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The Lived Experience of Informal Caregivers of Chronic Stroke Patients

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The Lived Experience of Informal Caregivers of Chronic Stroke Patients

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Bachelor of Science
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Submitted to the Faculty of the Graduate School of
Eastern Kentucky University
in partial fulfillment of the requirements
for the degree of
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DEDICATION

This thesis is dedicated to my late grandfather,

Roy Lee Wigginton,

who inspired my interest

in the occupational therapy profession.

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Dr. Camille Skubik-Peplaski
Dr. Dana Howell
Dr. Renee Causey-Upton
Dr. Melba Custer

ABSTRACT

The purpose of this phenomenological study is to contribute to the literature surrounding stroke-survivor caregivers and to understand the caregivers' perspective on leisure participation and quality of life. Four caregivers of clients with chronic stroke were recruited for the study via convenience sampling. Participants were audio-recorded during a semi-structured interview lasting 60-80 minutes. The interview guide was consistent across participants and included open-ended questions about the caregiver's leisure participation and quality of life. Recorded data was transcribed and in-vivo coding was completed. Eight categories were developed from the identified codes and narrowed into primary meaning units: role shift, loss of control, and occupational deprivation, consistent with Moustakas (1994) as adapted by Creswell (2013). Understanding the essense of the lived experience of caregivers is important to the occupational therapy profession because of the prevalence of caregiver-burden and the impact such role-transition has on their occupational participation and that of the client.

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CHAPTER 1

INTRODUCTION

Stroke impacts approximately 795,000 people annually (American Heart Association [AHA], 2010). With the evolution of modern medicine, more effective treatment options have emerged and been implemented. This has resulted in a 21% decrease in the number of stroke deaths over the past 10 years (AHA, 2014). Stroke is a serious medical condition that proves to be a traumatic, life-altering event that typically impacts the individual with permanent disabilities (Pierce, Thompson, Govoni, & Steiner, 2012). These circumstances result in stroke being the leading cause of disability in the United States (AHA, 2014). In addition to the primary impact on the patient, stroke also impacts those people that are close to them, including friends and relatives (Pierce et al., 2012). In fact, the majority of stroke patients return to home settings, requiring assistance in daily activities that was not needed prior to the stroke (AHA, 2007). For those caring for stroke survivors, this often leads to emotional distress and burden as exhibited by disruption of employment, leisure, social participation, and quality of life (Greenwood, Mackenzie, Cloud, & Wilson, 2010)

LITERATURE REVIEW

Caregiving

Caring for a stroke survivor is both physically and emotionally taxing (Cecil, Thompson, Parahoo, & McCaughan, 2013). Evidence suggests that caring for stroke survivors at home leads to emotional distress and burden in informal caregivers as exhibited by disruption of employment, leisure, social participation, and quality of life (Greenwood et al., 2010). Researchers have explored the strain experienced by new family caregivers of stroke patients, and found that caregivers experience the most stress during the acute hospital phase and during the early transitional period back home (Cameron, Naglie, Silver, & Gignac, 2013; King & Semik, 2006).

Caregivers often perceive their role in terms of heavy responsibility, uncertainty about care needs, worry, and restraints in social life (Scholte op Reimer, de Haan, Rijnders, Limberg, & van den Bos, 1998). During the first month of caregiving, safety, difficulty in managing activities of daily living, and cognitive behavioral and emotional changes of the stroke surviors are problems commonly identified by caregivers (Grant, Glandon, Elliott, Giger, & Weaver, 2004). A study by Pierce, Tompson, Govoni, and Steiner (2012) conducted interviews over a one-year period with 73 caregivers that were new to this role. The authors found three themes that emerged from their informal caregiver interviews: being worried, running on empty, and losing self (Pierce, Thompson, Govoni, & Steiner, 2012).

A study by Elmstahl, Malmberg, and Annerstedt (1995) explored the reliability and validity of a novel caregiver burden scale through a longitudinal study assessing caregivers soon after assuming this role and three years later. Within the scale, caregiver burden was broken down into five indices: general strain, isolation, disappointment, emotional invovement, and environment. They found a negative correlation between caregiver burden and patient quality of life as well as patient extroversion (Elmstahl, Malmberg, & Annerstedt, 1995). Implications of this study point toward the patient-caregiver relationship as being a mediating factor of perceived burden for the caregiver. Additionally, the authors highlight that to improve the caregiver situation, their perception of quality of life must be considered.

