

VALIDATION OF A TEST ASSESSING FUNCTIONAL CAPACITY IN STROKE
SURVIVORS: UCSD PERFORMANCE-BASED SKILLS ASSESSMENT (UPSA)

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VALIDATION OF A TEST ASSESSING FUNCTIONAL CAPACITY IN STROKE
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ABSTRACT

Everyday functioning is an important outcome that is evaluated and targeted in stroke rehabilitation programs. Therefore, it is important to identify assessments of functional capacity that are feasible, acceptable and valid to predict daily life abilities among stroke survivors. The purpose of the present study was to determine the feasibility, acceptability and validity of the UCSD Performance-Based Skills Assessment (UPSA) in a stroke population. Participants were 40 stroke survivors, 22 Caregivers, and 20 Healthy Controls. The UPSA was validated against the Executive Function Performance Test (EFPT), a valid measure of daily functioning in stroke survivors, and Social Participation was measured using the Assessment of Life-Habits Scale (LIFE-H) which was completed by the stroke survivor's caregiver. Significant correlations were found between UPSA total and EPFT total scores, UPSA Communication and EFPT Telephone scores, and UPSA Household Management and EFPT Simple Cooking scores. However, no significant correlation was found between the UPSA Finance and the EFPT Bill Payment scores. Additionally, stroke survivors' Social Participation was significantly predicted by UPSA total scores, controlling for age, education and severity of stroke. Regarding our sensitivity analysis, no differences were found between stroke survivors' and healthy controls' performance in UPSA

total scores and domain scores, except in the transportation domain. The UPSA provides advantages for its use in this population including: the limited amount of training needed to administer and score it, its portability, and the time of administration (i.e., 30 minutes). In summary, findings from this study offer preliminary support for the feasibility, acceptability and validity of the UPSA as a performance-based measure of functional capacity in stroke survivors.

APPROVAL PAGE

The faculty listed below, appointed by the Dean of the College of Arts and Sciences have examined a thesis titled “Validation of a Test Assessing Functional Capacity in Stroke Survivors: UCSD Performance-based Skills Assessment (UPSA)” presented by Denisse Tiznado, candidate for the Master of Arts degree, and certify that in their opinion it is worthy of acceptance.

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CHAPTER 1

INTRODUCTION AND BACKGROUND

Each year in the United States 795,000 people experience a new or recurrent stroke (Lloyd-Jones et al., 2010). Mortality rates in stroke survivors have declined by 18.4% from 1996 to 2006 (Lloyd-Jones et al., 2010), and both life expectancy after a stroke and the number of stroke survivors has been increasing (Hannerz & Nielsen, 2001). These numbers indicate that living with disability following stroke is becoming an increasingly large public health problem. Indeed, people who experience a stroke tend to suffer from a number of disabilities, including impaired physical mobility, balance, gait speed, upper extremity function, cognition, and functional ability (Mayo et al., 1999). The World Health Organization has proposed the International Classification of Functioning, Disability and Health (WHO ICF) framework for understanding disability involving body functions, activities and participation, and environmental factors (Üstün, 2003). An important advantage of using this framework to define disability is the incorporation of psychological, environmental, and social factors, rather than focusing solely on the biology of the illness or condition. This framework emphasizes the importance of activities (tasks and actions by an individual) and participation (involvement in a life situation) for maximizing quality of life. Using this model to characterize disability following stroke requires a focus on functional ability, rather than deficits. In order to better target the difficulties faced by stroke survivors, rehabilitation professionals need to know the best way to assess functional abilities in order to tailor strategies to serve those survivors.

Assessing Functional Capacity

As stated in the WHO ICF framework, everyday functioning is an important outcome that should be evaluated and targeted in stroke rehabilitation programs. Indeed, impairment in daily

functioning has been found to have a significant negative impact in stroke survivors' overall quality of life (Carod-Artal, Egido, González, & Varela de Seijas, 2000; Kim, Warren, Madill, & Hadley, 1999). Efforts in stroke rehabilitation programs and research have been made to utilize the WHO ICF framework to operationalize outcomes of interest, such as activity and participation. In reviews of outcome measures used in drug trials and rehabilitative therapies (e.g., occupational, speech and language, cognitive) for stroke survivors, the most common activity measure used was the Barthel Index, followed by the Rankin Scale and Modified Rankin Scale (mRs) (Geyh et al., 2004). The Barthel Index (BI) is a measure completed by the clinician that assesses participants in two different domains, mobility and self-care. The Rankin Scale and mRs are also completed by the clinician who assesses the individuals' global disability on a 5-point scale, ranging from *no symptoms at all* to *severe disability; bedridden, incontinent and requiring constant nursing care and attention*. These measures are cost-effectiveness and quick to administer, but do not capture the range of ability an individual may have.

Everyday functioning can be measured using many different methods including self-report, proxy reports, behavioral observations and performance-based measures. A problem with self-report measures is the possibility that the person's cognitive functioning or other factors such as communication problems, may be a threat to the validity and accuracy of their responses. Although self-report measures are cost-effective and provide a voice for the person, they may not represent an accurate evaluation of the person's level of real-world functioning.

There are advantages of assessing daily-living functioning via proxy reports. For instance, stroke survivors who suffer from communication difficulties such as aphasia, or motor impairments, may have difficulties performing self-report measures. However, assessing daily-living functioning with proxy reports also can be problematic. For example, in a study by Dassel

and Schmitt (2008), the educational background and executive function levels of Alzheimer's patients' caregivers significantly predicted discrepancies between caregiver's report of the patient's functioning and direct assessment of patient's activities of daily living. These results suggest caregivers are not always accurate judges of their care recipient's abilities (Dassel & Schmitt, 2008).

Another source of every-day functioning reports are clinicians' evaluations like those described above using the Barthel Index or Rankin Scale. However, a drawback to clinician ratings is the limited range of behaviors that they can report due to lack of direct observation in real-world settings. Behavioral observation *in situ* is the ideal method to assess real world functioning. However this method is not very cost-effective and the presence of an observer can influence a person's behavior and not truly reflect their level of functioning.

The closest approximation to behavioral observations would seem to be performance-based measures. Performance-based measures are assessments that ask the individual to perform everyday living tasks such as writing checks, cooking meals, preparing a grocery list, or managing medications under standardized, simulated conditions. Extensive research on performance-based measures has been conducted in people with schizophrenia, bipolar disorder, dementia, and older healthy adults, finding that these measures tend to be more reliable and valid than self-report or proxy reports of functioning. In a review of performance-based measures of functional living skills, it was found that most measures reviewed demonstrated good internal validity, test-retest reliability, and concurrent validity (Moore, Palmer, Patterson, & Jeste, 2007). In these studies, concurrent validity was assessed by examining the relationship between performance-based measures and other measures of daily functioning, other performance-based measures, and/or cognitive and neuropsychological assessments (Moore et al., 2007). Although

no stroke-specific performance-based measure was identified in this review, other authors have published validity and reliability data on performance-based measures in stroke survivors. Two of these measures that show the most promise for capturing functional ability among stroke survivors are the Functional Impact Assessment (FIA) (Heaton et al., 2004) and the Executive Function Performance Test (EFPT) (Baum et al., 2008).

