Freeman, Gange, Munoz, & West, 2006; Kostyniuk, & Shope, 2003; Ralston, Bell, Monte, Rainey, Brayman, & Shotwell, 2001; Touhy, 2008).

The decreased driving independence appeared to impact performance of most other IADLs including community participation, managing finances, shopping for groceries, and planning a trip. The participants stated that they had difficulties managing medication because they were unable to drive to the pharmacy to pick up their medication. Community participation appeared to be hindered because the participant had to depend on someone else to transport them where they wished to go. Others stated difficulties with managing their finances because they had to be driven to pay their bills. This finding supports the results of a study by Marottoli, de Leon, Glass, Williams, Cooney, and Berkman which concluded that driving cessation decreased the performance of activities outside the home (2000).

These results support other findings that indicate depression levels increasing as participation in community activities decreases due to inability to drive (Fonda, Wallace, & Herzog, 2001; Ragland, Satariano, & Macleod, 2005; Windsor, Anstey, Butterworth, Luszcz, & Andrews, 2007). Although depression was not directly measured in this study, participants reported feeling depressed with their inability to drive underlying the importance of driving to older adults.

Managing medication was also a valued activity of the participants. Participants reported feeling a loss of independence and limited mobility secondary to their recent
medical condition and appeared eager to return to their previous level of function. Since returning to health entails vigilance to medication, it is not surprising that adhering to medication would be of great importance.

*Phone use* was another IADLs rated as very important. Since studies have found social interaction to attribute to feelings of independence and dignity (Baker, 2005; Touhy, 2008), this should not be a surprising finding. The fact that the participants are not driving may mean that they rely even more so on the phone to continue their social connectedness.

Results revealed that the least meaningful IADL in this study was *planning a trip*. A reason for this result may be due to the older adults’ inability to drive; therefore the older adults do not feel the desire to plan trips. This was supported by the fact that some caregivers reported that the older adult could probably still plan a trip but that the participants did not seem to want to do so. Reasons given included the fact that they had to depend on someone else to take them, were nervous to go out in public, or fear that they would get sick and not be able to go on the trip. Specifically, the caregivers reported that the older adults would fatigue easily and did not believe that would have the energy to go a trip.

*Phone use* was the only IADL perceived by the participants to be not impacted by their medical condition. The participants all indicated that they still felt able to use the phone independently. However, many of the participants reported that they needed assistance with dialing, answering, or hanging up the phone, which would indicate that, in fact, this IADL has been impacted by their disability. This contradiction might be explained by the fact that they were still able to physically talk on the phone and therefore believe they do not have difficulty with this task.
In contrast, the caregivers perceived the only IADL to not be impacted by the participant’s medical condition was *managing finances*. Caregivers reported the participants could instruct others on which bills to pay, conduct payments over the phone, or use a non-dominant hand to write checks. Because the caregivers perceived the participants able to perform parts of the task they did not feel the participant was as dependant in *managing finances* as in other tasks.

The results of this study clearly indicated that the caregivers perceived the older adults to have been at a higher level of function prior to their health condition and hospitalization in the activities of *managing medication* and *phone use*. Caregivers stated that many of the older adults were feeling depressed because of their decline in performance. Depression is common following onset of a chronic illness (Gillen, 2006; Matthews, 2006; Turvey, Klein, & Pies, 2006). Several caregivers and older adults reported having low self-esteem, depression, and embarrassment by their current limitation. Many did not want to be seen in public or even participate in community events for fear of judgment. These feelings of depression are supported by other studies that indicate depression is related to a decrease in self-efficacy (Jerant, Kravitz, Moore-Hill, & Franks, 2008; Robinson-Smith, Johnston, & Allen, 2000). Since many of the participants reported feeling depressed, it is possible they had lowered self-efficacy which would explain why they did not rate themselves as having a higher previous level of function.

Although there was not a significant difference between the caregiver’s and the participant’s perception of *current driving ability* it does seem that the caregivers perceive the participant’s driving ability to be more impacted by their health condition than the participant. Each of the caregivers reported that the participant was currently
unable to drive due to deficits related to their medical condition; however, three of the participants stated they were still able to drive. Since this study indicated that driving is the most meaningful task of the instrumental tasks of daily living to participants, it is understandable that it would be hard to admit they are having difficulties with this. Unfortunately, misconceptions of driving ability can pose significant safety risks. Participants who believe they are able to drive despite their limitations may harm themselves or other motorists if they attempt to operate their vehicle. The fact that recently hospitalized older adults want to return to driving and do not want to give up this valued occupation is supported by research that shows that at least 25% of older adults who are told not to drive, continue to do so (Dobbs, Carr, & Morris, 2002). Since there is discrepancy of performance capacity between the caregiver and older adult there is a need to look at functional performance of IADL tasks.