Within the literature, the term "caregiver" is often preceeded by a descriptive term such as "formal" or "informal" to specify the type of caregiver involved (Kemper, 1992; Noelker & Bass, 1988). The term informal caregiver is utilized for the present study and is defined as a person providing unpaid care within the last 12 months to a family member, partner, or friend that needed care because of physical or mental deficits (Tuithof, ten Have, van Dorsselaer, & de Graaf, 2015).

Leisure & Roles Among Older Individuals

McKenna, Broome and Liddle (2007) conducted a cross-sectional study that found that older individuals engage in a variety of occupations and roles and that advancing age does not appear to decrease their overall engagement. Specifically, they examined time use for older adults (defined as 65 years+) and found that these adults spent the majority of their time engaging in sleep (8.4 h./day), solitary leisure (4.5 h./day), instrumental activities of daily living (3.1 h./day), social leisure (2.7 h./day), and basic activities of daily living (2.6 h./day) (McKenna, Broome and Liddle, 2007). Results indicate that leisure is the largest categorization of how elder adults spend their time, second only to sleeping. Thus, among caregivers, this is an area of occupation that would be disrupted the most. Within the same study, the most commonly identified roles were friend, family member, and home maintainer. Ultimately, this study surmised that the time devoted to roles does not always reflect the value placed on them and the facilitation of continued involvement in valued roles is imperatative for life satisfaction among older individuals (McKenna et al., 2007).

It is important to note that roles are closely tied with identity, which is often conceptualized as the arrangement of self-perceptions and self-evaluations that are meaningful to a person (Laliberte-Rudman, 2002). A secondary analysis of data derived from three qualitative studies found that among older adults, maintaining an acceptable self-identity was linked to maintaining continuity within their identity and the sense that they are the same person they had been earlier in life or prior to the onset of disability (Laliberte-Rudman, 2002). These studies have important implications for caregivers for their overall well-being and perceived quality of life.

Quality of Life and Leisure

Post (2014) found that caregiving can be incredibly time consuming, leading to significant life changes in the realm of leisure participation and perceived quality of life. The term "quality of life" began appearing in medical literature in the 1960s and it is a growing area of research (Post, 2014). There have been many attempts to define quality of life within the literature. One accepted definition that is utilized to define the term for the present study is the individual's perception of their position in life in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards, and concerns (Post, 2014). In the early transitional period into caregiving, Pierce et al. (2012) described how caregivers feel that their lives are lost to caregiving and that they experience deep emotional strain with day-to-day situations.

Using outcomes such as quality of life and life satisfaction, literature has supported that leisure participation is beneficial for health and well-being (Ponde & Santana, 2000). Specifically, life satisfaction was found to be positively associated with leisure engagement among older adults (Hersch, 1990; Patterson & Carpenter, 1994). Life satisfaction was also positively associated with an increased variety of leisure activities (Bevil et al., 1993). Additionally, research supports leisure activity as a predictor of mental well-being among older adults (Lampinen, Heikkinen, Kauppinen, & Heikkinen, 2006).

A review of quantitative literature concerning factors influencing the caregivers of stroke survivors found that the most frequently measured outcomes for caregivers were emotional health defined generally or more specifically identified as anxiety or depression, burden, quality of life, life satisfaction, physical health, stress, and strain (Greenwood, Mackenzie, Cloud, & Wilson, 2008). While past research studies have explored quality of life among caregivers, indicating a decrease in caregiver quality of life over time post-stroke, few qualitative studies have specifically explored leisure participation and quality of life among caregivers of stroke survivors beyond the first year (Warlbey, Mollers, & Blomstrand, 2004). A study by Yoong and Koritsas (2012) specifically explored how leisure participation impacted quality of life of caregivers, revealing both a positive and a negative impact; however, the population studied were children diagnosed with Intellectual Disability. For the present study, leisure is defined in accordance with the Occupational Therapy Practice Framework as "nonboligatory activity that is intrinsically motivated and engaged in during discretionary time, that is, time not committed to obligatory occupations such as work, self-care, or sleep" (AOTA, 2014, p. S21).

