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The Experience of Adults with Chronic Stroke who have Participated in Occupation-Based or Modified Constraint Induced Interventions as a Part of a Research Study

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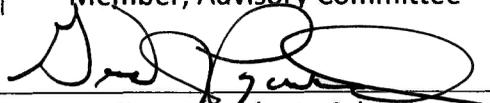
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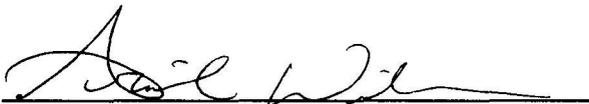
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Master of Science
Eastern Kentucky University
Richmond, Kentucky
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Bachelor of Science
Eastern Kentucky University
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DEDICATION

This thesis is dedicated to my parents
Anita and Keith Wilson
for their unconditional love, prayers, and support.

ACKNOWLEDGMENTS

I would like to thank my thesis chair, Dr. Dana Howell, for her guidance, patience, and the lengthy amount of time she spent editing. She sincerely cared about my success in this project and challenged me to push myself and strive for my best work. I would also like to thank my committee members, Dr. Melba Custer and Dr. Camille Skubik-Peplaski, for assisting me in the recruitment of participants and for their help throughout the research and editing processes. As for my four participants, I thank them for inviting me into their homes and taking the time and energy to be a part of this research study.

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ABSTRACT

There is a lack of qualitative research about the client perspective of specific chronic stroke interventions for motor recovery. The purpose of this phenomenological study was to understand the experiences of adults with chronic stroke who have participated in occupation-based (OBP) or modified constraint-induced (MCIT) interventions as a part of a research study. Four participants were recruited through convenience sampling and interviewed about their participation in research. Interviews were audio recorded, transcribed, and analyzed until themes emerged. Results showed participants engaged in the research interventions because of a desire to achieve a lost sense of 'normalcy' and perceptions of their outcomes were dependent on the type of intervention received (OBP or MCIT). Therapists can use knowledge of effective interventions, resiliency of clients, and their own therapeutic use of self to increase hope and motivation in recovery.

Chapter 1: Literature Review

Introduction

There is a lack of qualitative data for clients' perspectives of specific chronic stroke interventions in literature. The opportunity to collect this type of data was found in a recent study comparing modified constraint-induced therapy (MCIT) with occupation-based therapy interventions for individuals with chronic stroke (Skubik-Peplaski, Custer, Sawaki, Stroud, & Howell, 2015). In the study, the investigators measured change in motor and occupational performance before and after intervention; however, the participants' perspectives about participation in the study, and their experiences with these specific interventions were not recorded. Understanding their experiences may provide valuable insight that clinicians could use to design better, more client-centered interventions to improve motor and occupational performance.

Therefore, the purpose of this phenomenological study was to understand the experiences of participants from that recent study, who participated in either upper extremity occupation-based interventions or MCIT. This research study was conducted as a part of a Master of Science in Occupational Therapy thesis project. Four participants were interviewed concerning their participation in the recent unpublished study to gain insight into their experiences. The literature review within this first chapter provides background information for research, while the manuscript for the study follows in chapter two.

Understanding a Cerebral Vascular Accident

A stroke, or cerebral vascular accident (CVA), is a type of non-traumatic brain damage caused by a decrease or lack of blood flow and inadequate supply of oxygen to the brain, leading to damage and/or death in brain tissue (National Stroke Association,

2015). Common causes of CVAs include aneurysms, arteriosclerosis (ischemic vascular disease), thromboses, and embolisms. Risk factors include hypertension, high cholesterol, diabetes, sedentary lifestyles, obesity, and tobacco use (Centers for Disease Control and Prevention (CDC), 2014). There are different types of strokes. An ischemic stroke is caused by a thrombus (blood clot) formed inside an artery that supplies blood to brain tissue or by an embolism (when a clot forms elsewhere and then moves through vessel to the brain) (Falvo, 2014). A hemorrhagic stroke occurs when a blood vessel ruptures, causing intracranial hemorrhaging (National Stroke Association, 2015). Deprivation of oxygen and intracranial pressure are then the causes of tissue infarction. According to Falvo (2014), transient ischemic attacks (TIAs) called 'mini-strokes' may occur, but usually do not cause the infarction of brain tissue. However, they may lead to a larger stroke.

Each stroke causes unique, life altering experiences for survivors (Williams & Murray, 2013b, p. 370). The effects can manifest themselves cognitively, physically, emotionally, and in other ways, disrupting the lives of those who experience them (Falvo, 2014). According to Falvo's description of manifestations, motor impairments include paralysis, paresis, ataxia (loss of control/coordination of movements), and apraxia (loss of ability to perform purposive movements). Sensory impairments include paresthesia (tingling sensation), hemianopsia (inability to see half of vision field), inability to judge distance, and loss of feeling. Cognitive impairments include alexia (inability to read), agraphia (inability to write), agnosia (inability to recognize common items with senses), difficulty decision making, loss of judgment abilities, and difficulty planning and sequencing. Communication impairments include Broca's aphasia (difficulty putting sentences together, but can comprehend language; labored speech), dysnomia (difficulty finding words), Wernicke's aphasia (reduced ability to use correct words in an order that makes sense; effortless speech), and global aphasia (difficulty using or understanding language) (Falvo, 2014). These effects decrease the ability to

function in various activities of daily living, such as cooking, bathing, and even standing (Williams & Murray, 2013a).

After the initial incident, there are acute care, inpatient, and outpatient services to care for and rehabilitate these individuals (Peoples, Satink, & Steultjens, 2011). Occupational therapy (OT) is included in those services. According to the American Occupational Therapy Association (AOTA), these therapists “help people across the lifespan participate in the things they want and need to do through the therapeutic use of everyday activities (occupations)” (American Occupational Therapy Association, 2015). It is the OT’s role to aid stroke survivors in regaining independence and/or ability to participate in meaningful occupations, such as dressing, bathing, cooking, playing a favorite game, and working. Areas that occupational therapists may address fall under the categories of Activities of Daily Living, Instrumental Activities of Daily Living, Rest and Sleep, Education, Work, Play, Leisure, and Social Participation (American Occupational Therapy Association, 2014). Client factors, performance skills, performance patterns, and context are also addressed in conjunction with theory and evidence-based intervention.

Occupational therapy services for the acute stages of stroke (the first few weeks after the incident) are important, and generally provide intense therapy sessions. However, the effects of CVA may be lifelong and chronic (Price, Kinghorn, Patrick, & Cardell, 2012), requiring additional rehabilitation services over time. Neural plasticity of the brain allows for changes for improvement, even years post stroke (Schouten, Murray, & Boshoff, 2011). Individuals may continue to improve in all areas following stroke, even in the chronic stage (Williams & Murray, 2013b). While deficits in many areas may persist after CVA, this review will focus on motor control since that was the focus of intervention experienced by the participants in this study.

There are multiple evidence-based interventions that may be included in occupational therapy services to improve motor performance in both the acute and chronic stages after a stroke. Repetitive task practice is one such intervention, defined as the “performance of goal-directed, individualized tasks with frequent repetitions of task-related or task-specific movements” (Nilsen, Gillen, Geller, Hreha, Osei, & Saleem, 2015). Nilsen, Gillen, Geller, Hreha, Osei, and Saleem (2015) completed a systematic review of evidence to understand the effectiveness of repetitive task practice and found that it improves occupational performance after stroke by enhancing upper extremity function, balance, and mobility.

Bilateral passive range of motion during the stages of acute stroke has also been seen to increase upper extremity function, performance of activities of daily living, and decrease secondary complications, such as edema and contractures (Hyun, Yaelim, & Kyeong-Yae, 2014). This is performed by moving the affected limbs at individual joints up to the point of joint resistance or within the range of comfort depending on consciousness of the patients (Hyun, Yaelim, & Kyeong-Yae, 2014).

Mirror training is also used in stroke intervention and is implemented by placing “a mirror or mirror box...in the midsagittal position between the extremities” (Nilsen, Gillen, Geller, Hreha, Osei, & Saleem, 2015). The affected limb is placed on the back side of the mirror so that only the affected limb is in the reflection. The client is then asked to concentrate on the mirror image of the unaffected limb as they practice moving it to complete exercises or goal-directed tasks, giving the illusion that the affected limb is moving properly. This activates mirror neurons in the premotor cortex of the brain, leading the mind to believe that the hand and arm are moving (Beaumont Health, 2013). Through a systematic review of literature concerning the effectiveness of this intervention, Nilsen et al. (2015) found that mirror training improves upper extremity function and participation in meaningful activities.

The creation of treatment schedules concerning upper limb interventions may also be used by therapists and clients (Jarvis, Reid, Edelstyn, & Hunter, 2014). These schedules are created in collaboration with clients and families to anticipate therapy sessions and prepare to practice activities at home. Jarvis, Reid, Edelstyn, and Hunter (2014) found that these treatment schedules have aided in improving function of upper extremities by providing advice and education, promoting practice outside therapy sessions, and including psychosocial interventions.

Modified constraint-induced therapy and occupation-based therapy interventions are two more types of treatment often used to address motor control with clients after stroke. This study collected and analyzed the experiences of participants from a recent study (Skubik-Peplaski, Custer, Sawaki, Stroud, & Howell, 2015) that examined the effectiveness of these two interventions during the chronic stage of stroke. Because the participants' experiences were focused on these specific chronic stroke interventions, these two interventions will be discussed in further detail.

Modified Constraint-Induced Therapy (MCIT)

According to Lima, Nascimento, Michaelsen, Polese, Pereira, and Teixeira-Salmela (2014), a common and successful intervention to improve motor control after CVA is constraint-induced therapy (CIT). Constraint-induced therapy is defined as task practice that is performed for six hours each day while the client's unaffected extremity is constrained for 90% of his/her waking hours for two weeks (Souza, Conforto, Orsini, Stern, & André, 2015). It also requires supervision for several hours each day.

The modified version of this intervention (MCIT) is provided for less than the six hours each day of treatment used in CIT, where the client's unaffected extremity is constrained by a cast or sling to promote the use of the affected extremity (Page, Levine, Leonard, Szaflarski & Kissela, 2008). This modification necessitates fewer hours

of supervision, but still requires the client to use his/her affected extremity for task practice, such as repetitive exercises, fine motor tasks (e.g. pegboards), and simulated movements used in everyday life (Barzel, Ketels, Tetzlaff, Krüger, Haevernick, Daubmann, Wegscheider, & Scherer, 2013).

