2023

THE PERCEPTION OF STROKE ON IADL

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THE PERCEPTION OF STROKE ON IADL

Presented in Partial Fulfillment of the
Requirements for the Degree of
Doctor of Occupational Therapy

Eastern Kentucky University
College of Health Sciences
Department of Occupational Science and Occupational Therapy

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2023

Executive Summary

Background: Residents in a skilled nursing home receiving rehabilitative services following a stroke may value instrumental activity of daily living (IADL) tasks more than ADL tasks. This research investigates the impact of IADL tasks on quality of life (QoL)**.**

Purpose: The research questions were: How do individuals post-stroke and receiving occupational therapy services in a skilled nursing facility perceive their participation, or lack of participation, in IADL, and how does this impact their perceived QoL?

Theoretical Framework. The theoretical framework that guided this project was the Model of Human Occupation.

Methods. A phenomenological research-based qualitative approach designed to understand perceptions of stroke on QoL from lived experiences. Participants were recruited through convenient sampling, and interview questions and a Likert scale were employed.

Results. There were three themes: Doing things by myself, My level of confidence, and IADL tasks impact my QoL. This study revealed that participants found performance in IADL tasks meaningful despite having challenges with ADLs. They described how they valued doing things independently and would give their full effort to regain function. Some participants also demonstrated self-awareness on their limitations and plans for effective discharge. Finally, all the participants expressed how IADL tasks impact their QoL.

Conclusions: There was a positive connection between the performance of IADL tasks and QoL. Invariably, participants described a meaningful QoL with an increased chance of returning to IADL performance.

Acknowledgements

I want to acknowledge God almighty for the resilience to finish this project, my family for their support and encouragement, and my professors for their dedication to my success and the support to see me through it.

I want to appreciate the administration of the skilled nursing home where the research was conducted for their understanding and willingness to accept changes in providing optimal quality of care.

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CERTIFICATION OF AUTHORSHIP

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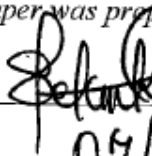
Student's Signature: 

Date of Submission: 04/02/23

Table of Contents

List of Tables

Section 1: Nature of Project and Problem Identification

Introduction

According to the Occupational Therapy Practice Framework (OTPF-4; American Occupational Therapy Association [AOTA], 2020), instrumental activities of daily living (IADL) "support daily life within the home and community" (p. 30). IADLs include homemaking, medication management, laundry, meal preparation, and social and emotional health promotion and maintenance (AOTA, 2020). Individuals living in the community rely on engagement in IADL for independence and quality of life. However, participation in IADLs may be significantly compromised following a stroke, particularly for individuals who are discharged to a skilled nursing facility (SNF) and can no longer engage in IADLs.

A stroke occurs when the blood supply to the brain is interrupted (National Institute of Neurological Disorders and Stroke, n.d.). This results in deficits such as loss of muscle movement, usually affecting one side (hemiparesis), decreased ability to engage in bilateral tasks, poor balance, impaired coordination, and impaired speech. These deficits impact IADL tasks. For example, someone who suffered a stroke might find it hard to iron clothes or make a sandwich. Individuals who are post-stroke and receive rehabilitative services in a SNF may seek to improve their independence and function to return home. Often though, rehabilitation services, including occupational therapy (OT), are primarily focused on basic activities of daily living (ADL) with little emphasis on IADLs. Basic ADLs, such as bathing, grooming, dressing, and safety with transfers, may be the focus of intervention. Clients may expect to receive more training with IADLs once they return home and begin home health or outpatient services.

Post-stroke patients receive skilled rehabilitation services that restore function, such as therapeutic exercises to strengthen the weak muscles and balance training to support the safe performance of various tasks. Other approaches to treating a stroke patient include adaptive and compensatory techniques where the clinician teaches the patient alternative ways of accomplishing functional goals. For example, the use of hemi-dressing techniques to dress (compensatory approach) or the use of button hooks to button a shirt (adaptive approach). Those engaged in IADLs may benefit from energy conservation and work simplification techniques to enable the clients to perform such tasks at an optimal and safe level. It is common practice in a SNF for OTs to base their treatment protocol solely on ADL performance with less emphasis on IADL (Ghaffari et al., 2021). This is mainly because the third-party payors often base the justification of continued skilled OT services on ADL metrics without considering IADL performance. In other words, when a client can dress, bathe, toilet, and complete bed mobility, then a discharge date is set. This is concerning as many of these clients have a desire to return home and may need to participate in IADL tasks to be successful at home. It is also concerning because a lack of participation in IADL while in a SNF may hurt the client's quality of life (QoL). According to the study conducted by Leach et al. (2011), "greater independence in IADL was strongly associated with better quality of life seven years post-stroke". Hartman-Maeir et al. (2007) revealed in their study that individuals who returned to the community after one year of suffering a stroke expressed dissatisfaction with their quality of life and felt a sense of activity limitation and restricted participation in life activities. Evidence from these finding highlight the importance of incorporating tasks during the rehabilitation process to enhance this population's meaningfulness and quality of life. When OTs in a SNF are not encouraged to assess IADL tasks during the initial evaluation, valuable information may be missed and consequently not

addressed during the treatment plan. This may result in restricted participation in meaningful activities and compromised QoL for patients that genuinely value IADL tasks.