Another safety concern is managing medication. Pohjasvaara and colleagues (2007) found managing medication to be impaired by chronic illness. Overall it was found that the participant’s health condition has impaired their ability to managing medication due to decline in fine motor skills and decreased comprehension of dose requirements. As stated earlier, participants expressed feelings of depression because of their functional decline and desired to regain their independence. It was also found that managing medication was one of the most important tasks to participants. Therefore it can be surmised that the participants will be adhering to their medication requirements. The question that remains is whether the participants will be adhering to their medication in a safe manner, as in following correct dose requirements and schedules. This raises concerns with not only recovery from their current illness but also with prevention of further decline of health.
The main limitation of this study is the sample size. Only twelve pairs of participants were interviewed. Although the plan was to have thirty pairs of participants, there were a limited number of referrals from the hospital which made it difficult to recruit more participants.

A second limitation was the survey instrument used self report. Actual performance was not being tested and it is clear that observed performance is the best measure (Taylor & Kielhofner, 2006; Yasuda, Zimmerman, Hawkes, Gruber-Baldini, Hebel, & Magaziner, 2004).

However, the goal of this study was not to develop a performance screening tool, but to identify which IADL tasks are seen as meaningful and important to clients, as well as to determine which are most affected by the identified medical conditions. This will help determine if there is risk for injury or nonperformance for each IADL task addressed.

Another limitation was there was no investigation of the possible influence of types of caregivers. It is proposed that results may have varied depending on if the caregiver was a paid caregiver verses nonpaid or if the caregiver had only taken a ‘care giving’ role for a short amount of time. Also it is possible that family members would not give a true objective representation of the participant’s level of function because family members may not want to admit their true level.

A final limitation is this study was unable to assess the affect of varying diagnostics on IADLs. Eleven of the twelve participants had a CVA therefore it was not possible to compare each chronic illness. Also, there was no further investigation of whether the CVA was on the left or the right side to determine if the difference in deficits would affect the performance of IADLs.
To increase the significance and validity of this study, it is proposed that the data should be expanded to provide more numbers for analysis. Subjects could be recruited from the same hospital as used for this study as well as possibly other institutions that would have cliental who would meet the inclusion criteria. With an increased sample size, the results of this study can be assessed with more conclusive evidence.

In order to further examine perception and performance ability, the next step of this study should be to assess functional performance and compare it to perception of performance. By looking at actual performance of the IADLs selected in this study and comparing this to self report of function, a better presentation of the affects of chronic illness could be attained as well as a clearer understanding of the discrepancy between caregiver and participant perception of performance. The results of this study could assist the development of tools to decrease safety risks.

In conclusion, the purpose of this study was to further the understanding of the impact of chronic disease on functional ability in older adults by determining which IADL tasks are most meaningful and which may pose a safety hazard for medically-at-risk older adults who plan to live independently. The most meaningful IADLs to medically-at-risk participants were driving and managing medication. Participants reported all IADL tasks were affected by chronic disease except managing finances and phone use. There was some discrepancy between the caregiver’s and participant’s perception of driving ability which leads to concerns for safety. Because of this concern for safety and because this study confirms the importance of driving to older adults, it is suggested to thoroughly evaluate driving performance by assessing driving skills including vision, cognition, and motor performance. Safety issues are also a concern with medication management as this study found; all the participants had impairments
with this task due to their health condition. It is suggested further examination and research should illuminate older adults’ understanding of the importance of proper medication management in relation to chronic illness.
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<th></th>
<th>Older adults N=12</th>
<th>Caregiver N=12</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Frequency</td>
<td>Percent</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
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<td>50</td>
</tr>
<tr>
<td>Female</td>
<td>6</td>
<td>50</td>
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<td><strong>Education</strong></td>
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<td></td>
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<tr>
<td>Some High school</td>
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<td>33</td>
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<tr>
<td>High school diploma</td>
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<tr>
<td>Some college</td>
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<tr>
<td>Associates Degree</td>
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<tr>
<td><strong>Ethnicity</strong></td>
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<td></td>
</tr>
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<td>25</td>
</tr>
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<td>Caucasian</td>
<td>9</td>
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Table 2
Older Adult Chronic Illness

<table>
<thead>
<tr>
<th>Chronic Disease</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>CVA*</td>
<td>7</td>
</tr>
<tr>
<td>Heart Disease &amp; CVA</td>
<td>2</td>
</tr>
<tr>
<td>Heart Disease &amp; Diabetes</td>
<td>1</td>
</tr>
<tr>
<td>Heart Disease, CVA, &amp; Diabetes</td>
<td>1</td>
</tr>
<tr>
<td>CVA &amp; Diabetes</td>
<td>1</td>
</tr>
</tbody>
</table>

Note: N= 12
* Only CVA
Table 3
Frequency and Percent of Caregiver Relationship and Amount of Contact with Older Adult