The FIA is a performance-based measure designed to assess participants in different everyday living tasks, specifically finances, communication, shopping, cooking, and medication management. The subtests in the FIA are composed from different published measures of IADLs and newly developed subtests. The subtests of financial skills, shopping, and communication were selected from the Direct Assessment of Functional Status (DAFS) (Loewenstein et al., 1989) and the medication management subtest was selected from the Medication Management Test (MMT) (Albert et al., 1999). The two new subtests include advanced finances and cooking. However, the initial reliability and validity study (Sadek, Stricker, Adair, & Haaland, 2011) suggested that more evidence is needed before the FIA is a good option for use with stroke survivors.

The EFPT was designed to assess executive function in everyday tasks by asking individuals to perform tasks including cooking, finances, telephone use and medication management. In each task, the person is assessed in their initiation, organization, sequencing, safety and judgment, and completion of the task. If the person is having difficulties performing the task, the examiner can provide them with cues. If needed, there are five levels of cuing, including indirect verbal guidance, gestural guidance, direct verbal assistance, and physical assistance. If the person still cannot complete the task, the examiner will perform the task for the person. The examiner is required to give the cues progressively starting from no cue to indirect

verbal guidance, gestural guidance, direct verbal assistance, physical assistance and finally to perform the task for the participant if necessary. In comparison to other tests that take off points for errors in task performance, the EFPT does not allow the examinee to make errors. Rather, the examiner provides cues to support successful task completion, and records the level of cueing required to complete the task. This scoring system was designed to identify what individuals can do and how much assistance they need to complete each task. The EFPT has been validated in adults with multiple sclerosis (Goverover et al. 2005), in people with schizophrenia (Katz, Tadmor, Felzen, & Hartman-Maeir, 2007) and with stroke survivors (Baum et al. 2008).

There are several advantages to the EFPT. In contrast to other performance-based measures the EFPT provides the person with cues, and assesses what type of assistance they need to successfully perform the task instead of assessing their level of impairment. Therefore, examiners can better understand the type of assistance participants need versus only knowing that they need assistance. Also, the EFPT provides scores for the executive function components of initiation, organization, sequencing, safety and judgment, and completion. This provides the examiner with a better idea of which executive functions are impaired. However, the EFPT also has a few drawbacks. The EFPT requires extensive training on its administration and scoring. For example the examiner needs to know the appropriate level of cuing and has to carefully time the cueing that the participant requires to successfully complete the task. That is, the examiner needs to provide the examinee with enough time to work on the task, but also needs to provide the cue before the examinee makes a mistake. In addition, the EFPT requires a variety of materials and equipment (e.g. hot plate, phone line) making it challenging to transport the test to field settings.

Even though performance-based measures often require significant time to administer, training of examiners, and the expense of gathering and transporting a variety of materials, these measures also tend to be more reliable, valid and less likely to have ceiling effects than self-report or proxy reports, therefore providing more accurate assessments of real-world functioning. Accuracy in measuring individuals' real-world functioning can aid researchers, clinicians and therapists in improving rehabilitation placement and effectiveness in assessing readiness to function independently. However, there are a limited number of performance-based measures available that assess daily functioning in stroke survivors, and these may not be appropriate for every situation or purpose. Therefore, it is necessary to investigate other performance-based measures that have not yet been applied in the stroke population, to assess their appropriateness for this population and provide clinicians, therapists, and researchers a range of options to best fit their setting and needs. One such option that is similar to the EFPT is the UCSD Performance-based Skills Assessment (UPSA), a measure of daily living skills.

The UCSD Performance-Based Skills Assessment (UPSA)

The UPSA has been validated and tested in different populations such as older adults diagnosed with schizophrenia (Patterson, Goldman, McKibbin, Hughs, & Jeste, 2001), bipolar disorder (Depp et al., 2009), mild cognitive impairment (Goldberg et al., 2010) and Alzheimer's disease (Goldberg et al., 2010). A study conducted by Harvey, Velligan, and Bellack (2007), assessed the reliability of different performance-based measures and found very high test-retest and inter-rater reliability data for the UPSA in people diagnosed with schizophrenia. The UPSA has also been found to correlate with cognitive performance, specifically processing speed, attention and working memory (Bowie et al., 2008), which have been shown to be good predictors of functional ability (Bowie, Reichenberg, Patterson, Heaton, & Harvey, 2010). The

UPSA has also been found to have good criterion validity in people diagnosed with schizophrenia. In a study by Mausbach et al. (2008), an UPSA total score of 75 or above significantly predicted living status in a large sample of people diagnosed with schizophrenia or schizoaffective disorder. The UPSA was also found to be related to degree of independence in the community defined by living situation (Twamley et al., 2002) and greater community responsibilities such as doing volunteer work, household chores, or taking care of children (Cardenas et al., 2008). These results suggest that this test is valid and reliable for use with the populations studied. However, nothing is known about the use of this test for individuals who have experienced a stroke. We therefore propose to test the validity of the UPSA with stroke survivors.

Why the UPSA?

The UPSA has several features to commend its use in field settings. First, there is a large amount of research supporting its validity and reliability in other clinical populations. Additionally, the UPSA takes approximately thirty minutes to administer. The props for this assessment do not require complex equipment that may be difficult to obtain or transport. For example, the EFPT asks participants to cook oatmeal and make a phone call, requiring a hot plate or stove and a working telephone. The UPSA, however, only requires a disconnected phone, a bus schedule, a map, simulated currency, and pantry items. Therefore, the UPSA can be easily implemented in a variety of settings, including field settings. Another advantage of the UPSA is that it only requires a minimum amount of training, thereby allowing easy administration and scoring (Patterson & Mausbach, 2010). Thus it may provide the sensitivity and validity of other performance-based measures, while also being easier and quicker to administer in a variety of settings. The utility of the UPSA with stroke survivors will be examined in the present study.

Purpose of the Present Study

The purpose of the present study was to determine the feasibility, acceptability and validity of the UCSD Performance-Based Skills Assessment in a stroke population. To address the question of feasibility, we assessed the practical aspects of task administration. We counted the number of people that could perform the UPSA, and the number who could not. We modified tasks requiring motor skills to be sure performance was not an artifact of their physical disability. For example, when participants were unable to hold the telephone and dial a number, we assisted them by holding the phone and dialing for them. However, they still had to perform the task, meaning that they had to provide us with instructions on how to make the phone call. We kept detailed notes of issues that arose during test administration, and any task modifications that were necessary.

To address the question of acceptability, we assessed participants' responses to both the UPSA and EFPT. Participants were asked about the clarity of the instructions for both the UPSA and the EFPT. We also asked participants to rate the UPSA, EFPT and their subscales as "fun", "difficult", "familiar", "complex", "simple" and/or "confusing." Participants were encouraged to provide feedback explaining their ratings. Time taken to complete each measure was recorded.

To address the question of sensitivity we compared performance on UPSA total scores and UPSA subscales scores between stroke survivors and healthy controls. To address the question of validity we compared performance scores of the UPSA with performance on the EFPT which has been validated in stroke survivors, and we assessed whether the UPSA predicted stroke survivor's social participation.

Hypotheses

1. Our hypothesis regarding the sensitivity of the UPSA to stroke related deficits is:

- a. Participants with a diagnosis of stroke will perform significantly poorer on the UPSA relative to comparably aged participants without a diagnosis of stroke (i.e. healthy controls).
2. Our hypotheses regarding the validity of the UPSA for assessing stroke related deficits are:
 - a. Scores on the UPSA will be significantly correlated with scores on the EFPT, meaning that people who perform poorly on the UPSA would also exhibit worse performance on the EFPT; and
 - b. Total scores on the UPSA will significantly predict participation (as defined by the WHO ICF) in stroke survivors as measured by the Assessment of Life Habits (LIFE-H), over and above age, education and stroke severity.