The work of Cameron et al. (2014) conducted structured, quantitative interviews to explore the psychological well-being of the caregivers of stroke survivors. They found that caregivers who maintained valued activities experienced greater mastery, were in better physical health, and self-reported greater psychological well-being (Cameron et al., 2014). Additionally, a study by Kniepmann (2014) explored stress, leisure changes, burden levels, and health-related quality of life among 20 caregivers of working-age husbands with mild to moderate stroke within the past 2 years. Results of the study indicated loss of leisure participation (identified via the Activity Card Sort) was positively related to the level of disability of the stroke patient. Consequently, a higher level of disability for the stroke patient led to greater leisure loss for the carer, resulting in higher perceived burden among caregivers (Kniepmann, 2014). These results, when considered through the lens of the Person-Envrionment-Occupational Performance Model (PEOPM) of Occupational Therapy, highlight that the new personal role of caregiver carried out within the formerly established physical environment, interfered with caregivers' valued leisure occupations (Reitz & Scaffa, 2001). While Kniepmann (2014) outlined that leisure was lost, the study did not establish what, if any, similarities exist among how the loss of leisure was experienced by the caregivers. Such research has the potential to provide detailed insight on ways to improve the health and well-being of caregivers of stroke survivors and subsequently the stroke survivors themselves.

It is important to note that caregiver support has been identified as being an integral factor of client improvement following stroke (Harris, Eng, Miller, & Dawson, 2010). Researchers have begun studying the psychosocial aspects of caregiving, some even among the population of stroke caregivers. However, further research needs to be conducted to explore the lived experience of caregiver leisure participation and how this impacts their quality of life after the initial transitional period. Within the advancements of modern medicine, individuals are living longer with debilitating conditions, such as chronic stroke. It is important to consider that this has implications beyond the primary patient and can create serious physical and mental health concerns for informal caregivers. Occupational therapists are allied health professionals that have the potential to promote health and well-being among informal caregivers through their therapeutic relationship with the client (American Occupational Therapy Association [AOTA], 2014).

Lack of Control

A study by Schulz and colleagues (2012) utilized data collected on informal caregivers to older adults from a national database to explore the consequences of a lack of choice in assuming the caregiver role. They found that caregivers who explicitly reported a lack of choice experienced greater emotional stress, physical strain, and negative health impacts than those who did not indicate a lack of choice. They found this result even after controlling for potential confounds such as the level of care provided, relationship type, the primary health condition of the care recipient, as well as demographics. (Schulz et al., 2012). Having a stroke is a spontaneous, unpredictable event, thus all informal caregivers of such patients experience such lack of choice. Additionally, this new role changes their pre-existing lifestyle because they are depended upon more and they must depend more on others to help them in fulfilling their role (Greenwood et al., 2010).

Grant and Davis (1997) explored the losses specifically felt by the family caregivers of stroke patients. They found that family caregivers experienced four main things: loss of the familiar self, loss of the autonomous self, loss of the affiliative self, and loss of the knowing self. Greenwood and colleagues (2010) conducted a qualitative study of informal caregivers of stroke patients at one month and three months post-discharge. They found that caregivers identified a reduction in their independence and autonomy, but over time identified strategies to manage these losses and to increase their control. Some of these strategies included optimization, which involved techniques such as planning ahead. Compensation was another strategy, which included giving up activities that they previously enjoyed without any substitutions. It is important to note that across the life span continuum, perceived control has been linked to many health-related outcomes, including coping and personal adjustment (Greenwood et al., 2010).

Occupational Deprivation

Occupational deprivation is a term that is defined as a state in which a person or group of people are unable to do what is necessary and meaningful in their lives due to external restrictions (Whiteford, 2000). Specifically, it is a state in which engaging in occupations that have social, cultural, or personal relevance is determined to be difficult, if not impossible (Whiteford, 2000). The term is often considered within the literature as relating to issues of direct social and cultural exclusions (Whiteford, 2000). A study by Christiansen, Backman, Little, & Nguyen (1999) found that there is a positive relationship between time spent engaging in meaningful occupation and perceived well being. Specifically, they found that occupational deprivation among individuals in a prison setting was detrimental to health, self-efficacy, and personal identity, which are all important components of quality of life (Whiteford, 2000). As a result, the overarching purpose of this phenomenological study is to contribute to the literature surrounding stroke-survivor caregivers and to understand the caregivers' perspective on leisure participation and their perceived quality of life.