<table>
<thead>
<tr>
<th>Amount of Contact</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lives with</td>
<td>8</td>
<td>67</td>
</tr>
<tr>
<td>Visits several times a day</td>
<td>1</td>
<td>8</td>
</tr>
<tr>
<td>Visits once a day</td>
<td>1</td>
<td>8</td>
</tr>
<tr>
<td>Visits 4-5 times a week</td>
<td>2</td>
<td>17</td>
</tr>
<tr>
<td>Relationship</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spouse</td>
<td>3</td>
<td>25</td>
</tr>
<tr>
<td>Child</td>
<td>6</td>
<td>50</td>
</tr>
<tr>
<td>Friend</td>
<td>3</td>
<td>25</td>
</tr>
</tbody>
</table>

Note: N=12
Table 4
Older Adult Meaningfulness and IADL Level of Function

<table>
<thead>
<tr>
<th>IADL</th>
<th>Meaningfulness Mean (SD)(N)</th>
<th>PLOF Mean (SD)(N)</th>
<th>Current level Mean (SD)(N)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Shopping for groceries</td>
<td>3.17 (1.12) (12)</td>
<td>4.33 (.52) (6)</td>
<td>3.83 (.41) (6)</td>
</tr>
<tr>
<td>Planning a meal</td>
<td>3.33 (1.23) (12)</td>
<td>4.12 (.35) (8)</td>
<td>2.75 (1.03) (8)</td>
</tr>
<tr>
<td>Cooking</td>
<td>3.67 (1.30) (12)</td>
<td>4.50 (.55) (8)</td>
<td>4.25 (.46) (8)</td>
</tr>
<tr>
<td>Driving</td>
<td>4.08 (1.08) (12)</td>
<td>4.60 (.52) (10)</td>
<td>3.80 (1.14) (10)</td>
</tr>
<tr>
<td>Planning a trip</td>
<td>2.58 (1.08) (12)</td>
<td>4.00 (.00) (5)</td>
<td>3.40 (.89) (5)</td>
</tr>
<tr>
<td>Community Participation</td>
<td>3.25 (1.14) (12)</td>
<td>4.00 (.00) (7)</td>
<td>4.29 (.49) (7)</td>
</tr>
<tr>
<td>Home Management</td>
<td>3.33 (1.23) (12)</td>
<td>4.25 (.46) (8)</td>
<td>4.00 (.00) (8)</td>
</tr>
<tr>
<td>Yard work</td>
<td>3.42 (1.31) (12)</td>
<td>4.29 (.49) (7)</td>
<td>4.00 (1.00) (7)</td>
</tr>
<tr>
<td>Managing Finances</td>
<td>3.42 (1.31) (12)</td>
<td>4.29 (.49) (7)</td>
<td>3.43 (.98) (7)</td>
</tr>
<tr>
<td>Managing Medication</td>
<td>4.00 (1.04) (12)</td>
<td>3.70 (.68) (10)</td>
<td>3.60 (.84) (10)</td>
</tr>
<tr>
<td>Phone use</td>
<td>3.50 (1.38) (12)</td>
<td>4.00 (.00) (8)</td>
<td>2.25 (.71) (8)</td>
</tr>
</tbody>
</table>

Note: PLOF = previous level of function
Table 5  
Caregiver Perception of Older Adult Meaningfulness and IADL Level of Function

<table>
<thead>
<tr>
<th>IADL</th>
<th>Meaningfulness Mean (SD)(N)</th>
<th>PLOF Mean (SD)(N)</th>
<th>Current level Mean (SD)(N)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Shopping for groceries</td>
<td>3.83(1.03) (12)</td>
<td>4.60(.52) (10)</td>
<td>4.20(.92) (10)</td>
</tr>
<tr>
<td>Planning a meal</td>
<td>3.64(1.20) (11)</td>
<td>4.44(.53) (9)</td>
<td>3.67(1.32) (9)</td>
</tr>
<tr>
<td>Cooking</td>
<td>3.55(1.29) (11)</td>
<td>4.25(.463) (8)</td>
<td>4.25(1.04) (8)</td>
</tr>
<tr>
<td>Driving</td>
<td>4.17(.92) (12)</td>
<td>4.55(.52) (11)</td>
<td>4.64(.51) (11)</td>
</tr>
<tr>
<td>Planning a trip</td>
<td>3.55(1.04) (11)</td>
<td>4.38(.52) (8)</td>
<td>3.12(1.55) (8)</td>
</tr>
<tr>
<td>Community Participation</td>
<td>3.64(1.21) (11)</td>
<td>4.50(.54) (8)</td>
<td>4.38(.52) (8)</td>
</tr>
<tr>
<td>Home Management</td>
<td>3.73(1.19) (11)</td>
<td>4.25(.46) (8)</td>
<td>4.25(1.04) (8)</td>
</tr>
<tr>
<td>Yard work</td>
<td>3.75(1.06) (12)</td>
<td>4.18(.87) (11)</td>
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<td>Managing Finances</td>
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<td>Managing Medication</td>
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<td>4.55(.52) (11)</td>
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<td>Phone use</td>
<td>4.08(1.31) (12)</td>
<td>4.70(.48) (10)</td>
<td>2.40(1.17) (10)</td>
</tr>
</tbody>
</table>