CHAPTER 2

METHODOLOGY

Recruitment and Data Collection

Forty stroke survivors, 22 family members or caregivers, and 20 healthy older adults as a comparison group were recruited to participate in this study. The data used in this study were collected as part of a larger study designed to examine determinants of functional ability among stroke survivors. Stroke survivors and caregivers were recruited from the American Stroke Foundation, a local organization providing post-rehabilitation services to adults living with a stroke, and the Landon Center on Aging at the University of Kansas Medical Center. Stroke survivors (both male and female) were enrolled if they were at least 6 months post-stroke and living in the community and if they were able to identify a caregiver or family member who was familiar with the participant's daily functioning and willing and able to sign an informed consent. Exclusion criteria included severe difficulties with motor function that would prevent task performance, and an inability to communicate with the experimenter, as measured by the NIH Stroke Scale. Healthy older adults were recruited from the SilverRoo database developed by Dr. Joan McDowd in the Department of Psychology at the University of Missouri-Kansas City (UMKC). We recruited a sample of 20 persons with no history of stroke (i.e. healthy controls), both males and females who were 45 years of age or older and free of neurological disorder. Stroke survivors and healthy controls were matched on age and educational levels. The assessment for both the stroke survivors and caregivers took place at the American Stroke Foundation Mission Kansas Center, The Landon Center on Aging, or at the SilverRoo lab at UMKC. Healthy adults were assessed at the SilverRoo Lab. Stroke survivors and healthy adults were offered a 40 dollar incentive and caregivers were offered 10 dollars for their participation.

Measures

Demographic Information

Demographic information was collected using a self-report demographic questionnaire. Information collected included age, education levels, gender, income level, marital status, living situation, ethnicity, and employment status. Participants were also asked to report time since stroke, number of strokes, length of time in the hospital, length of time in a rehabilitation program after the stroke, medical and psychiatric history.

Beck Depression Inventory (BDI-II)

Symptoms of depression were measured using the Beck Depression Inventory-II (BDI-II). The BDI-II is comprised of 21 items, rated in a 4-point scale; total score could range from 0 to 84. Scores of 0 to 13 indicate no to minimal depressive symptoms, 14 to 19 mild depressive symptoms, 20-28 moderate depressive symptoms and 29-63 indicate severe depressive symptoms. The BDI-II takes approximately 5-10 minutes to administer. The BDI-II has been found to have good validity and reliability in stroke survivors (Aben, Verhey, Lousberg, Lodder, & Honig, 2002).

NIH Stroke Scale (NIHSS)

Chronic stroke severity was measured using the NIH Stroke Scale (NIHSS) (Brott et al., 1989). The NIHSS is a brief measure that assesses stroke patient's neurological status in three different domains. These domains include: (a) Movement; (b) Sensation; and (c) Perception. The NIHSS has been found to have good validity and reliability (D'Olhaberriague, Litvan, Mitsias, & Mansbach, 1996), and is typically administered shortly after stroke to assess stroke severity. However, in the absence of severity measures for chronic stroke, we applied the measure to this

context. Scores for this measure were converted to percentage scores with higher scores representing more severe symptoms of stroke.

UCSD Performance-Based Skills Assessment (UPSA)

The UPSA (Patterson et al., 2001) assesses the person's ability to perform a variety of everyday living tasks in the following domains: (a) Finance; (b) Communications; (c) Organization/Planning; (d) Transportation; and (e) Household Management.

The UPSA involves role-play tasks similar in complexity to situations that an older community-dwelling person is likely to encounter. For example, the finance domain provides participants with simulated bills and real coins. The first task asks participants to count specific amounts (e.g., \$12.49, \$6.73, \$1.02) and to make change from ten dollars. For the second part of this domain participants are given a utility bill and are asked to provide information included in the bill (e.g., check is written to utility company, how much to pay, when to pay). This subtest takes about five minutes to complete.

In the communication domain participants are provided with a disconnected telephone and are asked to dial the number they would call if they had an emergency (correct response is 9-1-1). An additional task is to role-play a call to "information", asking for a number and dialing the number from memory. The final communication task asks participants to read a letter they received from their doctor about an appointment, and then to call the hospital and leave a voice mail requesting to reschedule their appointment. Participants are scored on the quality of their message. In addition, participants are also asked to recall information from the letter, such as how they were to prepare for their medical appointment (e.g., fast for a blood draw) and what two items they were to take to their appointment (e.g., insurance card and list of medications). This subtest takes approximately five minutes to complete.

The organization/planning domain asks participants to read a “newspaper article” describing the opening of a new Water Theme Park. They are then asked to recall important information from the article, and to generate a list of seven objects they should take to the waterpark (e.g., sunscreen, swimsuit, sandals, towel, sunglasses). This subtest takes approximately five minutes to complete.

In the transportation domain participants are provided with three bus schedules and are asked about the cost of the bus ticket, the telephone number they could dial to obtain more information on bus schedules, and to point to the different trolley stations. They are also asked to point to the correct bus schedule to get to a particular location and where they would get off the bus to transfer to a different bus. The last task asks participants to use the information from the bus schedule to answer questions about when to catch a bus in order to arrive early to an appointment. These tasks take approximately five minutes to complete.

The household management domain provides participants with a recipe for rice pudding along with an incomplete shopping list. Participants are then presented with 29 items that can be found in their pantry (e.g., potato chips, rice, crackers, jelly, toothpaste) and are asked to write a shopping list based on the missing and necessary items they need to buy to cook rice pudding. This task takes about five minutes to complete.

Administration of the UPSA requires approximately 30 minutes to complete. Participants receive scores for each of the 5 subscales (range = 0-20), which are summed to create a summary score ranging from 0 to 100. Higher scores represent better performance on the UPSA.

Executive Function Performance Test (EFPT)

The Executive Function Performance Test (EFPT) (Baum et al., 2008) assesses executive function by requiring role-playing of everyday living tasks including (a) Simple Cooking; (b)

Telephone use; (c) Medication Management; and (d) Bill Payment. All of the materials required to accomplish the tasks in the EFPT are found in a clear box provided by the examiner, and participants are required to search for the necessary materials to accomplish each specific task.

The cooking subtest provides participants with an oatmeal recipe and requires participants to prepare oatmeal by following the instructions. The telephone use subtest requires participants to look up the number for a grocery store in a telephone book, and call the grocery store to ask if they deliver groceries. For the medication management subtest participants are asked to find their prescribed medication among two pill bottles (one bottle without their name, one has their name on the label), to follow the instructions on the pill bottle and to take their medicine. They are also asked when they need to take their medication, what they are supposed to take with it, and what do they need to be careful about with this medication. And finally, the bill payment task requires participants to find their bills, check the amount of money in their check register, pay their bills and balance their checkbook. The EFPT takes approximately 45 minutes to complete.

Prior to performing each task, participants are asked how familiar they are and how much assistance they will need to perform each task. In contrast to the UPSA, participants are scored depending on the level of cuing needed for each task. Participants receive scores for each task (range = 0-25), and a total score (range= 0 to 100). Higher scores on the EFPT indicate the need for more assistance performing the tasks.