Park (2015) used MCIT in his study to better understand the effectiveness of the intervention on chronic stroke clients. He measured outcomes through the Action Research Arm Test (ARAT), the 66-point upper extremity section of the Fugl-Meyer Assessment of Motor Recovery after stroke (FM), and the Korean version of the Modified Barthel Index (K-MBI). The participants' unaffected hand and wrist was restrained every week day for four hours and they received 30 minutes of therapy, five days per week for six weeks. After those six weeks, all participants' scores for the ARAT, FM, and K-MBI significantly increased (Park, 2015).

According to Nilsen, Gillen, Geller, Hreha, Osei, and Saleem (2015), an increase in occupational performance after MCIT has also been seen in numerous other studies. Their systematic review of evidence for this specific intervention showed significantly positive outcomes for improved upper extremity function and increased activity and participation after participating in MCIT. Variations on the time for this intervention exist, as their systematic review discovered a study that restrained participants' unaffected extremity for two hours per day, five days per week, for four weeks. While successful according to the review, the time is different from Park's (2015) study previously described.

Occupation-Based Therapy (OBP)

While studying the effectiveness of interventions to improve motor control, as well as stroke survivors' approaches to recovery, researchers have realized there is a need for more individualized treatment plans (Peoples, Satink, & Steultjens, 2011).

Occupation-based practice (OBP) may be defined as client-centered activities that focus on the occupations that the client finds meaningful, through which participation in these becomes the intervention process and outcome (Law, Baum, & Baptiste, 2002). Meaningful occupations can include various activities and/or tasks that fall under the areas of occupation as defined by the American Occupational Therapy Association (American Occupational Therapy Association, 2014). For example, this could include folding laundry, feeding oneself, and gardening.

A review of literature showed that there is strong evidence for the use of everyday life occupations in stroke rehabilitation (Kristensen, Persson, Nygren, Boll, & Matzen, 2011). Researchers have found that occupation-based interventions have improved participation in multiple areas of occupation after having a stroke (Wolf, Chuh, Floyd, McInnis, & Williams, 2015). An occupation-based approach has also been effective in improving health-related quality of life and physical function, including self-care activities (Tomori, Nagayama, Ohno, Nagatani, Saito, Takahashi, Sawada, & Higashi, 2015). Williams and Murray (2013a) also found it to be linked to positive implications for the ability to adapt, self-identify, and regulate emotional responses.

Client-centeredness is one essential aspect of OBP. Tomori et al. (2015) found that a client-centered approach improved ADLs, increased life satisfaction, and decreased feelings of caregiver burden for inpatients patients who had a stroke. Kristensen et al. (2011, p 14) also states that a client-centered approach “improves satisfaction with services, increases adherence to therapy recommendations, and improves function outcome in everyday occupations.” While this approach is highly successful, it may be difficult to implement in a medical model setting (Bigelius, Eklund, & Erlandsson, 2010). This may be especially true when addressing deficits under the areas of leisure or play (Wolf, Chuh, Floyd, McInnis, & Williams, 2015).

There is little literature available regarding using both MCIT and occupation-based therapy interventions. Roberts, Vegher, Gilewski, Bender, and Riggs (2005) researched how an aspect of occupation-based therapy (a client-centered approach) could be used in constraint-induced therapy. They found that client-centered constraint-induced therapy services improved occupational performance and life satisfaction. However, there is very little published evidence available that compares the effects of the two interventions.

A Client's Perspective of Intervention

Interventions for motor control are designed to promote independence for clients through various approaches, therefore increasing their overall occupational performance (Kristensen, Persson, Nygren, Boll, & Matzen, 2011). Often meaningful ADLs, IADLs, and work become the focus of interventions, leaving leisure and other areas of occupations untouched (Wolf, Chuh, Floyd, McInnis, & Williams, 2015). Since a stroke causes deficits in performance in all areas of life, differently for every person, a broader client-centered approach is necessary (Williams, & Murray, 2013a).

Since each recovery experience is unique, there is a need for qualitative data to better understand the perspective of those receiving therapy services and create client-centered intervention plans (Peoples, Satink, & Steultjens, 2011). Qualitative studies examining this issue are few, however. One study provided stroke clients' perspectives of acute care rehabilitation, using Wii Sport as an occupation-based intervention (Celinder & Peoples, 2012). In this study, researchers found that patients participating in this as an acute intervention felt it allowed them to feel more engaged in an activity, provided a variety of therapy, and afforded obstacles and challenges to overcome during their stay. Likewise, a study evaluating the effectiveness of OT in stroke rehabilitation found that clients favored a client-center approach to intervention (Kristensen, Persson, Nygren, Boll, & Matzen, 2011). This was due to an increase in

satisfaction and involvement in their recovery. There are also studies that provide clients' experiences with group programs for those living with chronic stroke effects, such as community-based day therapy centers (Schouten, Murray, & Boshoff, 2011). With this study, researchers found that groups, such as this one, improved psychosocial aspects of those living with chronic stroke, including decreasing social isolation and building confidence to try new things.

Clients' perspectives on their engagement in occupations post stroke have also been studied. William and Murray (2013a) performed a meta-synthesis of qualitative research on this topic and discovered how clients viewed their participation in occupations. They found that emotional responses, such as frustration, sadness, boredom, grief, and worry, may hinder occupational engagement, while a sense of hope and finding importance in life may support it. They also found that a sense of confinement had resulted for many with the inability to access the community due to either transportation, environmental influences, and/or difficulty in leaving home (William & Murray, 2013a). These two researchers also found a theme in adapting occupations to return to typical routines and meaningful activities. They later reported that, "occupational therapists have a unique role in facilitating the physical, mental and environmental wellbeing of clients following a stroke through engagement in occupation" when their perspective is understood and used in practice (p. 376).

The Client-Therapist Relationship and its Impact on Recovery

There is a relationship between an OT and a client during any intervention session, whether it is good or bad (Palmadottir, 2006). After a stroke, clients may have a unique relationship with many therapists as he/she progresses through different stages of therapy. The relationship with a therapist during intervention has a large impact on the effectiveness of therapy services and how the client responds to therapy (Palmadottir, 2003). Because of this, OT students are taught about therapeutic use of

self and positive/negative types of roles as a therapist (Bonsaksen, 2013). Other researchers have tried to simulate therapy sessions in order to gain a better understanding of what client's value in client-therapist relationships (Vegni, Mauri, D'Apice, & Moja, 2010). Vegni et al. (2010) found that while the simulations were realistic in creating time restrictions, it was unrealistic in how clients responded to therapists because they were not receiving therapy as a part of rehabilitation services. Therefore, they were unable to gain enough information concerning this relationship.

To better understand this dynamic between therapist and client, Palmadottir (2006) interviewed 20 individuals that had received therapy as a part of rehabilitation services. He discovered that people liked different qualities about their therapists, based on their own preferences for this client-therapist relationship. The main difference between the occupational therapists and physiotherapists when compared to other healthcare professionals was the informality of the interaction. This was further explained as a close, trusting relationship and frequent contact on an individual basis (Palmadottir, 2006). Blank (2004) found similar results when she interviewed seven individuals receiving community mental health services from an OT. She found that positive experiences with the therapists included respect, trust, and empathy. In this study, the clients more highly valued the therapists who demonstrated sincere interest and concern. Personality appeared to be noted as well, with calm, soothing, gentle therapists who enjoyed their jobs being regarded as more valuable.

The way that therapists approach the partnership also has an impact on the clients' perceptions of the client-therapist relationship and response to therapy (Blank, 2004). Aspects of partnerships that clients value are concern (warm, considerate, and interested in the client), direction (a leader therapist who decides intervention goals), fellowship (equal roles between client and therapist), guidance (client sets pace and goals, but therapist offers suggestions along the way), and coalition (both work toward

goals together) (Palmadottir, 2006). According to Blank (2004), there are also barriers to recovery because of negative partnerships between clients and therapists. She found a lack of an individual approach, lack of communication, lack of confidentiality, and an inequality between the two to be qualities found in relationships of which clients spoke negatively. Palmadottir (2006) found detachment, or a lack of closeness, and rejection, or a lack of care and trust, to be negative and potentially damaging.

Palmadottir (2003) interviewed clients concerning their overall view of occupational therapy. He found that the dynamic between the therapist and client had a large impact on their experiences. Those who complained about poor planning, lack of knowledge, lack of trust, and poor communication skills of their therapist experienced little power in their relationship. Those who felt their therapist was trustworthy, a close friend, and knowledgeable felt as though they were equal in their relationship and that it was based on respect and trust from them both. They also felt as though the therapy had a greater positive impact on their lives than those that had negative experiences with their therapist (Palmadottir, 2003). Because of the impact that this dynamic has on the effectiveness of therapy, occupational therapists value the therapeutic use of self and the quality of therapeutic relationships between themselves and clients (Gorenberg, 2013).

Resiliency in Recovery

Resiliency can be defined as, “the process and experience of being disrupted by change, opportunities, stressors, and adversity and, after some introspection, ultimately accessing gifts and strengths...to grow stronger through the disruption” (Price, Kinghorn, Patrick, & Cardell, 2012, p. 111). There have been quite a few studies to examine this quality and its effects on the body. Zeng and Shen (2010) found it contributed to longevity in life. In their research, resilience was correlated with improved physical and

psychological health, causing individuals to hold positive outlooks and resist and/or recover from stress.

Resiliency has also been correlated with the belief that an individual has gained benefits from the struggle of the experience of having a disabling condition (Salick & Auerbach, 2006). Salick and Auerbach (2006) interviewed 10 individuals who experienced a traumatic disabling injury or chronic illness. While they all described a sense of hopelessness and loss after the injury, they all related their choice to move on with an inner strength. The researchers found that most of their participants were surprised about their own strength because it was the first time experiencing this need to do what was necessary to move forward, past such a negative experience. The participants felt it was their disabling experience that highlighted their resiliency. However, not everyone believes that their experience with a disabling chronic condition is what sparks a sense of resiliency.

When asked by researchers if he felt there were positive outcomes from having a stroke, a man living with chronic stroke effects answered, "I'm very reluctant to even hint that having a stroke is a good thing. I think that's self-delusion, and perhaps other people's delusion. Now, making the most of the situation...which is just what I think we ought to be focusing on, is probably good for one in general" (Price, Kinghorn, Patrick, & Cardell, 2012, p. 114). Price et al. (2012) studied the resiliency of this man after his stroke. They discovered that there were many things that contributed to his ability to emotionally recover and move past his limitations. His personal traits that added to his resilient quality included change viewed as a challenge, commitment, recognition of limits, self-efficacy, past successes, faith, patience, adaptability, secure attachment to others, and optimism. He felt that his stubbornness and resourcefulness were strong attributes that helped him to move forward.