Note: PLOF= previous level of function
Table 6  
Meaningfulness of IADLs to Older Adults

<table>
<thead>
<tr>
<th>IADL</th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neutral</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
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<td>1</td>
<td>5</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Planning a meal</td>
<td>5</td>
<td>5</td>
<td>2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cooking</td>
<td>4</td>
<td>4</td>
<td>4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Driving</td>
<td>2</td>
<td>5</td>
<td>5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Planning a trip</td>
<td>9</td>
<td>2</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Community Participation</td>
<td>5</td>
<td>6</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Home Management</td>
<td>5</td>
<td>5</td>
<td>2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yard work</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td></td>
<td></td>
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<tr>
<td>Managing Finances</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td></td>
<td></td>
</tr>
<tr>
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<td>6</td>
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<td></td>
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<tr>
<td>Phone use</td>
<td>1</td>
<td>3</td>
<td>5</td>
<td>3</td>
<td></td>
</tr>
</tbody>
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Note: N= 12, Question: (IADL) is meaningful and important to you.
Table 7
IADL Meaningfulness to Older Adults

<table>
<thead>
<tr>
<th>IADL</th>
<th>Not Important</th>
<th>Neutral</th>
<th>Important</th>
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<th>Sig. (2-tailed)</th>
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* p < 0.05
Table 9

Paired Sample T-test Comparing Older Adult Perception of IADL Function

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<th>Sig.</th>
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Note: Previous and current level of function were not measured for IADLs that were not considered meaningful, PLOF= previous level of function, Scores for current level were reversed.

* p< 0.05
Table 10
Paired Sample T-test Comparing Caregiver Perception of IADL Function

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Note: Previous and current level of function were not measured for IADLs that were not considered meaningful, PLOF= previous level of function, Scores for current level were reversed.
* p< 0.05
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Note: PLOF= previous level of function
* p< 0.05
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* p < 0.05
Graph 1

IADL Meaningfulness to Older Adults

- Driving
- Managing Medication
- Cooking
- Phone Use
- Planning a meal
- Community Participation
- Home Management
- Yard work
- Managing Finances
- Shopping for groceries
- Planning a trip

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<th>Importance</th>
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Graph 2

Caregiver Perception of Older adult IADL Meaningfulness

Note: mean scores used
Graph 3

Mean Perception of Meaningfulness of IADL tasks to Older Adults and their Caregiver

Note: Mean scores used
APPENDIX A: PARTICIPANT ACTIVITY SURVEY

Participant Activity Survey

Q1  Shopping for groceries is meaningful and important to you.
    Strongly Disagree ........................................... [ ]
    Disagree ................................................................ [ ]
    Neutral .................................................................... [ ]
    Agree ....................................................................... [ ]
    Strongly Agree .................................................... [ ]

Q2  Prior to your health condition, you were able to shop for groceries without help.
    Strongly Disagree ........................................... [ ]
    Disagree ................................................................ [ ]
    Neutral .................................................................... [ ]
    Agree ....................................................................... [ ]
    Strongly Agree .................................................... [ ]

Q3  Your health condition has significantly affected your ability to shop for groceries independently.
    Strongly Disagree ........................................... [ ]
    Disagree ................................................................ [ ]
    Neutral .................................................................... [ ]
    Agree ....................................................................... [ ]
    Strongly Agree .................................................... [ ]

Q4  What specific difficulties are you having with this task right now?


Q5  How are you addressing each difficulty?


Q6  Planning a meal is meaningful and important to you.
    Strongly Disagree ........................................... [ ]
    Disagree ................................................................ [ ]
    Neutral .................................................................... [ ]
    Agree ....................................................................... [ ]
    Strongly Agree .................................................... [ ]

Q7  Prior to your health condition, you were able to plan a meal without help.
    Strongly Disagree ........................................... [ ]
    Disagree ................................................................ [ ]
    Neutral .................................................................... [ ]
    Agree ....................................................................... [ ]
    Strongly Agree .................................................... [ ]

Q8  Your health condition has significantly affected your ability to plan a meal independently.
    Strongly Disagree ........................................... [ ]
    Disagree ................................................................ [ ]
    Neutral .................................................................... [ ]
    Agree ....................................................................... [ ]
    Strongly Agree .................................................... [ ]

Q9  What specific difficulties are you having with this task right now?


Q10 How are you addressing each difficulty?
Q11 **Cooking** is meaningful and important to you.