The Assessment of Life-Habits Scale (LIFE-H)

Participation was assessed using The Assessment of Life-Habits Scale (LIFE-H). The LIFE-H is a self-report measure that assesses individuals in 12 different categories including, nutrition, fitness, personal care, communication, housing, mobility, responsibilities, interpersonal

relationships, community life, education, employment, and recreation. The LIFE-H consists of 77 items and responses are measured in a Likert type scale assessing level of difficulty, the type of assistance needed for each task and the level of satisfaction with the way the task is accomplished. The LIFE-H takes approximately thirty minutes to administer and because of concerns about self-report, it was completed by the stroke survivor's caregiver. The LIFE-H has been found to have good validity in older adults (Desrosiers et al., 2004), adults with physical disabilities (Noreau, 2004) and in stroke survivors proxy report (Poulin & Desrosiers, 2008).

Analysis

Feasibility

To assess the feasibility of the UPSA with stroke survivors, we tabulated the number of issues that arose during the administration of the UPSA. Feasibility of the UPSA was analyzed by reporting the percentage of stroke survivors who were able to complete the test. We also reported the mean time for UPSA and EFPT completion.

Acceptability

To assess the acceptability of the UPSA participants were asked about the clarity of the instructions for both the UPSA and the EFPT.

Sensitivity

Sensitivity of the UPSA was assessed by comparing healthy controls and stroke survivors on the UPSA subscales and total scores. If the UPSA is a sensitive measure of stroke-related disability, we hypothesized that (1) participants with a diagnosis of stroke will perform significantly poorer on the UPSA relative to participants without a diagnosis of stroke (i.e. healthy controls). To test hypothesis (1), we conducted a nonparametric equivalent of a MANOVA to compare UPSA total scores and subscale scores between stroke survivors and

healthy controls. UPSA total scores and subscale scores were entered as outcomes and participant status (healthy controls, stroke survivors) were entered as the independent variable.

Validity

We assessed the validity of the UPSA in two ways. First, the relationship between the UPSA and the EFPT was analyzed to assess construct validity. We hypothesized that (2) if the UPSA is a valid measure of stroke-related disability, then scores on the UPSA will be associated with scores on the EFPT. Hypothesis 2 was tested by analyzing the correlations between UPSA total scores and EFPT total scores. In addition, correlations were analyzed between the UPSA subscale scores in the communication and finance domain and the telephone task and bill paying subscales of the EFPT.

Second, the ability of the UPSA to predict participation was tested using the LIFE-H measure. If the UPSA is a valid measure of everyday functioning, (3) then it was hypothesized that total UPSA scores will predict participation as measured by the LIFE-H. This hypothesis was tested by conducting a hierarchical multiple regression. LIFE-H total score were entered as the outcome; age, and education were entered in step one, stroke severity in step two, and UPSA total scores were entered in step three.

CHAPTER 3

RESULTS

Participant Characteristics

Participant demographics can be found in Table 1. Participants were 40 stroke survivors (M age= 62.75, $SD = 9.76$), 22 Caregivers (M age= 61.95, $SD = 10.00$), and 20 Healthy Controls (M age = 68.90, $SD= 9.48$). More than half of the Stroke Survivors were male (62.5%) and identified as White (82.5%). The average years of education was 14.78 ($SD = 2.92$). Seventy percent of the Stroke Survivors had had experienced only one stroke and 45.0% had experienced an ischemic stroke. Thirty-three percent of stroke survivors reported experiencing the stroke on their left side of the brain. The majority of the stroke survivors were right handed (92.5%). The average number of years since stroke was 6.25 ($SD = 5.43$) and the average number of days in the hospital after their stroke was 26.59 ($SD = 27.98$). Thirty-three percent of stroke survivors reported currently being part of a rehabilitation program such as the American Stroke Foundation or an exercise rehabilitation program.

Ninety-six percent of caregivers were spouses of the stroke survivor and 45.5% were males. The majority of caregivers (95.5%) reported not having any formal caregiving training and 86.4% reported not receiving any help with their caregiving duties. Seventy-percent of healthy controls were male and 90% identified as White. The average years of education was 17.00 ($SD =2.94$).

Feasibility of the UPSA

To assess the feasibility of the UPSA with stroke survivors, we noted the number of issues that happened during the administration of the UPSA. One problem encountered during the administration of the UPSA was the size of the print on some of the UPSA material. Some

other difficulties were related to participants who had aphasia or apraxia problems. Four participants asked the researcher to write the grocery list for them as the participant dictated to the researcher what to write. This accommodation was done because the participant had difficulties with movement in their arm. Additionally, three participants failed screening and did not qualify for the study. Two of these did not qualify because of mild to moderate aphasia and dysarthria (as assessed by the NIHSS), and the third participant did not qualify because he reported he was legally blind. Finally, 4 of the participants had to stop the assessment. The reasons for stopping participants were difficulties reading the material or cognitive difficulties preventing task completion.

Acceptability of the UPSA

UPSA Acceptability

See Table 2 for the summary of acceptability ratings for the UPSA. Almost half of Stroke Survivors reported the finance domain was “familiar” and more than half reported it was “simple.” For example, one participant stated the finance domain was familiar and simple because “I am used to making change and working with money.” A second participant reported, “I like working with money-it was relatively simple. Familiar with counting money.”

More than half of participants reported the communication domain was “familiar” and “Simple.” As one participant reported, “I do that every day. Easy to remember names and numbers.” Also, one participant stated “I deal with the doctor’s office quite a bit.”

After the organization/planning domain, 37.5% of participants reported the task was “difficult.” For example, one participant stated “Fun to do but long so difficult to remember all of the information. Normally the article would be there to refer back to.” Also, 25% of participants reported the task was fun, “I like to plan vacations-sounds fun.” Thirty-eight percent

of participants reported the task was difficult because of the amount of information they have to remember to answer the questions correctly.

Regarding the transportation domain, more than half of participants reported the Transportation task was difficult, confusing and 40% reported it was a “complex” task. For example, one participant stated “It was very difficult and very confusing. The times table. I really had trouble. Not making any sense. Again, my number problem. A lot of decision based on times of day.” A different participant stated “The layout of the schedule kind of threw me. I don't utilize buses. It was difficult. Finding where I was going and where I was coming from.”

Finally, more than half of the participants reported the household management domain was “familiar” and 72.5% reported it was a “simple” task. As one participant stated, “I like to cook. I used to really like to cook, the fun is coming back. I used to cook and want to cook. I am used to it. Thinking about what to do.” Another participant stated, “My wife always wants me to get stuff at the store.” A number of participants reported this was a task they often have to do and having the recipe made it simple to accomplish.

In addition, participants were asked to rate the complete set of UPSA tasks on a scale going from tedious at one end, to engaging on the other end. The response scale ranged from 1 (tedious) to 7 (engaging). Eleven percent of participants rated the tasks from 1 to 3, 21.1% as 4 and 68.3% rated the tasks from 5-7. More than half of the participants found the complete set of tasks to be engaging. In this study, the UPSA took on average 31.45 ($SD = 7.60$) minutes to administer.

EFPT Acceptability

After performing the cooking task, more than half of the participants reported the task was “simple.” For example one participant stated, “Very limited amount of instructions to

follow.” Forty-three percent of the participants also reported the task was “familiar” and 27.5% reported it was “fun.” As one participant stated, “I cook oatmeal. I thought it was fun. Everything I do is fun. It's still a challenge.”