De Guzman et al. (2012) studied nine Filipino post-stroke men living with residual paralysis and found similar results as Price et al. (2012). Despite cultural differences, de Guzman et al. discovered that there were personal traits of the men that added to their resiliency, as well as occupations in which they participated that helped them to cope with the emotional and physical effects. He found that they participated in exercise, yoga, water therapy, and regular doctor check-ups. All of the participants also received hope and comfort through faith and spirituality. They prayed for bravery and used this to let go of their worries and anxieties. De Guzman et al. also discovered that all of his participants stated that they had accepted their condition.

A sense of hope and the ability to 'look on the bright side' were two key points that were found to add to the resiliency of participants of two different studies. Salick and Auerbach (2006) found that locating hope was essential to moving forward. Those researchers, as well as William and Murray (2013b) found that their participants were able to compare themselves to others that had more disabling conditions after experiencing a similar injury or illness. They often viewed themselves as fortunate despite their limitations, because it could be worse. This viewpoint also added to their resiliency.

Impact of Participating in a Research Study

There is a lack of research concerning the experiences of those living with chronic stroke, who have participated in research studies. However, research has been conducted with other populations to better understand the phenomenon of participating in a research study. Irani and Richmond (2015) conducted a secondary analysis of data from a longitudinal cohort study to understand the reasons for participating in research as well as any reservations about participation. After the study, 214 participants were asked about their reasons for participating in the initial study, which consisted of adults who sought emergency care for an acute injury. They found

that common reasons for participating in research included being asked by a researcher, altruism (either to help the researchers or others who have experienced a recent injury), an opportunity for personal benefit, financial gain (the researchers offered \$150 for participation), and curiosity. The least common reason was for the value of research or knowledge.

Irani and Richmond (2015) also found some common reservations about participating, although most of their participants did not voice any. Among those common were time constraints and scheduling issues, issues of confidentiality and privacy, concern that they would not be an adequate participant, concern that injuries were too minor, and a worry for becoming too depressed during while being interviewed. These researchers found that participants also enjoyed the supportive and flexible research team, which allowed them to participate around their busy schedules.

Biddle, Cooper, Owen-Smith, Klineberg, Bennewith, Hawton, and Gunnell (2013) also recorded a few reservations from participants who were asked to complete a follow up study. These researchers interviewed sixty-three people that had participated in a suicide and self-harm based research. They were asked to rate their emotional state before and after being interviewed on their experiences. Most of the participants' moods improved after speaking about their experience with research, while a small portion of the groups' moods decreased. The reservations were similar to those found by Irani and Richmond (2015): worrying about becoming depressed or brought down when speaking about difficult times. However, the participants that did have a decrease in mood stated that the contribution to research and benefits of being able to reflect about experiences and progress outweighed the distress that was felt.

Conclusion

The neurological effects of a cerebral vascular accident (CVA) manifest themselves in various ways, affecting multiple bodily functions. These symptoms can cause life disruptions in all areas of occupation. For this reason, OTs address client factors, performance skills, and environmental modifications by implementing interventions supported by theory and evidence. These interventions may be used in OT services to improve motor performance during the acute or chronic stages of a stroke. Modified constraint-induced therapy (MCIT) and occupation-based therapy interventions have both shown to be successful in improving motor and occupational performance.

The effectiveness of a client-centered approach calls for more qualitative data regarding the clients' perspectives of intervention. This information is especially lacking in regards to specific chronic stroke interventions. The effects of client-therapist relationships and resiliency in stroke recovery can also be investigated through qualitative research. The opportunity to collect this type of data was found in a recent study comparing the effects of MCIT with occupation-based therapy interventions on those experiencing chronic stroke (Skubik-Peplaski, Custer, Sawaki, Stroud, & Howell, 2015). The manuscript for the phenomenological study of those who participated in that unpublished study is provided as the following chapter.

Introduction

In the United States, approximately 795,000 people have a stroke each year (Centers for Disease Control and Prevention (CDC), 2015). The CDC reported that cerebral vascular accidents (CVA), or strokes, are one of the leading causes of long-term disabilities in the United States. Each stroke causes unique, life altering experiences for survivors (Williams & Murray, 2013b, p. 370). The effects can manifest themselves cognitively, physically, emotionally, and in other ways, disrupting the lives of those who experience them. These effects decrease the ability to function in various activities of daily living, such as cooking, bathing, and even standing (Williams & Murray, 2013a). There are numerous interventions that occupational therapists implement during therapy to address motor control in the chronic stage of CVA, such as modified constraint-induced therapy and occupation-based intervention. However, there is little literature to provide the client perspective of specific chronic stroke intervention. Therefore, the purpose of this study was to understand the experiences of those who have participated in upper extremity occupation-based or constraint-induced interventions as adults at least one year post stroke as a part of a research study.

Literature Review

Occupational therapy services for the acute stages of stroke (the first few weeks after the incident) are important, usually providing more intense therapy sessions, however; the effects of this condition are lifelong (Price, Kinghorn, Patrick, & Cardell, 2012). While many individuals struggle to adapt and relearn throughout their lives (Williams & Murray, 2013b), there is still room for improvement in the chronic stages (after the first year that follows the incident). The neural plasticity of the brain

allows for changes for improvement, even years post stroke (Schouten, Murray, & Boshoff, 2011).

There are various evidenced-based interventions that may be included in occupational therapy services to improve motor performance in both the acute and/or chronic stages after a stroke. According to Lima, Nascimento, Michaelsen, Polese, Pereira, and Teixeira-Salmela (2014), a common and successful intervention to improve motor control after CVA is modified constraint-induced therapy (MCIT). It is a modified version of constraint-induced therapy (CIT) and is provided for less than the six hours each day of treatment used in constraint-induced therapy, where clients' unaffected extremities are constrained by a cast or sling to promote the use of the affected extremities (Page, Levine, Leonard, Szaflarski & Kissela, 2008). This modification necessitates less hours of supervision than CIT, but still requires the client to use his/her affected extremity for task practice, such as repetitive exercises, fine motor tasks (pegboards), and simulated movements used in everyday life (Barzel, Ketels, Tetzlaff, Krüger, Haevernick, Daubmann, Wegscheider, & Scherer, 2013).

Park (2015) used MCIT in his study to better understand the effectiveness of the intervention on chronic stroke clients. He measured outcomes through the Action Research Arm Test (ARAT), the 66-point upper extremity section of the Fugl-Meyer Assessment of Motor Recovery after stroke (FM), and the Korean version of the Modified Barthel Index (K-MBI). Participants' hands and wrists were restrained every week day for four hours and they received 30 minutes of therapy, five days per week for six weeks. After those six weeks, all participants' scores for the ARAT, FM, and K-MBI significantly increased (Park, 2015).

While studying the effectiveness of interventions to improve motor control, as well as stroke survivors' approaches to recovery, researchers have realized there is a need for more individualized treatment plans (Peoples, Satink, & Steultjens, 2011).

Occupation-based practice (OBP) may be defined as client-centered activities that focus on the occupations that the client finds meaningful, through which participation in these becomes the intervention process and outcome (Law, Baum, & Baptiste, 2002). Meaningful occupations can include various activities and/or tasks that fall under the areas of occupation as defined by the American Occupational Therapy Association (American Occupational Therapy Association, 2014). For example, this could include folding laundry, feeding oneself, and gardening.

A review of literature showed that there is strong evidence for the use of everyday life occupations in stroke rehabilitation (Kristensen, Persson, Nygren, Boll, & Matzen, 2011). Researchers have found that occupation-based interventions have improved participation in multiple areas of occupation after having a stroke (Wolf, Chuh, Floyd, McInnis, & Williams, 2015). An occupation-based approach has also been effective in improving health-related quality of life and physical function, including self-care activities (Tomori, Nagayama, Ohno, Nagatani, Saito, Takahashi, Sawada, & Higashi, 2015). Williams and Murray (2013a) also found it to be linked to positive implications for the ability to adapt, self-identify, and regulate emotional responses.

There is little literature available regarding the use of both MCIT and occupation-based therapy interventions. Roberts, Vegher, Gilewski, Bender, and Riggs (2005) researched how an aspect of occupation-based therapy (a client-centered approach) could be used in constraint-induced therapy. They found that client-centered CIT improved occupational performance and life satisfaction. However, there is very little published evidence available that compares the effects of the two interventions.

Since each recovery experience is unique, there is a need for qualitative data to better understand the perspective of those receiving therapy services and create client-centered intervention plans (Peoples, Satink, & Steultjens, 2011). Qualitative studies examining this issue are few, however. One study provided stroke clients'

perspectives of acute care rehabilitation, using Wii Sport as an occupation-based intervention (Celinder & Peoples, 2012). In this study, researchers found that patients participating in this as an acute intervention felt it allowed them to feel more engaged in an activity, provided a variety of therapy, and afforded obstacles and challenges to overcome during their stay. Likewise, a study evaluating the effectiveness of OT in stroke rehabilitation found that clients favored a client-centered approach to intervention (Kristensen, Persson, Nygren, Boll, & Matzen, 2011). This was due to an increase in satisfaction and involvement in their recovery. There are also studies that provide clients' experiences with group programs for those living with chronic stroke effects, such as community-based day therapy centers (Schouten, Murray, & Boshoff, 2011). With this study, researchers found that groups, such as this one, improved psychosocial aspects of those living with chronic stroke, including decreasing social isolation and building confidence to try new things.

However, there is still a lack of qualitative research provided for the client perspective of specific chronic stroke interventions. The opportunity to collect this type of data was found in a recent study comparing occupational therapy interventions (COTI study; Skubik-Peplaski, Custer, Sawaki, Stroud, & Howell, 2015). The COTI study compared occupation-based therapy interventions with MCIT for individuals with chronic stroke. In the study, participants in both groups received eight, fifty-five minute therapy sessions with goals solely focused on their Canadian Occupational Performance Measure (COPM) results. The investigators measured change in motor and occupational performance before and after intervention; however, the participants' perspectives about participation in the study, and their experiences with these specific interventions were not recorded. Understanding their experiences may provide valuable insight that clinicians could use to design better, more client-centered interventions to improve motor and occupational performance. Therefore, the purpose of this phenomenological

study was to understand the experiences of participants from the COTI study, who participated in either upper extremity occupation-based interventions or MCIT.

Methods

Participants

Upon acquiring approval from the Eastern Kentucky University Institutional Review Board (IRB), participants were recruited from the COTI study using convenience sampling (See Appendix A for IRB approval). The investigators of the COTI study contacted four of their participants and asked if they would like the opportunity to participate in another study. Two participants from each group (OBP and MCIT) were purposefully chosen for this study to ensure that the overall experience of the study was captured.