Factors that Impact IADL after Stroke

A variety of factors may impact performance in IADLs following a stroke. For example, Blomgren et al. (2019) found evidence that cognitive deficits, depression, and fatigue worsened IADL performance after stroke. Ghaffari et al. (2020) revealed predictors for increased independence in IADL performance. Their study showed that depression and other crucial factors must be addressed to enable the desired outcome in the IADL performance. The study also revealed that motor function limitations did not significantly impact IADL task performance. Suchy et al. (2010) found that components of personality, including self-awareness, of older individuals living in the community may impact IADL performance and perception of task performance. Consequently, these factors may need to be assessed explicitly as part of the OT evaluation process.

Understanding IADL Performance after Stroke

It is crucial to better understand the perspectives of individuals who have had a stroke. Barello et al. (2016) explored patients' experiences following a stroke who engaged in therapeutic gardening. Five themes emerged from the exploratory qualitative study based on interviews and diaries of 22 participants: experience of nature, contact with nature resulted in a self-efficacy boost, therapeutic gardening provides a connection between the hospital and the outside world, therapeutic gardening serves as a self-expression space, and the plant was considered a catalyst for the patient-therapist relationship. In essence, patients who participated in therapeutic gardening felt it was a way to foster an active role in medical care, which allowed

for a positive attitude toward managing their impairments from the stroke (Barello et al., 2016). This study provides evidence to support the relevance of IADL tasks such as home and yard maintenance on QoL following stroke. Similarly, Murphy et al. (2019) revealed evidence that supports the idea that when IADLs are implemented during a group intervention for people with aphasia, the intervention resulted in desired outcomes, inclusion, and life participation at home and within the community, thereby impacting the participants' overall QoL. In addition, feedback obtained from those participants and their caregivers strengthens the idea of the relevance of IADLs. For example, they described a sense of well-being, meaningfulness, and valuing social participation with group members. The study provides evidence to support the benefit of IADL participation. These activities must be assessed to support positive outcomes among post-stroke clients for improved QoL. However, little qualitative research has been performed related to IADL following a stroke.

To explore the rate and degree to which physical activities are encouraged in nursing homes and the impact of these activities, Ouden et al. (2015) conducted a study involving seven different nursing homes and a total of 723 home residents. Results from their observation at various times of the day revealed that 45-77% of the residents' time was directed towards sedentary tasks (sleeping, watching TV, idleness), followed by ADL participation (15-38%), mobility-related activities (10-19%), eating and drinking (2-17%), and finally, IADL activities constituted up to 3% of their time. In addition, 89-92% of the residents were observed to be lying or sitting. Inactivity adversely affected their quality of life, physical fitness, and activity performance (Ouden et al., 2015). Furthermore, evidence from multiple literature sources demonstrates that those physical activities support overall wellness and mental/physical health. Results from this study can educate therapists to incorporate more meaningful IADL tasks during

rehabilitation; it can also create awareness and encourage the management and leadership team within nursing homes to address the need for increased physical activities among nursing residents.

Problem Statement

Even though IADL is essential to the quality of life, post-stroke individuals often do not receive this treatment while in SNF, which can impact their perceptions of life and their abilities once they return home. More qualitative research is needed to understand the perspectives of residents in SNFs, who have experienced stroke and are receiving OT services, regarding IADLs.

Purpose of the Project

Therefore, this project aims to describe how post-stroke individuals receiving OT services in a SNF perceive IADL and how the lack of performance of such activities impacts their QoL.

Research Questions

This capstone seeks to answer the question: How do individuals post-stroke and receiving OT services in a SNF perceive their engagement, or lack of engagement, in IADLs, and how does this impact their perceived QoL?

Sub-research questions include:

- How do the clients perceive the meaning of IADL engagement?
- What IADL patterns, habits, and routines are impacted while in SNF?
- Are the post-stroke patients motivated and interested in engaging in IADL while in the SNF & upon returning home?
- How do the clients perceive that their QoL has been impacted by engagement in, or lack of, in IADL?

Theoretical Framework

This capstone is based on the Model of Human Occupation (Tayler, 2017), which explores components of the individual that influences and shapes their choice of meaningful activities, including motivation, personal causation, interest, and values. The MOHO encapsulates three interrelated components: Person factors (Volitional Subsystem: Personal Causation, Values, Interest), Habituation (Habits and Roles), and Mind-Brain-Body (Musculoskeletal, Neurological, and Cardiopulmonary). When a person's habits and roles are disrupted and they can no longer perform IADL, this may impact their performance capacity and volition. The MOHO model guided the research questions to enable an understanding of perceptions and meaningfulness. The model provides a platform to understand how routines, interests, and roles are integral to a person and factors that may allow or hinder participation in meaningful IADL activities.