Half of the participants reported the communication task was “familiar,” more than half reported it was “simple” and 27.5% reported it was fun. During our interview one participant stated, “Just a matter of calling and asking a question.” Another participant indicated, “Once I realized you just wanted me to make a call and ask a question, it was no problem.”

Regarding the Medication task, half of the participants reported the task was “familiar” and “simple.” However, 22.5% reported it was “confusing.” Participants stated “Directions [were] unclear. Confusing, not sure what the goal was. [I have] difficulties opening bottles without the device I have at home.” Other examples of participants’ statements are “[I] did not realize that other people’s meds might be in the box” and “[Familiar] I take medications on a regular basis. Simple task.”

Lastly, after participants completed the Bill Paying task 47.5% reported the task was “familiar” and 25% reported it was “complex.” As one participant stated, “All of it. It is kind of a trick, see if you catch it. I didn't read it well enough I make it harder than it has to be. Too much of a hurry. Should have taken my time. You have more time at home.” Also, another participant reported “[Familiar] Paying bills is something I do at home. [Difficult] Not at all like I do things at home. I don't balance my check book for one thing.” Participants reported that even though it was a familiar task, it was “tricky” and it involved many steps.

In addition, participants were asked to rate the complete set of EFPT tasks on a scale going from tedious at one end, to engaging on the other end. The response scale ranged from 1 (tedious) to 7 (engaging). Thirteen percent of participants rated the tasks from 1 to 3, 5.3% as 4

and 81.6% rated the tasks from 5-7. The majority of participants found the complete set of tasks in the EFPT to be engaging.

Sensitivity of the UPSA

Hypothesis 1: Comparison between healthy controls and stroke survivors

To test hypothesis 1 a nonparametric equivalent of a MANOVA was conducted to compare UPSA total scores and domains scores between stroke survivors and healthy controls. See Table 3 for the means and standard deviations on the UPSA and EFPT in stroke survivors and healthy controls. UPSA total scores and subscale scores were entered as outcomes and participant status (healthy controls, stroke survivors) was entered as the independent variable. Preliminary screening indicated that scores on all UPSA domains, except communication and total score for Healthy Controls, were not normally distributed.

As a result of the violation of normality and homogeneity of variance a Mann-Whitney test was conducted to test for differences in UPSA total scores and domain scores between stroke survivors and healthy controls. There were no significant differences between stroke survivors and healthy controls scores in the UPSA Finance, Communication, Organization/Planning, Household Management and total scores. However, there was a significant difference between Stroke Survivors (Mdn = 13.33, Mean= 12.67) and Healthy Controls (Mdn = 13.33, Mean = 14.89) scores on the Transportation domain, $U = 537.50$, $z = 2.24$, $p = .025$, $r = .29$.

Validity of the UPSA

Hypothesis 2: Relationship between EFPT and UPSA

We hypothesized that scores on the UPSA will be associated with scores on the EFPT. Hypothesis 2 was tested by calculating the correlation between UPSA total scores and EFPT total scores in stroke survivors. Correlations were also calculated between the subtests on the two

measures that assessed similar areas of functioning. UPSA domain scores on the communication, finance and the household management domains, were correlated with the telephone use task, bill payment task, and simple cooking tasks of the EFPT.

As hypothesized, a negative significant correlation was found between UPSA total scores and EPFT total scores, $r(37) = -.602, p < .001$, as the two measures are scaled in opposite directions. Also, significant negative correlations were found between the UPSA Communication domain scores and the EFPT Telephone use task scores, $r(37) = -.579, p < .001$, and the UPSA Household Management domain scores and EFPT Simple Cooking task scores, $r(36) = -.391, p = .015$. However, no significant correlation was found between the UPSA Finance domain scores and the EFPT Bill Payment task scores, $r(37) = -.272, p = .094$. See Table 4 for the correlations between the UPSA and EFPT in stroke survivors and Figures 1-4 for the scatterplots of these correlations.

Hypothesis 3: Predicting social participation with UPSA scores

A hierarchical multiple regression analysis was conducted to test the hypothesis that total UPSA scores would predict social participation. For this analysis age and years of education were entered in step one, NIHSS (stroke severity) in step two, and UPSA total scores were entered in step three.

Preliminary analysis suggested no violations of linearity and normality of the residuals. Examination for outliers suggested the presence of one outlier. However, further investigation of casewise diagnostics suggested no extreme cases influenced the model. The assumption of no multicollinearity was upheld by examining the VIF and tolerance statistics. The assumption of independent errors was met as examined via the Durbin-Watson statistic.

A hierarchical multiple regression was performed to assess the contribution of UPSA total scores, over and above age, education, and NIHSS to LIFE-H total score. In step 1, neither age nor education were significant predictors of LIFE-H total score. In step 2, NIHSS score was not a significant predictor of LIFE-H total scores. Lastly, in step 3 UPSA total score was a significant predictor of LIFE-H total score, $\beta=.96$, $t(18) = 3.26$, $p = .005$, while age, education and NIHSS remained non-significant. A significant R-square change in step 3 also indicated that UPSA total score made a significant contribution to predicting LIFE-H scores, $\Delta R^2=.33$, F change $(1,17) = 10.64$, $p = .005$, over and above age, education and NIHSS scores. The overall regression including age, education, NIHSS scores, and total UPSA scores was statistically significant, $R^2 = .35$, $F(4,17) = 3.86$, $p = .021$. Detailed results of this regression are summarized in Table 5.

CHAPTER 4

DISCUSSION

The primary purpose of the present study was to assess the validity of the UCSD Performance-based Skills Assessment for use with stroke survivors. The goal was to identify an additional assessment that is feasible, acceptable and valid to predict daily life abilities among stroke survivors.

Validity and Sensitivity of the UPSA

Using the EFPT as the standard against which to evaluate the UPSA, we predicted that significant correlations would be observed between the two assessments. The relationship between scores on the UPSA and the EFPT was found significant in stroke survivors.

Participants who had less difficulty performing the complete set of tasks in the EFPT also had less difficulty on the UPSA, suggesting the UPSA and EFPT measure similar constructs. These results provide support for the UPSA as valid assessment of functional ability in stroke survivors, comparable to the EFPT.

Regarding the acceptability of the UPSA, overall stroke survivors reported that the instructions for the UPSA subscales were clear and indicated no difficulties with the majority of the tasks. However, stroke survivors did report difficulties with the transportation domain. Participants reported this scale was confusing and therefore difficult to accomplish. Overall, the UPSA was well accepted by our participants.

In addition to the significant relationship between the UPSA and the EFPT on total scores, significant relationships were found between the EFPT Telephone task and the UPSA Communication task, and the EFPT Simple Cooking task and UPSA Household Management task, meaning these subtests measure similar constructs. However, no relationship was found

between the UPSA Finance domain and the EFPT Bill Paying task, suggesting this UPSA domain may be measuring a different construct compared to the EFPT. A possible explanation for these results is that the UPSA Finance domain measures knowledge of information and the ability to work with money. Specifically, this task provides participants with simulated bills and real coins and participants are asked to count specific amounts (e.g., \$12.49, \$6.73, \$1.02) and to make change from ten dollars. For the second part of this task participants are given a utility bill and are asked to provide information included in the bill (e.g., check is written to utility company, how much to pay, when to pay). In contrast to the UPSA, the EFPT Bill Paying task is concerned with whether participants understand and can carry out the process of paying bills (e.g., checking the balance, opening the mail) involving a number of different steps.