In order to meet inclusion criteria for this study, participants must have participated in either occupation-based intervention or MCIT as a part of the COTI study, be over the age of 18, at least one year post stroke, and able to verbally express themselves. Participants were excluded from the study if they did not or did not plan on participating in the occupation-based intervention or MCIT, under the age of 18, experiencing moderate to severe aphasia, or were in the acute stages of stroke (< one year post stroke). Participants who may have been decisionally-impaired, have a history of head injury with loss of consciousness, seizures, severe alcohol or drug abuse, severe psychiatric illness, or cognitive deficits severe enough to preclude informed consent would have been excluded from the COTI study, and therefore did not participate in this research study.

Data Collection

The primary student researcher sought and gained informed consent from each of the participants (see Appendix B for informed consent). Informed consent was discussed verbally and a written description was provided for each individual. All participants signed the informed consent forms, which were stored in a locked cabinet for purposes of confidentiality. After receiving written consent from each of the research participants, individual semi-structured interviews were conducted. All interviews took place in private, quiet, and convenient locations for the participants. The first two interviews took place in the homes of the participants, while the second two interviews took place in a rehabilitation facility where they were already participating in research earlier in the day.

The student researcher and participant were the only two in the rooms during each interview. The investigators of the recent study were in the room while consent was given, but left before the interviews began. The interviews were voice-recorded and the average length of the four was approximately 60 minutes. They were each semi-structured with potential questions available, however, the participants guided the interviews. Questions regarded the participants' involvement in a previous research study and their life after having a stroke (see Appendix C).

Data Analysis

The student researcher used a general qualitative approach to analyze data. This included transcribing interviews, reading through material, creating codes, generating themes, and then describing themes as an experience (Creswell, 2014). Each interview was transcribed while listening to the audio recordings. After each transcript was complete, the participants were contacted via email and phone to provide the opportunity to look over them for accuracy and member checking. All participants were

given copies of their transcripts and they all returned them with only a few changes. Transcripts were updated before the data was analyzed. The researcher went through the transcripts and highlighted potential words and/or phrases as in vivo codes (Creswell, 2014). The codes were then divided on separate slips of paper (one per slip) and grouped together into categories. From the categories emerged common themes. Participants were again contacted via email, phone, or mail to provide the opportunity to review the themes for further member checking. Only one of the four participants completed the member check at this step. The resulting themes were the findings of this research study. Throughout this process, the student researcher maintained a reflexivity journal and audit trail to ensure trustworthiness, in addition to member checking with the participants.

Results

The purpose of this phenomenological study was to understand the experience of those who have participated in upper extremity occupation-based intervention or MCIT as adults at least one year post stroke as a part of the COTI study. Participants recruited fit the inclusion and exclusion criteria described earlier. Table 1 depicts those who participated in the study. Pseudonyms are used in place of the names of participants to ensure confidentiality.

Table 1: Participant Information

Name (Pseudonym)	Age	Gender	Years Post Stroke	Type of Intervention Experienced	CVA Hemisphere
Linus	63	Male	5	OBP	Right
Ralph	60	Male	2	OBP	Right
Dwayne	62	Male	6.5	MCIT	Right
Billy	68	Male	3	MCIT	Left

Six themes emerged as the result of this research study. They are 'I would like to get back to my normal life,' 'I'll take all the therapy I can get,' 'This hospital got me working again,' 'Got me thinking more about trying to use it,' 'The most uplifting therapy sessions I had, overall,' and 'No one ever said life was fair; it's what you make of it.' Each theme is described below, with verbatim quotes provided for support. A table summarizing the results can be found in Appendix D.

I Would Like to Get Back to My Normal Life

All participants spoke about living with the effects of having a stroke. Linus compared his previously good health to his current physical state after having a hereditary stroke. He stated, "I know what to do; I know how to do it, but things just don't work right." He went on to describe his walk as, "Not the prettiest thing." Others also commented on their physical state with remarks, such as, "Haven't got use of my left arm" and "Fingers don't do anything for me." These physical effects restricted their participation in meaningful and valuable occupations. Linus said that he still sees flaws in a magazine rack he recently refinished during a research study, and that he would have taken different steps in completing those tasks if it were not for his physical state. Ralph could not even lie down in bed or sit on the couch because of the pain that resulted from his stroke. He went on to describe his limited interaction with his wife and the impact that his stroke has had on their time together, only being married a year before the incident. He explained that it "put a damper on the plans."

The physical impairments were shown to have an emotional effect on all of the participants, as they spoke about their daily frustrations and the overall impact on their lives. The fact that their lives were changed after the incident was evident in remarks such as, "My life has done a 360" and "Everything has changed since the stroke." Linus described it as "Running through a brick wall, knowing you can't get through it." Ralph explained that, "Everything's a hassle...why am I putting this much effort into trying to

just lift the thing, you know?” Billy also mentioned frustration in knowing what he was trying to do, but being angry about not being able to do it. His also explained that his difficulty in expressing himself (due to mild aphasia as a result of his stroke) made him sad.

While explaining the physical and emotional effects of stroke, all of the participants mentioned a need to “Get back to my normal life.” A concept of normalcy was expressed in each interview. This was demonstrated by either a desire to perform certain occupations as one once did before the stroke, a desire to participate in all of the same occupations as before, a want to go back to similar work as before, and/or a wish to relate to a spouse in the same way as before. Ralph connected this with the hope to “Get a little bit back to myself.” Dwayne also connected this to self-improvement by stating, “I had to do it [previous research study] to get my stuff back together.” They each described a desire to ‘go back’ to normal in some way, whether it was in connection to occupations, life roles, and/or self-identity.

While they all spoke about improvements that still needed to be made, they acknowledged the large amount of progress that had been made since the incident, as well as through the research study. The effects of stroke had changed their lives forever, but they were still striving for normalcy through any avenue available. This was evident in their statements and personalities. Linus attributed much of his recovery to his determination and will power. Ralph considered himself “fix-it-up oriented.” These personality traits were reflected in their approaches to the condition. Billy stated, “It’s really been difficult, but you have to do what you have to do.” Ralph explained that he cannot change what has happened, but he can decide on how he will move forward. He said that he had a common phrase that he used with his family when things happened; “it is as it is...No one ever said life was fair; it is what you make of it.” Each participant

was frustrated by the effects of the stroke, but with each new ability and/or skill, they continued to improve as best they could.

“I’ll Take All the Therapy I Can Get”

Along with a desire to achieve a sense of ‘normalcy’ in life, each participant expressed the need to receive more therapy services. They spoke about the potential gains that could be made through further therapy sessions, even in the chronic stages of stroke. Statements about these improvements included, “[a] new [brain] pathway will say, ‘I remember,’” “there is a chance they can get better,” and “Something can happen that I can learn.” For one man specifically, receiving more treatment was directly correlated with being able to return to work. He stated, “Wanting my hand to work so I could work,” as something he wanted to improve.

While each participant expressed a need for more services, listening to each man’s story proved the complexity that involved. One participant spoke about a prescription for occupational therapy that he needed to put in, while another participant spoke about the number of his remaining sessions for the year. In order to receive OT services, the first participant had to receive a referral from his neurologist. After that, he had to make the appropriate calls to order the services, which his wife completed for him. The second participant explained his frustration with limited therapy sessions due to insurance. He was only able to receive so many visits a year, which he tried to restrict and spread out throughout the year in order to make more gains. Dwayne spoke about his experiences with financial hardships involved in paying for therapy services in the acute and chronic stages of his stroke. Dwayne explained that his insurance had dropped and he was not put on disability right away. Because of this, he and his wife went through difficult times trying to pay for necessary rehabilitation services. Ralph expressed a similar experience, stating that he and his wife were paying out of pocket for services.

This similar experience with complexity, financial hardships, and limited sessions overshadowing their desire to receive more therapy led each of the men to speak about their experiences of receiving therapy through research studies. Three out of four of the participants had participated in multiple studies, while the recent study was Billy's first experience. Those who had participated in previous studies had positive experiences with them and were unable to recall a negative moment. Ralph said that because of his experiences with research, he was "more prepared to do any study I can get a hold of." Dwayne stated that he's gotten "something out of every study I've been to" and "[I] couldn't afford it any other way."

The research study in which the four participants had just recently participated paid them for their involvement. Dwayne expressed his positive views of the study by saying that, "the study was a blessing." He explained that the study gave him the chance to receive more therapy without having to deal with insurance and be restricted in the number of sessions. It also helped him financially, as they were paid a small sum for participating.

Each participant was willing to receive therapy through the form of a research study, despite their expectations of the study. None of them knew what to expect out of the study before they became involved. Each had become involved through a therapist at the rehabilitation center in which they were each receiving services. Billy stated that he "didn't know what particularly I was gonna do or work about," but he "was really excited about starting it." Again, he stated that he could learn something new that would help him. Ralph's first thoughts about the study were not as positive as he did not want to see the rehabilitation center again. The facility triggered negative thoughts since he had not been there since he initially received therapy for his stroke over a year ago. Although he had reservations about the place, he explained that he was willing to go for the opportunity to make improvements.

After expressing their desires to receive more therapy, despite their various expectations and/or thoughts about the study, each participant also stated that they were helping others with their participation. While part of their willingness to participate was for potential improvements in their physical states, another was for the possibility of helping others; whether they are the researchers, students, or other stroke patients. Linus said that maybe it would “Help someone else along the way.” Similarly, Ralph stated, “If it doesn’t help me, it might help somebody else in the future.” Dwayne and Billy both expressed their willingness to help the researchers and students involved in the study. Dwayne said, “I’ll teach anybody anything they want to learn...[I] don’t mind helping young people out if they work at it.”

Despite the progress made during the research study, they all wished to continue receiving more therapy. While Billy was saddened by the end of the study, Ralph and Linus both saw room for progress. Linus exclaimed, “[I] still can’t do as much as I’d like to do.” Dwayne continued to use therapy strategies at home in order to continue advancing in his recovery. They were all interested in participating in other research studies and/or going back to receiving more outpatient therapy services.

“This Hospital Got Me Working Again”

Each participant talked about his experiences with acute, inpatient, and outpatient therapies after having a stroke. All of the participants were admitted to the same rehabilitation hospital for their inpatient stays. However, there were some variances in facilities for outpatient services. Service providers that were included in their experiences were occupational therapists, physical therapists, neurologists, and hand therapists (physical and occupational therapists). One participant was attending a gym rehabilitation and worked with a personal trainer there for further treatment.

There were similar treatments that the participants received as a part of past therapy services. These included neuromuscular electrical stimulation (ESTIM), foot and leg exercises, balancing, hand and arm exercises, joint compressions, stretching, relearning to walk, and fine motor activities (such as peg boards). Ralph also experienced massage and acupuncture intervention as a part of therapy. Some of the specific walking exercises mentioned were moving between two balance bars and stepping onto higher surfaces, such as stairs or stools.