Significance of the Study

Frequently, insurance companies deny payment for continuous skilled OT services by issuing a notice of Medicare non-coverage (NOMNC). The primary justification for skilled services is based on ADL outcomes. The third-party payers cut patients from skilled services once the clients achieve reasonable ADL outcomes. Consequently, there needs to be more regard for IADL tasks and the implication of deficits in these areas. This capstone will demonstrate the importance of IADL tasks, especially for clients expected to return to the community. In addition, this capstone will reveal how IADL impacts QoL and minimizes the risk of other health implications, such as depression. Finally, this capstone will provide needed data to justify the inclusion of IADL as measuring outcomes for patients returning home for continued skilled services, which will provide a sense of the importance of IADL to OT clinicians.

The value of this project will help reveal to third payers the relevance of IADL tasks, which can then be prioritized and considered in addition to ADLs in justifying continued OT services. Evidence from research supports activities other than ADLs that impact QoL. Sveen et al. (2004) supported the notion that leisure activities present a paramount and positive correlation to subjective well-being based on the outcomes of their research. They further encouraged clinicians that leisure activities must not be undermined during stroke rehabilitation's evaluation and intervention phases. This provides valuable considerations during the treatment of post-stroke clients among clinicians. In addition, the management staff of the SNF will also value the benefits of IADLs and perhaps other activities that were not considered initially and encourage the clinicians to incorporate them during the intervention process. Furthermore, with the support from management staff, clinicians will thoroughly assess individuals who have suffered a stroke to obtain further data that drives client-centered interventions.

Operational Definitions

Instrumental Activities of Daily Living: Activities that support daily life within the home and community (AOTA, 2020)

Quality of life: Quality of life is an "individual's perception of their position in life in the context of the culture and value systems in which they live and concerning their goals, expectations, standards, and concerns" (World Health Organization, 1998)

Summary of Section 1

Individuals who have suffered a stroke and are living in a SNF with plans to return home may consider IADL tasks meaningful. They may find that reducing participation in IADL tasks negatively impacts their QoL. Consequently, this capstone project aims to understand better how patients who are post-stroke and receiving OT services in a SNF perceive IADL and how the

lack of performance of such activities impacts their QoL. The capstone is based on MOHO and will be significant in helping to justify clinicians, administrators, and third-party payors to provide IADL services in the SNF to stroke survivors. The following section will be a detailed literature review.

Section 2: Detailed Review of the Literature

The following literature review explores the benefit of incorporating IADL tasks or the implication of the lack of IADL activities during stroke rehabilitation within a SNF. In addition, it provides evidence of the types of outcomes resulting from IADL participation in a SNF and within the community. There needs to be more research evidence that provides valuable insight into the degree and impact of IADL participation with post-stroke patients in SNF. Consequently, this literature review investigates current evidence to obtain meaningful insights into how IADL participation impacts QoL post-stroke.

Participation in IADL and Quality of Life after Stroke

Following a stroke, patients suffer losses that impact their abilities to engage in meaningful tasks, including IADL tasks. Evidence shows that stroke negatively impacts QoL and occupational performance (Haan et al., 1995). Leach et al. (2011) found that individuals seven years post-stroke who had greater independence in IADL reported better QoL compared to those with less independence in IADL tasks. Mayo et al. (2002) espoused that many people post-stroke reported a lack of participation in meaningful activities, particularly higher-level activities of daily living such as homemaking and shopping. They went on to say that boredom from lack of participation may result in further decline in function, health, and QoL.

Blomgren et al. (2019) revealed in their study of the long-term performance of IADL in young and middle-aged stroke survivors the impact of cognitive dysfunction, emotional problems, and fatigue among 296 stroke survivors seven years after stroke with a median age of 64 (18-69) from the hospital stroke unit in Sahlgrenska University. The results showed that cognitive dysfunction, fatigue, and emotional problems impacted long-term IADL performance. However, the impact was higher for more complex activities and participants with more

neurological deficits. Results revealed that cognitive impairment, post-stroke depression, and fatigue have been potentially undiagnosed and under-treated. Results also showed an association between depression and fatigue in IADL in chronic stroke. Emotional problems and depression are other themes that emerged as impacting IADL performance. This research presents evidence of other factors that may be missed during treatment as patients are discharged home. Consequently, these factors must be assessed explicitly as part of the evaluation process to monitor outcomes for effective discharge.

IADL for Stroke Survivors in the Community

Rehabilitation for individuals with stroke in skilled nursing facilities often does not address IADL performance; however, the individual may seek to return to the community and will need to perform IADLs. Guo et al. (2021) conducted a systematic review of qualitative studies focused on community-dwelling stroke survivors to determine if they felt their needs had been met in rehabilitation. Their study revealed unmet needs with disease information, physical recovery participation needs, social and environmental resources, and psycho-emotional needs. Individuals expressed a desire to participate in all activities, including IADL, but were not always able to do so. Outcomes from the study revealed a gap between rehabilitation outcomes and QoL.