The difference between these two tasks illustrates a fundamental difference in the principles and motivations that guided the design of the UPSA and the EFPT. Specifically, the UPSA was developed with the goal of quantifying functional outcomes and improvements in social disabilities and testing the skills and abilities needed to function independently in the community. Also, the UPSA was developed to address the limitations of other approaches for evaluating functioning (e.g., self-report, proxy reports) by collecting observable data in people with schizophrenia (Patterson et al., 2001). In contrast to the UPSA, the EFPT had a more limited purpose. It was designed to assess executive functional abilities (i.e., initiation, organization, judgment and task completion) in an everyday context. The goal of the developers of the EFPT was to create an ecologically valid assessment of executive functions in stroke survivors (Baum et al., 2008) as a predictor of occupational performance and participation. Thus the surface similarity of these two subscales (UPSA Finance and EFPT Bill Paying) may not reflect the underlying differences produced by their different purposes.

Concerning the predictive validity of the UPSA, as hypothesized, stroke survivors' Social Participation was significantly predicted by UPSA total scores, controlling for age, education, and stroke severity. These results suggests that stroke survivors with better performance on the UPSA were more likely to have been reported via proxy as more socially engaged and as having greater levels of participation. Specifically, stroke survivors with better performance on the UPSA were reported to have less difficulty with activities related to nutrition, fitness, personal care, communication, housing, mobility, responsibilities, interpersonal relationships, community life, and recreation. These findings with the UPSA are consistent with previous work showing everyday functioning to be related to an individual's social engagement and participation (Cardenas et al., 2008; Patterson & Mausbach, 2010).

Regarding our sensitivity analysis, surprisingly there were no differences between stroke survivors' and healthy controls' performance in UPSA total scores and domain scores, except in the transportation domain. In the case of the transportation domain, stroke survivors performed less well than the healthy control participants. Interestingly, many of the stroke survivor participants had reported that the transportation domain was difficult and confusing. This domain appears to be sensitive to differences between stroke survivors and healthy controls; it would be interesting for future research to identify the task components that distinguished the performance of stroke survivors and healthy controls. Possible candidate components are task familiarity, task complexity, and print size on the bus schedules, any one of which might be responsible for the group differences.

There are several hypotheses that could explain the lack of differences between stroke survivors and healthy controls on the UPSA total scores and domain scores. First, it may be that the stroke survivors in our sample had only minor levels of disability, as suggested by low scores

on the NIH Stroke Scale. In addition, half of our stroke survivors were engaged at the American Stroke Foundation (ASF) where they participate in a variety of activities designed to promote functional independence. Stroke survivors who attend the ASF may be engaged in a number of activities in the community as the Foundation promotes social engagement. Also, ASF participants may be working to reduce disability and may have achieved levels of functioning not different from healthy controls.

A second possibility is that the assistance provided to stroke survivors who experienced physical difficulties during their performance of the UPSA reduced the sensitivity of the task. For example, the examiner provided physical assistance to stroke survivors who had difficulties writing the shopping list (household management domain), thus possibly decreasing task sensitivity to stroke specific deficits. We may have inadvertently assessed stroke survivors' knowledge of *how* tasks should be performed, rather than their actual ability to perform those tasks.

Lastly, the lack of difference between healthy controls and stroke survivors could be explained by possible functional difficulties experienced by our sample of healthy controls. The data from the initial validation studies of the UPSA and EFPT were examined and it was found the healthy controls in the present study scored significantly lower on UPSA and EFPT total scores compared to the original UPSA (Patterson et al., 2001) and EFPT (Baum et al., 2008) sample of healthy controls. In an effort to further examine the characteristics of our sample of healthy older adults, we assessed their RBANS performance against RBANS norms. Healthy controls in this study were performing in the average/above average range relative to RBANS norms, suggesting that they were not experiencing cognitive difficulties. Stroke survivors performed less well than healthy controls, and were in the average/below average range relative

to RBANS norms. Thus impaired cognition among the control participants does not appear to explain the pattern of results found in this study. However, even though no differences were found between stroke survivors and healthy controls, the UPSA was found to be related to other measures of everyday functioning and social participation in stroke survivors. Future studies that examine the suggested hypotheses may help to tease out the adequacy of these explanations.

Limitations and Future Directions

This study has limitations that are important to mention. The sample size of stroke survivors, caregivers and healthy controls is small, therefore limiting the types and number of analyses that could be conducted for this study. Specifically, the number of caregivers enrolled in this study is low compared to the number of caregivers we planned to enroll. Caregivers for this study were difficult to contact and schedule within the time constraints of the present study.

Also, social participation was assessed via caregiver report of the stroke survivor's functioning and was used as the outcome measure to assess the predictive validity of the UPSA. Even though previous research has found agreement between proxies' and stroke survivors responses to the LIFE-H (Poulin & Desrosiers, 2008), assessing social participation via caregiver report could be problematic in the interpretation of our findings as caregivers are not always accurate judges of their care recipient's abilities (Dassel & Schmitt, 2008). Therefore, future studies should assess the predictive validity of the UPSA utilizing different real-world outcomes (e.g., living independently in the community).

Lastly, a large number of stroke survivors were involved in the services provided by the American Stroke Foundation. This could be problematic in the generalization of our findings because stroke survivors involved in the American Stroke Foundation engage in a number of classes such as balance, fitness, mobility, and stress management which have been found to

increase functioning in stroke survivors (Werner & Kessler, 1996). Therefore, future studies should assess stroke survivors with broader range of stroke severity and stroke survivors who are not currently involve in post-rehabilitation activities. Future studies can assess how these samples of stroke survivors perform in the UPSA compared to healthy controls. This could provide a better understanding of the UPSA's sensitivity.

Conclusion

Although the UPSA provides a number of advantages to use with this population, disadvantages of the UPSA are worthy of mention. The sensitivity of the UPSA in stroke survivors needs further evaluation as no differences were found between stroke survivors and healthy controls. Additionally, stroke survivors with severe motor, communication and cognitive difficulties were unable to complete the UPSA, thus limiting the assessment of stroke survivors with a full range of abilities. Finally, the everyday tasks assessed by the UPSA may be outdated for a number of individuals as more of these tasks are being performed online (e.g., online banking, shopping). However, the UPSA provides advantages for its use in this population including: the limited amount of training needed to administer and score it, the portability of the UPSA (e.g., requiring only a few easily-obtained materials that are easy to transport), and the time of administration (i.e., 30 minutes). The UPSA could aid researchers, clinicians and therapists in improving rehabilitation placement and effectiveness. In summary, findings from this study offer preliminary support for the feasibility, acceptability and validity of the UPSA as a performance-based measure of functional capacity in stroke survivors.