The participants had various experiences with these interventions. Linus described the stretches and ESTIM he received as being painful. He joked, describing the therapists as complying with the motto, 'no pain, no game [i.e. gain].' He was unsatisfied with the lack of intervention focused on his arm, as well as with the rote exercise he endured. He felt as though it was impersonal and that he was not making large improvements. However, Billy was excited about the therapy in which he participated. He stated, "[Rehab Facility] got me ready to go when it was time to go." He described the process through which he went to relearn walking, only to fall a few months later and be restricted to using his wheelchair again.

Dwayne and Ralph both had similar experiences and were satisfied with the therapy they received at the facility. Dwayne described how his jokester personality fit in well with everyone there. He shared many stories about interactions with his roommates and the staff, with whom he still speaks. Ralph discussed how the demeanors of his therapists affected his positive and negative experiences with therapy, which will be discussed later.

"Got Me Thinking More About Trying to Use It"

While specific outcomes of the occupation-based or modified constraint-induced interventions were different and unique to each individual, each participant

emphasized certain outcomes from the study. They all described the study as a benefit to their overall recovery process, allowing them to further advance towards normalcy. Linus stated, "It helped more than any study that I've been through." Dwayne said, "I got a lot of stuff out of it," while Ralph explained that it "gave me more freedom." Billy was upset about the study ending, saying, "I'm feeling bad that I'm not gonna have to do this anymore; disappointed that it's finished." He described this interview as a great chance to reflect back on his life and experiences since having the stroke. They summed up their achievements, with Ralph describing the overall experience as a "good thing to do."

One cognitive and physical outcome, in particular, stood out. As Linus put it, it "made me try to work with this hand more" (speaking about his affected upper extremity). Each participant stated the same concept in their own words. Ralph went on to say that, "I wouldn't have before," speaking about using his hand in functional tasks around the home. They all explained that the research study caused them to think more about using their affected arm and hand in activities. Linus also stated that this new idea was "letting you know that arm is still there; it's useful."

Those in the occupation-based group recalled more specific examples of functional tasks in which they use their affected extremities. Those in the modified constraint-induced therapy group detailed more about the gains they made from using their affected arms more often. Activities in which the first two participants would use their affected hands and arms at home included shutting and opening doors with various knobs/handles, using the microwave, holding down papers while writing, propping on a table, carrying grocery bags, and pushing a cart. According to Billy, this idea and the study as a whole "taught alternative ways of doing things," as Dwayne felt that it, "Got me moving my hand a little better than what I used to do." Other trends concerning the outcomes of intervention between the participants were found based on

whether they received occupation-based intervention or modified constraint-induced therapy, as described below.

Occupation-based Intervention.

Linus and Ralph both received occupation-based interventions as a part of the research study. When describing goals for the study, Ralph stated, “Basic everyday things; that was my goal.” He explained that his goals included donning a jacket and various shirts, and other things, such as folding. Linus also considered his goals to be everyday tasks, stating that he felt that the therapy really aided him in relearning practical skills that he used before his stroke (such as refurnishing furniture).

Ralph’s intervention included dressing, folding, and practicing pushing a grocery cart in a room that was set up like a mock apartment. He enthused about his skill to don a jacket, which he did not possess prior to the study. He stated, “That was a massive thing that she taught me.” He explained that being able to put on his jacket made him “feel so normal, nearly.” It helped him to achieve a piece of normalcy, which each participant desired. He stated that it also gave him more freedom. He no longer relied on his friends or his wife to don his jacket before leaving, especially in the winter. He solely had to don his jacket and leave the house. This also allowed his wife to be less of a caregiver in that aspect; one of his concerns in their relationship.

Linus’s intervention included refinishing a magazine rack, which he now displays in his home. This was directly related to one of his interests: refinishing antique furniture. He detailed the steps that he and the therapist researcher took in disassembling the pieces, sanding the wood, rebuilding the furniture, and finishing the surface. He also recalled the way in which he was able to incorporate his affected hand and arm. He described feeling more accomplished at the end of his therapy sessions. He was proud of his work, even though he still saw flaws in the workmanship that he

wished to fix. He felt that “more hands on makes a difference; not just laying there.” He expressed numerous times that having meaningful occupations in therapy aided him in further rehabilitation.

Linus and Ralph both spoke about their roles within the therapy sessions. Each felt like they were there to help the researchers, but also to improve themselves. They said that the therapist researcher asked them about their goals before beginning. Linus stated that she, “ask[ed] me what I wanted to do.” When talking about the interventions, Ralph said, “I had a lot of control in what I wanted to try and include.” According to their statements, these participants took on an active role in therapy by deciding the goals and intervention activities.

Modified Constraint-Induced Therapy.

Dwayne and Billy participated in MCIT as a part of the research study. Neither of the two recalled their specific goals of the study, other than to make improvements in their abilities. Each detailed some of the specific interventions that were included in their sessions. The two described the intervention tasks with similar names for the intervention tools. They described stretching, a block and tackle, and a Velcro and rod activity. They also explained that the therapy included work with their arms, hands, and fingers.

Dwayne enjoyed the atmosphere of the sessions. He explained that he loves to joke with people and that the people there were able to laugh with him. He was also able to make his own breaks as he went along, which allowed him to rest when needed. He had difficulty recalling many details about the interventions other than their names since months had elapsed between participating in the research study and being interviewed for this qualitative study. However, he did remember disliking the Velcro and rod activity because of its difficulty. He stated, “[I] never complained, but that was

hard to do.” He explained that he did basic daily tasks and that the interventions were “a little bit of what you can come up with and what you’ve learned.” Overall, he felt as though he had gained better control over his affected extremity and enjoyed the company of his therapist researchers.

Billy also described his participation in the study as a positive one; being his first experience with a research study. He stated that they would, “Go across this room and would work on different things.” He enjoyed the interventions, saying, “Time flew and could work extra if needed” and that the session was “an hour that was an exciting part of the day for me.” He also enjoyed working with the therapists, explaining that they did not force any intervention, so he had the choice to participate or not. However, he stated that he always participated because of the benefit that it could have on his rehabilitation. He was excited about the improvements he made in the use of his affected upper extremity and was looking forward to more opportunities such as that one.

Dwayne and Billy spoke about their roles in therapy as accomplishing the tasks set forth by the therapist researchers. Dwayne stated, “She decided what we did.” He followed up by saying that he would “go in and see what they’ve got to do.” Billy, however, spoke more about being able to work on tasks he wished to work on, but that the therapist would decide how to work on those tasks. He stated, “I could do what I wanted to do and she showed me what she wanted.” He went on to say, “I did whatever I was supposed to do.” While they had choice in activities, they took a passive approach in relation to the intervention session.

“The Most Uplifting Therapy Sessions I Had, Overall”

All four participants expressed a very positive experience with the therapist researchers involved in the study. Later in the interview, each was prompted to recall

any negative experiences with either of the two therapists. Even when asked to provide negative feedback, none of them could think of a bad moment, regarding the two. They explained why they enjoyed working with their therapists during this study.

Ralph was especially impressed with their personalities, listing numerous characteristics that he enjoyed. He described his therapist as, “extraordinary, helpful, encouraging, knowledgeable...upbeat, pleasant, happy go lucky, informative, and motivating.” He mentioned “upbeat” more than the other adjectives, including that he felt the therapy he received in the study was more upbeat than past therapy sessions. Billy described his therapist as, “really nice people everyday...[it] made me feel good around her.” He also felt that she was encouraging to him and others there. He was most impressed with the positive relationship between the two, stating that, “Having a relationship with me that was really nice...working with her made me feel good about everything they were doing.” He enjoyed working with people that were interested in him and his recovery.

Linus stated, “[Therapist name] is the best part of therapy I’ve ever had.” He described her as having a positive attitude, hyper, motivating, and a good person, overall. He explained that the therapy sessions he received during the study really turned his perspective around. He felt a sense of hope from working with his therapist; which is something that he had not felt before in previous therapy sessions. He stated that he felt as though he could be normal again; that he could have his life back.

Dwayne enjoyed the therapists’ personalities, as well as the way they interacted with him. He had a lot of fun during the therapy sessions because of their abilities to joke with him. He also felt that while they were having fun, the therapists were going “at the problem whole haul.” He felt that they were really accomplishing their goals because of their work ethic. Billy also liked the way that the therapist

worked with him. He said that, “[we] worked on things together” and that “she made sure this was okay; that it could work for me.”

When describing their experiences with the therapists from the research study, they also described past experiences with other therapists and healthcare professionals. Most of the stories they recalled were positive, however, three out of four of participants had at least one problematic therapy session to speak of. When explaining the negatives of those bad experiences, the descriptions they provided related to characteristics of the therapists, as well as the interactions between them.

Ralph described a previous therapist as demeaning and sarcastic. He did not enjoy going to those intervention sessions and stated that if he had to do it again, he would not want to go to that therapy. Billy revealed that one of his previous therapists had no interest in him or his recovery. He explained that they were too preoccupied with an upcoming move to a different facility for work. Because he felt she was insincere in her practice, he did not enjoy going to therapy sessions with her. Dwayne did not recall any troubling incidents in his previous sessions or with his therapists. He stated, “Love every one of them.” He still speaks with many of them on his visits to the rehabilitation facility.

Discussion

The purpose of this phenomenological study was to understand the experience of those who have participated in upper extremity occupation-based intervention or MCIT as adults at least one year post stroke as a part of the COTI study. The themes included the participants’ experiences with the study, such as the outcomes from therapy, their therapy and research experiences, and how they perceived the study based on which type of therapy they received. Concepts of normalcy, resiliency, and the

client therapist relationship were also evident throughout the themes and are supported by previous research.

All four participants reported experiencing improvements in their ability to move their affected arm and to use it in daily activities as a result of participation in the study. They completed tasks that they would not have thought about trying before the interventions, such as Ralph using both hands to change a hearing aid battery. They recognized physical improvements in their motor control of their affected limbs. This included moving their arms, hands, and fingers more than they were able to before the study. Through study participation, the four men experienced an increase in their attempts to use their affected limb functionally. Siebers, Öberg, and Skargren (2010) also found that using the affected arm and hand during therapy promotes its use during functional occupations and tasks.