To support the importance of IADL participation among community dwellers who suffered a stroke, Orellano et al. (2012) conducted a systematic review to determine the value of occupation and activity-based activities. Their study showed a strong correlation between carefully planned interventions and IADL participation. In other words, client-centered and occupation-based interventions significantly increased the chances of IADL participation among community-dwelling older adults (Orellano et al., 2012). Concurring with this evidence, Hunter

and Kearney (2018) presented the effectiveness of tailoring interventions to each client's scenario to improve IADL outcomes. Evidence revealed the benefit of customized home-based care programs in improving IADL outcomes among this population. Furthermore, evidence supports how tailored home-based preventive sessions can restore functional capacity and increase satisfaction with task performance (Hunter & Kearney, 2018).

Factors that Influence IADL Performance

Until clinicians thoroughly assess personal factors and consciously incorporate IADL tasks during the intervention, the QoL may be compromised for some individuals who suffer a stroke. To assess predictors of IADL performance in patients with stroke, Ghaffari et al. (2020) explored cognitive, psychological, and motor skills and contextual factors that impacted IADL performance. A cross-sectional study recruited ninety participants between 30 and 80 years through a convenience sample. The results from 82 participants were analyzed and revealed that successful BADL performance correlated with IADL performance. Age revealed a negative correlation with IADL performance. Older participants with stroke experienced more limitations in IADL performance. This supports research by Haan et al. (1995) on the significance of age as a factor impacting IADL function. Depression was another predictive factor for IADL performance, with greater depression severity resulting in less independence with IADLs (Ghaffari et al., 2020). However, the authors argued that motor function did not predict IADL performance. Ghaffari et al. (2020) found that depression and other crucial factors must be addressed to enable the desired outcome in the performance of IADLs.

IADL Assessment Tools

Jaywant et al. (2021) introduced a weekly calendar planning activity to capture functional performance deficits in stroke patients relative to healthy adults of similar age groups. The study

aimed to determine whether the Weekly Calendar Planning Activity (WCPA-10) would identify Cognitive-ADL (C-IADL) limitations in stroke patients with intact cognition. The WCPA-10 is an objective of C-IADL performance and requires the examinee to input a series of appointments in a mock weekly calendar while adhering to specific guidelines. The WCPA-10 identified C-IADL deficits and worse cognitive strategies used with participants who scored within the normal range. In addition, the study reveals the effectiveness of using only one screening tool during an assessment that may undermine the deficits and limitations with post-stroke patients. The study provides further insight into exploring various assessments to capture data that can target desired intervention outcomes comprehensively.

Outcomes of Interventions of IADL Tasks

Following a thorough assessment of the client's values, interests, and IADL activities that impact QoL, interventions are designed to address findings from evaluation data. Interventions tailored toward client-specific needs usually result in desired outcomes. In their study, Chatterton et al. (2008) aimed to investigate the effect of an individualized observation program of the meaningful activities of a 44 y/o male who was 12 months post-stroke. Impairment was measured by the Scandinavian Stroke Scale (SSS) fluidity scale, Time Up and Go (TUG), Post - Authorization safety study (PASS), and Stroke-Specific QoL scale. In addition, interviews were conducted at home for one hour to determine pre-stroke meaningful tasks. PETTLEP model, which identifies behavioral factors (physical environment, tasks, learning, timing, emotion, and perspective) was used to guide the observation. Consequently, the interview questions were based on this model and developed into film storyboards/DVDs. The results revealed that an intervention strategy was effective in stroke rehabilitation, especially in integrating meaningful

support systems for the patients. This unique research based on personal action observation suggests a meaningful intervention that may impact the QoL of post-stroke patients.

Similarly, Wolf et al. (2015) argued that occupation-based intervention improves areas of occupation after stroke. In their evidence-based review based on thirty-nine studies that were critically evaluated (26 level 1, 4 level II, and 9 Level III), they determined the evidence for the effectiveness of activity and occupation-based interventions to improve areas of occupation post-stroke. Articles were clustered into five areas of occupation (ADLs, IADLs, Leisure, Social participation, Rest & Sleep). Of the total of 39 articles, 21 articles addressed ADL performance. Evidence that supports IADL tasks was much disparate compared to ADL activities, as there was limited literature on IADL performance and the impact on QOL following stroke. This further makes it imperative to study the impact of stroke on IADL and how it impacts QoL.