APPENDIX A

Table 1
Participant Characteristics

Participant Characteristics	Stroke Survivors	Healthy Controls
Age at study enrollment, mean (SD)	62.75 (9.76)	68.90 (9.48)
Gender		
Male	25 (62.5%)	14 (70.0%)
Female	15 (37.5%)	6 (30.0%)
Years of Education, mean (SD)	14.78 (2.92)	17.00 (2.94)
Marital Status		
Never Married, n (%)	1 (2.5%)	3 (15.0%)
Cohabiting, n (%)	1 (2.5%)	0 (0.00%)
Divorced, n (%)	3 (7.5%)	5 (25.0%)
Married, n (%)	34 (85.0%)	12 (60.0%)
Civil Union, n (%)	1 (2.5%)	0 (0.00%)
Ethnicity		
White, n (%)	33 (82.5%)	18 (90.0%)
Black, n (%)	3 (7.5%)	2 (10.0%)
Hispanic, n (%)	3 (7.5%)	0 (0.00%)
Other, n (%)	1 (2.5%)	0 (0.00%)
Handedness		
Left, n (%)	3 (7.5%)	1 (5.3%)
Right, n (%)	37 (92.5%)	18 (94.7%)
Experienced Multiple Stroke		
Yes, n (%)	11 (29.7%)	
No, n (%)	26 (70.3%)	
Type of Stroke		
Ischemic Stroke, n (%)	18 (45.0%)	
Hemorrhagic Stroke, n (%)	8 (20.0%)	
Transient Ischemic Attack, n (%)	6 (15.0%)	
Don't Know, n (%)	8 (20.0%)	
Side of Stroke		
Left, n (%)	13 (32.5%)	
Right, n (%)	23 (57.5%)	
Both, n (%)	1 (2.5%)	
Does not know, n (%)	3 (7.5%)	
Years Since Stroke, mean (SD)	6.25 (5.43)	
Stroke Severity, mean (SD)	38.24 (10.22)	

Table 2
Summary of acceptability ratings for the UPSA and EFPT

	Clear Instructions		Fun		Difficult		Familiar		Complex		Simple		Confusing	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%
EFPT														
Cooking	39	97.5%	11	27.5%	2	5.0%	17	42.5%	2	5.0%	28	70.0%	2	5.0%
Communication	40	100%	11	27.5%	4	10.0%	21	52.5%	2	5.0%	24	60.0%	2	5.0%
Medication	37	92.5%	4	10.0%	2	5.0%	22	55.0%	1	2.5%	21	52.5%	9	22.5%
Bills	38	95.0%	7	17.5%	8	20.0%	19	47.5%	10	25.0%	13	32.5%	7	17.5%
UPSA														
Financial	40	100%	12	30%	6	15%	17	45.5%	5	12.5%	24	60%	3	7.5%
Communication	40	100%	4	10%	5	12.5%	22	55%	2	5.0%	24	60%	2	5.0%
Household	40	100%	15	37.5%	3	7.5%	20	50.0%	0	0.0%	29	72.5%	2	5.0%
Comprehension	39	97.5%	10	25%	15	37.5%	7	17.5%	9	22.5%	12	30%	5	12.5%
Transportation	33	82.5%	1	2.5%	21	52.5%	2	5.0%	16	40.0%	2	5.0%	21	52.5%

Table 3
UPSA and EFPT Means and Standard Deviations

	Stroke Survivors	Healthy Controls
UPSA Financial	16.91 (3.69)	18.64 (1.43)
UPSA Communication	14.21 (3.52)	15.92 (1.91)
UPSA Comprehension	15.50 (3.90)	15.93 (2.55)
UPSA Transportation	12.67 (3.53)	14.89 (2.61)
UPSA Household	17.38 (2.99)	16.50 (2.86)
UPSA Total	76.66 (12.68)	81.87 (6.39)
EFPT Cooking	2.37 (2.02)	1.63 (1.50)
EFPT Telephone	1.23 (3.41)	0.37 (0.96)
EFPT Medication	2.10 (2.19)	1.21 (1.58)
EFPT Bills	3.64 (2.58)	3.21 (1.40)
EFPT Total	9.28 (7.21)	6.42 (2.97)

Table 4
Correlations between UPSA and EFPT in Stroke Survivors

	1	2	3	4	5	6	7	8
1. UPSA Total Scores	--							
2. UPSA Communication	0.74**	--						
3. UPSA Household	0.69**	0.35*	--					
4. UPSA Financial	0.75**	0.43**	0.45**	--				
5. EFPT Total Scores	-0.60**	-0.56**	-0.35*	-0.31	--			
6. EFPT Telephone	-0.45**	-0.58**	-0.26	-0.13	0.80**	--		
7. EFPT Cooking	-0.45**	-0.27	-0.40*	-0.26	0.68**	0.38*	--	
8. EFPT Bills	-0.48**	-0.33*	-0.30	-0.27	0.81**	0.51**	0.32	--

** $p < .01$ (2-tailed)

* $p < .05$ (2-tailed)

Table 5
Predicting social participation

Predictor	LIFE-H Total Scores		
	<i>B</i>	<i>SE B</i>	<i>p</i>
Step 1			
Constant	68.11	30.32	
Age	-.25	.40	.536
Education	1.65	1.23	.195
$R^2 = .004$			
Step 2			
Constant	80.67	32.67	
Age	-.32	.40	.441
Education	1.51	1.23	.236
NIHSS Scores	-.61	.59	.319
$R^2 = .006$			
Step 3			
Constant	-2.46	36.67	
Age	.11	.35	.757
Education	.30	1.06	.779
NIHSS Scores	-.68	.48	.172
UPSA Total Scores	.96	.29	.005
$R^2 = .353$			

APPENDIX B

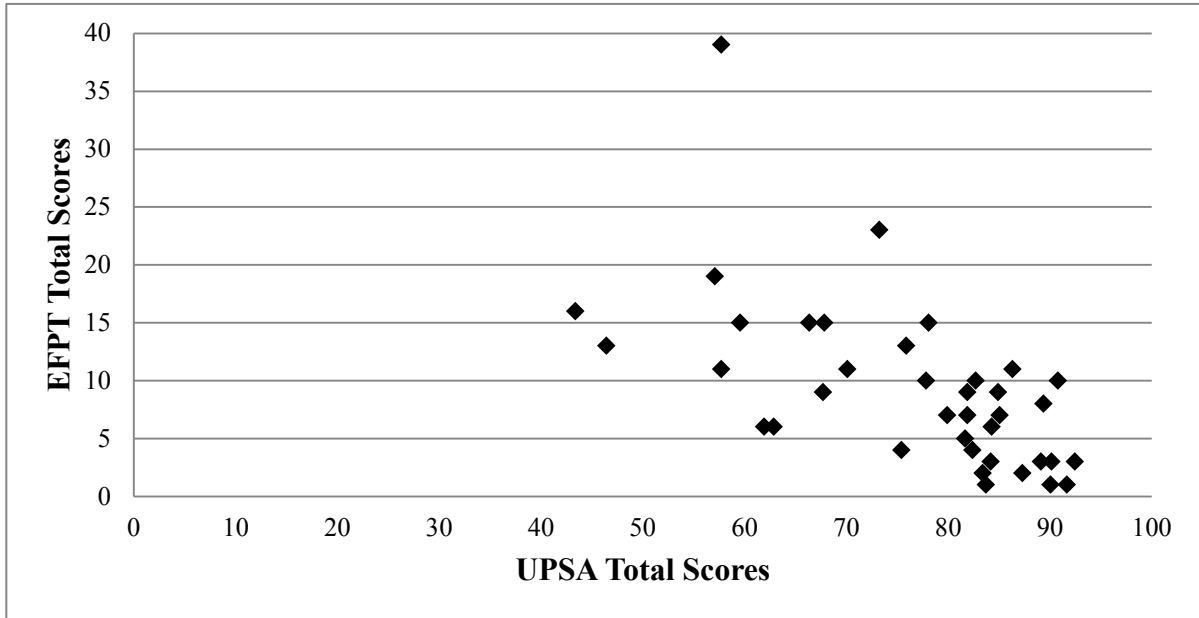


Figure 1. Correlation between UPSA total scores and EFPT total scores.