CHAPTER 2

JOURNAL ARTICLE MANUSCRIPT

Introduction

Stroke impacts approximately 795,000 people annually (American Heart Association [AHA], 2010). With the evolution of modern medicine, more effective treatment options have emerged and been implemented. This has resulted in a 21% decrease in the number of stroke deaths over the past 10 years (AHA, 2014). Stroke is a serious medical condition that proves to be a traumatic, life-altering event that typically impacts the individual with permanent disabilities (Pierce, Thompson, Govoni, & Steiner, 2012). These circumstances result in stroke being the leading cause of disability in the United States (AHA, 2014). In addition to the primary impact on the patient, stroke also impacts those people that are close to them, including friends and relatives (Pierce et al., 2012). In fact, the majority of stroke patients return to home settings, requiring assistance in daily activities that was not needed prior to the stroke (AHA, 2007).

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A study by Shultz and colleagues (2012) utilized data collected on informal caregivers to older adults from a national database to explore the consequences of a lack of choice in assuming the caregiver role. They found that of the caregivers that reported a lack of choice, these persons experienced greater emotional stress, physical strain, and negative health impacts than those who did not explicitly report a lack of choice. Having a stroke is a spontaneous, unpredictable event, thus all informal caregivers of such patients experience such lack of choice. Additionally, this new role changes their pre-existing lifestyle because they are depended upon more and they must depend more on others to help them in fulfilling their role (Greenwood et al., 2010).

Using outcomes such as quality of life and life satisfaction, literature has supported that leisure participation is beneficial for health and well-being (Ponde & Santana, 2000). Specifically, life satisfaction was found to be positively associated with leisure engagement among older adults (Hersch, 1990; Patterson & Carpenter, 1994). Additionally, research supports leisure activity as a predictor of mental well-being among older adults (Lampinen, Heikkinen, Kauppinen, & Heikkinen, 2006).

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Terms Defined

The term informal caregiver is utilized for the present study and is defined as a person providing unpaid care within the last 12 months to a family member, partner, or friend that needed care because of physical or mental deficits (Tuithof, ten Have, van Dorsselaer, & de Graaf, 2015).

There have been many attempts to define quality of life within the literature. One accepted definition that is utilized to define the term for the present study is "the individual's perception of their position in life in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards, and concerns" (Post, 2014).

For the present study, leisure is defined in accordance with the Occupational Therapy Practice Framework as “nonobligatory activity that is intrinsically motivated and engaged in during discretionary time, that is, time not committed to obligatory occupations such as work, self-care, or sleep” (AOTA, 2014).

Method

Research Design

This study utilized descriptive qualitative research methodology, specifically transcendental phenomenology, which is recommended within the literature when trying to understand several individuals’ common or shared experiences of a phenomenon (Creswell, 2013). Bracketing is an important component of this process and involves the investigator setting aside their biases and experiences to take on a fresh perspective throughout the research process (Creswell, 2013). This technique was utilized through reflective journaling about personal biases and opinions throughout the entire research process.

Participants

Convenience sampling was utilized to select four caregivers of clients with chronic stroke to participate in this study. Their family members with chronic stroke had participated in a previous research study and that is how the potential participants were identified. They were contacted via email or phone about their potential participation, expressed their interest, and were provided with an informational flyer. In order to be considered for study inclusion, individuals were required to be 18 years or older and be the informal caregiver of a stroke client (as previously defined). Participants with any previous neurological insults, complications, and/or dementia were excluded from the study.