Model of Human Occupation

Occupational practice models provide a platform to thoroughly assess clients based on their specific preferences, needs, values, and meaningfulness, with the intent for clinicians to provide client-centered interventions for positive outcomes (AOTA, 2020). Shinohara (2012) suggested that the Model of Human Occupation (MOHO), when utilized as a platform for intervention, significantly improved QoL and ADL scores. Based on their study, thirty-six participants were randomly assigned to an experimental or a control group. The ADL and QoL values were obtained before and after a 12-week OT intervention. The experimental group (participants who received MOHO-based OT) significantly improved ADL and QoL scores compared to the control group. In addition, the experimental group improved five domains of QoL: physical functioning, social functioning, bodily pain, physical role, and general health perception. The evidence showed the significance of an occupation-based model in impacting the QoL of post-

stroke patients. The findings help structure this capstone project to determine factors that impact post-stroke patients' perceptions of QoL.

Summary of Section 2

This capstone project is focused on revealing tasks beyond basic ADLs that impact post-stroke quality. A common theme that stands out from most of the research articles currently in the literature is that IADL task performance is considered a valuable and meaningful task post-stroke. Individuals who have suffered a stroke consider tasks, particularly social participation, meaningful in impacting their quality of life. Other important themes that emerged include the deficits that impact occupational performance post-stroke. This was interesting because these deficits differ from those considered by the student researcher before conducing this study. The common deficits identified include fatigue, depression, and cognitive factors. Moreover, and more importantly, a theme revealed that these diagnoses might be underdiagnosed and, therefore, under-treated. Consequently, utilizing OT practice models might effectively capture data during the evaluation process, providing a platform to achieve desired outcomes post-stroke.

Section 3: Methods

Project Design

A qualitative descriptive approach helps a researcher to obtain lived experiences of a phenomenon being studied (Doyle et al., 2020). This study focuses on explaining the lived experiences of patients after a stroke and determining the value of participation in IADL tasks and their impact on their QoL. The study was approved by the University's Institutional Review Board (IRB). See Appendix A.

Setting

This research focuses on post-stroke patients in a SNF who anticipate returning home and to the community. The SNF has a total of 45 beds, offering both long-term and short-term stays. The SNF offers various services, including rehabilitation, catering, transportation to medical appointments, and social events and activities. This SNF was selected because the primary researcher is a rehabilitation director and occupational therapist within the setting. Additionally, it is a setting where ADL activities are overemphasized, and IADL tasks are undermined.

Inclusion Criteria

To be included in the study, participants must have met the following criteria:

- Be between the ages of 45-95
- Have suffered a stroke in the past five years
- Speak and understand English
- Be planning to return to the community
- Be cognitively intact and able to provide their consent to participate
- Be a patient in this particular SNF

Exclusion Criteria

Participants were excluded if they:

- Have significant cognitive impairment; participants need to be cognitively intact to describe their experience and the impact of IADL participation or lack of impact on their OoL
- Have Global Aphasia; participants need to have the ability to understand and express themselves in a comprehensible manner without the researcher inferring
- Are long-term care residents; long-term care patients do not generally perform IADL tasks like those returning to the community

Recruitment

Participants were recruited through purposeful sampling. According to Doyle et al. (2000), purposeful sampling targets the desired research audience participants. Participants who were known to the researcher, were currently receiving skilled OT services, and who met the inclusion criteria were approached by the researcher. Participants were assured that refusal to participate would not jeopardize current and future therapy services. The following is the verbal script that was used to recruit participants.

"*I am researching how you feel about your participation, or lack of participation, in tasks other than self-care, such as laundry and making the bed. I am interested to know how this impacts your quality of life and your plans to return home. I would like you to be part of this research*."

Five to seven participants were sought, and recruitment was planned to stop when a maximum of seven participated or when data saturation was reached.

Data Collection

Data were collected by interviewing the clients one-on-one and audio-recording responses for an average of 30 minutes but no more than 45 minutes. Doyle et al. (2000) maintained that face-face interviews are the most popular medium for data. However, the authors added that open-ended responses provide a rich data source in qualitative descriptive research.

Upon consent and willingness to participate, participants were interviewed individually in a private area within the SNF's premises. A semi-structured interview guide was used. A Likert Scale was also used for some questions to minimize fatigue from excessive talking and to provide opportunities for participants with expressive aphasia.

Examples of Prompted Questions and Likert Scale

1. What activities other than self-care tasks were important to you before your stroke and are still important to you after you suffered a stroke?
2. How do you value engagement in activities such as laundry, making a meal, and housekeeping tasks after suffering from a stroke?
3. Can you list three top-priority IADL tasks? (Researcher will explain the examples of IADL tasks).
4. How do these activities listed in question "3" above impact your quality of life?

Select the best appropriate response to the prompt based on the Likert scale. (Strongly agree, agree, neither agree, disagree, strongly disagree).

1. "IADL is considered valuable regardless of my difficulties with self-care tasks."
2. "I am confident in my ability to engage in IADL tasks upon return home."
3. "I would engage in IADL tasks when I return home."
4. "Performing IADL tasks are meaningful despite difficulties I may have to perform them."