- Strongly Disagree
- Disagree
- Neutral
- Agree
- Strongly Agree

Q12 Prior to your health condition, you were able to cook without help.

- Strongly Disagree
- Disagree
- Neutral
- Agree
- Strongly Agree

Q13 Your health condition has significantly affected your ability to cook independently.

- Strongly Disagree
- Disagree
- Neutral
- Agree
- Strongly Agree

Q14 What specific difficulties are you having with this task right now?


Q15 How are you addressing each difficulty?


Q16 **Driving** is meaningful and important to you.

- Strongly Disagree
- Disagree
- Neutral
- Agree
- Strongly Agree

Q17 Prior to your health condition, you were able to drive without help.

- Strongly Disagree
- Disagree
- Neutral
- Agree
- Strongly Agree

Q18 Your health condition has significantly affected your ability to drive independently.

- Strongly Disagree
- Disagree
- Neutral
- Agree
- Strongly Agree

Q19 What specific difficulties are you having with this task right now?


Q20 How are you addressing each difficulty?


Q21 **Planning trips** is meaningful and important to you.

- Strongly Disagree
- Disagree
- Neutral
- Agree
- Strongly Agree

Q22 Prior to your health condition, you were able to plan trips without help.

- Strongly Disagree
- Disagree
- Neutral
- Agree
- Strongly Agree

Q23 Your health condition has significantly affected your ability to plan trips independently.

- Strongly Disagree
- Disagree
- Neutral
- Agree
- Strongly Agree

Q24 What specific difficulties are you having with this task right now?

Q25 How are you addressing each difficulty?

Q26 **Participating in church and/or social events** is meaningful and important to you.

- Strongly Disagree
- Disagree
- Neutral
- Agree
- Strongly Agree

Q27 Prior to your health condition, you were able to participate in church and/or social events without help.

- Strongly Disagree
- Disagree
- Neutral
- Agree
- Strongly Agree

Q28 Your health condition has significantly affected your ability to participate in church and/or social events independently.

- Strongly Disagree
- Disagree
- Neutral
- Agree
- Strongly Agree

Q29 What specific difficulties are you having with this task right now?

Q30 How are you addressing each difficulty?
Q31 **Home management** (for example cleaning the house, laundry, dishes, sweeping) is meaningful and important to you.

- Strongly Disagree  
- Disagree  
- Neutral  
- Agree  
- Strongly Agree  

Q32 Prior to your health condition, you were able to care for your home without help.

- Strongly Disagree  
- Disagree  
- Neutral  
- Agree  
- Strongly Agree  

Q33 Your health condition has significantly affected your ability to care for your home independently.

- Strongly Disagree  
- Disagree  
- Neutral  
- Agree  
- Strongly Agree  

Q34 What specific difficulties are you having with this task right now?

Q35 How are you addressing each difficulty?

Q36 **Yard work** is meaningful and important to you.

- Strongly Disagree  
- Disagree  
- Neutral  
- Agree  
- Strongly Agree  

Q37 Prior to your health condition, you were able to complete yard work without help.

- Strongly Disagree  
- Disagree  
- Neutral  
- Agree  
- Strongly Agree  

Q38 Your health condition has significantly affected your ability to complete yard work independently.

- Strongly Disagree  
- Disagree  
- Neutral  
- Agree  
- Strongly Agree  

Q39 What specific difficulties are you having with this task right now?

Q40 How are you addressing each difficulty?
Q41 Managing your finances (paying bills) is meaningful and important to you.

- Strongly Disagree
- Disagree
- Neutral
- Agree
- Strongly Agree

Q42 Prior to your health condition, you were able to manage your finances without help.

- Strongly Disagree
- Disagree
- Neutral
- Agree
- Strongly Agree

Q43 Your health condition has significantly affected your ability to manage your finances independently.

- Strongly Disagree
- Disagree
- Neutral
- Agree
- Strongly Agree

Q44 What specific difficulties are you having with this task right now?


Q45 How are you addressing each difficulty?


Q46 Managing your medication is meaningful and important to you.

- Strongly Disagree
- Disagree
- Neutral
- Agree
- Strongly Agree

Q47 Prior to your health condition, you were able to manage your medication without help.

- Strongly Disagree
- Disagree
- Neutral
- Agree
- Strongly Agree

Q48 Your health condition has significantly affected your ability to manage your medication independently.

- Strongly Disagree
- Disagree
- Neutral
- Agree
- Strongly Agree

Q49 What specific difficulties are you having with this task right now?


Q50 How are you addressing each difficulty?