While all of the men perceived benefits to their affected upper extremity after participation in the research study, some of the improvements seemed to be specific to the type of intervention they received: occupation-based therapy or modified constraint-induced therapy. The two men who received occupation-based therapy, Ralph and Linus, tended to report improvements with their abilities to perform daily tasks related to their personal interests, such as dressing, grocery shopping, and refurnishing furniture. Their improved upper extremity function enhanced their participation in ADLs, IADLs, and leisure occupations. This reflects findings of Wolf, Chuh, Royd, McInnis, and Williams (2015), who conducted an evidence-based review to analyze the literature regarding the use of occupation-based interventions. They found that occupation-based interventions improved performance in various areas of occupation after a stroke, and that there is ample evidence to support the improvement of ADLs and IADLs, such as dressing, hygiene, transfers, and driving.

While there was an abundance of evidence to support the positive effects of occupation-based interventions on ADLs and IADLs, there was a lack of evidence to support its effects on leisure occupations, which was recognized as an important aspect of the participants' lives and therapy experience. Teasell et al. (2005) studied the use of an interdisciplinary rehabilitation program including principles of occupation-based interventions and found that their participants showed greater independence in ADLs upon discharge. Similarly, Bode, Heinemann, Zahara, and Lovell (2007) conducted a study to compare ADL performance outcomes after participation in more intense occupation-based therapy or rote exercise through physical therapy. They found that those who received occupation-based therapy had a greater life satisfaction and improved ADLs. While these articles support the use of occupation-based interventions to improve ADLs, Wolf, Chuh, Royd, McInnis, and Williams (2015) acknowledged a lack of evidence to support its use for improving performance in leisure activities. They found two studies to support its use, including those by Corr, Phillips, and Walker (2004) and Desrosiers et al. (2007). Corr, Phillips, and Walker (2004) conducted a randomized crossover study on the effects of interventions including leisure activities and found that participants reported improvements in self-rated performance and satisfaction with performance in leisure activities. Desrosiers et al. (2007) studied a home-based leisure program and found that participation in leisure awareness, self-awareness, and competency development in treatment increased satisfaction with time spent in active leisure activities. Even though there was limited evidence to support the use of occupation-based interventions to improve leisure activities, Linus and Ralph both valued the study's effects on their leisure. For example, Linus described the process through which he refinished a magazine rack, which is one of his personal interests. He explained that improving that skill and involving his interests gave him a new hope for recovery.

In contrast, the two men who received MCIT, Dwayne and Billy, tended to recall specific physical gains in their affected upper extremities, as opposed to gains in occupational performance. For example, Dwayne described having more control over his affected arm and fingers after completing the study, while Ralph, who received occupation-based intervention, discussed learning to put on a jacket using his affected arm. Even though Dwayne and Billy reported progress in finger, hand, and arm function, they also noted increases in their abilities to use their affected limb during functional tasks. Lima, Nascimento, Michaelsen, Polese, Pereira, and Teixeira-Salmela (2014) found that clients experiencing chronic stroke made improvements in bimanual tasks after unilateral task practice during MCIT.

Researchers and therapists have put an emphasis on studying the physical outcomes after participating in MCIT, while few have focused on the link between MCIT and occupational performance; an outlook that was similar to the recollections of therapy revealed by the four participants' interviews. Barzel et al. (2009) conducted research to compare the effects of two different constraint-induced movement therapy treatment methods and found that both were effective in improving motor function. Similarly, Wu et al. (2011) studied the effects of CIT and bilateral arm training for chronic stroke clients and found that CIT was effective in improving the use of the affected arm in daily life. In each of those studies, the physical outcomes were examined. During interviews with the four participants in this study, clients who participated in MCIT tended to recall their specific physical gains. Those who participated in OBP tended to recall the effects on their occupations. Recollections and perspectives of physical and/or occupational gains in therapy could vary depending on what the therapist (or researcher) places an emphasis. More research concerning this concept should be conducted.

Another finding of this study was the importance of individualized therapy approaches, and the match of the intervention to the individual. The therapeutic approach and the participants' individual personalities went hand in hand. For example, Linus was not happy with some previous therapy sessions prior to participation in the recent study because he felt that the intervention was not individualized to his needs. In his interview, he reported enjoying OBP because it applied to his interests and worked towards improving his individual skill set. Likewise, Dwayne enjoyed participating in MCIT because the interventions focused on his physical deficits so he could have more control over his arm and hand. Some of the participants enjoyed working on occupations, while the others enjoyed a more biomechanical approach. This is similar to previous research on individuals' experiences with stroke intervention. Williams and Murray (2013a) found that the impact on life and needs following a stroke were unique to each participant, and in another study (2013b), found that each person overcame their deficits and solved problems in ways unique to their own personalities.

It could be speculated that those unique personalities also contributed to the participants' satisfaction with the level of control over intervention experienced regardless of the two groups. Dwayne enjoyed completing repetitive tasks that were decided on solely by the therapist. In contrast, Linus spoke of his experiences with a similar approach, stating that he felt more accomplished after participating in interventions that he chose with the therapist. This is similar to previous research on individuals' experiences with stroke and a sense of paternalism that is sometimes demonstrated in collaborating with health professionals. Peoples, Satink, and Steultjens (2011) found that clients valued paternalism in regards to the decision-making of treatment, but not when it was connected to their daily occupations. Some individuals would rather let the therapist decide the best course of action, while others desire to be a part of the decision-making process.

When compared to therapy received as a part of rehabilitation services, those who participated in MCIT did not explain a difference between the two. Those who experienced OBP explained the difference clearly by stating that they performed day-to-day activities during the study sessions, but their outlooks on the benefits were different. One of the men explained how much he loved being able to work on daily tasks and improve those skills; that it had given him a whole new hope for his recovery. The other said that he was glad to have improved the skills that he did, but that the therapy was just as beneficial as others he has had.

The participants noted benefits of participating in research studies. Most of the participants had previously been involved in a research study before participating in the COTI study, and they referred to their experiences in research first, rather than their original inpatient and outpatient rehabilitation services received following their stroke. They recalled the different activities they had completed through research over the past few years, with one participant stating that he had benefited from every study he had been a part of.

The participants described benefits of participating in a research study as being physical improvements, psychosocial effects, financial gains, the ability to help others, and social interactions. One participant was especially grateful to be interviewed about his experiences so that he could reflect on his progress and the benefits of the recent study. These were all benefits seen in research conducted by Irani and Richmond (2015), who performed a secondary analysis of data to understand the reasons people had for participating in a research study regarding emergency room visits. They found reasons included altruism, personal benefits, financial gains, and fulfillment of curiosity. While there is minimal available research concerning the experiences of participating in research studies after a stroke, the benefits described by participants of this study may

be similar to different populations that have been involved in research. This warrants further study.

Participants' experiences in previous therapy, as a part of rehabilitation or through participation in earlier research studies, served as a reference point for all participants. They each made the decision to participate in the current study based on those experiences, in part via comparisons of interactions with previous therapists. They reported mostly positive interactions, with a few exceptions in the early rehabilitation process. The four men spoke about their therapists in the recent study as being knowledgeable, interested in their recovery, optimistic, encouraging, motivating, upbeat, and nice. They also enjoyed how the therapists worked with them on tasks, creating a sense of togetherness and sharing power with clients. They tended to describe past positive interactions with therapists, via rehabilitative and research experiences, as being similar. These are much like the characteristics that Blank (2004) found to be positive qualities for occupational therapists according to individuals receiving mental health services in a community setting. She found that her participants valued respect, trust, sincere interest, and empathy from their therapists.

The four men described poor interactions with past therapists prior to participation in the recent study. They explained that they were disinterested, sarcastic, and had poor listening skills. The participants in Blank's (2004) study listed similar characteristics as being negative, including a lack of communication, inequality between the two, and the putting down of clients. Despite their few poor experiences, the four participants did not hold that against the therapists in the study, or others they were around. Negative experiences with therapists were waved as a few bad peas in the pod.

While they did not judge future therapists based on previous ones, their client-therapist relationships did color their perceptions and outcomes of therapy. When they spoke about the therapy sessions involving therapists they were not fond of, their

demeanor changed and they stated they either dreaded those sessions or wished to never go through them again. They reported not trying as hard with those therapists and felt less motivated to complete the challenges in front of them. Palmadottir (2006) found that perceiving a client-therapist relationship as negative can be potentially damaging. On the other hand, when the participants spoke about progress they made through participation in the recent study, they each cited the relationship with their therapists as an essential piece of that process. One participant stated that he gained a whole new sense of hope from working with his therapist in the study; a feeling that he had not yet experienced in his recovery. Palmadottir (2003) stated that the relationship between the client and therapist has a huge impact on the way that clients perceive therapy. This was further supported by the participants' view of therapy based on characteristics of and interactions with their therapists.

No matter the type of client-therapist relationship experienced in previous therapy, participants all felt satisfied with the therapy they received and experienced a drive to participate in even more therapy. This was driven by a need to achieve normalcy in life, which was a concept that spanned across all of the themes. Despite the progress made by all of the participants, they all desired to have more therapy to continue improving. They all described a need to get back to their normal lives. Similarly, William and Murray (2013a) found that clients experiencing chronic stroke were still going through occupational adaptations, despite the number of years since their stroke. For each of the participants, 'normal' was the way in which they each experienced life before having a stroke. They spoke about the way they adapted activities and altered their routines, but according to them, this was still not fully normal. One participant spoke about returning to his 'old self,' or linking his lost sense of normalcy to his own identity. De Guzman et al. (2012) found that one's self-concept was mostly determined by physical qualities and functions, primarily prior to stroke. He stated, "post-stroke patients with loss of functional ability see themselves as abnormal

and not as their real selves” (de Guzman et al., 2012, p. 438). This need for normalcy may have also impacted their desire to participate in the research study.

While the effects of stroke were still hard to accept, even in the chronic stages, all of the participants demonstrated a determination to keep improving. This was motivated by a desire to achieve normalcy, and may be linked to the concept of resiliency. Resiliency can be defined as, “the process and experience of being disrupted by change, opportunities, stressors, and adversity and, after some introspection, ultimately accessing gifts and strengths...to grow stronger through the disruption” (Price, Kinghorn, Patrick, & Cardell, 2012, p. 111). While none of them used the exact word, they all displayed this concept in their approach to recovery. For example, Linus reported that his determination and will power enabled him to make so much progress in his rehabilitation. Two of the participants spoke about how lucky they were that their incident happened when it did. They were grateful that they were not working or driving at the time, as the results in those situations could have been fatal. William and Murray (2013b) found that when participants compared their incidents to others or other scenarios, they were able to look at their conditions from a new viewpoint, which added to their resiliency. Recognizing that it could have been worse helped these two participants to feel fortunate for the way in which their strokes occurred, adding to their resilient qualities. Price et al. (2012) found other resilient qualities to include commitment, change viewed as a challenge, recognition of limits, self-efficacy, past successes, faith, patience, adaptability, secure attachment to others, and optimism. Salick and Auerbach (2006) interviewed 10 individuals who experienced a traumatic disabling injury or chronic illness and found that while they all described a sense of hopelessness and loss after the injury; they all related their choice to move on with an inner strength. The four men in the recent study used resilient traits to move past a difficult time in life, and to continue to make it through daily challenges and frustrations

by pushing their limits and continuing to make progress. They were also open to participating in future studies, if opportunities to improve further were possible.