Procedure

Approval to conduct this study was granted from the Internal Review Board at Eastern Kentucky University. Informed consent documentation was reviewed in verbal and written format and all of the participants consented to participation. A list of relevant resources about local support groups and community supports available for caregivers was prepared for each participant in the instance that they became emotionally distraught and unwilling to continue. Each of the participants participated in a semi-structured interview lasting between 60-80 minutes. The interview guide was consistent across participants and included open-ended questions about the caregiver's leisure participation and quality of life. All interviews were audio-recorded and then transcribed to ensure the credibility of the participants' comments. Each interview was conducted by the principal investigator in a quiet location that was selected by the participant. At least one additional consultant of the research project was also present at each interview. Two interviews took place in the home context of the participants and two took place in a conference room at a private, neutral location. The spouses were not present for any part of the interview to ensure further credibility and candidness of the responses of the participants.

Data Analysis

Following the recorded interviews, the principal investigator transcribed the audio-recorded data verbatim, significant statements, sentences, and quotes were identified, and horizonalization was conducted. This is consistent with Moustakas (1994), as adapted by Creswell (2013). Eight categories were developed from the identified statements and then narrowed into three primary meaning units or themes. These themes are utilized to construct a description of the phenomenon experienced through textural (i.e. what participants experienced) and structural description (i.e. how participants experienced it). Following this, the "essence" of the phenomenon is described (Creswell, 2013).

Rigor was obtained through three main strategies for measuring the quality and credibility of the data: member checking, reflexivity, and a detailed audit trail. Member checking was conducted by obtaining feedback from two participants on the results of the study. These participants were asked to respond as to whether or not they felt the results were reflective of what they shared in the interview and they both expressed that the results were indicative. Specifically, one participant responded by stating, "I thoroughly enjoyed reading this. I found my feelings throughout this paper". The other participant responded, "This lets people know what we are going through and it made me feel connected to other people, knowing I am not alone". Rigor through reflexivity was obtained by bracketing conducted by the principal investigator. The researcher reflected upon her biases and opinions concerning the phenomenon being studied through journaling after the participant interviews and throughout the transcribing, coding, and writing process. Because the researcher was actively involved in the qualitative research process, such reflexivity is essential to reduce confounding the results based upon their own experiences (Creswell, 2013). Rigor was also obtained through a detailed audit trail that ensured the development of results that were as in-vivo as possible.

Results

All study participants were female, over the age of 50, and married to the person they care for. Participants, which are identified via pseudonym throughout this section, had acted as caregivers to their spouse for as long as 2 to 7 years at the time of the study. Three meaning units or themes illustrating the lived experience of the caregivers of chronic stroke patients were identified:

1. Loss of Control
2. Role Shift
3. Occupational Deprivation

Loss of Control

All four participants described a sense that they were no longer in control of their own lives. Specifically, the caregivers highlighted the concept of independence. They no longer felt that they had the independence to choose what they did or when they did it due to their many responsibilities as a caregiver. Joan stated:

> *"I think the thing that's hardest for me is whatever independence I had…is totally gone because of the fact that he is so dependent."*

Joan further commented:

> *"I don't have the freedom that I got so used to having. I think that is something that every human needs."*

Additionally, the caregivers reported feeling they had lost control over how they allocated their time after becoming a caregiver to their spouse. They did not feel that they had much, if any, free time for themselves. They further described that if they did have some time, it was rarely large blocks of time. Joan reflected on her experience and stated:

> *"My life mainly now is…taking care of what has to be taken care of as opposed to what I would choose to do if I had the option or had the free time".*

Participants also discussed feeling as if they had lost control of the direction of their lives. This feeling was so profound to caregivers sometimes that they felt they were not the same person they used to be. Helen described her sentiments:

> *"With his stroke—there is a point that you realize…maybe I'm not going to quite get back to the person I used to be."*

Caregivers also conveyed a loss of flexibility within their daily routine and indicated that this negatively impacted their perception of their quality of life. They described having to completely relinquish leisure activities that were highly meaningful to them prior to becoming a caregiver. Several examples of leisure activities that were lost included operating an antique booth, daily walking, and listening to music. When asked about what quality of life meant to them, they described it as *"doing things that give you enjoyment", "just being able to have time to reflect, take it easy, and work at your own pace", "not having to clock-in", and "a sense of control over your time and how you utilize it"*. Mary described her experience as follows:

> *"If I had to put one thing on the line about what a stroke does to your personal life, it is that once the terror is over of what has happened to you, then you sit*

> *and you stop and think about what are we going to do with our life because the life that you knew is gone. It's gone. It's not there anymore."*

Role Shift

All four participants also discussed a shift in roles after becoming the caregiver to their spouse. Not only did they have to maintain the roles that they were already fulfilling in everyday life, but they had to assume new roles that were formerly filled by their husbands. Furthermore, these roles were not just temporary, but permanent changes. Some caregivers provided specific examples, such as driving, purchasing clothes, and managing the finances. In addition to the specific role changes mentioned, more general changes in roles within the dynamics of their relationship were also described. For example, Alice stated:

> *"I miss him being the one to drive, him being the one to take the lead. So that has been something that's been one of the changes that's been really difficult. That has taken a lot to get used to."*

The caregivers also discussed how transitioning into their new role as caregiver was a difficult change to manage because they still wanted to try to see themselves as the wife and not the caregiver to their husband. Helen reflected upon her experience:

> *"I think for a relationship…you don't want to get caught in that caregiver piece too much because that's where that whole stress comes in and you know I have to be the wife and not the caregiver."*

Nevertheless, some caregivers acknowledged that there were still things that they did that made them feel that they were fulfilling the caregiver role. The added responsibility of maintaining this new role was seen as an extremely emotional and personal sacrifice lasting beyond the acute phase of rehabilitation. For example, Mary stated:

> *"I don't want to feel selfish, but sometimes I feel like I don't have a life anymore. I feel like my life has kind of been put on the back burner because I'm a caregiver…"*

Occupational Deprivation

All four participants discussed their desire for "Me Time" and the longing to get back to engaging in valued occupations. Through their reflections, caregivers described that activities that were so integral to their life prior to becoming a caregiver had been lost. As discussed previously, caregivers felt they had to give up valued occupations out of necessity due to a lack of time. Travel was a leisure activity that was commonly identified by all participants as an occupation they also had to give up following their husband's stroke. It was also the top leisure activity they cited as wanting to do in the future. For example, when asked about things they would hope to do Helen said:

> *"Well trips because that's…kinda my new mode when I take time off I try to do… things that I think would be fun [to] kind of keep the balance."*

All caregivers also discussed changes in their leisure participation following their transition into their caregiving role through limited outings. They discussed that contextual barriers, such as parking, walking, and stairs are limiting to what they are able to do and where they are able to go. Some described it as requiring more effort to the point that it takes the fun out of going and doing the activity. For caregivers, this resulted in less engagement through fewer outings and avoiding going to new places. For example, Alice stated:

> *"It has definitely slowed us down…it's not as easy to do things without thinking. You have to think about the place that you're going [and] whether or not he is going to have to do a lot of walking."*

Anxiety was another factor that reduced occupational engagement among caregivers. Several participants described feeling fear that it may happen again or that their spouse might fall if they were not around. Mary described:

> *"I got to the point where I was afraid to leave the house. I would stay and put it [grocery shopping] off and put it off."*

Additionally, some caregivers discussed changes in their social participation, which they viewed as a form of leisure. Joan described her experience with this as follows:

> *"I lost my focus—I used to love to cook meals and have people over and we don't do that anymore. People don't come over anymore."*

Mary described her experience:

> *"We had several couples that we had been friends with for like 30 years and after his stroke, they just stopped coming around, they stopped calling, we don't see them…it's like our quality of life, that was our enjoyment time. It took years to make those friends and it took seconds to lose them."*

Two of the four caregivers described the pleasure they experienced upon seeing their spouse make progress through the therapeutic process when asked about their own quality of life. For example, Mary stated:

> *"It gives me great joy to know that he has gotten back so much [through therapy]."*

Alice reflected:

> *"When I could see little things getting better that really kind of helped me to keep going."*

Since all participants did not share this, it was not identified within the themes, but may be an important means to improve caregiver quality of life.