<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
<th>Rating</th>
</tr>
</thead>
<tbody>
<tr>
<td>Q51 The ability to use the phone is meaningful and important to you.</td>
<td>Strongly Disagree</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Disagree</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Neutral</td>
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<td></td>
<td>Agree</td>
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<tr>
<td></td>
<td>Strongly Agree</td>
<td></td>
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<tr>
<td>Q52 Prior to your health condition, you were able to use the phone</td>
<td>Strongly Disagree</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Disagree</td>
<td></td>
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<td></td>
<td>Agree</td>
<td></td>
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<tr>
<td></td>
<td>Strongly Agree</td>
<td></td>
</tr>
<tr>
<td>Q53 Your health condition has significantly affected your ability to</td>
<td>Strongly Disagree</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Disagree</td>
<td></td>
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<td></td>
<td>Agree</td>
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<tr>
<td></td>
<td>Strongly Agree</td>
<td></td>
</tr>
<tr>
<td>Q54 What specific difficulties are you having with this task right</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Q55 How are you addressing each difficulty?</td>
<td></td>
<td></td>
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<td></td>
<td></td>
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<tr>
<td>Q56 Is the another meaningful task that your health condition has</td>
<td></td>
<td></td>
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<tr>
<td>Q57 What specific difficulties are you having with this task right</td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Q58 How are you addressing each difficulty?</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Demographics

Q59  How old are you?

Q60  Gender
    Male
    Female

Q61  What is the highest academic qualification you have attained?
    High school diploma
    Some college
    Associates Degree
    Bachelor of Arts or Bachelor of Science Degree (BA/BS)
    Master's Degree
    Ph. D.

Q62  What is your ethnic background?
    American Indian/Alaskan Native
    Black/Non-Hispanic
    Asian/Pacific Islander
    Hispanic
    White/Non-Hispanic

Q63  What is your main disability? (Check one)
    Heart disease
    Stroke
    COPD
    Dementia
    Diabetes

Q64  If you have been hospitalized recently, please tell me the date.

Q65  How long were you in the hospital?

Q66  Do you live alone?
    Yes
    No

Q67  Where does your closest family member live?
**APPENDIX B: ACTIVITY SURVEY FOR CAREGIVERS**

**Activity Survey For Caregivers**

**Instructions:** Please answer each of the following questions regarding your family member's ability to complete the identified instrumental activities of daily living. If the activity has little meaning to your family member or if your family member does not complete the activity feel free to skip that page.

Are you available for a follow up phone interview? (optional) __________

Is so, what is your phone number? ____________

**Grocery Shopping**

<table>
<thead>
<tr>
<th>Q1</th>
<th>Your family member's ability to shop for groceries is meaningful and important to him/her.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Strongly Disagree □</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Q2</th>
<th>Prior to your family member's health condition, he/she was able to shop for groceries without help.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Strongly Disagree □</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Q3</th>
<th>Your family member's health condition has significantly affected his/her ability to shop for groceries independently.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Strongly Disagree □</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Q4</th>
<th>What specific difficulties is your family member having with this task right now? (Please list)</th>
</tr>
</thead>
<tbody>
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</table>

<table>
<thead>
<tr>
<th>Q5</th>
<th>How is your family member addressing each difficulty?</th>
</tr>
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<tbody>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Q6</th>
<th>How are you addressing each difficulty?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Planning a meal

Q7 Your family member’s ability to plan a meal is meaningful and important to him/her.

Strongly Disagree... □ Disagree... □ Neutral □ Agree... □ Strongly Agree... □

Q8 Prior to your family member’s health condition, he/she was able to plan a meal without help.

Strongly Disagree... □ Disagree... □ Neutral □ Agree... □ Strongly Agree... □

Q9 Your family member’s health condition has significantly affected his/her ability to plan a meal independently.

Strongly Disagree... □ Disagree... □ Neutral □ Agree... □ Strongly Agree... □

Q10 What specific difficulties is your family member having with this task right now? (Please list)


Q11 How is your family member addressing each difficulty?


Q12 How are you addressing each difficulty?


Cooking

Q13 Your family member's ability to cook is meaningful and important to him/her.

Strongly Agree........ □ Disagree....... □ Neutral .......... □ Agree........... □ Strongly Agree........ □

Q14 Prior to your family member's health condition, he/she was able to cook without help.

Strongly Agree........ □ Disagree....... □ Neutral .......... □ Agree........... □ Strongly Agree........ □

Q15 Your family member's health condition has significantly affected his/her ability to cook independently.

Strongly Agree........ □ Disagree....... □ Neutral .......... □ Agree........... □ Strongly Agree........ □

Q16 What specific difficulties is your family member having with this task right now? (Please list)


Q17 How is your family member addressing each difficulty?


Q18 How are you addressing each difficulty?


Driving

Q19  Your family member's ability to drive is meaningful and important to him/her.

Strongly Disagree  □  Disagree  □  Neutral  □  Agree  □  Strongly Agree  □

Q20  Prior to your family member's health condition, he/she was able to drive without help.

Strongly Disagree  □  Disagree  □  Neutral  □  Agree  □  Strongly Agree  □

Q21  Your family member's health condition has significantly affected his/her ability to drive independently.