Implications for Occupational Therapy Practice

Even though the participants were in the chronic stages of stroke, they were all driven to participate in further therapy, motivated by the desire to achieve normalcy. After participation in the recent study, they all felt as though they had progressed in their recovery. They were all grateful for the opportunity to receive those services as a part of a research study. Clients in the chronic stages still wish to improve and obtain 'normalcy,' and do continue to make progress years post stroke. For clinicians, this demonstrates the value of occupational therapy intervention for those experiencing chronic stroke.

In providing services for individuals experiencing chronic stroke, it is important to create client-centered goals, regardless of the type of approach or specific intervention used to achieve those goals. The participants from both therapy groups were all satisfied with the services they received. However, the participants who received OBP intervention placed a high value on the goals and outcomes of the sessions and were able to clearly explain the differences from therapy they received in the past. One participant experienced a whole new sense of hope for recovery after achieving his personal goals through therapy. Clinicians can use this knowledge to create client-centered goals with their clients to increase satisfaction and improve occupational performance.

In addition to using client-centered goals, clinicians should reflect on their interactions with clients and attempt to apply their therapeutic use of self to build positive client-therapist relationships in practice. The client-therapist relationship was an underlying component that shaped how the participants responded to therapy.

When they experienced negative relationships in the past, they stated that they did not feel as motivated to work with those therapists to achieve their goals. However, they reported that positive relationships encouraged them to work harder and meet their goals. This relationship could either support or hinder clients' progress in therapy. The results of the interviews for study can aid therapists in understanding clients' perspectives of positive and negative relationships and apply them to their own therapeutic relationships in practice.

Conducting more research can give clients the chance to participate in studies, which has shown to positively impact the lives of those who have been involved in research as participants. There is still a need for research regarding specific interventions for chronic stroke clients. Participants of this research study were very grateful for the opportunity to be involved and reported to have gained many benefits as a result of participation. Clinicians could conduct more research to meet the need for this knowledge and also to provide clients with the opportunity for therapy services as a part of research.

Whether implementing occupational therapy services in the field or as a researcher, therapists can use these results, their knowledge of effective interventions, resiliency of clients, and their own therapeutic use of self to increase hope and motivation in recovery. This study not only adds to the body of knowledge available for the physical effects of intervention, but provides personal perspectives of occupational therapy services.

Limitations

There are a few limitations of the research study. The participants were chosen by the investigators of the other study, potentially affecting the experiences revealed. The primary investigators from the COTI study were also present before and

after the interviews to aid in establishing rapport and the consenting process with the primary researcher of this study. In order to decrease the chances of biasing the results, the COTI researchers were not in the room during the interviews so that the clients did not alter their comments based on their presence. Also, two participants were interviewed in a clinical setting while the other two were interviewed in their homes. Since the clinical setting may not have been as comforting as the home setting, they may not have relayed as much information. To reduce the chances of this, they were still interviewed in private, quiet rooms in the facility.

All of the participants in the study were males, potentially affecting the results of the study. Also, the time lapse between the interviews and completion in the previous study varied for each participant, potentially affecting results. Some participants found it difficult to recall as much information because of the amount of time that had passed. However, the participants were screened for cognitive impairments before becoming involved in the previous study, decreasing the chances of having problems remembering the study. Finally, another limitation of the study was the small sample size. Having only four participants decreased the chances that saturation was achieved. While an essence of this experience was captured and all four men had many similar stories to tell, adding additional participants could add more depth to the findings.

Future Research

In order to address the limitations, another study could be conducted to further these results. Including more participants would increase the chances of achieving saturation among participants. Participants could also include women that had previously been involved in the COTI study to represent their experiences. Also, for studies similar to this, qualitative data could be collected during participation so that details are not forgotten or dismissed due to a time gap.

A need for future research was found while analyzing the results of the study. There is a lack of information regarding the experiences of those in the chronic stages of stroke who have participated in a research study. However, the results showed a large impact of this sort of involvement on the participants' lives. In addition to this study, further research could be performed to gain more of an understanding of the experiences of this population. This sort of research could affect how future clinicians conduct research and who they will recruit for those studies.

Conclusion

Four participants were interviewed to gain an understanding of the experience of those who have participated in upper extremity occupation-based or modified constraint-induced interventions as adults at least one year post stroke as a part of a research study. Their experiences led to the emergence of five themes and two subthemes. The themes included the participants' experiences with the study, highlighting their outcomes and perceptions of interventions based on the therapy they received. Emphasis for perceived outcomes were placed on the enhancement of everyday occupations (occupation-based intervention group), as well as physical improvements in the fingers and hand (MCIT group). Concepts of normalcy, resiliency, and the client therapist relationship were also evident throughout the themes, providing further support for previous research. Further support for client-centered interventions also resulted. Whether using occupation-based interventions or MCIT, his or her goals should be reflected in therapy. This, along with a positive client-therapist relationship can support progress in therapy and after discharge.

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APPENDIX A:

IRB Approval



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NOTICE OF IRB APPROVAL

Protocol Number: 15-247

Institutional Review Board IRB00002836, DHHS FWA00003332

Review Type: Full Expedited

Approval Type: New Extension of Time Revision Continuing Review

Principal Investigator: **Ariel Wilson**

Faculty Advisor: **Dr. Dana Howell**

Project Title: **The Experience of Adults with Chronic Stroke who have Participated in Occupation-Based or Modified Constraint Induced Interventions**

Approval Date: **5/7/2015**

Expiration Date: **5/1/16**

Approved by: **Dr. Jonathan Gore, IRB Member**

This document confirms that the Institutional Review Board (IRB) has approved the above referenced research project as outlined in the application submitted for IRB review with an immediate effective date.

Principal Investigator Responsibilities: It is the responsibility of the principal investigator to ensure

that all investigators and staff associated with this study meet the training requirements for conducting research involving human subjects, follow the approved protocol, use only the approved forms, keep appropriate research records, and comply with applicable University policies and state and federal regulations.

Consent Forms: All subjects must receive a copy of the consent form as approved with the ECU IRB approval stamp. Copies of the signed consent forms must be kept on file unless a waiver has been granted by the IRB.

Adverse Events: Any adverse or unexpected events that occur in conjunction with this study must be reported to the IRB within ten calendar days of the occurrence.

Research Records: Accurate and detailed research records must be maintained for a minimum of three years following the completion of the research and are subject to audit.

Changes to Approved Research Protocol: If changes to the approved research protocol become necessary, a description of those changes must be submitted for IRB review and approval prior to implementation. Some changes may be approved by expedited review while others may require full IRB review. Changes include, but are not limited to, those involving study personnel, consent forms, subjects, and procedures.

Annual IRB Continuing Review: This approval is valid through the expiration date noted above and is subject to continuing IRB review on an annual basis for as long as the study is active. It is the responsibility of the principal investigator to submit the annual continuing review request and receive approval prior to the anniversary date of the approval. Continuing reviews may be used to continue a project for up to three years from the original approval date, after which time a new application must be filed for IRB review and approval.

Final Report: Within 30 days from the expiration of the project, a final report must be filed with the IRB. A copy of the research results or an abstract from a resulting publication or presentation must be attached. If copies of significant new findings are provided to the research subjects, a copy must be also be provided to the IRB with the final report.

Other Provisions of Approval, if applicable: None

Please contact Sponsored Programs at 859-622-3636 or send email to tiffany.hamblin@eku.edu or lisa.royalty@eku.edu with questions about this approval or reporting requirements.

APPENDIX B:

Consent Form

Consent to Participate in a Research Study

The Experience of Adults with Chronic Stroke who have Participated in Occupation-Based or Modified Constraint Induced Intervention

Why am I being asked to participate in this research?

You are being invited to take part in a research study about experiences of those who have participated in upper extremity occupation-based or constraint-induced interventions as adults at least one year post stroke as a part of a research study. You are being invited to participate in this research study because you fit the inclusion criteria, which include being at least one year post stroke, have participated in the Occupation-Based vs. Modified Constraint-Induced Therapy research study at Cardinal Hill, and are able to expressively communicate. If you take part in this study, you will be one of about 4-7 people to do so.

Who is doing the study?

The person in charge of this study is Ariel Wilson at Eastern Kentucky University. She is being guided in this research by her professor, Dr. Dana Howell. There may be other people on the research team assisting at different times during the study.

What is the purpose of the study?

By doing this study, we hope to learn about the overall experience of completing the occupation-based or constraint-induced interventions in which you have participated.

Where is the study going to take place and how long will it last?

The research procedures will be conducted at a private, quiet location of your choosing, such as EKU's campus, the library, or your home. You will be there up to 3 times during the study. You will also be given the opportunity to review the transcripts from your interview(s), which will also take place at a private, quiet location of your choosing. The total amount of time you will be asked to volunteer for this study is up to 6 times over the next year (Interviews and Transcript reviews).

What will I be asked to do?

During the study, you will be asked to answer a set of questions. The questions include information detailing your participation in the study, your thoughts and feelings about the study, the effects of your stroke (acute and chronic), as well as your relationship with therapists involved in the study at Cardinal Hill and those you have worked with in your past. The interviews will be recorded for referencing during the research study.

Are there reasons why I should not take part in this study?

You should not participate in this study if you do not wish to be interviewed about your experiences with the OB vs. mCIT study at Cardinal Hill or if you ended your involvement in the previous study prematurely.

What are the possible risks and discomforts?

To the best of our knowledge, the things you will be doing have no more risk of harm than you would experience in everyday life. Although we have made every effort to minimize this, you may find some questions we ask you to be upsetting or stressful. If so, we can tell you about some people who may be able to help you with these feelings.

You may, however, experience a previously unknown risk or side effect.

Will I benefit from taking part in this study?

You will not get any personal benefit from taking part in this study other than the opportunity to speak about your experiences in the previous study and chronic stroke state.

Do I have to take part in this study?

If you decide to take part in the study, it should be because you really want to volunteer. You will not lose any benefits or rights you would normally have if you choose not to volunteer. You can stop at any time during the study and still keep the benefits and rights you had before volunteering.

If I don't take part in this study, are there other choices?

If you do not want to be in the study, there are no other choices except to not take part in the study.

What will it cost me to participate?

There are no costs associated with taking part in this study.

Will I receive any payment or rewards for taking part in the study?

You will not receive any payment or reward for taking part in this study.

Who will see the information I give?