Discussion

Previous research has indicated that leisure participation and a sense of control are important components of health and wellbeing for all individuals (Ponde & Santana, 2000; Greenwood, Mackenzie, Cloud, & Wilson, 2010). This study identified that upon assuming the caregiving role, caregivers experienced a significant role shift. Following their husband's stroke, caregivers were required to assume more responsibilities that were formerly looked after by their spouse. Driving and financial management were among some of these new roles and added stress and greater responsibility to the caregiver's life. Their new role of caregiver consisted of absorbing multiple roles that their husbands could no longer fulfill, in addition to continuing all of their former roles. These roles are typically fulfilled by the caregiver initially, but also appear to be carried out on a permanent basis, even after the client has made functional gains.

Fulfilling more roles results in more responsibilities that take time to complete. In the long-term, caregivers experienced their shift into the caregiving role as a loss of free time and control over how they spend their time. This is consistent with current literature surrounding caregivers of stroke clients, which identified losing self as a common theme (Pierce, Thompson, Govoni, & Steiner, 2012). Caregivers experienced the sense that they always had something they could or should be doing and that they had little to no time to themselves. This was experienced as a transformation upon assuming the caregiver role and one that did not diminish over time. Literature has shown that across the life span continuum, perceived control is linked to multiple health-related outcomes, including coping and personal adjustment (Greenwood et al., 2010). Given this integral connection, it is likely that caregivers are not able to adequately cope or fully adjust within their role. Because they feel a loss of control over their lives, they experience a constant state of adjustment.

Additionally, with the added responsibilities of being a caregiver, this study found that the caregivers were deprived of time to engage in valued occupations, specifically for leisure. Literature has shown that life satisfaction positively correlates with leisure engagement among older adults (Hersch, 1990; Patterson & Carpenter, 1994). Assuming the caregiving role required long-term sacrifice by giving up valued leisure activities that provided caregivers with a sense of enjoyment and accomplishment in life. Over time, this occupational deprivation, specifically concerning leisure activities, amplifies the experience of loss of control and negatively impacts the quality of life of the caregiver.

Previous literature has shown that caregivers experience the most stress during the acute hospital phase and during the early transitional period back home (Cameron, Naglie, Silver, & Gignac, 2013; King & Semik, 2006). This study showed that the caregiver role should be considered beyond the initial transition period. Specifically, this study highlights how role shifts that are realized later in the caregiving process (2-7 years post-stroke) initiate a cascading effect of greater responsibility and decreased ability to allocate time as chosen. Because caregivers experience an inability to select what they want to do and when, they feel forced to adapt by giving up valued leisure occupations. This process contributes to the sense of loss of control among caregivers. Over time, this occupational deprivation impedes the quality of life of the caregiver.

Literature has indicated that progress of the client is related to the support of the caregiver (Harris, Eng, Miller, & Dawson, 2010). If caregivers do not experience a positive sense of quality of life, their health and wellbeing suffers (Ponde & Santana, 2000). This study revealed that caregiver involvement within the therapy process and witnessing progress can bring pleasure to caregivers, thus strengthening the client-caregiver relationship. In order to ensure optimal support to the client and to promote client progress, it is important to support the quality of life of the caregiver and to understand their experience.

Implications for Occupational Therapy Practice

This study has valuable implications for how occupational therapists observe and interact with the caregivers of clients with chronic stroke. Understanding their caregiving role and the stresses that accompany it is vital to providing family-centered care. Specifically, the key point is to listen and to engage with caregivers to fully understand their context, not to judge them (Toth-Cohen, 2000).

The findings highlight the importance of being proactive through dialogue with caregivers and promoting occupational justice among caregivers. Occupational justice is oriented to promoting fairness, equity, and empowerment to enable opportunities for participation in occupations for the purposes of health and quality of life (Durocher, Rappolt, & Gibson, 2013). This can be achieved through providing necessary resources and referrals to empower caregivers in their roles.

Findings highlight the positive benefits of therapists inviting caregivers to join in and/or observe therapy sessions. This would provide more educational opportunities for the caregivers that would allow them to further support the independence of the client at home. Additionally, seeing progress in their spouses may help to facilitate psychosocial benefits that improve quality of life among caregivers. This could even be achieved without attending sessions through non-traditional methods such as video, photos, or taking home a tangible, finished product the client made. Furthermore, fostering leisure exploration and participation as a means to support the quality of life of the caregiver would be a valuable way for occupational therapists to support the caregivers of clients with chronic stroke. Engaging the caregiver, even after the acute stages of rehabilitation, is an imperative component of the rehabilitation process. Findings of this study raise the question as to whether or not caregivers actually ever cope with their new role as a caregiver or if, over the long-term, they compensate to the point of occupational deprivation. Possibilities to promote occupational engagement include providing suggestions about overcoming barriers to travel or arranging respite care. These would be valuable points of impact for occupational therapy.