Strongly Disagree  □  Disagree  □  Neutral  □  Agree  □  Strongly Agree  □

Q22  What specific difficulties is your family member having with this task right now? (Please list)

Q23  How is your family member addressing each difficulty?

Q24  How are you addressing each difficulty?
Planning trips

Q25  Your family member's ability to plan trips is meaningful and important to him/her.

Strongly Disagree □ □ Disagree □ □ Neutral □ □ Agree □ □ Strongly Agree □ □

Q26  Prior to your family member's health condition, he/she was able to plan trips without help.

Strongly Disagree □ □ Disagree □ □ Neutral □ □ Agree □ □ Strongly Agree □ □

Q27  Your family member's health condition has significantly affected his/her ability to plan trips independently.

Strongly Disagree □ □ Disagree □ □ Neutral □ □ Agree □ □ Strongly Agree □ □

Q28  What specific difficulties is your family member having with this task right now? (Please list)


Q29  How is your family member addressing each difficulty?


Q30  How are you addressing each difficulty?
Participating in church and/or social events

Q31 Your family member's ability to participate in church and/or social events is meaningful and important to him/her.

- Strongly Disagree
- Disagree
- Neutral
- Agree
- Strongly Agree

Q32 Prior to your family member's health condition, he/she was able to participate in church and/or social events without help.

- Strongly Disagree
- Disagree
- Neutral
- Agree
- Strongly Agree

Q33 Your family member's health condition has significantly affected his/her ability to participate in church and/or social events independently.

- Strongly Disagree
- Disagree
- Neutral
- Agree
- Strongly Agree

Q34 What specific difficulties is your family member having with this task right now? (Please list)


Q35 How is your family member addressing each difficulty?


Q36 How are you addressing each difficulty?


Home Management

Q37 Your family member's ability to manage their home (for example cleaning the house, laundry, dishes, sweeping) is meaningful and important to him/her.

Strongly Disagree... □ Disagree..... □ Neutral ....... □ Agree .......... □ Strongly Agree .......... □

Q38 Prior to your family member's health condition, he/she was able to care for their home without help.

Strongly Disagree... □ Disagree..... □ Neutral ....... □ Agree .......... □ Strongly Agree .......... □

Q39 Your family member's health condition has significantly affected his/her ability to care for their home independently.

Strongly Disagree... □ Disagree..... □ Neutral ....... □ Agree .......... □ Strongly Agree .......... □

Q40 What specific difficulties is your family member having with this task right now? (Please list)

Q41 How is your family member addressing each difficulty?

Q42 How are you addressing each difficulty?
Yard Work

Q43 Your family member's ability to do yard work is meaningful and important to him/her.

Strongly Disagree □ Disagree □ Neutral □ Agree □ Strongly Agree □

Q44 Prior to your family members health condition, he/she was able to complete yard work without help.

Strongly Disagree □ Disagree □ Neutral □ Agree □ Strongly Agree □

Q45 Your family member's health condition has significantly affected his/her ability to complete yard work independently.

Strongly Disagree □ Disagree □ Neutral □ Agree □ Strongly Agree □

Q46 What specific difficulties is your family member having with this task right now? (Please list)

Q47 How is your family member addressing each difficulty?

Q48 How are you addressing each difficulty?
Managing Finances

Q49 Your family member's ability to managing their finances (paying bills) is meaningful and important to him/her.

- Strongly Disagree
- Disagree
- Neutral
- Agree
- Strongly Agree

Q50 Prior to your family member's health condition, he/she was able to manage their finances without help.

- Strongly Disagree
- Disagree
- Neutral
- Agree
- Strongly Agree

Q51 Your family member's health condition has significantly affected his/her ability to manage their finances independently.

- Strongly Disagree
- Disagree
- Neutral
- Agree
- Strongly Agree

Q52 What specific difficulties is your family member having with this task right now? (Please list)

Q53 How is your family member addressing each difficulty?

Q54 How are you addressing each difficulty?
Managing Medication

Q55 Your family member's ability to managing their medication is meaningful and important to him/her.

Strongly Disagree □ Disagree □ Neutral □ Agree □ Strongly Agree □

Q56 Prior to your family member's health condition, he/she was able to manage their medication without help.

Strongly Disagree □ Disagree □ Neutral □ Agree □ Strongly Agree □

Q57 Your family member's health condition has significantly affected his/her ability to manage their medication independently.

Strongly Disagree □ Disagree □ Neutral □ Agree □ Strongly Agree □

Q58 What specific difficulties is your family member having with this task right now? (Please list)


Q59 How is your family member addressing each difficulty?


Q60 How are you addressing each difficulty?


Phone Use

Q61 Your family member's ability to use the phone is meaningful and important to him/her.

<table>
<thead>
<tr>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Neutral</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
</table>

Q62 Prior to your family member's health condition, he/she was able to use the phone without help.