Trustworthiness

According to Stahl and King (2023), trustworthiness in qualitative research is subjective, yet it is a constructive measurement of interpretations from research data. One method that strengthens this research's trustworthiness includes triangulation. Stahl and King (2023) suggested that triangulation allows multiple sources to verify and establish themes. Consequently, the research utilized triangulation of the audio recording and data from transcripts to verify the information received. Data was also triangulated with the literature.

The researcher implemented other trustworthiness strategies, including journaling, where the researcher kept a journal record of biases. The researcher also maintained an audit trail that shows how data was analyzed; expert review by the research supervisor; and finally, member check where the researcher revisited the participants with emerging themes to determine if the interpretation was consistent with shared facts. According to Stahl and King (2023), member checking is often considered a productive practice in research.

Data Analysis

The data in this study was analyzed using descriptive qualitative analysis methods as described by Sandelowski (2000) and Doyle et al. (2020). The Likert scale data was placed in a descriptive table. The interview data was transcribed verbatim and coded using both *a priori* (pre-determined) codes and emergent, *in vivo* codes. Sandelowski (2000) suggested that in a qualitative study, a researcher may start with pre-existing codes before carrying out the research; however, these codes are subject to changes during analysis and are sometimes completely deleted. During this study, preexisting codes based on the research question were developed such as “impact of IADL on QoL.” Other codes were generated by using the words of

the participants as the transcripts were coded. Following data coding, codes were grouped into similar categories and examined until themes emerged.

Ethical Considerations

Ethical considerations included obtaining verbal consent from participants while ensuring they did not feel coerced and conveying that a refusal would not jeopardize their therapy services now or in the future. Another ethical concern was conducting research in the primary investigator's work setting. However, participants were assured that participation was voluntary and could be withdrawn at any time, and that there would be no negative impacts of declining to participate in this study.

Timeline of Project Procedures

The IRB approval for this study was obtained in early Spring 2023. Data collection and analysis also occurred in Spring 2023. The written capstone report was finalized and presented in Summer 2023.

Section 4: Results and Discussion

Results

Results from the study are presented in the sections that follow. Participants will be briefly described and results from the Likert scale data and interview data will be described in detail. There were 5 participants who participated in this study. The following is their demographic information below (see Table 1). All participants were women.

Table 1. Participant Demographics

Participant Initials	Age	Race	Length of time in facility at time of interview
LN	83	African American	3 weeks
WB	76	African American	4 weeks (in and out)
SS	70	Caucasian	6 weeks
MX	81	Hispanic	2 weeks
CG	74	Caucasian	4 weeks

The participants were asked to answer questions about the value and meaning of IADL participation as well as their confidence for completing these tasks using a Likert scale. See Table 2 for their responses.

Table 2. Participants' Likert Responses

Participants	"IADL is considered valuable regardless of my difficulties with self-care tasks."	"I am confident in my ability to engage in IADL tasks upon return home."	"I would engage in IADL tasks when I return home."	"Performing IADL tasks are meaningful despite difficulties I may have to perform them."

LN	Strongly agree	Disagree	Strongly agree	Strongly agree
WB	Strongly agree	Strongly disagree	Strongly agree	Strongly agree
SS	Strongly agree	Strongly disagree	Strongly agree	Strongly agree
MX	Strongly agree	Neither agree nor disagree	Strongly agree	Strongly agree
CG	Strongly agree	Disagree	Strongly agree	Strongly agree

The participants noted IADL activities that they enjoyed prior to their stroke (see Table 3). Even with cuing, participants had difficulty focusing in only on IADL tasks, but they were able to each identify multiple valued IADL occupations they engaged in before experiencing a stroke.

Table 3. IADL Activities Enjoyed Prior to Stroke

LN	Grocery shopping, house duties, cooking
WB	Grocery shopping, religious participation, light meal prep
SS	Puttering, online shopping, laundry
MX	Outdoor activities, planting/gardening
CG	Make up, shopping for cosmetics, dining out with husband, light cleaning

There were three themes that emerged from analysis of the interview transcripts that represent participants' perceptions about IADL participation post-stroke (see Table 4). Each theme will be described in the pages that follow with direct quotes for support.

Table 4. Themes and Subthemes

Themes	**Subthemes**
Doing things by myself	• Not wanting to disturb others • Sense of independence • Unique ways of doing things

	• Desire to be back to prior functioning and return home
My level of confidence	• Self-awareness of current status • Consideration of effective discharge plans
IADL tasks impact my quality of life	• Sense of identity • Sense of space • Sense of control • Sense of purpose

Doing Things by Myself

Participants described a sense of independence and a desire to do things independently without relying on others. They described various reasons for not wanting to depend on others, including not wanting to disturb others, a strong sense of independence, guilt, and a unique way of doing things. For example, SS reported: “I do not like to depend on others. I do not like to bother people; everybody is busy with their own lives.” TM felt that he had a unique way of doing things, saying: “No one can do it like you want it, so I would do things myself than have others do them.” LN stated: “Everybody is busy; I feel guilty asking my family.” When WB was asked why she does not like asking others, she responded: “Everyone has families of their own, they have their work, and I do not want them to feel guilty if they cannot help. So, I am trying to do my best for myself.” MX differed, saying: "It is okay, I do not mind help. I guess if they are okay to help. My daughter used to help me sometimes."