Your information will be combined with information from other people taking part in the study. When we write up the study to share it with other researchers, we will write about this combined information. You will not be identified in these written materials.

We will make every effort to prevent anyone who is not on the research team from knowing that you gave us information, or what that information is. For example, your name will be kept separate from the information you give, and these two things will be stored in different places under lock and key.

However, there are some circumstances in which we may have to show your information to other people. For example, the law may require us to show your information to a court or to tell authorities if we believe you have abused a child or are a danger to yourself or someone else. Also, we may be required to show information that identifies you to people who need to be sure we have done the research correctly; these would be people from such organizations as Eastern Kentucky University.

Can my taking part in the study end early?

If you decide to take part in the study, you still have the right to decide at any time that you no longer want to participate. You will not be treated differently if you decide to stop taking part in the study.

The individuals conducting the study may need to end your participation in the study. They may do this if you are not able to follow the directions they give you, if they find that your being in the study is more risk than benefit to you, or if the agency approving the study decides to stop the study early for a variety of scientific reasons.

What happens if I get hurt or sick during the study?

If you believe you are hurt or if you get sick because of something that is done during the study, you should call Ariel Wilson at (859) 248-6668 immediately. It is important for you to understand that Eastern Kentucky University will not pay for the cost of any care or treatment that might be necessary because you get hurt or sick while taking part in this study. That cost will be your responsibility. Also, Eastern Kentucky University will not pay for any wages you may lose if you are harmed by this study.

Usually, medical costs that result from research-related harm cannot be included as regular medical costs. Therefore, the costs related to your child's care and treatment because of something that is done during the study will be your responsibility. You should ask your insurer if you have any questions about your insurer's willingness to pay under these circumstances.

What if I have questions?

Before you decide whether to accept this invitation to take part in the study, please ask any questions that might come to mind now. Later, if you have questions about the study, you can contact the investigator, Ariel Wilson at (859) 248-6668 or ariel_wilson93@eku.edu. If you have any questions about your rights as a research volunteer, contact the staff in the Division of Sponsored Programs at Eastern Kentucky University at 859-622-3636. We will give you a copy of this consent form to take with you.

What else do I need to know?

You will be told if any new information is learned which may affect your condition or influence your willingness to continue taking part in this study.

I have thoroughly read this document, understand its contents, have been given an opportunity to have my questions answered, and agree to participate in this research project.

Signature of person agreeing to take part in the study

Date

Printed name of person taking part in the study

Name of person providing information to subject



APPENDIX C:
Interview Questions

Interview Questions:

1. Can you tell me a little about what you like to do?
 - a. Interests
 - b. Hobbies
2. Can you tell me a little about your experience with your stroke?
 - a. How did it happen?
 - b. When did it happen?
 - c. What is your hand dominance?
3. How does your stroke affect your life now?
 - a. Daily routines, habits, interests, values, social life, family, work
4. What kind of therapy did you receive after your stroke?
 - a. Were you still receiving therapy at the same time as the study?
 - b. What did you do in those therapies?
 - c. What are your thoughts and/or feelings about them?
5. Tell me about the therapists you've had in the past.
 - a. How would you describe them?
 - b. How would you describe your interactions with them?
6. How did you become involved in this research study?
 - a. How did you hear about it?
7. What were some thoughts and/or feelings you experienced concerning the study before becoming involved?
 - a. What were your motivations?
 - b. Why did you want to become involved?
 - c. What did you imagine the study to be like?
8. What were some thoughts and/or feelings you encountered during the research study?
 - a. What were your goals during the study?
 - b. How difficult or easy was the therapy?
 - c. Was it like what you had imagined?

9. Can you tell me about your experience with the therapist researchers?
 - a. How would you describe your relationship with them? Why?
10. In your opinion, who decided what you did in the therapy session?
 - a. What happened in a typical session and how was that activity decided upon?
 - b. Who planned the activities in the sessions?
11. Describe your role in the therapy research study.
12. Can you tell me about your experience with the student researchers?
 - a. How would you describe your relationship with them? Why?
13. What was your favorite part of the research study?
 - a. Can you tell me a story of a good experience you had during the research?
14. What was your least favorite part of the research study?
 - a. Can you tell me a story of a bad experience you had during the study?
15. What did you find challenging about participating in the research study?
 - a. Describe a difficult experience you had while involved in the study?
16. What are some thoughts and/or feelings you now have about the study?
 - a. Do you feel positively or negatively towards your experience? Why?
 - b. Were you satisfied with your involvement?
17. How does the therapy in this study compare to therapy you have received in the past?
 - a. Can you talk about the goals you've had in the past?
 - b. Can you compare the activities you completed?
18. How has this research study affected your life, if at all?
 - a. Motivations, view of therapy, daily routines, social life, work, goals
19. Is there anything else you would like to add or comment on?

APPENDIX D:
Summary of Results

Theme	Description of Theme	Supporting Quotes
I would like to get back to my normal life	There are many physical and emotional effects of having a stroke. They limit participation in valuable occupations and hinder the ability to perform activities of daily living. It also restricts the fulfillment of roles, affecting relationships with friends, family, and spouses. A desire to achieve 'normalcy' in life is a concept that has driven participants to participate in therapy and other therapeutic activities. Even though there are still improvements to make, each person described the progress he has made so far. They are all striving to make gains despite daily frustrations.	<p>"I know what to do; I know how to do it, but things just don't work right."</p> <p>"Why am I putting this much effort into trying to just lift the thing, you know?"</p> <p>"Get back to my normal life."</p> <p>"No one ever said life was fair; it is what you make of it."</p>
"I'll take all the therapy I can get"	Each of the participants wished to receive more therapy, whether it is through outpatient services or as a part of a research study. Three out of the four had been involved in previous studies and had experienced positive outcomes from them. Even though there were various expectations before beginning the study, each man participated based on a desire for further progress in rehab, positive experiences	<p>"Something can happen that I can learn."</p> <p>"Wanting my hand to work so I could work."</p> <p>"I've gotten something out of every study I've been to."</p> <p>"Didn't know what particularly I was gonna do or work about."</p> <p>"If it doesn't help me, it might help somebody else in the future."</p> <p>"[I] still can't do as much as I'd</p>

	<p>with past studies, and/or the possibility of helping others in the process. Even after the study was completed, there were still obvious improvements that needed to be made, and so participants continued to want more therapy.</p>	<p>like to do.”</p>
<p>“This hospital got me working again.”</p>	<p>Experiences with rehabilitation services were detailed. Each participant had been involved in some sort of inpatient and/or outpatient services at the same facility, however there were a few other facilities at which some participants received further therapy. Service providers included occupational therapists, physical therapists, neurologists, and hand therapists. Specific interventions mentioned included ESTIM, stretching, balance bars, joint compressions, hand, arm, and leg exercises, and fine motor activities (such as pegboards). One participant spoke of his experiences with acupuncture and massage therapy. Perspectives on these interventions were mostly positive and a few were carried over to the home. However, one participant</p>	<p>“No pain, no game.” “[Rehab Facility] got me ready to go when it was time to go.”</p>

	stated that he did not feel that they were very individualized to his needs.	
“Got me thinking more about trying to use it [affected arm]”	All participants felt that they benefited from the study. They all made some sort of improvement or achieved a new skill as a result of participating in the study. All participants were more mentally aware of their affected extremity during activities. Those who participated in occupation-based interventions detailed their increased involvement of their affected extremities in activities. Those who participated in modified constraint-induced therapy detailed the improvement in dexterity that was made.	<p>“It helped more than any study that I’ve been through.”</p> <p>“[It] gave me more freedom.”</p> <p>“I got a lot of stuff out of it,”</p> <p>“[A] good thing to do.”</p> <p>“Made me try to work with this hand more.”</p> <p>“Letting you know that arm is still there; it’s useful.”</p> <p>“Got me moving my hand a little better than what I used to do.”</p>
A. Occupation-Based Interventions	The two participants that experienced occupation-based interventions described their goals in therapy and the type of sessions they went through. One participant recalled refurbishing a magazine rack as a part of therapy, while another spoke about practicing dressing skills. There was a sense of accomplishment from their responses. They enjoyed working on daily tasks and were able to improve a skill that they had wished to	<p>“Basic everyday things; that was my goal.”</p> <p>“That was a massive thing that she taught me.” (Putting on a jacket)</p> <p>“More hands on makes a difference; not just laying there.”</p> <p>“Ask[ed] me what I wanted to do.”</p> <p>“I had a lot of control in what I wanted to try and include.”</p>

	work on. These same participants described more of a sense of freedom in their ability to choose what to work on. A higher sense of control was described.	
B. Modified Constraint-Induced Therapy	The two participants that experienced modified constraint-induced therapy interventions did not recall specific goals, but they did detail physical improvements in their affected upper extremities. They spoke about stretches, a block and tackle activity, and a Velcro and rod activity. They both noticed an improvement in their affected arms/hands. One participant stated that he felt as though he had more control over his arm. They both look forward to more opportunities, such as this one. These participants described the therapists as having more control over the activities and/or how they were completed.	<p>"[I] never complained, but that was hard to do."</p> <p>"A little bit of what you can come up with and what you've learned."</p> <p>"Go across this room and would work on different things."</p> <p>"An hour that was an exciting part of the day for me."</p> <p>"She decided what we did."</p> <p>"I could do what I wanted to do and she showed me what she wanted."</p> <p>"I did whatever I was supposed to do."</p>
"The most uplifting therapy sessions I had, overall."	All four participants expressed a very positive experience with the therapists involved in the study. They all thought highly of their therapists and could not say enough about them. Reasons for their positive experiences	<p>"Extraordinary, helpful, encouraging, knowledgeable...upbeat, pleasant, happy go lucky, informative, and motivating."</p> <p>"Really nice people everyday...[it] made me feel</p>

	<p>involved the therapists' personalities and relationships with them. Therapists were described as being upbeat, knowledgeable, encouraging, motivating, hyper, extraordinary, and helpful. Experiences with previous therapists (before the research study) were also described. While most experiences were helpful, there were some negative incidents. The bad experiences with therapists involved their lack of interest in client recovery, sarcastic and non-constructive remarks, and not listening to the clients. Despite a few problematic sessions, none of the participants seemed to hold this against other therapists. One participant enjoyed all of his therapists so far because of their abilities to joke with him and their strong work ethics.</p>	<p>good around her.”</p> <p>“Having a relationship with me that was really nice...working with her made me feel good about everything they were doing.”</p> <p>“[Therapist name] is the best part of therapy I've ever had.”</p> <p>“[Go] at the problem whole haul.”</p> <p>“[We] worked on things together.”</p> <p>“Everyone tries their best.”</p>
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