<table>
<thead>
<tr>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Neutral</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
</table>

Q63 Your family member's health condition has significantly affected his/her ability to use the phone independently.

<table>
<thead>
<tr>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Neutral</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
</table>

Q64 What specific difficulties is your family member having with this task right now? (Please list)


Q65 How is your family member addressing each difficulty?


Q66 How are you addressing each difficulty?
Other

Q73 It there another meaningful task that your family member's health condition has affected?

Q74 What specific difficulties is your family member having with this task right now? (Please list)

Q75 How is your family member addressing each difficulty?

Q76 How are you addressing each difficulty?
Demographics

Q77 How old are you?

Q78 Gender

Male
Female

Q79 What is your relation to the client?

Spouse
Child
Grandchild
Sibling
Friend

Q80 How often do you see your family member?

He/she lives with me
Several times a day
At least once a day
4-5 times a week
1-3 times a week
once a week
1-2 times a month

Q81 What is the highest academic qualification you have attained?

High school diploma
Some college
Associates Degree
Bachelor of Arts or Bachelor of Science Degree (BA/BS)
Master's Degree
Ph. D.

Q82 What is your ethnic background?

American Indian/Alaskan Native
Black/Non-Hispanic
Asian/Pacific Islander
Hispanic
White/Non-Hispanic

Q83 What is your family members main disability?
(Check one or more)

Heart disease
Stroke
Cardiac Obstructive Pulmonary Disease (COPD)
Dementia
Diabetes

Q84 What was the date of your family member's last hospitalization?


Q85 How long were they in the hospital?


Thank you for your time!
APPENDIX C: CONSENT FORM

CONSENT DOCUMENT

Title of Research Study: Assessing the Risk of IADL Tasks from the Perspective of Medically-at-risk Older Adults and their Caregivers.

Principal Investigator: Jennifer Gaudy
Institution: East Carolina University, Occupational Therapy Department
Address: 3452 West Gate Dr Greenville, NC
Telephone #: (910) 612-7184

PURPOSE AND PROCEDURES

The purpose of this study is to determine what tasks or activity demands pose a safety hazard for medically-at-risk older adults who plan to live independently. Data will be collected by survey and interview from older adults with a recent health/medical conditions and a family member/caregiver.

POTENTIAL RISKS AND DISCOMFORTS

We don't anticipate any risks to you from participation in this study.

POTENTIAL BENEFITS

There will be no direct benefit to the study’s participants. However, the results of this study will impact future planning for occupational therapy intervention for medically-at-risk older adults. The study will identify IADL tasks that may present safety risks and will help plan a screening tool to determine what kind and level of risk for older adults.

SUBJECT PRIVACY AND CONFIDENTIALITY OF RECORDS

Your privacy and confidentiality will be maintained. The completed surveys and interview will be locked away. While there will probably be publications as a result of this study, your name will not be used. Only group characteristics will be published.

COSTS OF PARTICIPATION & COMPENSATION

You will not receive any monetary compensation for your participation in this study.

VOLUNTARY PARTICIPATION
Participating in this study is voluntary. If you decide not to be in this study after it has already started, you may stop at any time without losing benefits that you should normally receive. You may stop at any time you choose without penalty.

**PERSONS TO CONTACT WITH QUESTIONS**

The investigator will be available to answer any questions concerning this research, now or in the future. You may contact the investigators, Jennifer Gaudy at (910)612-7184 anytime or Anne Dickerson (252) 744-6190 M-F 8am to 5pm.

If you have questions about your rights as a research subject, you may call the Chair of the University and Medical Center Institutional Review Board at phone number 252-744-2914.

If you would like to report objections to this research study, you may call the ECU Director of Research Compliance at phone number 252-328-9473 or the PCMH Risk Management Office at 252-847-5246.

**CONFLICTS OF INTEREST**

This study is funded by East Carolina University which is supporting the costs of this research. Neither the research site, nor the investigator will receive any financial benefit based on the results of this study.

**CONSENT TO PARTICIPATE**

**Title of research study:** Assessing the Risk of IADL Tasks from the Perspective of Medically-at-risk Older Adults and their Caregivers.

I have read all of the above information, asked questions and have received satisfactory answers in areas I did not understand. (A copy of this signed and dated consent form will be given to the person signing this form as the participant or as the participant’s authorized representative.)

<table>
<thead>
<tr>
<th>Participant's Name (PRINT)</th>
<th>Signature</th>
<th>Date</th>
<th>Time</th>
</tr>
</thead>
</table>

**PERSON ADMINISTERING CONSENT:** I have conducted the consent process and orally reviewed the contents of the consent document. I believe the participant understands the research.

<table>
<thead>
<tr>
<th>Person Obtaining consent (PRINT)</th>
<th>Signature</th>
<th>Date</th>
</tr>
</thead>
</table>