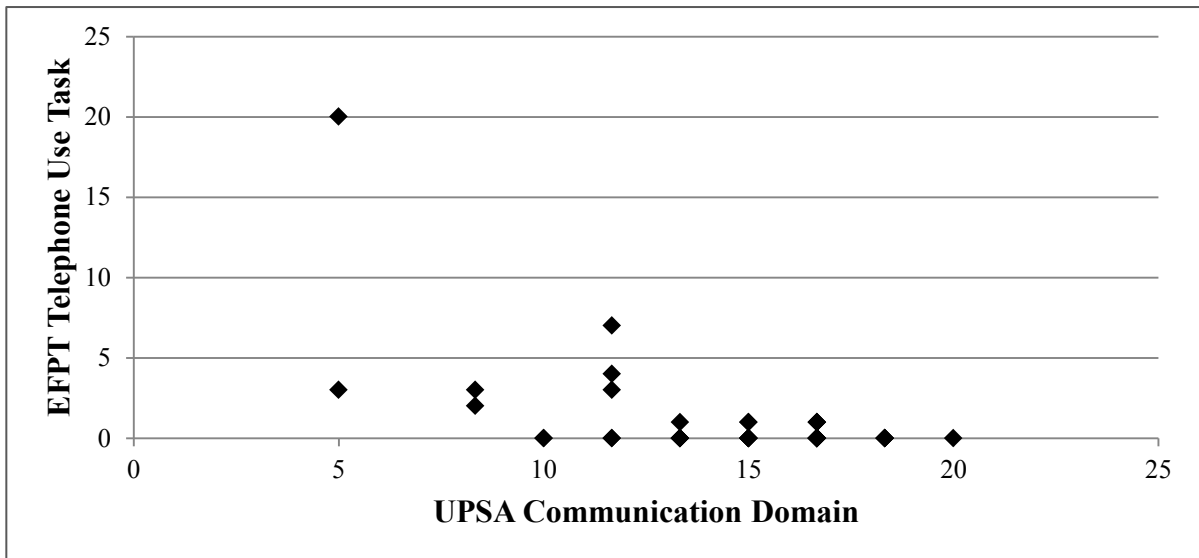


Figure 2. Correlation between UPSA communication domain and EFPT telephone use task.

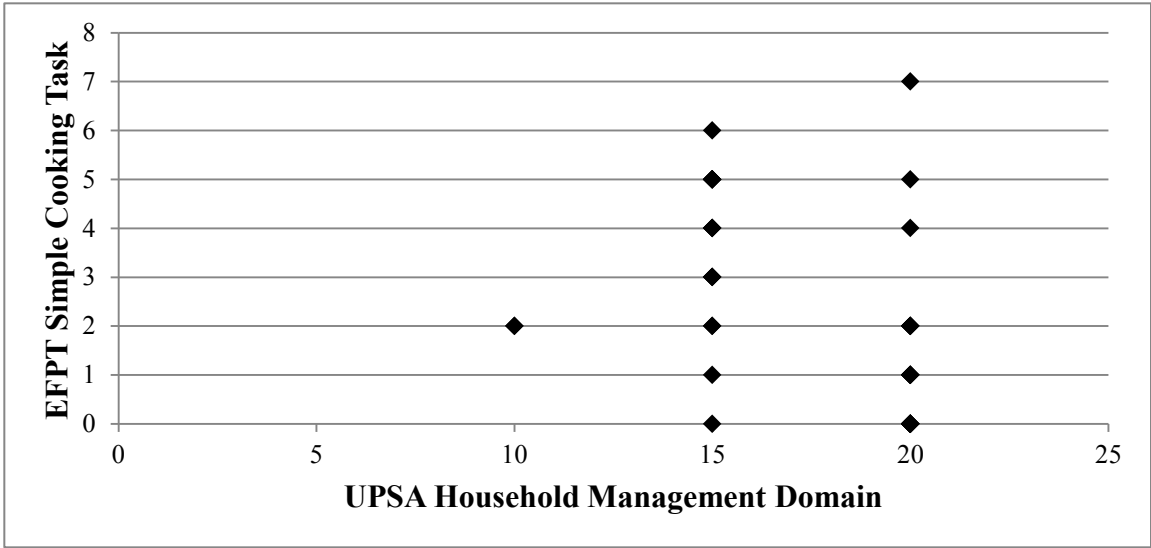


Figure 3. Correlation between UPSA household management domain and EFPT simple cooking task.

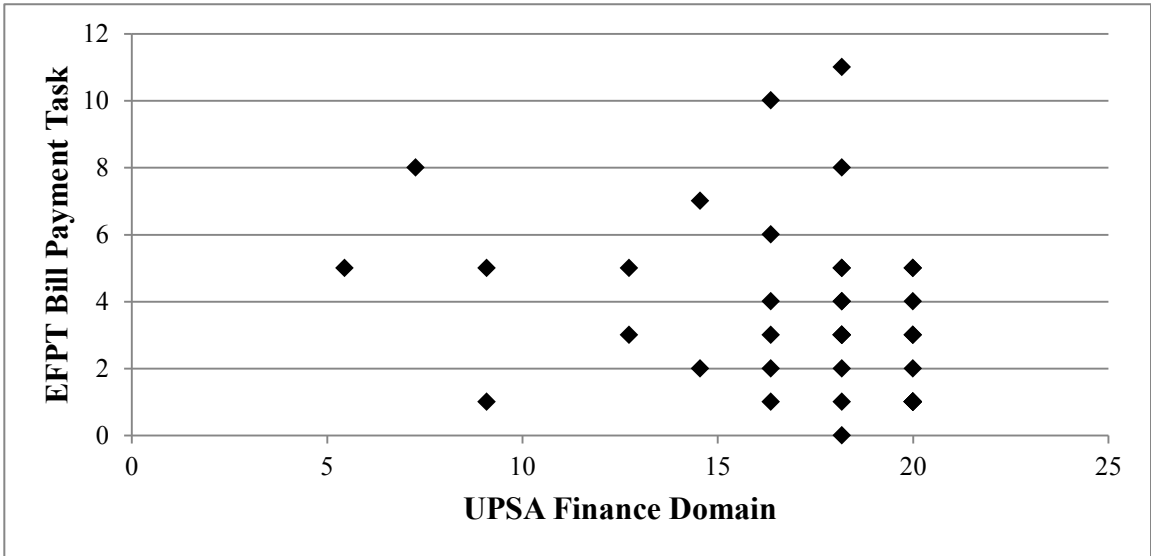


Figure 4. Correlation between UPSA finance domain and EFPT bill payment task.

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VITA

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Prior to graduating from SDSU, Denisse was accepted to the Clinical Health Psychology doctoral program at the University of Missouri-Kansas City (UMKC), which she began in August, 2011. Since that time, Denisse has been involved in research assessing everyday functioning in stroke survivors. Additionally, Denisse is the co-principal investigator of a project designed to develop a self-efficacy of health literacy measure. Denisse has completed and collaborated in multiple research projects that has presented in national research conferences. She is a member of the Gerontological Society of America, American Psychological Association and the Society of Behavioral Medicine.