Limitations

This study had a limited sample size with only four participants and all caregivers interviewed were female and married. Thus, saturation was not reached. This study may benefit from continued data collection to include participants who were not married females.

Conclusion

The caregivers of chronic stroke clients experienced role shift, loss of control, and occupational deprivation that exists after the early transitional period. Consequently, it is imperative that occupational therapists working with a chronic stroke population in an outpatient setting understand the importance of promoting occupational justice among caregivers, interacting with the caregiver, and inviting them to observe therapy sessions. This has important implications for the health and wellbeing of both the caregiver and ultimately the client, as they are inextricably linked.

Future research needs to be conducted including more client-caregiver pairs to provide greater generalizability. Exploring whether or not male caregivers have similar or different experiences to female caregivers would also be meaningful. Because some caregivers expressed gaining reward from observing their husband in therapy, further research should explore this to discern the psychosocial implications for the client-caregiver relationship.

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APPENDIX A:

IRB Approval

Graduate Education and Research
Division of Sponsored Programs
Institutional Review Board

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NOTICE OF IRB APPROVAL

Protocol Number: 15-246

Institutional Review Board IRB00002836, DHHS FWA00003332

Review Type: ☐Full ☒Expedited

Approval Type: ☒New ☐Extension of Time ☐Revision ☐Continuing Review

Principal Investigator: **Annie Wigginton** Faculty Advisor: **Dr. Camille Skubik-Peplaski**

Project Title: **The Lived Experience of Informal Caregivers of Stroke Patients**

Approval Date: **5/4/15** Expiration Date: **6/1/16**

Approved by: **Dr. Ida Slusher, IRB Chair**

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 EKU 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.

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APPENDIX B:

Consent Forms

Consent to Participate in a Research Study

The Lived Experience of Informal Caregivers of Stroke Patients

Why am I being asked to participate in this research?

You are being invited to take part in a research study aimed at exploring the leisure participation of caregivers of stroke survivors and the implications this has for quality of life. You are being invited to participate in this research study because of your experience and role as the caregiver of a stroke survivor.

Who is doing the study?

The person in charge of this study is Annie Wigginton at Eastern Kentucky University. She is being guided in this research by Dr. Camille Skubik-Peplaski. 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 leisure participation of caregivers and how this impacts their quality of life. Thus, through conducting this research study, the goal is to gain a greater understanding of the experience of caring for an individual that has had a stroke.

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

The research procedures will be conducted in a quiet, private location, such as the caretaker's home. You will need to engage in a maximum of 3 interviews. Each of those interviews will take a maximum of <u>90 minutes.</u> You will be asked to volunteer for this study 1 time.

What will I be asked to do?

As a participant, you will be asked to engage in an audio-recorded interview at your home that will last for a maximum of 90 minutes. The interviewer will be prepared with questions to ask you about your experience of being a caregiver for a stroke survivor. There are absolutely no right or wrong answers. All of your responses will be anonymous and neither you or the person you care for will be named or identified in any other regard. Your responses will be utilized to gain a greater understanding of the experience of the caregivers of individuals that have had a stroke.

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

You should not participate in this study if you feel that it is going to cause you extreme emotional discomfort to discuss your experience as a caregiver.

What are the possible risks and discomforts?
To the best of my 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 inform you of 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?
There is no guarantee that you will get any benefit from taking part in this study. However, some people have experienced emotional benefits from self-reflection when engaging in the interview process. We cannot and do not guarantee that you will receive any benefits from this study.

Do I have to take part in this study/interview?
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 the data in a combined manner in which individual participants are unidentifiable. 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 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 Dr. Camille Skubik-Peplaski at 859-338-2651 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 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, Annie Wigginton at 502-544-6002. 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