The participants shared a sense of commitment and determination towards their goals to return to their prior level of function. For example, when asked how confident they were about doing the things they value once they return home, LL expressed the desire to return to a prior level of function and willingness to give it all it takes. LL reported: "I have been trying to do my best, even on my own so that I can go home quickly." In some instances, the ability to give their all also stemmed from a desire to increase the chances of returning to their homes and not to

depend on others. SS understood that circumstances at home would require some demands which she must meet. TM said: " I have to be better to do well at home," reflecting on his desire to give it his all.

My Level of Confidence

Participants had a sense of awareness of their current deficits and understood the limitations and the need for their efforts to drive toward their prior level of function status. SS explained: "I wish I could do it, but now I cannot." TM: "I hope to do it when I get home, but now, I cannot." LN expressed: "No, I cannot do it. I am working hard so I do not have to depend on others when I get home." WB had a good level of confidence, saying: "I am weak now, but confident I can do it; I have done it all these years." MX said: "Not sure, I guess I cannot."

Three of the participants appeared to be confident about their goal attainment upon discharge. SS stated: “I will give it my best shot, I have a mother to return to who is 91 years old and won’t be able to help me.” On the other hand, after some consideration of an effective discharge plan in the event they could not return to their prior level of functioning, they seemed to consider alternative and feasible plans; namely help from others. TM said: “My husband helps out when he can. I guess he can help until I get better.” LN said: “My son lives not too far and may help me to some extent; I’d hate to bother him. I also have a caregiver who use to come four hours every day, she can help more if I can’t do these things.” MX stated: “My daughter will help me as much as I need.”

IADL Tasks Impact My Quality of Life

Another theme that emerged was that participation in IADL tasks (or the inability to perform IADLs independently) had a strong impact on their QoL, including self-identity. For example, TM reported: "The way I look and present myself is my identity; when I lose the

ability, it hurts.” Participation in IADL impacted their sense of purpose, space, and control. SS described participation in IADL this way: "My time is spent on little things you may not quantify, but it gives me immense joy to stay engaged in bits of things to occupy my time." LL said: "I enjoy doing these activities with my spouse, sometimes alone. It gives me control of my space." WB described participation in religion as an IADL: "A deeper spiritual connection is my lifeline; I love engaging in religious programs in person or the media. I cannot read anymore due to my cataract, so I often listen."

Discussion

This study found that persons who have suffered a stroke and are returning to the community highly valued IADL tasks despite their difficulties in performing ADL tasks. The participants became emotional when discussing the value of these tasks and the desire to maintain independence in meaningful tasks. The findings support that participants understand their limitations and current inabilities to engage in these tasks, demonstrating some confidence to regain function. Interestingly, the participants expressed joy and meaning when talking about their IADL tasks compared to ADL tasks. This supports existing literature that IADL relevance may have needed to be addressed. Guo et al. (2021) conducted a systematic review of qualitative studies focused on community-dwelling stroke survivors to determine if they felt their needs had been met in rehabilitation. Their study revealed unmet needs with disease information, physical recovery participation needs, social and environmental resources, and psycho-emotional needs. Individuals desired to participate in all activities, including IADL but were only sometimes able to do so. Outcomes from that study revealed a gap between rehabilitation and QoL. Likewise in this study, participants valued IADL participation but this was not a primary focus of their rehabilitation following stroke.

Tailoring intervention to include a focus on IADL may be warranted given the participants' desire to engage in these types of occupations. Other studies have revealed the importance and relevance of IADL participation for community dwellers. Orellano et al.'s (2012) systematic review showed a strong correlation between carefully planned interventions and IADL participation. In other words, client-centered and occupation-based interventions significantly increased the chances of IADL participation among community-dwelling older adults (Orellano et al., 2012). Hunter and Kearney (2018) presented the effectiveness of tailoring interventions to each client's scenarios to improve IADL outcomes. In their study on what interventions enhance IADL participation among community-dwelling adults, evidence revealed the benefit of customized home-based care programs in improving IADL outcomes. Furthermore, evidence supports how tailored home-based preventive sessions can restore functional capacity and increase satisfaction with task performance (Hunter & Kearney, 2018).

Theoretical Framework

This capstone was based on the Model of Human Occupation (Taylor, 2017), which explores components of the individual that influences and shapes their choice of meaningful activities, including motivation, personal causation, interest, and values. The results revealed how the participants' volitional subsystem affected their choices and desire to return to prior level of function. Evidently, most participants valued their independence and had specific interests that motivated them to return to their prior level of function status. It appeared their personal causation was driven by these values and interests. Results also revealed that the model's habituation system influenced their motivation and desire for meaningful IADL tasks. Some participants expressed habits and routines which influenced them to give it their all to regain their function. Another participant describes how her routine influences her choice in

desired IADL tasks. The MOHO provides a platform to understand how routines, interests, and roles are integral to a person and factors that may allow or hinder participation in meaningful IADL activities.

Relevance

This study is relevant to determine the need for a thorough evaluation process to fully understand the tasks meaningful to the patient rather than a theoretical assumption of tasks deemed necessary by the therapist. In their study on the long-term performance of IADL in young and middle age stroke survivors, Blomgren et al. (2019) revealed that cognitive dysfunction, fatigue, and emotional problems impacted long-term IADL performance. Further results revealed that cognitive impairment, post-stroke depression, and fatigue have been potentially undiagnosed and under-treated. Results also showed an association between depression and fatigue in IADL in chronic stroke. Emotional problems and depression are other themes that emerged as impacting IADL performance. This research presents evidence of other factors that may be missed during treatment as the patients are discharged home. Consequently, these factors must be assessed explicitly in the evaluation process to monitor outcomes for effective discharge.

A thorough evaluation process increases the chances of an effective client-centered intervention. This would improve the QoL of patients returning home after a stroke. Wolf et al. (2015) argued that occupation-based intervention improves areas of occupation and after stroke. In their evidence-based review based on thirty-nine critically evaluated studies (26 Level 1, 4 Level II, and 9 Level III), they determined the evidence for the effectiveness of activity and occupation-based interventions to improve areas of occupation post-stroke. Articles were clustered into five areas of occupation (ADLs, IADLs, Leisure, Social participation, Rest &

Sleep). Of the total of 39 articles, 21 articles addressed ADL performance. Evidence that supports IADL tasks was much disparate compared to ADL activities. In other words, there was limited literature on IADL performance and the impact on QOL following stroke. This further makes it imperative to study the impact of stroke on IADL and how it impacts QoL.

Limitations

The size of this study was small in size and may need more generality. While the intent of qualitative research is not to generalize to broader populations, more participants would have increased the diversity of perspectives represented in the results. In addition, most of the participants in the group did not have a severe residual weakness. This increased their confidence to return to the prior level of function of IADL tasks, with the assurance that they can manage their ADLs. However, further research is needed with a broader range of patients with different levels of severity of deficits to understand if there is a correlation between deficits' severity level and the value placed on IADL. Finally, all participants were women. It would have been helpful to hear male perspectives.

Conclusion

This study highlighted the impact of IADL participation among five participants following a stroke despite consideration of ADL restriction. Three main themes emerged: Doing things by myself; My level of confidence; and IADL impact my QoL. Implications for health care providers, particularly occupational therapist working this setting, management staff, and third party, were discussed to address significant activities that impact QoL of these residents on what is deemed meaningful.

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Appendix A: IRB Approval

EKU
SPONSORED PROGRAMS

Hello Olufunmi Buari,

Congratulations! Using a limited review process, the Institutional Review Board at Eastern Kentucky University (FWA00003332) has approved your request for an exemption determination for your study entitled, "Perception of stroke on IADL" This status is effective immediately and is valid for a period of three years as long as no changes are made to the study as outlined in your limited review application. If your study will continue beyond three years, you are required to reapply for exemption and receive approval from the IRB prior to continuing the study.

As the principal investigator for this study, it is your responsibility to ensure that all investigators and staff associated with this study meet the training requirements for conducting research involving human subjects and comply with applicable University policies and state and federal regulations. Please read through the remainder of this notification for specific details on these requirements.

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

Changes to Approved Research Protocol: If changes to the approved research protocol become necessary, a Protocol Revision Request must be submitted for IRB review, and approval must be granted prior to the implementation of changes. If the proposed changes result in a change in your project's exempt status, you will be required to submit an application for expedited or full review and receive approval from the IRB prior to implementing changes to the study. Changes include, but are not limited to, those involving study personnel, subjects, recruitment materials and procedures, and data collection instruments and procedures.

Registration at ClinicalTrials.gov: If your study is classified as a clinical trial, you may be required by the terms of an externally-sponsored award to register it at ClinicalTrials.gov. In addition, some medical journals require registration as a condition for publication. In the case of journals with membership in the International Committee of Medical Journal Editors, clinical trials must be registered prior to enrolling subjects. It is important that investigators understand the requirements for specific journals in which they intend to publish. In the case of sponsored project awards, timeline requirements will vary for awards that require registration. Approved consent forms must be uploaded in the system for all Federally-funded clinical trials after subject enrollment has closed, but earlier registration is not required for all agencies. If you have questions about whether a sponsored project award requires registration and on what timeline, please send an email to tiffany.hamblin@eku.edu before beginning recruitment so that the specific terms of the award can be reviewed. If you have a need to register your study and do not have an account in the system, please send an email to lisa.royalty@eku.edu and request to have a user account created.